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(Volume II)

(July 30, 1990 - 2:15 p.m.)

MR. SCOTT ALLEN: We are going to go ahead and begin and some of the Commissioners will be coming in after making telephone calls. I would like to make an announcement that those that would like to speak at the end, 6:00 to 6:30, if you would please sign the register outside. And you get three minutes each, if you want to share your concerns with the Commission.

Now we are returning a little behind schedule. We will take the full 45 minutes that is alloted here to deal with the housing programs -- a half-hour, sorry, folks.

Our next speakers will deal with the housing program and they are Patricia McInturff, Director, Regional Division, Seattle-King County Department of Public Health; and Harris Hoffman, Project Manager for the AIDS Housing of Washington; and is there a Harry Thomas here? I see. Okay. I have been working on a different agenda here.

And what we are doing is having six minutes of testimony, and then you will hear the buzzer, the beep, and then you will have one minute to close, and then we will have some dialogue time. So, Harris, if you would begin, or Patricia.

MS. McINTURFF: I think I'm going to get it over with; it will work a little better that way. Good afternoon. I would like to give you just an overview of

the Seattle Housing continuum of care.

Seattle-King County basically took a system approach to all of our care systems, and housing of course is one of the most critical ones, and our goal was to provide housing in our community that matched the financial resources and medical needs of the community.

Our housing program in this community has a primary goal and four guiding principals. The primary goal is to provide housing services for persons in need of the services at various stages of HIV, ranging from independent living to 24-hour nursing care. The continuum goes from emergency housing, independent living, private homes, adult family homes, long-term care, and hospice.

Our four guiding principals are that persons living with AIDS should be assisted in retaining their own personal living situation as long as possible; that alternative living situations appropriate to client needs and desires will be made available; that clients will be supported in the least restrictive setting for the maximum duration possible; and that housing will be centrally monitored and coordinated throughout the community.

In Seattle-King County today we have approximately 625 people living with AIDS. In 1993 we will have over 2,500. In 1995 we will have 4,000. That gives you some idea of the job we have ahead in terms of independent

continuum.

Our continuum today is cordinated through the Northwest AIDS Foundation, the lead agency. In 1989, 50 percent of the people living with AIDS in our community approached the Northwest AIDS Foundation for assistance. The Foundation was able to assist 85 percent of those. However, all of our current housing options remain at capacity with waiting lists.

I will just quickly go over what our continuum looks like. In terms of independent housing, we have 20 Section 8 vouchers that are available to people with terminal illness living in approved housing. Basically, that means you can get your own home or your own apartment designated. All 20 of those are being used by people living with AIDS, although they are available to anyone with a terminal illness.

The person who is approved for this program must pay one-third of their income for the housing. This is our most requested option in our community and the waiting list stays at about 30 most of the time.

We use Seattle Housing Authority conventional housing programs which are not specific to AIDS or any illness. And we just use apartment complexes owned by the Seattle Housing Authority. To date, we have served over 100 people with this option and it is the most expedient way

we have of providing people with independent living situations.

We have church-supported homes in our community. DeWolfe House is one of those which we will visit tomorrow and a group of apartments also owned by other religious organizations. We have a cluster of apartments owned by the Seattle Housing Authority.

In terms of 24-hour nursing care, we have traditional nursing home beds, not many, but a few. We also have a unique adult family home called Rosehedge which I will give you a little bit of later. Also, we give people direct subsidies to stay in their own homes, financial subsidies, through the Northwest AIDS Foundation.

I thought I'd take just a few moments to tell you about Rosehedge House, an adult family home. I use Rosehedge because I think it illustrates the kind of process we have gone through to develop each of our options, the kind of pain and suffering that it takes to get each of these up and going.

Rosehedge House is the first licensed adult family home offering 24-hour nursing care. It opened two years ago. It's a demonstration of an adult home model of skilled nursing care. It's a private project and we are looking at both the financial feasibility and the client acceptance of this model.

Our existing law limits adult family-life homes to only four people and it must be operated by the individual or family who permanently resides there. The Northwest AIDS Foundation Health Department spent months negotiating with the State of Washington to lift those restrictions. They did waive them and licensed a home that has six individuals in it and allowed a nonprofit home healthcare agency to run it.

The agency that was selected to run this was the existing agency, Community Home Health Care, rather than start a new agency in our community. They went out and found a home to rent and then we had to raise about $77,000 to bring it up to standards. It was a community-wide project to raise that money, $35,000 coming directly from the Northwest AIDS Foundation.

In addition, we had to get another branch of the state to agree to pay community home healthcare, what we call an exceptional rate of pay, to allow us to operate without going in debt. And they do allow $223 a day, significantly more than they allow for other adult family homes. I think that gives you some idea of the processes and changing rules and regulations and people involved to get any one home up and going.

Services provided at Rosehedge include case management, skilled nursing, IV therapy, physical therapy,

hospice, and a strong volunteer support system. It serves 74 clients, has a waiting list of anywhere from 5 to 15 on a daily basis and the mean length of stay is 60 days. I think it was first seen as a place to go and die. Today it is seen as a place to come and live.

It is being evaluated by the Seattle-King County Department of Public Health. The agency, Community Home Health Care, has now located another home, second adult family home. It will be opening next year, but this one will be owned not rented, and it will be bought with a combination of state housing trust dollars, United Way, and federal money coming through the McKinney Act.

We see this demonstration project as something that might be available to smaller counties throughout our state or rural places in the United States that would never need a large facility and also the kind of model that we might use for special population groups, such as women and children who are diagnosed mentally ill. We see this as an option and so we are continuing to look at this kind of special model in our community.

I think as we look at our success to date in housing, we measure three things. The response of the people living in those homes has been very good. We have been able to reduce hospital stay about to half in our community and we have been able to get support at all

levels of government and the private sector.

There are several reasons for this. One is a history of cooperation and going after these options in a cooperative manner. Two, time and comprehensive planning. We have been able to go to people with plans, telling them what we need based on facts and figures. We use the lead agency approach so we don't duplicate service; we work together. We have a strong centralized case management in order to keep people in the least restrictive setting for the maximum extent possible.

And we centralize our housing for efficient modeling. Whether it's church housing, DeWolfe House, or Seattle Housing Authority, it's all monitored through one agency and the person who is in charge of that is with me today. Actually, we just hired him away from the Northwest AIDS Foundation -- I didn't do that.

I think through all of this we have been really careful about talking with people involved and making sure they were part of planning, making sure that they're dictating self-esteem that is part of putting everything together.

And I think working hard at the beginning brought big community support, which doesn't happen because you want it to happen. It happens because you spend a lot of time talking to a lot of people and explaining to them why you

are doing it and why it needs supports and why it's important in the community. That's the good news.

The bad news is what faces us. As we see these numbers go from 625 to 4,000, we are going to have to expand our systems tremendously in order to maintain them. We are also going to have to start doing special compilations in our communities as the demographics change and that's going to be very difficult for us to do. However, as an alternate, the option is more expensive unless you maintain care, if we don't take on those two challenges. Thank you.

MR. HOFFMAN: Thank you very much. Seattle's response to the development of housing for people living with AIDS is much like the development of other services; it's a coordinated approach without the duplication of services, with one agency taking the primary lead. AIDS Housing of Washington was founded in May of 1988 to meet the specific gap in the care system of 24-hour residential long-term care and adult day care as a unit group.

As a result, in 1987 the Seattle-King County Department of Public Health convened a long-term care advisory committee to develop serious recommendations to address the development of long-term care and facilities for people living with AIDS. The Northwest AIDS Foundation, a community-based agency, made a decision not

to do the housing developments. Their focus as first mentioned, was providing case management services, education, raising money for AIDS services, and coordination and placement for people into housing.

AIDS Housing of Washington's sole purpose is to develop a 35 bed, 24-hour care residence and an adult day care center for people living with AIDS in Seattle-King County. The residential facility will serve people living with AIDS who need 24-hour care, yet do not need to be in an acute hospital bed and cannot be appropriately cared for at home. These People either do not have a home, or the resources for at-home care are not available to them, whether due to a lack of ability to pay or lack of available at-home care givers.

The residential portion of the facility first applied for a Certificate of Need from the State Washington Department of Social and Health Services and that was granted about a year ago. However, that particular Certificate of Need did not provide for enough nursing care to meed the needs that were going to be required in this facility and a bill had to be passed through the 1990 Washington State legislature which established a mechanism for reimbursement for about twice the number of nursing hours as a standard nursing home.

The rate for a nursing home is about $190 a day and

the rate for this facility will be $187. The Department of Social and Health Services will reimburse care for all eligible residents as a result of this bill that was passed and most of the people will qualify for that.

However, private insurance companies have also expressed interest in reimbursing for care in the facility because the cost of providing care in a hospital, which is often the alternative to this, is often three times as much.

The services in the residential portion of the facility will include 24-hour skilled nursing care, sub-acute step-down care, hospice services, as well as respit care. Each residence will have his or her own bedroom with space for a family member or friend to spend the night. We are anticipating the average length of stay to be about 45 to 50 days. And if we adhere to this after this facility is up, the facility will serve over 225 individuals a year.

The adult day care center will serve people living with AIDS who are still able to live in their homes but require some care during the day. Transportation will be provided as well as meals; therapies, including physical, occupational, respiratory, and IV, and recreation and social programs. The day care center is licensed separately from the nursing home but also by the

Department of Social and Health Services and will receive about $53 a day and that will be a combined program there.

AIDS Housing of Washington has a 21-person community board of directors that includes representatives from grass roots organizations, business, governmental, religious, and health agencies, as well as people living with AIDS. The board meets monthly, with committees meeting on a monthly basis as well. In addition, AIDS Housing of Washington has an advisory committee which represents many business and community leaders.

The facility will be operated by the Sisters of Providence, which is an experienced organization, through a lease arrangement with the AIDS Housing of Washington. The Sisters of Providence Health Care Corporation is the largest healthcare provider on the West Coast and operates more than 3,000 hospital beds and long-term care beds -- actually, that's 3,000 each.

Obviously, one of the things that was necessary to make this work was the raising of money and AIDS Housing of Washington has so far raised $5.1 million through the efforts of the board and other members of the community. And this came through the government, it came through the business communities, came through the private donors and private donations.

Funding has come from 30 major corporations and

foundations and over 1,500 individual contributors. We need to raise $800,000 in the next few months in order to start construction of the project. I'm sorry, I went over my minute.

In addition to the fundraising challenge, AIDS Housing of Washinging began community notification process once the site had been selected and an option secured on a parcel of land. And this involved monthly community meetings which were held for ten months addressing neighborhood concerns and providing educational sessions on AIDS.

In December of 1989, AIDS Housing of Washington received its Master Use Permit from the City of Seattle which entitled us to apply for a building permit for this facility. This Master Use Permit was challenged by some developers and residents in the neighborhood because of concerns they had and they started an appeal process which resulted in a lengthy hearing process that also was ruled in favor of the project.

The hearings were further appealed to the City Council and Superior Court. In June, a settlement was reached between AIDS Housing of Washington and the project's appellants with the help of ACT UP and other members of the community. All challenges were dropped and in return, AIDS Housing of Washington added 500 square

feet of retail space and some additional landscaping for the immediate neighbors.

Groundbreaking is now scheduled for this project on October 10, 1990, and occupancy is expected in the fall of 1991. It has clearly been the combined community, business, and government efforts that will make this groundbreaking possible.

MR. SCOTT ALLEN: Are there any questions?

MR. DALTON: First of all, I'm going to ask you more about the $5.1 million, the amount of money you said you raised from 30 major corporations, and I was curious about how you pulled that off. Basically, one corporate donor and then a spinoff off or was it because of your background in Pike Place?

MR. HOFFMAN: Again, one of the key elements I think in raising money from corporations was Seafirst Bank stepping forward, and Luke Helms, president of Seafirst Bank, agreed to co-chair the fund raising and also Sherrie Bridge of Bridge Jeweler, and those attached validity, and Paul Shell, they are all business leaders who stepped forward early and said they would support this project.

MR. DALTON: You said 1,500 individual donors. How did you do that?

MR. HOFFMAN: There was a whole fundraising plan that was put into effect and it wasn't dissimilar to some other

fundraisers that I've done, but also there were added elements. There's a telephone campaign that's going on right now, and a lot of personal contact that was made through the board of directors. There was, frankly, some high visibility. We made this a high-visibility project in the community and it really was just an effort. I guess that's it.

MR. DALTON: Are you movable to the East Coast?

MR. HOFFMAN: I'm probably not the right one but there are other members of the organization.

MR. DALTON: The other set of questions I have has to do with the community notification process. I certainly have indirect experience with AIDS advocate programs in my part of the world and the struggling issue of the community's phenomena of locating this housing and how to relate it to the community.

The question I guess is that you notified the community, but after securing a property. So you are committed to that particular piece of property but also committed to working your way through the community.

And I also heard you had to spend some time, both in administrative hearings and in court. And I guess I'm wondering, would you do this differently now?

MR. HOFFMAN: I think the answer is that actually the community notification was done in a timely manner and I'm

not sure that doing it differently would have resulted in less stress points. There was a lot of education done and to some degree the amount of opposition was focused pretty narrowly by the time it appeared in the form of an appeal. We never did go to court; we avoided that.

And I think what is always crucial is that notion of meeting people and I think that's good. The Executive Director of AIDS in the very beginning met with businesses on almost a daily and weekly level, meeting people in the community and then those people in the community meeting with other people in the community.

I think she had a lot of experience in getting this into a place where people could be comfortable with it and immediately building enough of a coalition that the opposition didn't overwhelm the people in support of it, and then slowly started building support from some of the opponents and getting them comfortable.

MR. DALTON: Can you characterize the neighborhood or location where this facility will be?

MS. McINTURFF: Actually, you will get to drive by it tomorrow.

MR. HOFFMAN: It's been a neighborhood somewhat in transition from a business point of view and probably from a housing point of view also, sort of in-between downtown and Madison Park.

And some businessmen there have struggled for probably ten years trying to make this a viable business community, and I think they were to some level the most concerned, and it was really took some effort, that's why the retail. But also saying that we would be a good neighbor and not a bad neighbor that would hurt business and many of their customers would be proud, for lack of a better word, to have this facility there as opposed to living in fear.

MS. McINTURFF: I think one of the things is that we picked a piece of property that was zoned appropriately. We didn't go in and pick a piece of property and then have to go through zoning fights. We were very careful about the piece of property we selected and that was one of the more difficult things to locate. I think if we had to go through that process we would have been fighting more battles.

MR. HOFFMAN: Actually, as it turned out, the zoning was R zoning which required retail for something nonresidential on the first floor and the day care facility really did affect the area well.

MR. SCOTT ALLEN: All right. Is that all?

MR. KESSLER: I think you just answered my question. I was curious what the nature of the business was and it's a not-for-profit day care?

MR. HOFFMAN: Correct.

MR. KESSLER: The other question, sounds like lots of housing options at the moment, but is there sill a waiting list?

MS. McINTURFF: Yes

MR. KESSLER: Any estimate of size?

MS. McINTURFF: Depends on the different options, but I think the statistics that we're able to take care of are about 85 percent. There's probably about 15 to 20 percent at any one time that we can't respond to. People that always get their first option is the issue.

MR. KESSLER: Third question. Later on this year we will be looking at the interface of organized religion, for lack of a better term, and this epidemic. Do you have a sense that because you have had some support from the various churches, congregations, in terms of some of the models, that has helped to create a better climate for these options?

MS. McINTURFF: Yes, I think so. I think the archdiocese was one of our bigger contributors to AIDS Housing in Washington and DeWolfe House which you will see tomorrow was purchased and bought by the Rotarian Church.

MR. HOFFMAN: I'll just add, it's reciprocal to the fact that the churches have responded in the sense to the community living with AIDS, there has been more trust back

and forth.

MS. DIAZ: I might have missed this in your presentation, but are any of the housing options now available for entire family units or mothers and children, infants?

MS. McINTURFF: No. I think if you look at the demographics, the reason is I believe we only have three or four children living with AIDS in our community. If our demographics were representative of San Francisco, then we would give all the support we could to keep the children in the home. We know in the future that's something that we have to look it and that's why the adult family home is a model that we're looking at, when our numbers start looking like other cities.

MR. JIM ALLEN: But, one of the things that continues to astound me about the AIDS epidemic is that we can make our projections in the future and for almost a decade now those projections have continued to be borne out, unfortunately, to be borne out incorrectly. And yet the planners and the funders, i.e., Congress and the legislators, seem not to really understand what is being said. How have you been able to do in this area with both educating your own congressmen and senators and your state legislative people?

MS. McINTURFF: Actually, I think we have done a

fairly good job. It's never good, but I think one of the things that I said was our reason for success is that it isn't something that just happens because you do good works. I think you have to spend a lot of time educating city council, county council, state legislators, congressmen. You have to tell them why you are doing it, why it makes sense, why it saves money in the long run.

You can't expect them to just by osmosis everytime you do a good thing that they're going to support it. I think it takes community-based agencies talking about it; it takes constituents talking about it; it takes public health officials talking about it; and I think it's a long-term project which you have to keep explaining why this is less expensive, why it's humane.

But I do think it's an ongoing battle though, that we all deal with on almost a daily basis and with the numbers going up the way they are, we will see how good a job we have done.

MR. SCOTT ALLEN: I have a question on your fund raising. I know that you are also losing some HRSA money and your personal money for other services in the city. Do you find that competing for the same dollars or the same foundations or how are you cordinating that effort and how do you maximize your efforts to also prioritize housing or other needs?

MS. McINTURFF: Well, we sort of approached it as a community approach and we have a five-year plan in this community for services and we have gone back to that to see what do we need.

We just went through a process of looking at our AIDS Omnibus dollars which we can reappropriate and we have just gone through a community process of about 25 people sitting around the table, making everybody come in with zero-based budgets and reappropriating dollars.

For things that we could give money to a year ago, that we thought we could, this year we can't because of losing dollars in other areas. That was a very painful thing that went on for us but we really felt we had to do it and it was a community process with a lot of folks sitting around the table.

We have reappropriated our Omnibus money for this year, and we have put together a stragegy for state dollars, and we'll be going to the state legislature in January asking for additional funds.

We have also upped our request from the city account and Northwest AIDS Foundation has upped their fundraising goal next year about 20 percent, so it's really all of us looking at all the different ways to bring money in and starting to prioritize.

MR. SCOTT ALLEN: It sounds very painful and I guess

you're holding your breath for the Kennedy-Hatch Care dollars. Any other questions? Thank you very much for your testimony.

So the next group of people is Rene Durazzo, San Francisco AIDS Foundation from California; Randall Gorbette, Phoenix Shanti Group, Phoenix, Arizona; Ronald Johnson, Minority Task Force on AIDS, New York City; John Pacheco, Minnesota Hispanic AIDS Partnership; and Lorraine Teel, Minnesota AIDS Project, Minneapolis. We will ask that you present in that listing, in that priority.

And again, if you came in late, six minutes of testimony and then we will have one minute to wrap up and I'd ask that you be sensitive to the other presenters and that we stay within that time frame.

MR. DURAZZO: Good afternoon. My name's Rene Durazzo. I'm the Director of Public Policy and Communications for the San Francisco AIDS Foundation and I want to thank you for inviting the Foundation up here today to participate in these proceedings.

I want to preface my testimony by just giving you some short background information on the Foundation and give you some examples of how we have worked with the business sector in a partnership fashion to pursue several different projects that have filled gaps and services in San Francisco and to give you also some recommendations on

how the business community can continue to be involved in the epidemic in the years to come.

Created in 1982, the San Francisco AIDS Foundation was the largest provider of state services in San Francisco. With a budget of about $4.3 million, the Foundation offers a wide range of services and programs to the community. Through it's Client Services Department, the Foundation offers housing, food, social benefits counseling, and emotional support group services to people with AIDS and ARC.

The Foundation also runs an education prevention program which includes English, Spanish, and now a Tagalog hotline, AIDS hotline, and year round multi-Tagalog risk-reduction campaign for the community.

The Foundation also maintains a public policy and communications program. The purpose of this program is to advocate for fair and practiced governmental policies related to HIV-AIDS and to foster accurate media coverage of the many issues facing the epidemic.

The Foundation's Education and Direct Services Program serves primarily gay and bisexual men, women, and junkie drug users of all colors. Last year thousands of men and women sought assistance from the Foundation services. For example, in 1989 the agency's food bank distributed over 24,000 bags of groceries to people with

AIDS and ARC.

Our emergency housing program provided over 5,000 days of shelter to over 400 people with AIDS and ARC. And over 2,200 people received counseling on social service benefit programs. If it were not for the strong support of the private sector, the AIDS Foundation could not offer this level of service or the depth of service.

Eighty cents out of every dollar that comes into the Foundation comes from the private sector, from the generosity of private individuals, businesses, and private foundations. Clearly, our agency, and I think the entire San Francisco network services, couldn't survive if it weren't for the private sector, in particular, the business communities. Over the past four years, the business community has contributed significant resources to the San Francisco AIDS response.

The extent the business sector is involved in is substantial, but there's plenty of room for growth today given the caseload projections over the next five years. The businesses communites provide a wide range of resources to the Foundation from direct program grants to support education activity to legal assistance on key public policy issues.

I want to focus on a few examples which demonstrate the scope of the impact of the business sector's

involvment with the AIDS Foundation. In 1986, the Foundation teamed up with a number of San Franciscan leading businesses and corporations to produce the first program to address AIDS education in the workplace.

Working with health educators, management consultants, employees, resource specialists, and other experts, this business and Foundation partnership is responsibile for providing HIV-prevention information to thousands of people across the country and establishing the workplace as a major channel for sensitizing the public to AIDS-related issues and to providing understanding and compassion of people with HIV disease.

Recently, this department has expanded the AIDS in the Workplace Program to include the next step and this program offers employers guidelines and resources for developing benefit programs for people with HIV and for developing reasonable accommodation standards and policies, and this has particular importance now with the passage of the ADA.

In 1986 the Foundation, again with strong support from the business communities, watched AIDS Walk San Francisco which has now become a major fundraiser and cornerstone to the San Francisco AIDS response.

Without the help from the business sector, we would have not seen this event grow from a fundraiser of about

$500,000 in 1986 to today of $1.8 million in our last AIDS walk a couple of weeks ago. The business communities recruited over 3,000 people to enter this walk. With a very aggressive recruitment drive, it has shown that it is squarely behind the epidemic for the long-haul.

In 1988, the Foundation also formed a partnership with the Westinghouse Broadcasting Company and its local San Francisco affiliate, KPIX TV. This partnership produced the Parent-Teenage Education Project, a project developed to address the growing risk of HIV infection among teens.

Through the resources of Westinghouse and KPIX, the Parent-Teen Project offers techinical assistance to community groups and individuals working to promote the discussion of AIDS among parents and teens, in the home, and in a variety of community settings.

Through a natural distribution effort, the teen-parent package has been disseminated in communities throughout the country, many communities which have very little AIDS education resources to begin with.

The AIDS in the Workplace, the AIDS Walk, the Parent-Teenage Project have proven to be effective and successful projects for partnerships between the Foundation and the business communities. And they were formed to really address very specific gaps in what we saw

as far as the services in San Francisco.

Looking to the future, a coalition of AIDS service groups and businesses are now reassessing service needs and business resources to see how this critical partnership can be expanded or reshaped for the years to come. This assessment is a key step in assuring and sustaining the business communities involved in the fight against AIDS.

In addition, discussions between AIDS service organizations and business service providers generated a long list of ways in which the business community could continue to support AIDS agencies. In general, these areas broke into five groups and I'll go through them very quickly.

Volunteer recruitment: We are still looking at services that are volunteer driven and could not be provided unless we have a stable full of volunteers. The business community can help us recruit volunteers from their employee base.

In-kind services: I think this is an incredibly important area that needs to be addressed down the road. Businesses have enormous resources such as advertizing space, such as printing resources, graphic design resources in-house that can offload other budgets and community AIDS organizations need to work with businesses

to see if they can take over large shares of our budget around these areas.

Technical assistance and training: Certainly the business community has marketing and promotion skills, accounting skills, that can be brought to bear on community agencies that really have to become efficient running forces if they are going to survive in the future.

Public policy advocates: Corporations and businesses have to become public policy advocates. We've had a fairly strong support from Levi-Strauss and a number of other corporations behind the Kennedy-Hatch Disaster Relief Measure. We need this kind of active, agressive lobbying from the business community to support the model of San Francisco. And finally, fundraising: The business community can get more involved in fundraising efforts. Thank you.

MR. SCOTT ALLEN: Thank you very much. Next speaker will be will be Randall Gorbette from the Shanti Group.

MR. GORBETTE: My name is Randy Gorbette and by profession I'm an architect, but I got involved with AIDS services in our community back in 1986, and we put together basically a Shanti model of San Francisco, a nonprofit organization in our community that we operated with volunteers. We have grown into a licensed healthcare organization and we now provide medical and healthcare

services throughout the community.

I want to give you a little bit of description about Arizona, because as I have listened to the other people here share and as I have traveled around the country for various purposes, I realized that we're real unusual down there and I think we make up a little America.

Arizona, Phoenix, and Maricopa County, which is the county in which we are based, are surburban, they're very conservative, and have a kind of transient population. The people that live there are very narrow minded; they're very rednecked; they're very home homophobic; they are very unconnected and a lot of the community is very closeted, in fact, in denial. And a lot of it appears to be as though there's not a community at all.

This is the kind of market in which we work with trying to creat AIDS services. AIDS is not something our community wants to look at. Therefore, there has been very, very limited HIV services that have been there. I call that place little America and I think that's where the epidemic is moving as it moves into the rest of the county.

Currently, just to give you a general idea of what we are serving, we have 400 cases of full-blown AIDS, people that we're working with in Shanti. The Arizona State statistics say that there are 719 in the entire state,

clearly those are not accurate figures and I think the epidemology in that state is really underreported. A lot of people that come there come from other parts of the country, have been living in other parts of the country and come home.

A little bit about us as an organization. I've given all of you a packet, I don't know if you have it now, but if you don't, you will. In there is a number of enclosures about our services and programs, things that we are doing. As we started, we realized that as we tried to provide services that we had nothing to go on, so we had to create, and being an architect, that process worked out real well for me.

I was able to have the oversight to start pulling resources together and networking in our community, with Public Health of Mericopa County, in particular, getting support from various individuals in starting to set up a system so we could create that process. And what we wanted to do was create a living center, something that we consider now as it starts to open, cost-effective in a fashion in the model of a continuum of healthcare services delivered in one environment.

We have taken over property and we are in the midst of remodeling that property with HRSA funding. We call it the Living Center. We see it as being on the cutting edge

of the changes that are going on within our fragmented system in Arizona and probably around the country.

We're not sure where it's going to go. We have been plodding through a community that hasn't really been giving us support so we've had to create our own support as we've gone along, utilizing some parts of the county's help and I will tell you in a moment what others.

Service-wise, we are doing a training and prevention education program that goes out for all our staff and all our volunteers. We run a volunteers program based on the Shanti model and we train all our volunteers and staff on the same kind of program. We run a centralized case management program in which that hub becomes the basis that we give all the people when we're serving their needs.

We are running a counseling and daybed health program. Right now the only part of that that's up is the counseling. We actually haven't opened up the daybed health unit which would be 24 beds when it actually opens in the Living Center.

We have got an HIV-wellness clinic that we did in partnership with Maricopa County which had received some HRSA funding, and it's an asymptomatic clinic which we put in tandem with physicians and a couple of other providers, and it's now treating symptomatic patients as well. We

also have dental services in that clinic.

We were awarded one of the few CBOs -- I think there were 18 sites named in the entire country -- that got community-based research funding from NIH, so we are running some of that funding through the center and we are developing some research protocol.

We have got a home health program that currently goes out of Maricopa County and provides services at home. And when the full capacity of the Living Center is open there will be 96 beds there serving patients from sub-acute care all the way to personal care.

We have now opened a 24-bed hospice unit and we are taking patients. That is running now. The 24-bed control unit won't open until late fall. The 10-bed control unit for patients with dementia will also open in the late fall.

We have been working with HRSA to get the architectural drawings approved, get all the leases approved, and all the other kinds of stuff you have to go through, let alone the licensing and everything that was shared with you in this previous presentation. We went through similar kinds of problems to get where we are with this thing now.

It's basically a 68,000 square foot nursing home that we took over. It's in Central Phoenix, right in the heart

where most of our patients are and close to county systems and close to a number of other hospitals. There's 27 hospitals in Mericopa County, all of whom are receiving AIDS patients, none of which will identify themselves as doing such -- a lot of support.

We will have, when the center is fully open, an adult AIDS healthcare program on site as well. And we are currently running a program for emergency housing which has been, again, very difficult because the community has not been very supportive. We are currently operating seven bedrooms and we just took over another triplex and so we will be opening that too.

Populations served: Again, very conservative community. Gay and bisexual men and their partners, obviously, as their primary focus. Women and children are becoming more focused as well as families. Arizona has Native Americans, lots of them, one of the largest populations in the country and yet we don't even know what the population is like. We do go on reservations and we have some idea. The state says like four to six HIV-infected full-blown cases of AIDS. We know there are 22 just on one reservation.

Substance abusers and their partners: We're going to the prisons and working with inmates. We do a lot of case management and we do a lot of entitlement through our case

management program.

Funding: Arizona has no funding for HIV. They have virtually given no funding for services for HIV. They have done some education but that's been about it. We received HRSA and NIH funding, but that's about it. We have some contracts from Mericopa County and of course the Living Center will have contracts for itself. So we have to do a lot of fundraising within our own community which is not easy and very, very limited.

I rely a lot on going to the federal government for funding. I do a lot of lobbying and a lot of networking with the state legislature and with the county to try to get more funding set up, but currently, very, very little funding. The state is not real willing to plan now for the future. They haven't seen that as an important issue.

I wrote down some notes quickly about linkages, partnerships, and coalitions which was what I was supposed to be talking about. I painted this picture just so you can see what kind of community we are dealing with. We need federal, state, and local public health working together with the CBOs -- almost done.

We need mandatory state funding and we need education that's mandated, and that doesn't occur in our state. We just got an Omnibus bill passed with some of those things called confidentiality and others protection issues,

finally. Just got it passed.

We need incentive in the private sector for corporations to get involved. It's great to hear other organizations share about the corporate support. Arizona gets very little of that.

And we need, when it comes to patients themselves, the eligibility criteria in that entire process of getting people entitlements and government networking and all of that at a state level and county level and federal level simplified so that there aren't so many papers and the process moves a lot sooner.

And we need a time lock. There is virtually no way to get people through a system very rapidly and a lot of people become sick rapidly, and therefore are dying, so I put down ASAP behind that.

Last but not least in this linkage, we spent a lot of time doing the necessary educating of state, county, and city authorities trying to get the board of supervisors and legislators to listen to what we are saying and make some sense out of it.

My summary of all of this is mandatory funding for services whether it be federal, state, or local; mandatory prevention education at all levels, including schools, healthcare providers, even doctors -- and I say doctors who practice with HIV disease -- early intervention

programs to people and their partners; treatment and services connected to research, which I think is a good means to get to the people in a positive way.

MR. SCOTT ALLEN: Can you wrap it up?

MR. GORBETTE: Okay. Two more. A focus on the quality of life and death issues, and raise people's consciousness in a positive way which would help a community like ours move in a good direction. Thank you.

MR. SCOTT ALLEN: Let's see. Ronald Johnson.

MR. JOHNSON: Thank you very much. In the early phase of the HIV-AIDS epidemic when medical and drug therapies and treatment were limited, responding to the social and human need was the principle and in some cases the only way of providing care for people affected by AIDS and HIV infection.

Starting with the Gay Mens Health Practice in New York, groups across the country were formed and an innovative form of providing services were developed. The achievements of these groups, many of which were formed in the lesbian and gay communities, will always be a hallmark in the history of this epidemic and the fight against it.

While AIDS and HIV infection have never been a simple problem, the broadening of the populations impacted by the epidemic has added by significant degree to the complexity of the social and human needs. In turn, the increased

complexity of needs has increased difficulty of providing social and human services that respond to those needs in any given community.

The task is made even more difficult when the social and human services needed by one population group are quite different from the services needed by another population group.

The kinds of programs that gay and bisexual men of color need to respond to their needs are often quite different from the kinds of programs needed by HIV-positive pregnant women and are quite different from the needs of a 50-year-old homeless man or an IV drug user who has HIV-related tuberculous. In this environment, it is very unlikely that any one organization can meet the needs of the various groups of people impacted by the HIV-AIDS epidemic.

Coalitions and partnerships between and among organizations are not just an ideal, but a virtual necessity and the multiple social and human needs of people living with AIDS, HIV-related illness, and HIV infection ought to be addressed in a meaningful manner.

I would like to quickly highlight six types of coalitions or partnerships that I see as being needed. I'm confident that these types of coalitions and partnerships are applicable nationwide. They are based

upon my experiences in New York and the Harlem community.

The first type of coalition that I highlighted is a neighborhood or small community coalition. This is a coalition that is defined by a definite geographic community or other recognized neighborhood. It would involve community-based organizations, hospitals, and other medical institutions, community health centers, mental health agencies, churchs, religious institutions, and the various other social and human organizations.

In Harlem and in New York City we have three programs that are being implemented on a demonstration model to implement this type of coalition. One is in the South Bronx, one is in Central Harlem with the participation of the Minority Task Force, and the third is in the East New York section of Brooklyn and we are trying to demonstrate and to realize the continuum of care model much like the model that you heard this morning here in Seattle. We realize that it would be virtually impossible to implement that kind of service delivery model on a total New York basis so we are trying to implement it in three defined communities.

The third coalition is a citywide and statewide coalition. Again, made up of community-based organizations, social service agencies and federations, advocacy groups, where the aim is to lobby city and state

government for the kind of funding and planning that is necessary to effect the delivery of services.

In New York City we have the Committee for AIDS Funding which is citywide funding and the New York AIDS Coalition which is a statewide group providing planning and advocacy for improving the delivery of social and human service.

A third type of coalition would be within individual racial and ethnic groups in New York City. An example would be the Black Leadership Commission for AIDS and the Latino AIDS Commission. I would like to pause here because this type of coalition represents something that for me I am both simultaneously very optimistic and pessimistic to the point of despair.

We need coalitions, particularly in communities of color. We have heard much today, and I'm sure throughout other hearings, about the levels of denial and the kind of pervasive denial that we have in communities of color.

The leadership in communities of color have to be more involved in this epidemic. To date they have been woefully uninvolved and in fact they are adding to the denial too often rather than fighting it.

We have to stop being polite about the lack of leadership in many communities of color regarding this epidemic and it would be very helpful if the Commission

could add its voice in urging the leadership in communities of color to become far more involved in this epidemic than they have been to date.

A fourth type of coalition or partnership are the kinds of partnerships between local and state governmental agencies and private sector agencies. I was encouraged, hearing some of the models from Seattle and Tacoma, to see the kinds of real working partnerships between local, private agencies, and government agencies.

A fifth example would be partnerships between two service agencies for the delivery of services. In New York City the Gay Mens Health Crisis is working with the Minority Task Force on AIDS and the AIDS Center for Queens County to develop for the first time HIV and AIDS specific legal services programs in communities of color in New York.

Finally, a type of coalition would be ad hoc coalitions on specific issues or problems. Again, in New York we have an ad hoc committee looking at supportive housing needs and we had a very good coalition that developed some sound policies and a bill of rights as far as HIV testing are concerned.

In our border discussions I hope we can perhaps get at some of the recommendations for how we can improve these types of coalitions and partnerships. Thank you.

MR. SCOTT ALLEN: Thank you very much. John Pacheco, you are next.

MR. PACHECO: Thank you. My name is John Pachecco and I'm Coordinator for the Minnesota Hispanic AIDS Partnership. First of all, I want you to know that there are Hispanics in Minnesota, and no, we do not wear down and sell drugs. But, wherever I go nationally, it's like, What are you doing down there? And when I go with somebody else, they think it's an epidemic back there.

So what happened in Minnesota is what we have called the Minnesota Hispanic AIDS Partnership and what that is is a true partnership and hopefully I will differentiate between the collaboration and a partnership as I go along.

What we have are about seven Hispanics agencies statewide meeting on a regular basis and they were meeting on a number of social issues -- this was in '87, early '88 -- and it was an effective method because with a executive director you don't have a peer, you have a board or a staff.

So we were meeting on just what different funding levels, different things that we were doing in the communities -- I will speak fast because I know that time is of the essence -- so what happened is that as we looked at what we were going to do with ARC-AIDS and how do we achieve what we need to achieve. We decided for once that

we were not going to compete, that we would try to put together a model of partnership in these areas.

So we called a conference of all Hispanic agencies together and brought in a couple of different health professionals throughout the country, and in some states the prevalence was much higher than in Minnesota, and looked at what kind of response we could have. From that, seven agencies decided we would try and put this partnership together. I was hired subsequently and what we have here is a partnership of seven Hispanic agencies.

One accomodates the Hispanic Battered Women's Shelter; two, Minnesota Migrant Council that handles all the upstate and rural Minnesotans; Hispanics in Minnesota which is a chemical dependency and drug outpatient treatment center; La Clinica, which is a full service clinic, both dental and medical;

CLEWS, (phonetic) which is channeled through United Good Service, which is mental health and employment; the other is Sancho Pro Chicano which is a multiservice organization; and the last one is the Spanish Human Affairs Council which is a state agency and because it was a state agency did not provide direct service. That's where I was hired on, because the state agency then did not compete, and we were really looking at trying to form a model that would not compete with each other, and we

chose not to do the lead agency.

Our partnership was built on two principles. One, the overriding fact of the devestation of the disease outweighed any political, corporatic, and competitive differences that we had. Two, we were not looking to create a new organization. We had some very skilled organizations that had long histories of working with the Hispanic communities and we didn't see the need to create another organization.

With the partnerships coming together, we then looked at how do we do this. And, again, we did not go the lead agency role. What was called together was every designated staff person from the particular agency, meeting on a weekly basis, and we set one agenda to work with AIDS in the Hispanic communities.

And so once you do that, then we quit with the boundaries. So if I wanted to send somebody to Duluth, Minnesota, which is quite different than Minneapolis, any staff that we chose from any organization would go. All the staff were trained at the same time. All staff, we use one brochure with all of the organizations named. We use one set of videos, depending on -- we have one set for the organization but we have different videos for rural Hispanics versus for urban and the different communities within.

We have one of the executive directors of the organization serve on the board and so they meet monthly. Again, the staff meets about weekly right now. And so in a sense we have an organization but without an organization. We don't compete for funding. We are fortunate in the state of Minnesota where the legislature did allocate $400,000 just for people of color in AIDS. Because they didn't quite now how to divide it, we're big enough competition, and so they just basically divided by color. And so $100,000 to Asians, $100,000 to Indians, $100,000 to Blacks and $100,000 to Hispanics.

Because we were in a partnership we received all of the $100,000 and we were aching to decide what we wanted to do. In some sense they had no option. If you are going to fund the Hispanic community in the area of AIDS then you are going to fund this partnership.

We have no bias within the Hispanic partnership and when we want to look at other efforts, we partner outside that. That's the partnership within the organization and we provide education, we provide -- we just started providing case management support services and the person from Minnesota AIDS Project will talk more about that.

An example of partnerships now. We were looking at a hotline and now why create a new hotline. What we wanted was bilingual services and so what we did, we partnered

with the Minnesota AIDS Partnership. Now I send three staff a week over to them and we provide viable services. I don't tie up a phone line. Why create something that doesn't have to be created?

The National Institute on Drug Abuse funded the IV Drug Use and AIDS Research Project in Minnesota and the University of Minnesota had that contracted. Well they needed somebody to do the Hispanic outreach so they contracted with me to provide Hispanic outreach.

The Minnesota Department of Education provided education for both teachers and principals. They needed to hire some people of color, frankly, and in Minnesota I think people of color represent about five percent of the state, so they are sorely lacking in the Department of Education with qualified people of color.

So instead of them looking at just their need of providing education that will treat teachers and principals, they looked at some ways that involved people of color, so they contracted with me. What happens, I send somebody a half-day and they take care of the teachers, and they in turn take care of my kids, and so that's a partnership where we both win.

Another one is the Minnesota AIDS Project. We are in partnership with the case management with the Indian AIDS Task Force and the Turning Point which is an

African-American drug treatment center. So those are the partnerships that we have formed.

I think the other point I will make is there are little barriers to these types of partnerships. First and foremost, most of them don't understand it. They really love the idea of partnership. They think it's wonderful that you can collaborate and become a partner. But when they send you an RMP that says, Who's your board? and you try and explain that and then they send you an RMP that gives you eight pages to explain something when you have seven agencies, it's real difficult.

I think I have one minute. The reasons that we are where we are today -- sorry, I can't provide enough information -- but I think from some of the testimony we have heard today we are a low-prevalent state. And so this has been accomplished, which you heard from Washington, it's very similar to Minnesota. We have real good support from the philanthropic community.

But because we are a low-prevalent state we have the time to look at these types of partnerships. We are not in a crisis mode. But what's happening is now the legislature is -- as the nation looks at funding only high-prevalent states, it's cutting back money to the State of Minnesota. You lose the model when you do that and I think we have been allowed to put this model

together and look at some real innovative ways to do this.

Finally, I think the assumption is that if you have a partnership, it's going to cost less. What you do with partnerships, you put together an efficient model and it doesn't cost any less. When they put NATO together, it didn't cost the countries any less. They had one group together doing it. And that's what's happened here.

We have all our agencies working together, and it doesn't cost less, but we have a very efficient model, so down the line we will save money. But when you start a partnership up, it's going to cost money. That's all I have.

MR. SCOTT ALLEN: Thank you. We have one final speaker before we have a chance to dialogue and I hope you will dialogue between yourselves in this wonderful opportunity. Next is Lorraine Teel from the Minnesota AIDS Project, Minneapolis.

MS. TEEL: I think as John has explained to you, we do have a good situation in Minnesota. I find, not only from this panel but also found this from other panels to date, the term partnership has been used in a variety of contexts. For the purposes of my time, let me be clear on what the role of partnerships does not mean for an AIDS service organization which is the type of organization I represent.

Partnerships in this field may not always involve two or more groups who are equal in power. For example, a partnership between the community of AIDS, the ASO and an advocacy group for the disabled may be better matched than the average partnership between the same ASO and a small nonprofit community center run by and for persons living with AIDS.

Second, partnerships are not always developed because both parties are willing. Often partnerships come together because of financial need or due to governmental edict. Certainly in those two examples power becomes an issue.

And finally, partnerships are generally informal and have few models with which to pattern themselves, and most often do not have guidelines with which to operate, resolve disputes, evaluate projects, or even terminate the relationship on amicable terms.

To make the establishment and usefulness of a partnership in the AIDS community even more troubled and in addition to the points I just mentioned, I see some 11 groups with which partnerships may be formed. I think we just reviewed for you some good coalitions. Within those coalitions the following 11 groups exist.

First of all, our policy makers. Those legislative, governmental, and self-appointed individuals who come

together in an ad hoc or formal basis to recommend and shape policies regarding AIDS in our community.

Second of all, the medical communities, including both those in direct patient care and those in research, including clinical trials.

Third, community-based organizations who do not have as their primary mission working with persons with AIDS or HIV disease. I think John outlined for you some of those types of organizations, including alcohol and drug treatment programs, shelters for battered women, programs for troubled youth and mental health clinics.

Fourth, criminal justice programs, including jails, prisons, and work release facilities. Developing AIDS-related education and treatment programs from these facilities is often problematic. This is true of the major infection routes, sexual activity, and use of IV drugs forbidden by the rules but practiced by the inmates.

Fifth, organizations formed by, run by, and dedicated to service for persons living with AIDS. These programs often include those services which are the most practical in terms of meals, home helpers, transportation on a daily basis in which persons living with AIDS can congregate.

Sixth, advocacy groups working in the area of equal access and equal rights for gays and lesbians, the disabled, and others who don't fit our mainstream

definition. These groups may be lobbying for issues such as access to healthcare, ARCS legislation, or changes of public housing policies.

Seventh, due to the unique natre of AIDS, the faith community as has already been outlined for you so well today, has come together and provided care and spiritual support to many.

Eighth, because of the elusive nature of the cure for AIDS, and for a variety of other political or personal reasons, the alternative-healthcare community is one in which we can form partnerships and collaborative efforts. Included in this group of practitioners providing alternative care are a few traditional western medicines, acupuncturists, naturopaths, and massage therapists, just to name a few.

Ninth, as AIDS and HIV disease become increasingly long-term chronic conditions, other chronic diseases or health-related coalitions and groups will become partners with those of us working with AIDS. For example, cystic fibrosis, MS, MD, cancer societies, and heart and lung associations just to name a few. All have educational programs and volunteer structures which might prove useful to examine and possibly duplicate in part.

Ten, many times funding sources are dated as adversarial by many of the groups I just mentioned,

regardless of the fact that by virtue of their contractural relationship they are most often those we are in partnership with.

Eleventh, I finally come to the realization which outside of the medical and alternative care communities is I feel most in the direct trenchs of day-to-day work and that's the AIDS service organization. Having as its primary mission working with persons at risk as well as those already living with HIV disease or AIDS, these groups find themselves either going it alone or striking up partnerships, formal or informal, with any or all of the ten AIDS prevention groups, sort of picking one from here and one from there.

These partnerships will most likely involve more differentials, differing organizational structures, religious, political, or philosophical differences, and even have different target populations. They will have in common, however, lessening the rate of HIV infection and improving the quality of care and quality of life of persons living with AIDS.

How then can those of us working and living in this field create and improve AIDS partnership? First of all, I think we need to identify the needs in the continuum of service. We can hold community forums regularly, network with persons living with AIDS groups to obtain feedback,

conduct surveys with clients and with community representatives, read reports prepared by staticians and trends, pay attention to the gay and lesbian crowds.

Bringing working groups together representative of any of the 11 groups identified by the community's unique problem will be helpful for us. If, for example, the problem is access to healthcare, bring together medical representives and advocacy groups and recipients of service. Second, blue-sky solutions. While I hesitate using such a word, I think we have to be careful not to have narrow vision.

Third, we can identify key players created in a community partnership. One of the things that John mentioned is that we need to be careful that it involves more than just the executive directors of these organizations. The frontline staff are often the most creative. And fourth, once the need for partnership has been identified, the agencies or programs selected develop a working agreement between the two groups.

As John mentioned, The Minnesota AIDS Project and three community-based organizations have solid-based partnerships. Turning Point, and the American Indian, AIDS Passport are coming together to provide case management services and we are beginning to develop that working

relationship which I hope will embody all of the points I mentioned earlier in terms of grievances, discussions, terminations, et cetera.

Finally, I just wanted to mention what I felt government's role could be in all of this. First, I think it's important to tie funding of projects to organizations and agencies which are able to recognize and implement some of these points.

Second, identify from provided models partnerships and finally, community-based organizations who do not have as their primary focuse working with AIDS and HIV-positive individuals should be able to demonstrate, in order to get their funding, their collaborative efforts with other organizations that do. Thank you.

MR. SCOTT ALLEN: Thank you very much. I'm sure that we'll have a few questions. Larry, do you?

MR. KESSLER: I have a question for Ron and John might want to comment on this too. You, Ron, stressed the importance of getting community leaders involved in AIDS at certain levels. I guess I wanted to say, they seem to be involved, at least in New York City. They seem to be involved in saying no, saying no to bleach, saying no to needle exchange programs, saying no to sex education and so on.

Do we want more of that or do we want -- how are we

going to get the other people that I think you want involved, involved? And perhaps this is an issue that John may want to comment on too because it is going on around the country and we have pockets of existence that are stronger in some ways in communities of power than in the conservative communities of other pressure groups, or at least equal to.

MR. JOHNSON: It's a good thing I'm in Seattle. No, I don't think we need more of that. That's not the kind of leadership on this issue that I think we need from communities of color and quite frankly I'm very disappointed in the black issue, in particular in New York City, on bleach distribution and other issues, but also, in general, on the AIDS epidemic.

And I think some of the problems that we have in New York City are indicative of the kinds of problems that we have nationwide. When those of us in the Community of AIDS Funding and the New York AIDS Coalition which are city and state coalitions, when we look to city or state legislatures for support on any funding and AIDS policies, nearly all the time those are white legislatures that we go to.

Our black and Hispanic legislatures have been remarkably uninvolved in New York City and State in this epidemic, and the kind of leaderships that we have,

unfortunately, have been very negative, and that is why I said I was pessimistic to the point of despair.

While at the same time I'm certainly hearing some of the things that are happening in other communities that does give lift to my optimism; that I feel it is possible for the leadership in communities of color to recognize the kind of impact that this epidemic is having and to develop some progressive policies. And as I stated in my testimony, to begin to speak to the denial of AIDS, that all too often serves as a barrier in communities of color.

So, I think we need leadership, not just negative, saying don't do this, don't do that, but providing some real alternatives in this epidemic. And as I said and I will stress adnauseam, working to educate to break the denial and the stigma.

MR. PACHECO: Some of the response that we had early on wasn't so much denial, but it's a question, when you are looking at people of color and AIDS and that is, when the message came out, there was some real resistance, saying, Look, they are blaming us for something else. I have got the highest deaths and the highest unemployment rate and now they are coming in my community and saying now we are the cause of it, we have AIDS. And so there are some people in the community that are thinking, I can't go back out there with another message, and so there

was some resistance early on.

I think after the community really looked at the effects of what is happening, fortunately, in Minnesota what happened was there was some more open discussion and then you had to get by, Well it's only within the IV drug use community, and certainly the gay and bisexual, and so we had to get even beyond that.

And then the organizations that we had to look at who traditionally have been long-time Hispanic organizations now had to get beyond looking at what's in front of them other than looking with narrow vision. Fortunately, in Minnesota we have been able to go beyond that and have had some of the leadership go beyond that and the others have either shut up or gotten out of the way.

MS. DIAZ: One brief question for Ron and another one for John. Ron, you had some, I guess, concern in your voice. I don't think you really got to elaborate regarding the compartmentalization of the work of the Black Commission on AIDS and the newly-formed Hispanic Commission on AIDS. Knowing well the history behind those two organizations, could you just elaborate a little more?

Because I can see that you probably share some concern that at the same time it would be very positive in bringing leadership together, and also a voice within those communities, particularly within the area of

advocacy, that perhaps the two, in their zealousness to now go at it from two different approachs in New York where there are two main populations that are being affected, Black and Hispanic with HIV. How do you see this being both positive and negative? Just elaborate a little more on that.

MR. JOHNSON: Well, certainly especially in the Latino AIDS Commission and it has been in New York City a long-time formation and many political and other cultural debates, arguments, et cetera. But on the whole, I think the formation of the Latino AIDS Commission is a positive-voice move just in the fact that they were able to coalesce and to diverse the Latino community in New York City, Puerto Rican, Dominican, Central American, et cetera. So that was an accomplishment.

I'm hopeful that we can take it another step forward and have more cooperation between the Latino Commission and the Black Leadership Commission. So far there has not been that kind of cooperation and, in fact, there is some real opposition where the two commissions, particularly around HIV education targeted to substance abusers, have taken some radically different approaches and we need to somehow find a way to get at that.

Unfortunately, I'm more in agreement -- well not unfortunately -- I'm in more agreement with the Latino

Commission on this particular subject than I am with the Black Leadership Commission on which I serve. But as I said earlier, I'm very disappointed in some of the kinds of conservative, to say the very least, stance of that commission.

And as I stated, it stands as an example of how the leadership can very often feed into the denial and the continued stigmatization around this issue rather than really informing and educating the community.

MS. DIAZ: I guess my concern, Ron, is that the leadership, which may be at this time using one opinion or one strategy against another, can really have us just play right into their hands and say, We hear from the Black Commission, a prestigious group that's been in existence for a number of years, this opinion and we hear from the newly formed Latino folks a different message, therefore that gives us an excuse to do nothing or to delay, which is the deadliest form of denial.

MR. JOHNSON: Also, I think we have to at some point get into these class issues that are at play here that too often get swept under the cover. There are some very real class issues within the Black community that somehow get smothered over in brotherly and sisterly solidarity which is more false than real. And I think there are these class issues, particularly when we look at how to deal

with substance abusers, we get into some real class issues that we are not confronting.

MS. DIAZ: John, brief question to you. Are you part of the Northeast Coalition?

MR. PACHECO: Midwest Hispanic.

MS. DIAZ: Is that funded by the CDC? I would like for you to explain a little bit about that because this is one of the most positive regional consortiums developed that came out of CDC funding and we haven't heard in our testimony people testifying what came from this type of collaborative efforts that was funded by CDC and if you just could comment on that.

MR. PACHECO: Sure. The Midwest Hispanic AIDS Coalition which is based in Chicago -- Illinois, Minnesota, Wisconsin, Michigan, Indiana, and I'm not sure if there is another one, but anyway, they, through the money that CDC -- in this case I'm on the board of Midwest Hispanic AIDS Coalition and so each state has a representative elected by the community to go to meet and then the money goes directly to the Midwest Hispanic AIDS which is divided among the different states to provide different partnerships or to look at direct services where there isn't any or in some states there's very limited services.

In our case, the money was spent on forming this

partnership. We meet quarterly. But an example of the partnership there is that in Minnesota we had moneys set aside for the legislature to conduct a knowledge and behavior survey.

And rather than having the existing organizations do the survey themselves -- which in some sense may be tainted here, I'm going to provide the survey as well as provide the service once the survay is completed -- I contracted with Midwest Hispanic AIDS Coalition, who completed this survey in Chicago, one in Detroit, and one in Indiana to come in.

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We hired some local folks through them and provided the resources but they pretty much conducted the survey. Therefore, they come in with a survey, saying here is what is exactly happening and we in turn can use that to design a lot of our programs and our efforts in a statewide area.

So the partnership has worked. One, as a funding source and another as a partner in producing a product which is a knowledge and behavior survey and a third is a regionalized look at how we can collaborate.

Another example is when we have our annual -- we have a statewide conference in which all Hispanic agencies close up for two days. They send secretaries, janitors, they send everybody to the state conference on Hispanics and AIDS, and at the same time we have the Midwest

Hispanic AIDS Coalition having their board meeting. So I'm using the expertise of these different states without having to pay twice the price and so it's another partnership, but that's another way to maximize resources to get something done.

MR. DALTON: I want to start by thanking Lorraine and Ron for kind of thinking ahead a little bit about this issue of partnerships and coalitions and helping us figure out how to organize this part of our report. I don't know if Jason Heffner who is the principal staffer that was working with us is in this room, but if not I will suggest to him that he sort of look back at your testimony because you really did help us sort of sort things out.

I was struck, Ron, that you did not have a category however, for interracial, inter-ethnic, but rather intra. And I basically go to ask the same question that Eunice did. You might want to invite Catlin Fullwood to come to the city.

MR. JOHNSON: I thought of that myself.

MR. DALTON: My question is for Randy and for Lorrraine. For the first time that I can remember -- I'm getting old -- this Commission or part of this Commission heard people talk about wellness, wellness clinic, talk about alternative or complimentary therapy. And I guess I want to invite you to say a word more about the role of

holistics, particular approaches, or folks in the wellness and complimentary therapy in the AIDS epidemic and give us some idea about barriers, if any exist, to helping people who are infected with HIV learn about and take advantage of alternatives to sort of traditional western medicine.

MS. TEEL: I think some of the areas that exist are more in our mind than they exist in the identifiable, if you will, patient's mind. And I think particularly in Minnesota in the American Indian communities there's been a lot of work, although there was some discussion this morning with resistance, but with traditional American Indian healing-type things and that is a very, very important part.

I think the American Indian community in Minnesota is more accepting of that than the traditional western medical community in Minnesota or even that of the average Joe or Joan down the street, if you will. So I think that's where the barriers exists. The barriers don't exist with the family or with the identified patient.

MR. GORBETTE: You know, one thing that we all do as human beings is that we often times just give up our power to doctors and say, Heal us, fix us, make us better. And so we are very much focused on empowerment and giving people as many as choices as possible, and our whole program runs in that direction.

And so with that kind of focus, we find that once people are given that permission, they start encountering new kinds of complimentary alternative treatments or therapies and they want to try them. If they have a doctor that is not in denial about it and they are not afraid to, the patient and the doctor talk as one human being to another, then things start to happen.

It doesn't always work and requires tremendous amounts of counseling and ongoing support. But we are finding more and more people realize that there is more than just their body, that their spirit and mind and mental issues are involved and if they get the right kind of support, whether it be counseling or training and education or early intervention, prevention education, it works and works well. How to get all that out there? I'm not sure. Because it really means changing what our belief systems are and expanding that process.

MR. SCOTT ALLEN: Rene, do you you have a comment? I know that San Francisco has been involved in alternative therapy for a long time.

MR. DURAZZO: Yes. I think that issue has drawn just as much opposition and resistence at being incorporated into the overall model of care in the city as in any other place in the country. There are certainly organizations that are promoting in many ways alternative care, but I

think that they have a very long way to go in being accepted and validated as part of the continuum of care in San Francisco. It doesn't exist basically. People really have to work hard to seek it out and get the information they want and incorporate that into the machinery, whatever it might be.

MR. SCOTT ALLEN: Do you have any other questions?

MR. JIM ALLEN: I want to thank you and I'm sure I'm not the only one here that does it for the leadership that you have all shown, because I think if we listen to testimony day after day around the country it becomes very apparent that there is a lot of leadership out there in the United States along this issue but it's not coming necessarily from the top.

Ron, I want to go back to that very disturbing issue that you raised that Larry picked up in his first question, and that is the issue of adequate recognition of this problem with HIV infection and AIDS in the minority and racial and ethnic minority population by the leadership, ethnic leadership, in those communities, and what can be done.

You had indicated at one point in a statement that you hoped the Commission would be able to do something. I think the Commission will make statements but I don't think that's going to begin to affect the problem. I look

at the conferences that have been held that were sponsored first of all by the Centers for Disease Control and last year by the Public Health Service as we attempted to broaden the issue in the planning stage.

Now, the response is primarily by the Office of Minority Health, regional conferences for racial and ethnic minority population. The Health Resources and Services Administration, Alcohol and Drug Abuse, Mental Health Administration, Centers for Disease Control, all planning their own types of education and awareness conferences. I think we are going to have a lot more effort on this.

But if it's going to be successful and really getting done what you indicated needed to be done in terms of involvement in leadership, I think somehow we need to sit down in some working group before all these conferences and really dig out how we are going to force the identifying leadership not to avoid this problem any longer, and we probably haven't done it very effectively and I don't think the white community can do it. I think we are going to have to work together in another type of partnership to figure out what we are going to do and if you want to respond to that.

MR. PACHECO: I think there is an assumption in what you are saying, I don't think the white community can it.

But the white community also tends to try and choose the same leaders for all the problems. You don't ask Lee Iacocca what he wants to do about AIDS, you ask him what he wants to do about auto workers and Congress.

And so the same white leaders are saying to the Hispanic leaders who have done something on unemployment and discrimination, why aren't you out there on AIDS? Well, that may not be what that person understands or what they're getting out. And so I'm saying it's not for anyone else to choose our leadership, but there has to be the median others that take a serious look to see what they expect out of leadership and it is not always going to be the same as in the past.

It may be that, you know, Ron here is the leader to talk to and not maybe somebody else or one of the legislators is. Because all the white folks don't always do the same things under their leadership and I don't think that's a realistic expectation that we want.

MR. JIM ALLEN: I think that's a good point and that's the kind of discussion that we need to have that is sort of strategy forming in order to figure out how they are going to get done what needs to be done.

MR. SCOTT ALLEN: Can this Commission make that kind of recommendation for this kind of thing to go out? That's a yes? We can go ahead?

MR. JOHNSON: But we will also need to have some closed-door conversations, particularly with our political leadership, members in Congress who are there and are active on legislation that has impact on this epidemic, whether it's federal legislation, state, or local legislation, we need to close the doors.

We Blacks and Hispanics and other people of color need to close the doors and say to these individuals and legislators, Cut the crap; it's your people; it's your voters; that's your constituency who are being impacted by this epidemic and you have got to take a more forceful role in this, and then we need to then tell them, Or we are going to go to your constituencies on election day to say there may need to be a change in who represents us in the various legislators.

MR. GORBETTE: I think this problem goes beyond the legislators, it isn't just an issue of legislators. Because even the agencies that are providing services, for example, to the Latinos and Blacks suffer from homophobia, do not want to jump in with both feet.

The money has gone to traditional agencies that have been rooted in the community for many years, and these agencies are no more sympathic to being agressive about this issue and are wasting the money than the legislators are in maintaining a posture of denial, and we have to

address that problem head-on.

And in my community, the Latino community, we suffer greatly because the agencies don't want to expand when they need to expand and they are doing other missions, they are carrying on drug programs, whatever. AIDS is not the priority.

MS. TEEL: I would just hope that in those closed-door meetings that the leadership would recognize that in AIDS work women constitute at least 50 percent of those in partnerships and I would hope that at those meetings we are correctly represented.

MR. SCOTT ALLEN: Is that a hint? Larry has a question.

MR. KESSLER: More of a comment. I'm so glad you, John and Ron, bring up some of these issues, because it's very difficult. As in my real life, I know what happens when the media calls and says, We want black leadership to speak on this, and we'd like that too. And who do they call but the minister in the community who won't square with them on AIDS for an opinion, and trying to get them to call the grandmother or hairdresser who might be a real indigenous leader around this issue is just impossible.

So I know we are going to have in the next four or five years a lot of knock-down-drag-out fights, I think, in confronting some of these kinds of issues. But it is

going to take place, some of it behind closed doors and some of it is probably going to get messy.

And also keep in mind, the media is terribly responsible in wanting to hide a lot of the dispute or the conflict that exists between all the communities involved, and somehow or another we have got to do what we were talking about, help leaders to help lead the media from a different perspective around this issue of leadership around AIDS.

Because it's debating all of us and it doesn't serve the purpose, just gives the virus a niche in which to eat away at all our communities. So I'm glad that you mentioned that 500 words with the media and their role in this as well.

MR. DALTON: Can I make one more comment? I know you guys want to close on this.

MR. SCOTT ALLEN: No, Harlan, you can't. Yes, go ahead.

MR. DALTON: We have got an industry in this country that says we have great mass communications and it revolves around marketing, and mass media, PR, and all that sort of thing, and yet it's an industry that we haven't tapped in any kind of positive, connected way to utilize getting a message out to the peer group leaders in this country which might be that hairdresser that you are

talking about or a lot of other people that don't necessarily surface or come to the top.

There has been no concerted effort that I can tell, where we have utilized those peer groups and we have networked them together and used that industry in a positive way like we do marketing foods. We do that great. We do Taco Bell and McDonald's great but we don't do AIDS great because everyone says it's a healthcare problem, public or private, but it shouldn't be out there in the streets being talked about in any of our worlds.

MR. SCOTT ALLEN: That is something that this Commission is very sensitive to, the lack of media and so forth. And we have looked at that, so that's a very good point.

MR. DALTON: I guess this has been really useful and teriffic and I'm glad that we're having these conferences. And I guess I want to approach that, your point about leadership and seeing who the real leaders are. One point, many times our leaders in the church are women even though they are the ministers to whom the media goes, so that all makes a lot of sense.

But we do have other leaders who have been sitting on the sidelines, and I guess my question to John is, do you think there's a role the Commission can play in bringing that closed-door, semiopen-door meeting to fruition in

which in particular the Black community -- well, the Black and communities can come together with other leaders like yourself other than people with AIDS in your community that have completed problems, and begin to talk about some of these things?

MR. JOHNSON: Very much so. If the Commission either as a whole or select individuals on the Commission could call this type of meeting of Black and Hispanic legislators, I think that could play a signaficant role in moving this issue forward.

MR. GOLDMAN: As long as there is a need. There needs to be substance behind it. Because we have all been meetinged to death forever. I'm sure everyone on this table has been on every commission and government thing and studied everything in their state and still gotten nowhere in a lot of ways.

MR. DURAZZO: I just have one comment. I think that in certain respects it might be useful, but I also think that you impose yourself into a, I think, city culture or community culture that may not necessarily -- you really have to tread fairly, and I understand that and exactly what you are proposing to do. I think the strongest -- I think the strongest thing you can do is to consistently restate this problem and the need to address it over and over again in every environment possible. I think that

would be most helpful in real terms.

MR. SCOTT ALLEN: Thank you very much. This has been very helpful to us. Before we take a 15-minute break I would like again to remind you all that we have a sign-up sheet outside if you would like to make public comments. If you, during the break, could sign-up and you will be given a few minutes at the end of this if you have any concerns regarding the the HIV epidemic.

(A recess was taken.)

MR. SCOTT ALLEN: I take it you all know who you are but we don't know, because the name plates were damaged by the coffee, by some liquid substance. But if you wouldn't mind, if you would just go through who you all are. And I understand you need to take a flight and so if no one minds, if you would like to be the first one. Please, all introduce yourselves.

MR. DALTON: If you don't mind, we have been sitting a lot today, if we stand to hear the testimony, because we hear better standing.

MR. MYERS: I'm Adam Myers, Denver Department of Health and Hospitals.

MS. CLEMENTS: I'm Maribel Clements, I'm with the Puget Sound Blood Center, Hemophilia Program.

MS. LEE: I'm Deborah Lee. I'm with the Association of Asian Pacific Community Health Organizations.

MS. VALDEZ: I'm Elizabeth Valdez. I'm with Concilio Latino de Salud, Phoenix, Arizona.

MR. MORRISON: And I'm Cliff Morrison with the Robert Wood Johnson Foundation, AIDS Health Services Program.

MR. SCOTT ALLEN: We can start and just go down this direction. And let me explain that it's going to be six minutes of testimony, then after that you will hear this, and then it will be one minute for closing. Then we will have dialogue time afterwards.

MR. MYERS: I would like to thank you for being invited to address the panel. I'm representing Denver County Hospitals, HRSA Administration Project Grant, which we are a recipient of. I'm an epidemiologist or infectious disease specialist in mononucleosis -- I see some smiles -- I'm an oncologist and I'm involved in this project because I also have some administrative responsibilities for the clinics in Denver and as an oncologist I treat AIDS patients who have AIDS associated diseases.

I thought I would start by just giving a brief overview of what our hospice program is in the City of Denver. We are fortunate to have a very well-developed and integrated program with the Public Health Department at the hospital for specialty tertiary care and the primary care headworker who all work under one roof at the

Department of Health and Hospitals.

So the opportunity to provide services to patients at all levels venturing into the system through either substance treatment services or sexually transmitted disease in a public health arena with primary care work is quite well established.

We have a variety of grants that support the program, the most important of which is the 31 City Community Health Program, which is one of the largest in the nation. The Community Health Program has eight clinics and sees about 450,000 patient visits a year.

We have been able to develop primary care physician clinics for HIV patients in the healthcare program where now we have approximately 200 patients involved. With the anticipation that as patients are coming into primary care and the level of infectious illness increases, that these physicians will be able to participate in that care and coordinate it through the levels of complexity that usually AIDS patients require through various tertiary services.

We also have a number of large public health grants from both CDC and other federal agencies which primarily fund outreach as in counseling types of activities. So that HSRA grant that came through our community, a coalition involving other community-based organizations,

was the first service when I came to the city to provide healthcare to patients with AIDS.

Our state legislator, our city council is very conservative and the orientation has not been aggressive in supporting AIDS health services in our community, so the hospital system has been stressed significantly by the development of the AIDS epidemic and the impact financially in the consequence to try and sustain services in our community.

Perhaps I have heard other precentors discuss resorting to prayer for resources. We didn't have a Hail Mary in Denver but we did have a hailstorm about four weeks ago. That was one of the largest influxes of cash in our community in the last ten years, for reimbursement on the average of about $360 million. I'm not sure that it provided any resource to AIDS care in our community, but we are looking everywhere we can for resources.

I would like to encourage the committees of not necessarily the quantitative need in the community, but the potential for that need to be great. Denver is 24th among the cities as far as incidence of AIDS in the top 27 listed.

But it's clear that our need will be significantly greater in years to come since epidemiologically we are several years behind other major cities of incidence. And

it will be of necessity, I think, in addressing needs in our community to appreciate that to anticipate those numbers will increase as far as demand on services rather than chasing after the services with resources after the fact, that it would be helpful to enable us to plan with support up front so that we would be better able to accomodate the need as develops rather than after the fact.

One of the things that we discovered in a recent hearing that was held in combination with the Governor's Cordinating Council on Aids and the HRSA AIDS Executive Committee was the incredible response of the communities to identify what they felt were the need and gaps in services and requested resources to address those needs.

There were about 43 organizations represented and one of the disappointments as the project went for the HRSA grant was the realization that those needs were real and important, but the resources available to us because of restrictive funding criteria, especially this year with it being a swing year -- hopefully the Kennedy-Hatch, if it's successfully appropriated -- with the 27 other cities competitively doing -- we are not -- but the resources that were allocated to us are being looked at very critically and the ability for us to support new organizations in the community is quite limited.

So we have organizations like AIDS Proxy at Large, Shanti, Gay Lesbian Latino Alliance, et cetera, and Parallel, which is a group that services women who for the most part are in need of -- basically trade their bodies for resources, usually drugs, that we were unable to include and incorporated in spite of the enthusiasm that was generated by revenues of the type of requests of resources that support these organizations.

So although our coalition building in our community has been quite successful, we are quite limited as far as running with the ball, effectively bringing resources to these particularly minority organizations because the resources are so limited. So unfortunately, it looks like we've come to them with promises more than resources and hopefully in the future, if we are successful we can be more effective with the tangible assets rather than just words.

Of interest, as has been demonstrated by other witnesses, the needs in the community are substantial in housing, nutrition, transportation, day care, legal services. And our HRSA grant, the criteria that were listed for us to consider, in which we could identify to whom we had allocated or how we'd used resources, most of these areas were not included in those criteria for which we can apply moneys.

So the resources that the community has identified most as they determined the need to be greatest are not those that fall in the same funding critera that our grant allows us to consider. Again, we seem to be able to generate interest and enthusiasm and response, but unable to respond to that appropriately. We need resources to help the community meet the needs they have identified.

In closure, I think the other items that you have learned today just listening to other witnesses, we need to more aggressively approach the private communities to try to bring alliance together with others in the public sector to more effectively address the need as well as improve linkages between the public and private providers in our community, so that gaps in services don't develop between those two areas. Thank you.

MR. SCOTT ALLEN: I know you have to leave for a plane pretty soon. Can you make it through the question time?

MR. MYERS: Yes, I think there will be enough time.

MS. CLEMENTS: Maribel Clements, from the Hemophilia Program. The Puget Sound Hemophilia Program follows all the patients with inherited bleeing disorders in the State of Washington. I have worked with the program for about 14 years now as a combination nurse and counselor.

Of the 400 patients in this state, 90 are

seropositive for HIV, 30 of those have developed AIDS and 16 have died. These numbers seem small compared with some of the other risk groups but for our families and for our program this has been devestating.

We went from a disorder that was easy, at least manageable, to one that family members now have possibly terminal illness and in the amount of time that it takes for coordination of care, support, education, has more than doubled.

With a grant through the Maternal Child and Health Division, we were able to hire another part-time nurse and part-time counselor. But if it weren't for the help from some of the other agencies, there would be no way that we could provide for the needs of our families.

To cross the state it takes at least five hours, and our families are scattered over the whole state, and so I make a lot of use of the other agencies that are involved in HIV, and it's my understanding that that's what I was suppose to address today, how we work together.

Here in the Seattle area, our families receive a lot of help from Northwest AIDS Foundation, AIDS Prevention Project, Shanti, Chicken Soup, the various hospice programs, and some of the other agencies as well.

In outlying communities, I work through the AIDS case managers in the state health department network. These

people know the resources in their own community and have provided invaluable support and cordination of services for our patients that we work with. Now I'm sure that part of the reason things work well here is the way it was set up through the health department which is an existing agency.

But from my standpoint as someone that uses services, what I do is go to the meetings that we have for our agencies. I go to the AIDS Central Health Care Providers meetings which involve people in the health department and medical care providers for HIV-infected patients, and also can go to an AIDS case manager meeting which involves people from Northwest AIDS, case managers from the various hospitals, from various other organizations and hospice programs, and also Pediatric AIDS Network Support meetings where, again, really all the agencies that provide care and services for children are represented at this meeting. And I think these frequent in-person contacts make a big difference as far as networking and making use of each other.

Now in spite of the fact that all the agencies involved with HIV care do make the best use of the resources, I would like to take a minute to talk about what I see as the unmet needs and because as you can imagine, finances is one of the main things.

I work with families from all socioeconomic backgrounds but it seems like all the families runs into difficulty when they have a member that's extremely ill over a long period of time. In the case of a child, one of the parents usually has to quit a job in order to stay home. In the case of a couple, when the spouse, you know, the person that's ill usually has to quite their job and later the spouse has difficulty working because of the care that is needed.

And what we have trouble finding is enough resources for the home healthcare nursing. You know, the families in most cases would feel better staying at home. But it's difficult to find not only nursing care but also nursing AIDS care for the families or individuals that maybe don't need full-time nursing care but are too weak or too confused to be left alone. And those are the families I've really had trouble, even working with all the agencies, to help them keep their members at home.

The other big need is for respit care and we often talk about this at our Pediatrics AIDS Network meetings. There just aren't enough licensed respit care workers and funding for that. It seems that only people in the Medicaid system can receive funding for respit care. It's not only the families that have children. I see the same where there are spouses caring for husbands.

And in one case one of our families, the parents have been caring for one adult child with AIDS for four years and now are caring for another adult child with AIDS. And even using all the resources that are available for home healthcare and so on, hospice, they really cannot get away even for a day.

So having more funding for home healthcare and for the respit care I think would make it not only save on the medical care costs but for the family or my families what are used to managing illness at home. It would be much more comfortable and much more natural.

MR. SCOTT ALLEN: Deborah Lee.

MS. LEE: I was waiting for the buzzer. First, I would like to thank the National Commission on AIDS for inviting me to testify before the working group today. I appreciate the opportunity to share with you information and recommendations on behalf of the Association of the Asian Pacific Community Health Organizations.

Although the numbers of Asian-Pacific Islanders who have HIV infection remain low as compared to the White, Black, and Latino communities, HIV transmission is increasing at a rate of 71 percent per year among the many ethnic groups under the umbrella term Asian and Pacific Islanders. Current statistics from the CDC revised surveillance report indicate there are 860 Asian-Pacific

Islander people living with AIDS in the U.S.

Access to multilingual and multicultural AIDS education and healthcare services is a must. Equally important is accurate and complete healthcare statistics that break down the number of AIDS cases for the Asian-Pacific Islander population, not just nationally, but on local and state levels as well.

ACT UP has been in the forefront of AIDS education and outreach efforts, collaborating with various individuals in organizations nationwide. But because of the lack of trained health professionals who are multilingual and who are culturally sensitive, the task of building partnerships is not an easy one.

Where do we begin and what do we mean when we speak about being culturally sensitive? Language barriers, understanding traditional customs and religious beliefs, and recognition of intergenerational approachs to outreach are just a few of the items I'm referring to.

Last week two health education workers from one of our clinics visited Mrs. Eng who is an elderly Chinese woman living with AIDS. As her nurse, who is a white male, began to discuss the issue of death with her the translator had to suddenly stop the conversation.

Although the issue of death is openly discussed among many people living with AIDS, for Mrs. Eng there are many

traditional Chinese customs and superstitions around dying that made it very uncomfortable for her to discuss. Death is not easy for anyone to discuss, but coupled with the cultural factors involved it becomes even harder.

The following recommendations all emphasize stronger partnerships between both the public and private sector.

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I would like to make the following recommendations to the Commission at this time.

First, that models such as the People of Color Against AIDS Network in Seattle be closely studied and replicated nationwide. Empowering people in our community to fully participate on advisory boards, community outreach, and in strategic key positions which ultimately affect the way AIDS Education and direct services are provided to the community is too often overlooked.

Second, that funding for culturally appropriate AIDS training programs and technical assistance be provided for multilingual healthcare professionals, community-based organizations, and AIDS service organizations. Linguistically and culturally appropriated programs are useless if you don't have people who speak your language and understand your culture. Along the same lines, training programs that educate medical practitioners is also extremely important.

Finally, that the media and organizations that

conceptualize AIDS health education campaigns address issues of racism within their own intrastructures. The modeling and perpetuating by these groups must be eliminated from such campaigns, as it communicates misinformation that Asian and Pacific Islanders do not get AIDS and do not have to be concerned about HIV infection.

On the flight here today from San Francisco I read an interesting article about Tommy Lasorda, manager for the L.A. Dodgers -- I have to admit though, I'm a devote Oakland A's fan -- but at one point LaSorta reminisces about his father.

He said that and I quote here, Even though he spoke broken English, he had the greatest philosophy of life of any person I met. He taught us by voice to love each other and to stick together. He said, If all five of you get on one end of the rope and pull together, you can pull half the town with you. But if two of you get on one end of the rope and three on the other, you'll pull all day long and not get anywhere.

I think that we all need to be on the same side of the rope, pulling together regardless of race, gender, sexual preference, or disabilities. Thank you.

MR. SCOTT ALLEN: Elizabeth Valdez.

MS. VALDEZ: That's hard to follow. Thank you. I don't know who I represent; I think I'm going to use the

Hispanic-Latino hat today. Thank you for inviting me, but I'm most thankful to all the families for all the time that you work.

Partnerships and coalition building has taken place in the Hispanic-Latino community on the national and the regional and local levels. It's not true that we do not respond to AIDS. National organizations like National Council of LaRaza, funded by CDC, have begun to develop a step-by-step manual for comunity-based organizations on how to create coalitions. It's very useful.

The intent of National Council of LaRaza was to serve the 300 affiliates. Concilio Latino de Salud today is an affiliate and has got so much help from them. I fully appreciate it.

On a regional level, Concilio and another national institutions have gathered data about the knowledge, beliefs, and attitudes in the Southwest, including a survey among the directors, the staff, and the clientele served by 50 community-based organizations serving Hispanics in the Southwest.

We have all the data about other factors. The Southwest is among the first of the states with the highest rates from dropouts, the highest rates of teen pregnancy, veneral disease. But still, we don't make data and numbers enough to be qualified to receive funds. We

have to wait until more people is infected or dies. And that's a shame. When you are talking about cultural, and I say this with a lot of respect, when you talk about cultural shock, it's a shock for me coming from Mexico and finding this in the United States.

What is needed? I do agree with what the rest of the panel has said. But I wanted to go a little further and talk about coalitions that are needed that require all our moneys and support and I'm talking about with respect to the Robert Wood Johnson Foundation. What wondrous efforts. We need a five to ten year plan to be able to deal with this problem in order to successfully identify and reach those that we have not already reached.

Except for the white, middle class gay community that has a lot of power and political leadership, Hispanic leadership does not exist for AIDS. It is just nondenial. It's the fact that we have to face so many socioeconomical, cultural, linguistic, and immigration issues that we are overloaded with other situations that have to do with AIDS too.

What about, we need coalitions to facilitate to at the same time pull together all these Hispanic leaders, gay men, to be able to act as a role model or at least take the responsibility to take care of lower-income gays and Hispanics.

We have to reach for the nongay bisexual men that are engaged in man-to-man sex or in rectal sex. That's one of the main problems we have, that there's a lot of Hispanics that engage in rectal sex that haven't to do anything with sex identity, it's a sex practice. And let's stop identifying AIDS or HIV with sex identity, sexual ignorance.

We need coalitions to be able to tell those parents of children, of those grandparents of mothers and children with AIDS, and be able to provide them the support that is needed.

We strongly believe in prevention in the three areas, primary, secondary, and the third of prevention. And the institutions have fragmented the first, second, and third level. We don't have a continuum of prevention. It's not even in our minds, it's not even in our planning process. That, I think, one of the first coalitions we need in a partership is the partnership among the federal entities in the government.

As the third one, I'm suggesting we need a programmatic interrelation. We have the strategic plan, that's very important for is. We have some issues like sexuality. The barrier among Hispanics is that we don't talk about sex -- well, perhaps what's needed to talk about sex. You know, we know a lot about sex but we don't

talk about, but of course we are experts in this. There are some misconceptions about that.

And suddenly we have median patients, where it's considered -- the Inca people who are asexual, no sex people, nonsex complaints, or we disseminize the sex and we drop all this condom part.

We are dealing with human sexuality. We need the time, we need the process to be able to have the gay bisexual community, the IV drug users, the parents, all these people to be able to coalesce. Because, regardless of what we do, ultimately it's a personal decision and the coalition have got to come not just from the federal government or the agencies, the people needs to coalesce and need to facilitate that. Thank you.

MR. SCOTT ALLEN: Thank you very much. Cliff Morrison.

MR. MORRISON: Thank you. I too thank you for the invitation. However, I must preface my remarks by saying I am not an employee of the Robert Wood Johnson Foundation. I'm an employee of the University of California, San Francisco, the Administrator of the AIDS Health Services Program for the Foundation. I also have to say that my views in this presentation are my own. They no in no way represent the Robert Wood Johnson Foundation or the University of California.

I would like to address issues that I only alluded to in the background materials that you have from me. I think that it's important for me, with the experience and the background that I have on a national level the last four years looking at AIDS health service programs and working with a number of communities around the country, that we talk a little bit more candidly about what some of those issues are in terms of coalition building and developing partnerships.

I think as I listened to some of the earlier presentations, and particularly with the panel that was before us, and we kept hearing about leadership in the ethnic minority communities or the lack of leadership, I kept being struck by how I hear this everywhere.

And yet I consider myself a minority person and in the years that I have had to deal with all of these issues around the country and having been a professional person for over 20 years, I have a lot of difficulty now in knowing that we are almost at the end of this demonstration program and looking at what's going on in terms of coalitions.

First of all, I think that we really can't deal with this issue until we look first at what the real problem is here. And I think the major problem is within the healthcare delivery system and I want to address that.

I think that we first have to pull back and look at what's going on within the healthcare delivery system in the United States today, and there are some major problems with it, and I don't think that we can really look at partnerships and coalitions unless we actually address some of these issues.

HIV is simply a symptom of everything that's wrong in society and in healthcare. Personally, I would like to be able to blame the government, and also I'd like to blame a lot of politicians, and I'd like to blame the States, and I probably will. But I think that first we have to blame ourselves. I mean, I'm part of this system, I'm part of the healthcare delivery system, and I'm a professional person, and I can't sit here and indict my peers without indicting myself.

We must first address some of the problems in a very traditional and very rigid and complicated system, our attitudes and how we approach healthcare delivery in the United States today.

We simply have not been good role models in the healthcare delivery system and I think that part of the problem is that we operate on a philosophy that is "do as I say and not as I do." And I'm beginning to have a lot of difficulty with that as a professional myself.

I think for years that I allowed myself to be

brainwashed by it and I think that it's now time that somebody begins to speak up. And I've have heard a number of my peers talk about it and we talk about it in small groups and talk about it between the individuals that are here, but yet we never publicly address many of the issues.

We have to change what we we're doing. We have to become better role models, not only for all of the public, but particularly whenever we look at this epidemic and we look at what's going on in the minority communities.

First of all, I see AIDS services in comunity-based organizations all around the country reaching out, reaching out to us in the traditional healthcare delivery system, and I see us ignoring them and I see us mistreating them.

I feel that we've had to fight from almost day one. We have had to fight a healthcare bureaucracy and we've had to fight professionals at almost every level to be able to accomplish anything.

The success of what we're trying to do really depends on the people at the grass roots level, at the community level. And yet as professionals within this traditional healthcare delivery system, we are almost completely unable to talk with them. And the reason why is because we are trying to hold on to so much control. We don't

want to see the system change. There is too much money being made by too few people, and the resources are dwindling, and we are going to hang on to this system as long as we can.

And I think there's a number of things that we can do that perhaps you as a group can recommend that maybe will start some dialogue for us to start addressing some of these issues. I want to repeat that we have to be role models and the only way we can be role models is we have to be honest with ourselves before we can be honest with anyone else.

First of all, we have to educate all healthcare providers, particularly professionals. We have to educate all of us to the issues of gays, African Americans, Hispanic Americans, and Asian Americans and particularly we have to look at the issues of IV drug use in the United States today.

The attitude in the healthcare delivery system is one of complete negativity in dealing with these groups and particularly with IV drug users. There is so little incentive among professionals to even deal with that group. I've heard it over and over again. I've heard it again today, how they are always treated last and so we seem to be so insensitive to their needs. That's not going to change until we address it.

Presently the system works haphazardly and I believe that's because there's a handful of very dedicated people that are on the front lines, those of us that have managed to elevate ourselves beyond that because it became too difficult to actually go out there and deal with it or we're a bit more fortunate. Maybe it's one of the reasons I have survived for eight years in doing this.

If we allow the whole issue of mainstreaming to occur at this point in time we are going to destroy probably most everything that we have been able to accomplish so far because the system wants us to maintain it. And if we allow mainstreaming to occur at this point in time, I think we should also know that if we allow it to occur at this time that all of these issues are going to bet buried and we're not going to deal with them.

There are some wonderful examples, however, and I think that we should look at the AIDS Health Services Program and some of its projects as well as the HRSA Demonstration Program. Seattle has been a wonderful model I think for all of us. There are other models as well.

But I also want us to look at involving and educating the public. The system will not work until we have an informed and involved public. We have to form different relationships with the media to assist us as well. And as I did mention in my background material, I do want to

emphasize the need for case management.

I know that was addressed this morning, however, there are some major problems with that. Consistently, the healthcare delivery system is its ridigity does not support case management. Very few of us actually understand what it is. I think I probably know six professional people who really know what case management is.

I think that you as a group could possibly recommend that a national task force be developed to look at case manmagement. Case management could help us with a lot of issues, particularly in terms of building partnerships and coordination. We need to define nationally and standardize the definition for case management, outline the components and the role of case managers.

At the same time we need to develop a flexible model that we can use. Right now, all around the country everybody is defining case management differently and most of us are not doing it very successfully. There is a lot that I could say about this issue but I really want to stop at this point.

I would like to finish by saying that I address this this particular way because I feel that it is important as I have come to the end of this program and know that I will be looking for a job, that I want to be part of the

solution and not part of the problem. Thank you.

MR. SCOTT ALLEN: Thank you. Any questions? Larry.

MR. KESSLER: Statement and question for Dr. Myers. First of all, I'd like to congratulate you and the folks at Denver General for your schools in Boston but if he's not happy with it, send him back right away, okay?

Secondly, for the record, I think it might be interesting if you could tell us how many people were killed by the hailstorm.

MR. MYERS: I don't think there was anybody killed. I think a lot of cars were.

MR. KESSLER: And $360 million or so came from the state or city --

MR. MYERS: Insurance carriers.

MR. KESSLER: Did the state put up any relief or emergency funds?

MR. MYERS: Not that I know of.

MR. KESSLER: I was just trying to -- I think you know where I was going.

MR. SCOTT ALLEN: Gee, where? Do you have another question? Eunice.

MS. DIAZ: I would like to ask Deborah -- thank you for your testimony. I wanted you to share with the group something that I know your agency has done which is a really valuable tool for the education of multiethnic

groups within the Asian-Pacific community and that was a production of a multilingual video. In fact, I think this is the only type that I have seen that addresses -- how many is it, six?

MS. LEE: It's produced in six different languages.

MS. DIAZ: Tell us about the difficulties in going about that.

MS. LEE: We are a national group of community health centers across the nation that provide services to predominantly immigrants and refugees and we are funded by the CDC as well as the OMH for two AIDS projects.

Through the CDC we developed the first national AIDS health education video for Asian-Pacific Islanders in six different languages, English, Tagalog, Chinese, Vietnamese, Korean, and Samoan. It was recently approved, but there was much -- there were a lot of problems surrounding the bureaucracy of having the government approve it.

However, it has been distributed internationally as well as nationally across the U.S., and I think that the impact that it will have in terms of educating our community will be pretty positive.

MS. DIAZ: How long did it take you to get it approved once you finished it?

MS. LEE: Once it was completed, because of some

bureaucratic BS that went on, it took almost a year to have the video approved, whereby we lost, I think, a lot of momentum that was generated from massive media campaigns and marketing strategies. However, I think that with the support of the community we were able to recoup on a lot of those costs.

MS. DIAZ: Did you ever receive a satisfactory response as to why it took a year?

MS. LEE: No.

MR. SCOTT ALLEN: Any other questions?

MR. DALTON: Deborah or Debbie -- or Miss Lee, I had to smile when you mentioned you had read an interesting article on the airplane, because my choice was either to read our briefing book or to see pretty women, and I don't quite remember what choice I made.

But I read your piece in the briefing book and I just wanted to say it was just wonderfully textured and nuanced and helped me understand. It was a concrete way of saying what I may or may not have understood otherwise.
If you are going to say something nice about Tommy Lasorda, I can at least say something nice about that.
and I appreciate your testimony.

This is to Ms. Valdez. In many respects I think the line I would take away is with respect to the need to have a partnership within the federal government as one of our

first priorities. I have become very frustrated to the extent the federal government doesn't talk to itself around the issue of AIDS or anything else, and I think that needs to be reflected in a report or anything else that we do. I appreciate that as well as the rest of your testimony.

Cliff, I appreciate your tossing what you put in the briefing book and speaking from the heart today. It has reminded me a little bit of testimony that Janis Boris gave us to in Dallas in which he also suggested that one of the barriers to doing something about AIDS might be those of us in the business, in the AIDS district. Though typically, the people like yourself who are most sensitive to this are the people who in some way meet the problem. It's hard to hear what you have to say.

MR. MORRISON: It's hard to say but I appreciate your comment.

MR. DALTON: Do I have a question here? Dr. Myers, I recently passed through Denver and I recently had occasion to think about oncologists and I'm sort of -- because of a friend of mine who was until last Saturday under the care of one, but I must say you made me appreciate how well with AIDS one can be.

And somewhere I guess I have a question here. Maribel, you stressed the need for respit care workers and

I believe there's one of those things that's terribly important but somehow doesn't tend to get funding or focused on.

But something you said confused me. You said there aren't enough licensed respit care workers, and I guess I was wondering whether the emphasis of licensing is only because one can get reimbursed for licensed respit care workers or is there something in respit care that you think requires a certain kind of professional training?

MS. CLEMENTS: At least in this, and this is something we discussed in our Pediatric AIDS Network meetings and people from the Department of Social and Health Services where they are responsible for the licensing, and foster homes have to be licensed, and again, the same with day care centers and so on that you use. And I suppose it's a matter of reimbursement, but it's a matter of having to list the people you go to as well.

And I think because of the liability and so on, most people won't just put their name up to do this unless it's through some organization that is an umbrella for them. In discussing it, they said we could possibly get respit care homes licensed as day care, and it's easier to get them licensed that way, and probably be licensed in that manner as a respit care facility.

But again, since there's not a way to pay for it, it really is only through DSHS. None of the insurance programs pay for them and the families are usually to strapped at that point to be able to for pay it themselves. And so until there is money to pay for it, they won't be getting more people licensed.

MR. JIM ALLEN: For Dr. Myers, listening to your testimony and I'm reading over the handout that you gave also, it certainly gives one a sense that these are services that are badly needed that ought to be in place for a wide variety of patient populations other than HIV infections and AIDS, and I think it draws on what others have said throughout today and you did earlier in terms of the healthcare system in the country and what we do and don't have.

My question really is, looking at your funding now, is this year-by-year funding? Where are you going to be in two years with that project? What is the state paying on this project? It's listed as a demonstration project, and obviously that clearly implies that at some point, once whenever the demonstration that one is supposed to be demonstrating has been demonstrated is going to be phased out, what do you see coming out of this and what are your concerns and what might the Commission look for or others do to put in place the continuing long-term-type

organizations that we need in order not to have to spend all of our concerns, all of our anxieties, over funding in the future, but providing the services that are badly needed?

MR. MYERS: We are most hopeful that the demonstration project will be continued, as have the initial grant recipients expected that their continuation or competitive application will be considered beyond the three years.

Right now our hope would be that by performance, by being effective, by providing service, by bringing community-based organizations into a coalition where their performances also improve through our coordination and collaboration with them, that we will enjoy greater support from the state. But, obviously it's a bit more than realistic I suspect, particularly in Colorado. I don't see what other resources would be forthcoming because of the general demands and the continuation of practice and expense of care.

I would like to endorse, likewise, what Cliff had to say, as far as the rigidity of the system and it's inability to really accommodate and encourage local creativity and innovation, and I realize that there need to be criteria for which resources are allocated and accountability for the way in which it is spent and

applied, and we need to look toward agencies that have credibility and performance histories, et cetera, et cetera.

But what that does is to restrict, and I think that now is the case as it perpetuates the whole theme, moving from the top down. We know what everyone needs and we will be the ones determining how these resources are allocated. And it limits the community's specific flexibility and creativity and innovative programs that really reflect what that community needs based on what the direct opposition is, how these community organizations are approaching the needs that have been identified. As I said, I think we are beginning to encounter that type of problem.

Latino groups that are now fairly fledgling in getting organized in Denver, their main approach to serving the community is an outreach education which is not a criteria for the AIDS Service Demonstration Project. But no one else will respect that need. Somewhere there has to be support for that to get developed and organized so they can become more into the service mode.

And the executive director has indicated to the staff the need to be less nitpicking about criteria specifics as to the elitist in the way in which the grants are awarded, be more flexible, encourage the recipients to be more

creative and innovative. Likewise, I think if the Commission in your report encouraged this type of flexibility in the community, specific flexibility, it would perhaps enable us to be more effective in what we are trying to do.

MR. SCOTT ALLEN: I'm sure we've had this conversation before. Not only in demonstrations being phased out but it also can be incorporated into the regular budget; is that correct? I may ask Joe when he comes up. But that is also an alternative, is to be incorporated right into the regular budget, which we haven't had much discussion on, so hopefully we will have some in the near future though. Thank you very much for sharing your thoughts.

I believe our next panel is Kristine Gebbie, King Holmes, and Joe O'Neill. Six minutes for testimony and when you hear the little beep you have one minute left to conclude your remarks, and then we'll have some dialogue after.

MS. GEBBIE: Thank you for the opportunity to speak this afternoon and for your coming to the West Coast, and I guess also the opportunity to be on the other side of a very familiar looking table based on my recent experiences.

Not having heard the presentations today I don't -- I

would like to avoid being too repetitious. It's my understanding that you are interested in issues around coalitions, coalition building, and how groups come together to provide services, and perhaps what some issues around that are.

I summarized the kind of coalitions that need to come together. First, as those that are involved connecting individuals with the system. However we do what we do, we have got to get individuals, people either who are already ill or becoming ill, connected with the system to get these services. And in order to do that, we need connections that are private-private, public-public, and then public-private, is the technology I throw at this.

Private-private means getting groups that span communities of color, communitiies of infected and affected people, communities of providers, and the long list of other kinds of communities connected with each other at the local community level.

We need public-public relationships. We need state agencies working with state agencies, perhaps in ways they haven't before. A example in this state is the work that the Department of Health and the Department of Social and Health Services has done to provide the Medicaid Way Program, a clear collaboration of programs.

We also need collaboration for the state to the local

and local to the state level. Again, in this state two good examples are the development of the AIDS NETS which are multicounty regions that coordinate and organize services at a substate level and the systems available of state and local partnerships to provide case management. And I would affirm what was said by previous witnesses, that we need to understand that term.

At a recent meeting on rural AIDS that I had an opportunity to attend, I think we produced five definitions of case management in three and-a-half minutes and then disagreed firmly about everyone of them. So we have got a long way to go there.

And then finally, public-private connections, in which the most notable example in this state is use of public funds. Using state or the local government to provide services that are actually delivered by local and private service agencies of various kinds.

Another connection that didn't quite fit that technology but needs to be mentioned is that of the academic and service areas. And this state is particularly a good example of some outstanding research development activities available at the state university. Their role as both educational providers and in the development of new models and services has been outstanding. And my perception as a relative newcomer to

the state is one reason they found it worked well because they have been in direct contact with the service providers at the local level and been in constant communication with them.

The point I want to underscore -- I think I'm getting close to the end of my time -- is that no part of this is to be excluded, that it doesn't happen simultaneously, and part of what we need is a backbone to hold it together. My own perception is you will not be suprised that state and local health agencies and official governmental agencies are a large part of that backbone and the reason for that is their permanence; they don't evaporate.

Sometimes their missionships, sometimes their money goes up and down, but they are there by law and that is an important part of the continuation. And to the extent the services around this disease have sprung up in agencies or groups that don't have that permanence, we run the risk of their money drying up, their mission evaporating, their key leader moving out of town, and services getting into disarray.

Not that government is the perfect answer at all, by far from it. It's got a lot of problems, but I think we need to find ways to build that backbone now so we can support and strengthen the services at the local levels and private sector. A lot of that is more than just

money. It is a lot of activities, meetings, exchanges of papers. You can fill a room with the paper that has flowed around this state and the State of Oregon where I came from nine months ago.

One of the dollar issues that I wanted to underscore is that I think we need to look very closely at the mechanism we use to make those dollars flow. I'm going to use a federal-state example and federal-local example, but I think the state government has done it too.

And that is, in our rush to be responsive to this epidemic we used the technique of pilot projects and demonstration projects as our way of getting money out there. And I think you have already heard and will probably hear again, the problem with that is that people grabbed that money because it was money and did not anticipate and understand what being a demonstration project means.

It has two burdens. One, that you do research, which is hard to do on a tight budget and hard to do in more isolated areas; and two, that it goes away after you demonstrate your point. It's that last piece that's most troublesome to me.

In many of these cases we really didn't have a point to demonstrate. We knew from the beginning we needed coordinated services; we knew from the beginning we needed

to integrate public and private; we knew from the beginning that case management would work. And the subterfuge of using demonstration projects to prove a point hasn't done much for us and it now leaves a number of excellent programs on the verge of abandonment as that money goes away.

We have got to re-examine that technique. It was a good device, but it was not defined. Administrations that might not have been responsive, congresses that didn't have good budgets, state legislators that were nervous about money, local governments that didn't want to take on a new device, any number of those, but it may well have done a disservice as we get to the next point in the epidemic.

The process we put in place as we move out of this will have to be one that respects differences. In all of what I have said, I want to underscore the idiosyncratic nature of every town, of every county, of every state. And whatever we recommend, whatever we have to recommend, we must be very careful and cautious about prescribing universal solutions because there is no universal solution in the exact day-to-day experiences that will work in every community.

This state has undergone some amazing changes over a three or four year period in where the structure is

centered and who is doing what. I think that's mirrored in every other state and every locality and I think we need that flexibility as we build the backbone of support for all of these partnerships that are needed.

MR. O'NEILL: Thank you. I think I first need to thank the Commission for inviting me to come here to speak, particularly for inviting me to come to Seattle which was my home for the four years prior to joining the Public Health Service and moving to Washington D.C. I found that in the short time I have been back here I have become a rare and popular person in Seattle in that I was a Californian who has actually moved away from the area rather than to here.

Seattle has great warmth and meaning for me for many reasons, none the least of which that this is the city in which I learned to become a physician and learned to care for HIV-infected and AIDS patients.

I owe much of my training and much of my education, I say, first to my patients, to my teachers, people like Dr. King Holmes and also to people like Pam Ryan who is the case manager at Harborview who wasn't able to speak here today.

I was a member of the Seattle community. I treated patients at the Harborview HIV Community Clinic; I attended patients at Rosehedge House; I volunteered as an

HIV testing counselor at the AIDS Prevention Project. In short, I was a small cog in a well-oiled machine which you have heard described earlier throughout the day. I now find myself a much smaller cog in a much larger machine back in Washington.

I'd like to tell you a brief story before I go on to make a few points about what I see to be issues that have to do with federal partnerships with communities. My closest friend from medical school died from AIDS several months ago. Somewhere about a year ago he said to me, You know, you would think that someone who is going blind, someone who is dying, could do something with the last few months of his life other than fight with insurance companies.

His wanting to not leave his elderly parents with medical bills that they felt obligated to pay was every bit as big of a problem to him as trying to balance the correct combination of antivirals.

He did not get his wish. I think he tired out well before the insurance company did. And he was a physician; he had advocates; he was straight; he was white; he didn't abuse drugs; he had a primary care physician. If anybody should have been able to have the path to death smooth, it would have been him, and his was a very tough one.

The issue that I wanted to bring up and to discuss in

the context of federal community partnerships are what about those people in this country with HIV disease who don't have the advantages that he had.

One of my patients who lives in inner-city Baltimore has three children, 34 T cells, and no home. If the social issues became such a bad dream for my friend from medical school, imagine what a nightmare they are for her. I'm sure that you have heard enough testimony in the years that you have been together that I don't need to dwell on this point.

What I do want to do is to emphasize several points about this epidemic that I think are pertinent and then to go on and describe an example of the federal community partnership that I think is important and well worth attention.

My points are, first, that this disease is becoming more complex socially as it affects third-world communities in this country in greater and greater numbers, and this social complexity is further exacerbated as we expand the borders of our medical knowledge.

Second, I think this should be fairly obvious by now, these complexities can only be addressed with the full participation and direction from affected communities.

Finally, I believe one of the most effective means of assuring and supporting affected community involvement in

this epidemic is through the utilization of existing primary healthcare systems. There are many examples of federal and community partnerships that have been forced as we face this disease. I will speak briefly of HRSA since that is the agency in my employment which I know the best.

We have sought out members of affected communities as advisers, as consultants and reviewers at both the agency level and its programmatic levels. I think this has been a good faith effort on our agencies part and I think it has had great import and development of our programs.

Dr. Valdez, who just spoke on the panel before, will be coming back next week to act as a consultant on one of our grant reviews for the express purpose of including her insight into the process that we go through in order to distribute moneys and grants in the program which I will be discussing in a moment.

University and service demonstration projects of significant resources have been directed to the development and maintenance of community-based coalitions in nearly every major city in the United States.

One of the most important of the federal programs which is at heart, one of the oldest examples of federal support of community-based healthcare activities, are the migrant community healthcare programs which were developed

and delivered through the assistance of HRSA. These are not new HIV-related community-based programs. These are, rather, programs which have a long tradition of community-directed healthcare which are now struggling to respond to the HIV crisis.

Migrant health centers serve approximately 500,000 seasonal farm workers annually through 105 centers at over 400 delivery sites. Community health centers serve 5.3 million individuals through 525 grantees over nearly 2,000 individual delivery sites.

These facilities are diverse but they have some important things in common. Most importantly, these are community based. Board of directors of these facilities are by and large users of the provided services. This ensures a degree of regional understanding and cultural sensitivity that would otherwise be elusive. These centers are providers of comprehensive primary healthcare.

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These centers are located in underserved areas. They serve minorities; in 1988, 31 percent of the users were Black, 28 percent were Hispanics. They serve poor people; 60 pecent of the users have income below poverty level, and another 25 percent have incomes between 100 and 200 percent of the poverty level.

Given these statistics, it should not be surprising that centers are also seeing HIV disease. It is

estimated, for example, that 10 percent of all HIV-positive patients in New York, 12 percent of such patients in Maryland, and 18 percent of such patients in Pennsylvania are seen in these community health centers.

In some migrant communities, health centers should be recognized for what they are. And these are federally supported systems of community-based primary care that people at risk for HIV use.

Our offices in the Bureau of Health Care Delivery and Assistance are at the moment in the process of awarding over $10 million in grants to community-based primary healthcare facilities such as these for the purposes of expanding the capabilities for providing prevention treatment and case management for HIV. We have received 129 applications for nearly $50 million worth of assistance.

These have been some of my simple recommendations out of many that I could make. When you think about the increasing complexity of management of this disease, and by this I mean both medical and social management, when you think about the face of AIDS, when you think about underserved minority communities, when you think about women, and you think about rural communities, and you think about federal and community partnerships, think about the community health centers and their role. We are

in the affected communities.

Community health centers have been in these communities for many years. Community health centers are directed by members of affected communities and people at risk for HIV go to these centers.

I believe these centers are one place, one of many, where we should continue to go to look for community-based solutions to the complex demand of this epidemic. Thank you.

MR. HOLMES: Thank you. I think for governmental agencies, including public universities, to foster partnerships and coalitions, one of the most critical steps is for the governmental agencies and universities to establish appropriate mechanisms for coordinating the role of areas within their own institutions.

And as director of the University of Washington's Center for AIDS and Sexually Transmitted Diseases, I have been working with the World Health Organization on a sabbatical this past year, chairing a task force that has presented a consensus during the past two weeks on combining AIDS and sexually transmitted disease programs on national and local levels.

I think this is an example of a very critical area of coordination and I'd like to spend a brief time describing that to you, because I suspect you probably haven't been

offered that message before. If you have, you can stop me.

The task force of WHO defined levels of coordination as ranging from the lowest level of sharing information, to intermediate levels of joint planning, to highest levels of sexual combined programs under single management. And they defined integration as programs which extend their activities into the existing health and nonhealth sectors using other intrastructures. This has been termed mainstreaming here and elsewhere.

The task force, the background on that meeting that I participated in occurred at the WHO at Lyon, in Switzerland, where all the European national AIDS program managers gathered to say where are we going and what are our problems. And they concluded that the resourses were drying up, there was loss of interest. It was true that the AIDS programs had personalized and were trying to do too much all by themselves and that they needed to be mainstreamed and to establish partnerships with other programs.

I think that the issue of combining AIDS and STD programs is perhaps the most critical and most important. The consensus meeting that was held at the WHO with 50 participants from countries around the world three weeks ago concluded the AIDS and STD program should be combined.

The rationale was that AIDS is a veneral disease, that the same method of transmission exists and therefore the same primary intervention strategies are used for preventing AIDS and these diseases. The same risk groups are involved and benefit from the services that have been heretofore mentioned.

STD clinical services offer direct access to people who are at highest risk for STDs and HIV. STDs are implicated as risk factors for such transmission of HIV. Therefore, control of STDs is found to be the primary medical intervention for preventing transmission sexually of HIV.

The benefits of combining were judged to be, number one, cost-effectiveness; number two, the era for resources are inadequate and both programs suffer, and combining leaves a critical mass that can improve power in the comprehensiveness of services; and third, the strategies for controlling HIV and STD are complimentary strategies.

It was felt that the combination should address eight program areas at least, and these include program planning and management, clinical and social services, laboratory services, health promotion, and IAT training, surveilance, evaluation, and research.

I'll just pick three of these. Clinical and social services, using clinics for delivery of HIV services. To

what extent STD clinics provide primary care for HIV-infection of indigent patients was something we've had a chance to talk about in the past.

Regarding training, we at the University of Washington had separte training programs for STD and for HIV, funded separately and functioned separately. Concerning research at the NIH, the primary agency for AIDS research is NIAID. There are two separate branches, one for STD research and one for AIDS research and they are not combined. The AIDS research branch has ten times as much funding as that which supports STD research.

The CDC has another division of STD-HIV prevention and there are also other programs within the CDC, including the AIDS program. I think there is some confusion about what is the primary research responsibility of the AIDS program and the STD-HIV prevention.

There are cautions about combining them. There are some aspects of the program that are separate. The area of overlap is primary prevention and secondary prevention, providing services for STDs and HIVs. But if you look at these two overlapping circles, the separate areas are within AIDS, primarily the IV drug use associated with HIV and the opportunistic infection. In the STD area, it's STD that primarily affects women and children, such as

infertility and cervical cancer and so on.

But the size of the separate components is really related to the effectiveness of combining for that center part of preventing. The less you combine to prevent, the bigger the areas that are separate. It's sort of a catch 22. If you combine things which are separate, they look different and if you don't, they wind up working together.

The U.S. approach has been that we had a large and well-organized national STD program at the CDC before the onset of the HIV epidemic. But initially, a separate AIDS task force was set up to rapidly address the problem and to develop innovative approaches, and many countries did this. But as the AIDS program matured, AIDS prevention was brought back into a close combination with STDs at the national level. This does not happen at state and local levels to anything like the same extent.

And the second factor is that clinical services for STD programs have not been strengthened at local levels like they have been to some extent at the national level.

For example, we surveyed 23 clinics last year, STD clinics, and found that over the last few years 19 of them had had significant increases of waiting times to be seen and were turning people away from the clinic earlier and earlier. At 11:00 they were closing their doors because the clinics were full. They can't do what needs to be

done for taking care of AIDS patients or for dealing with HIV.

Seattle-King County, just to conclude, had one of the strongest STD control programs in the United States at the onset of the AIDS epidemic with 30 full-time faculty at the University of Washington working on STD research. The STD program was a closely collaborated program between the University of Washington and the Health Department with the STD clinic actually being based in one of the teaching hospitals.

When AIDS came alone, the AIDS program was initially developed within the STD program and with strong involvement of the epidemic community. The participation evolved primarily with the Health Department playing the lead of involving community coalitions. The University was very slow in becoming involved in the involvement of community coalitions. I think this is typical and it's an area that we should be doing better at from the academic standpoint.

The Center for AIDS-STD at the University is responsible for coordinating research training and clinical services within the University and with external agencies and it's a concept that seems to work reasonably well.

I'll just summarize by saying that the role of

government agencies needs supporting networks and coordinating involves -- initially coordinating internally. And I would stress the consensus for combining STD and AIDS programs and for integrating them with related programs, such as the family planning and others by formal mechanisms. Thank you.

MR. SCOTT ALLEN: Questions?

MR. GOLDMAN: I have a few, if I may. First of all, as you know, I appreciate your comments and your thoughts, particularly those by Dr. O'Neill. This involves all of us and involves all of us by the passing of those of our dear friends. Hopefully they will move us to continue on in the fight against this disease.

I would like to thank Dr. Holmes for his hospitality and his lovely, lovely lake view And we appreciate your hospitality.

I have a question to Kristine Gebbie. You emphasized in your -- I thought you mentioned in your presentation the need for willingness to be flexible in terms of the different kinds of ways that structures exist across the country.

And hearing a lot of the testimony today and in the past, there are a few themes that to one member of this Commission seems to come through relatively consistently as to where things work well and where they don't work

well.

And two of these things that worked, number one, planning seems to be an intricate part of where things work well. Where things are planned, they work well; when things are not planned, they are less likely to work well. The second aspect is that really central role that I see of the state and local health cooperatives, I think you talked about in terms of being a backbone.

In some cases it becomes a lead agency. In other cases it's function perhaps is being an umbrella kind of thing, and in another fashion it really forms nothing more than a backbone and there are other agencies who really take the weight in doing so. And those things seem to be relatively universal in terms of where things work well and where things don't work well, to my perspective.

The concern I have is, what do you do in your communities where state and local health departments, largely as a result of perhaps reflecting what they believe are political needs of their community, refuse to participate? What do you do with communities in which the -- and it's interesting to talk about STD clinics and things like that, but, you know, there are some communities in which that situation couldn't even get funded because of the hostility toward funding dealing with issues of AIDS-HIV infection in the community.

And how do we deal with the people, with the poor people who live in those communities, who have to face, to face, Gee don't fund that, don't operate that. But that ends up making it even more painful for the poor people who live in those communities who then have to suffer the loss of funding from failure of those communities to deal with it.

MS. GEBBIE: There are a couple of things we can do and I appreciate an opportunity to comment on them, because it is extremely true that across this country there are both states and local governments who have not been responsive to this epidemic or as responsive in a timely manner as we want.

I don't know, at this point in the epidemic they still have their head completely in the sand and they are struggling against a lot of factors. One is the lack of support funding or just to be there for STD or other kinds of things. But I think we have to deal with a couple of things.

One of them is to find platforms for criticism of them to be done constructively, so that there are ways for a community to talk about whether their health department is being helpful or a hindrance. That can lead to progress rather than just yelling and screaming and shouting in the dark.

And I don't know whether that means a federal critical role of somebody coming along and critiquing or requirement of hearings at the state level or state health department perhaps being a little braver than we sometimes are about critizing the condition of local health departments that aren't quite measuring up to the mark and taking some heat for being critical. So I think that's a part of it.

I think the mechanism that is available in some states that works well and could also be structured between the federal and state government with some crafting, is that of giving the official agency essentially the right of first refusal on the role of coordinator and backbone, but with a very clear way to go around it when they aren't there.

I know about that structure from the State of Oregon so I use that as an example. The statute is very clear that the local health department is the provider, is the recipient of state support for local public health services.

But, if in the eyes of the state they are failing to meet that mandate, there's a minimum set standard, the state clearly has the right to take the money back from them and give it to any local contractor that can deliver the services for contract, to the neighboring health

department to do it.

That, in essence, has some of the effect of my first suggestion. The threat that you might not get the money because you are not living up to the contract gives an interest to the local government to say, "Why not" to the local health department, go to the local commission and say, I know you don't really like taking care of poor people or I know you didn't want to talk about HIV because it's a messy condition, but we will lose funding if we fail to do that and we will not be delivering to our constituency. And that's a very powerful tool for getting that going.

I think the other powerful tool for holding people accountable is the state equivalent of a commission. They exist, I think now in every state or nearly every state. In this state it's the Governor's Council on HIV-AIDS. There is a different name for it everywhere, but where it includes all aspects of HIV-affected communities, providers, infected persons, their families, official agencies. It provides a platform for that criticism to go on and for people to respond. I hope that's not too long an answer.

MR. GOLDMAN: If either of you two would like to comment on that? Thank you.

MR. DALTON: I have a question. Well, first I want

to thank Kristine Gebbie for the work, for your efforts with our predecessor commission. One of the nicest things about being on this Commission is that none of us has had to spend time educating our fellow Commissioners about AIDS, and we are among the beneficiaries of your efforts, so I say thank you.

King Holmes, I actually find myself very troubled by your testimony, although I appreciate your taking time to make your point and lay it out in some detail. I kept hearing in the back of my mind, in fact, Kristine Gebbie was saying we need to understand that each state is different, each community, each -- well, each state, each community. And what I heard from you was the universal kind of solution to the issue of mainstreaming versus nonmainstreaming, particularly in the context of HIV and sexually transmitted diseases.

I also heard Cliff Morrison, who is gone now, but him saying at one point in his testimony that at the moment he was against mainstreaming AIDS, that may be the ideal solution down the line but not now. We never got a chance to ask him why.

I know that I personally have sort of struggled with mainstreaming versus not and maybe the answer is that it is one of those things that is community by community, taking into account lots of other factors.

Now, specifically combining STD programs and HIV programs, this wouldn't work with testimony from our panels in our cities from folks who describe the actual on-the-ground operation of STD programs in ways that would not be wanting to enfold HIV into them because the kind of counseling that exists in many STD programs is perfunctionary at best -- not everywhere, which I guess that's my point.

But sometimes personnel who are employed in some of our STD programs are closely settled in, whereas a lot of folks have been left to drown in HIV, that may be tired, may be burned-out, but they tend to be creative, highly motivated.

And so I guess what you were suggesting was universal in a liberal sense, that is a consensus from the World Health Organization, and I just wonder about taking that and replicating it in King County and in whatever county Dallas is in. Can you respond to that?

MR. HOLMES: Well I'll try to respond to that. I think that the issue of mainstreaming, first of all, is one that represents a consensus that was reached among the European participants in that meeting in Lyon, and to speak to that a little bit more, there was a feeling that people working in the AIDS field were confronting a number of problems, increasingly diminishing resources, they were

burning-out, they were fatigued, they were exhausted, and at the same time they were experiencing hostility from other programs that felt they couldn't participate, wanted to participate but were not given an opportunity to participate.

And it was really a strong consensus of AIDS program managers that participated there, that the obvious solution to those problems was to mainstream; that they were right in the beginning to set up programs that were vertical because they needed to develop quickly and urgently core programs with core administrative structures that could administer budgets and design programs and not see the money filtered away.

But once those superstructures for AIDS programs were set up, they began to realize that without the mainstreaming and integrating with the other programs, they didn't have a program. And this was particularly true as the diversity of the patient population affected increased the mainstreaming.

The issue of having a uniform model, time constraints really don't allow me to go into the options for approaching this. We recognize that there are political and economic constraints on the level of coordination or integration that can be achieved from community to community.

At the meeting that I described on mobile strategies for coordinating or combining and getting an STD program at WHO two weeks ago, there were 50 participants there, including three from the U.S., two from CDC and one from NIH. And the consensus was that models needed to be developed according to what the community could accomodate but that the ideal model was one that was a combined model that didn't limit AIDS control activity, so those that were taken were taken on with a different STD structure but to use it to the maximum extent possible.

And where there are clinics that are substandard, for example, or people who don't use STD services but use other services in the community, for treatment for STDs, that defines the STD services for those communities, and we need to be apprised of this and recognize that's where those patients are going. We need to work with that system to use it to accomplish and improve prevention and services for HIV.

MR. DALTON: Let me just follow-up briefly. I heard what you said about the European countries being quite clear about the need for mainstreaming. It occurs to me that the mainstreaming question might look a little different in a country in which there is national healthcare.

It also might well turn on the kind of structures

that one has for picking up programs that were specialized and making them mainstream, that is, their effect with AIDS, that the mainstream here ought to be copies. But I'm not convinced that if we were to mainstream, what we've learned today could necessarily be replicated. So again, I guess that those are kinds of institutions at both the national level and somewhat the more local level.

And I guess the final point I wanted to make was that during your testimony it seemed to me that the advantages that you talk about all seemed to have to do with AIDS viewed as a biomedical phenomenon, and yet we all know that AIDS is every bit as much a social phenomenon as biomedical phenomenon.

And it seems to me that AIDS is very different from other STDs, even if it's transmitted much the same way and even if some of the populations are the same. I think socially it's very different and that has something to do with the debate about mainstreaming versus nonmainstreaming.

MR. HOLMES: I don't want to dominate the dialogue here and maybe we could talk about it about further afterwards, but I think some of the benefits of combining or coordinationg these two very specific areas actually lend themselves very much to the social and behavioral approachs rather than the biomedical approach.

For example, let's take health promotion in IVD. Do we focus on messages that deal specifically with HIV which is for some groups in the country a very rare disease but a very fearsome disease, or do we deal with a more balanced health promotion message that argues that there are certain risks, for example, for women, infertility and cervical cancer, that may be much more realistic and common addresses for them for which they may need to decide on their own behavioral approaches.

MS. GEBBIE: Let me just suggest, in considering how to interpret answers to this question it's important to keep separate the level of integration at the more abstract program planning, design interpretation level and what actually happens at a point where an infected or potentially infected person walks in the door.

One of the dangers that I have observed is having people who think about doing research on and plan for services to HIV-infected persons, if they are all by themselves, failing to take advantage of lessons well learned, to take advantage of systems well in place like migrant health centers, university research centers and a number of other people. Because many people going into HIV-AIDS have never been a part of a system before and they don't know the richness that could be there despite the problems. And that mainstreaming, if you will, at

that level is absolutely critical where the service delivery level where for a whole lot of reasons you might have any number of combinations in various places, and I see those as two different issues.

MR. SCOTT ALLEN: Eunice, you have a question?

MS. DIAZ: I have two, I guess, for Joe. Specifically with the HRSA demonstration projects, the initial group is 13; is that correct?

MR. O'NEILL: Yes. With the initial group section it was four. You mean the HRSA demonstration, right?

MS. DIAZ: Yes. Four. And now it's how many?

MR. O'NEILL: Up to about 27.

MS. DIAZ: For those that have been evaluated, I know that there was an initial evaluation of the effectiveness in reaching the expected program goals of building community coalitions and I'm talking about the ones that were in partnership with the RWJ funding. What in general terms has been found with these projects? Did they do what was expected they would do in the communities?

Because it kind of troubles me, everywhere we go we keep hearing the same thing. Now we are left with this gap that Dr. Gebbiie talked about. They are there, the vacuum is there just because a demonstration is a demonstration and the demonstration will soon be over, even with the new flock of projects.

So if in fact they did accomplish what they expected to accomplish, is the fact that we are left with that vacuum now, is what to do just a natural outcome or did the coalitions become that strong that they are in fact taking on the new wave of challenges, how to develop services that work within the systems or mainstream them or whatever else needs to be done.

MR. O'NEILL: I think that's probably the question that could be answered literally in 27 different ways. That evaluation of that program was done -- solid evaluation of that program was done in Region four, which would be New York, Los Angeles, Miami, and San Francisco.

This was really a process-oriented evaluation which traced the development of the coalition, the effect of it's money as it passed through the communities, and I think one of the things that we learned from that was that yes, in fact, there were, you know, strong -- that this money as we have heard throughout the day, this money has had the -- whatever money was available, has the effect of being able to bind people together. And I think that has been the evaluation from the original force, that did in fact occur.

MS. DIAZ: It occurred while the money was there.

MR. O'NEILL: Right. And all the places are still -- the money is still there as we speak right now.

MS. DIAZ: But basically beyond that, will there be enough though to retain that kind of coalition building and networking with the different institutions once the money is not there?

MR. O'NEILL: You are asking me a question that I have a difficult time answering. In other words, to look into the future and see what will happen to these coalitions should the money not be available from the federal or the state or other sources to hold these coalitions together.

I think the intent was never to bind these coalitions together for all time but was to help people pull together and form coalitions that would at some point no longer require this glue. I don't have a good answer for you, frankly, to tell you whether -- I have no date or no information to be able to tell you that in fact is going to happen.

MS. DIAZ: Thank you.

MR. KESSLER: I guess I want to share some of the same fears that Harlan has about mainstreaming of STD services. Because it seems to me that here in America that maybe mainstreaming is sort of your lowest common rung of services that often are overlooked. Especially if you compare to a place like Sweden that has a 17-year track record of upholding its real value of putting money

into it and making it work.

Separate from that, I'm just constantly going back and forth over the issue of mainstreaming. I guess if we are talking about mainstreaming and comparing mainstreaming with the Department of Transportation, with the licensing of drivers set up in other states, we would have a better law; it's more comprehensive and efficient and actually gets more people in a rather efficient way to deliver what people ask for at a fashionable and reasonable cost.

The other concern I have in terms of the STD mainstream issue is our inability in this country to talk about sex, let alone talk about healthcare systems and so on. And I'm wondering if we don't put ourselves in a new bind at a whole new level. Even though we've had a couple of sessions vis-a-vis AIDS, we don't talk about STD much better. We sort of whisper about that and make it very difficult to get services.

A final point, on what I have just been witnessing going on in my own state where we have an STD epidemic, where one out of seventeen teenagers has an STD and the state can't now for six months decide what to do about it because it involves controversial intervention.

So, whatever consensus was reached in Geneva or the Switzerland meeting, I think we need to view with some

caution and concern about how that would apply in the 50 states here in America and whether or not we would be setting ourselves back to 1940 or creating a whole new way to bury AIDS once and for all.

MR. HOLMES: Well I think we need to proceed with concern and caution. I certainly agree with you there. I was just reading for the second time the book, "No Magic Bullet" and I was thinking as you were talking about the difficulties we have about speaking openly about sex and sexual behavior and STD, how familiar that sounds to what was being said in the turn of the century in 1910 to 1920.

Hopefully we have progressed beyond that and we certainly need to if we are going to deal with AIDS as a sexually transmitted disease. I think that we should think about the implications of not coordinating AIDS control with STD control and strengthening the STD programs to deal with HIV infection.

There are 4,000 STD clinics in the country. In some communities like this one, they see a very large proportion of young adults who are engaging in sexual behaviors that place them at risk as far as STD as well as for HIV.

In many of the clinics in this country, as you have both pointed out, when patients come in, they do not get a meaningful consult; they do not have opportunity for

talking about HIV risk, for example; they are not given any of the information or health education; they are not tested for or can be tested for the commonly sexually transmitted disease, chlamydia infection, which has been implicated as a host factor for sexual transmission of HIV to women. It's been said that the largest attributable risk or risk factors for sexual transmission of HIV to women is chlamydia infection.

If we don't improve those services and give them the specific responses for dealing with HIV infection more effectively, then we are, I think, neglecting one of the most important behavioral and biomedical approaches to controlling this epidemic.

So I don't argue that we have got an ideal system that we jump into willy-nilly and begin using it. I'm arguing we have to look at it carefully and strengthen it where it's necessary, to address this and deal with HIV infection.

MR. KESSLER: My only other comment and I guess I would take the role of Dr. Rogers and say that we have got to be very careful about buying into the notion that there are no more resources, that we can't develop the resources that are necessary.

And I know we hear it and I know I'm bound up by it at times, my own agency and so on, but it does seem that

we need to go back to the drawingboard and really look at what's important in terms of funding, and the priority of this nation needs to be the health of its citizens and the future for the country. We are talking about the future here, I think, in large part.

MR. SCOTT ALLEN: Jim had a question.

MR. JIM ALLEN: I really have a comment more than a question. My comment is to enjoin the debate hear and provide or encourage an angle on it perhaps rather than building this tension back and forth. I think the model that you very briefly presented is extremely exciting and I look forward -- my question is, what is the next step or what are the next steps? How will it be flushed out and so on? And I will let you answer that in a minute, let me finish my comment.

I'm not sure that it necessarily is the absolute and final answer in one important place immediately, universally in the United States today. I'm thrilled, however, to see the question examined. Because, in fact, CDC through their Center for Prevention Services has in effect in terms of the sexual transmission of HIV already put the two together in board case conviction. And we did it without examining the controversy, without examining the question adequately.

And I hope what has happened during your sabbatical,

Dr. Holmes, is that you had a chance to look at how it's worked, what the problems have been, what the benefits are, and can help shed some light on this. Because I think it does need to be examined carefully.

I think the concern that's been expressed this afternoon clearly indicates that it needs a lot of further examination within the light of our own stages, the epidemic, where we are with the disease in the United States with the resources that we have got. We need to look at it very carefully because it's not a single model that can be quickly put in place elsewhere.

And I think as you clearly pointed out, that we cannot ignore the nonsexual transmission of HIV, particularly IV drug associated, which also interestingly does get tied up also in the sexual tranmission in that you have the view of exchange of sex for drugs, and all of the social issues that go along with that.

And I think, Dr. Gebbie, your points in terms of the healthcare models are also extremely important, where we go for prevention. It's not necessarily where we go for the early diagnosis, intervention, treatment, and the rest of the services. And we can't exempt all of the healthcare practitioners in our country from being involved. Everyone has to be involved with assessing risks, with appropriate early diagnosis or recommending

diagnosis and certainly with education.

So we have got to not ignore the very many faces of this epidemic and all that needs to be done, and I find your model very exciting, and I hope we will have a chance to learn more about that in the future.

MR. HOLMES: I would be glad to give you all the chance you need. The consensus meeting at WHO did lead to a consensus statement that is about ready to be finished in a report that will be five pages long that summarizes the specific steps that could be undertaken and each of those program areas that I outlined.

I think for this country, as you pointed out, we have already combined the HIV and AIDS prevention programs or the STD and HIV prevention programs at CDC in one division, which does not include the surveillance area or some of the research areas but includes the major responsibility for STD control and development of many of the services that you are interested in here.

But I think the next step is to begin to look down the line and find out how we can more effectively use the existing STD structure which probably is the second strongest in the world, the United States after the United Kingdom, and where we need to modify that system to use it more effectively.

MR. JIM ALLEN: I would just make one other comment

and that was that earlier we talked about the need to carefully define what we meant by case managment. I think we need to equally as well define what we mean by mainstreaming. And you did provide a very brief definition, but I think each one of us conceptually have our own idea of what it is, and before we use jargon terms like that we need very carefully to define what we mean in each context.

MS. DIAZ: Another question for Joe. You talked about the community health centers and migrant health centers to meet the needs of that population. I'm particularly happy to hear that in terms of the numbers of people of color that utilize these facilities as the one point of access to preventive care.

Without a great influx of dollars or resources, are the community health centers and migrant health centers ready to provide a comprehensive AIDS care to the populations you have described without additional resources? In other words, the budgets that are there now?

MR. O'NEILL: I think some have been doing a tremendous job. I think an example is right here in Seattle, The Pike Place Market Clinic, for example, that without any additional funding are doing a tremendous job of providing care to HIV-infected patients.

I think there are other -- as you know there are three demonstration sites that we are jointly funding with the Centers for Disease Control, and Dr. Valdez would be pleased to hear that there is at least one coalition between HRSA and CDC working on that level in this area. These are all centers that are -- one is in Liberty City, which is part of Miami, one is South Bronx, and one in New York, all very highly dense areas and places, and which have been in many cases due to the real heroism of one or two people who have been out there struggling and doing the really tremendous job with no additional resources.

But being able to supply them with an additional half-million dollars a year per clinic, they have been able to expand their services, hire case managers, hire additional staff in some cases, do more outreach, increase prevention activities.

So in answer to your question, there are many centers that are doing this, there are many centers that aren't. There are centers where additional amounts of money would be tremendously helpful to them and that's the purpose of the $10.16 million that will be distributed over the next couple of months to 330 centers, what we call "look alike centers," that may not be necessarily federal centers but operate in a similar kind of community-based way, to try to assist these places to expand.

MS. DIAZ: DO you feel we have moved anywhere since you left this side of the table?

MS. GEBBIE: I think we have moved. I think anybody that's watched the epidemic goes from high to low very fast because you don't have to look very far to find some success stories of services and programs that are very good, some combinations of funding that are pretty stable and some real progress, some much better support.

But you can also have down days and it can be very frustrating. We still have a disconnected system. We still suffer this epidemic from being part of a disconnected system for health and illness, and as long as that exists we will have a very difficult time getting anywhere. And the ups and downs of this is just not federal funding they get, but it's Medicaid reimbursement, and the system, and definition when there are programs for HIV infection, the programs and waivers and so on, when they are in a state directory and people forthrightly lack education to search these out.

There is much spottedness very clearly across the country, including drivers licensing, the waiting lines vary across the county and will continue to. Long answer. To get back to the short one, yes, we have made progress and I'm pleased at that.

MR. SCOTT ALLEN: I have a question. I'm concerned

about public health being the backbone and so forth. I come from Dallas, Texas, where Texas is not one of your most progressive states in the HIV epidemic. In fact, there are symptoms of hostility, especially in the legislature and so forth who rule the public health.

And also in Dallas we have some very good folks, that are focusing on Dallas public health, that I respect a great deal but their hands are tied fighting county commissioners and the difficulty there.

And there is a big concern when you have folks that are so insensitive, such as our county commissioners -- there are some that are very good -- but I'm just very concerned of placing the emphasis and structure at this time without the tremendous education that needs to go along with our political entities.

MS. GEBBIE: It's a reality with which I can't quarrel. Some of us are very concerned about the private sector because there are people of the private sector that are really insensitive and have problems. There isn't a perfect answer and that's why I think that we need a bailout or an option for any community to work around efficient structures.

But over the longhaul, if we want systems that survive and are held together, something permanent has to be there. And my impression is, and as I said, I

understand that that's biased and how I earn my living and have done so for the last 12 years in official agencies, is that governmental tie, you know, that direct access to tax dollars that gives us some glue that can be very helpful over time. It only works if the community is there expecting the government will be responsive.

MR. SCOTT ALLEN: But we have a state that turns away from us, from human service, and has ignored the tragedy of the people. But another issue is the demonstration money. You mentioned in your testimony that it was never intended to go beyond this point. And just one clarification, there are demonstration grants I understand that do get incorporated into the regular budgets and so therefore is incorporated, so that has taken place at some point. But if it's not going to take place, what is your recommendation for funding?

MS. GEBBIE: I think we need to lean more towards some core funding that is more long-term that is federal. I think one function with the federal government is to even out the disparity out across the country, even out disparity across tax bases and the mechanism of funding, and so I think some ongoing federal funding is appropriate.

And one of the solutions to this issue is to get somehow a system that pays for illness care no matter

where you live, no matter what disease you get, and that will be a good solution to a large chunk of the problem.

I think states also need to look beyond the point of funding. As I said, states and local government have been just as much a party to this process of playing games with demonstration projects as has the federal government, although it's been mostly federal money we have played the game with.

Whether we go in for demonstration projects, we will still need them. We probably ought to be more honest about them and figure out some more appropriate mechanism for talking about the pick-up process. I have been a party to other demonstration projects, grants or start-up grants, in which from the beginning you had to talk about your pick-up process. None of us talked about it and none of us should be suprised when it is running out, but a lot of people are acting like they are suprised.

MR. SCOTT ALLEN: It's not suprise, it's concern.

MS. GEBBIE:. If it's the AZT program, it was a one-time shot.

MR. SCOTT ALLEN: Right.

MR. GOLDMAN: In part reply to you and in part continuing what Kristine was talking about. Notwithstanding, at least from my observations, a terrific job today, as I think one witness talked about the

efforts, you know, five people on one side pulling as opposed to having three people pulling on one side and two on the other side.

Probably a good portion of the efforts and actions of AIDS Arms in Dallas have been fighting with the Health Department rather than supported by it. And I don't think anybody is saying that that AIDS Arms don't do the job, it does and it does do it best.

Clearly, if the people are given the same level and degree of efforts, the cooperation of the health department, for example, as here in Seattle where it is energetic with the efforts of the Northwest AIDS Foundation and one-on-one equals three and funds their efforts rather than what happened in Dallas. And maybe Seattle is a better place to have AIDS and HIV infection than Dallas is in any event, because of the effectiveness of a system. The public health department is doing a wonderful job and it sounds like there are some really good folks there.

MS. GEBBIE: I wanted to jump in with another point for the private sector. I have talked about that partnership as well. And private groups can do more to badger legislature and county councils and city councils that are official agencies. It's real hard to sell your position knowing your boss is against it, and you can't go

out and do it differently knowing that the boss will say, Thank you very much and there's the door. And people who are dedicated to their job walk that line with difficulty.

This community has benefited, and I mean the whole State of Washington has benefited, from the private groups that stood up to the state legislature several years ago and said, State government isn't working, you need to make state government work and they built a state government structure through AIDS that provided the creation of the Department of Health which I now run. That got the backbone in there for those private groups that have been there since the beginning, a process of bottoms-up or sideways or something, that rests in private lobbying and we need that across the country.

MR. O'NEILL: I was just going to say, when we were talking very much about distribution of HRSA resources, essentially I think one of the things that we really need to look at is we talked about where resources should go and in the context of talking about the STD clinics. And really, I think a question that we have to look at is where we as a society get the most impact from money that was spent. And I don't have an answer to this question. I don't think anyone has.

But a question was raised, I think, and it's been my experience that HIV-infected patients are in tremendous

need of what I would call a primary care system or a primary care provider. I think as we are faced with the questions about if we have a limited amount of funding, where do we get best effect from that money; and it may be from taking what is the STD clinic that is not a primary care system and turning it into a primary care system, that may in fact be the best way to do it or it may not.

I think when we look at this question, and I think that there are many issues to be decided as we look at one system versus another, what the actual needs are, and there are economies that are involved here, that we need to be paying very close attention to as we look at different models, which type of system we may want to expand to meet those needs.

MR. SCOTT ALLEN: Any final questions? This was very fruitful dialogue here and we certainly appreciate it. There is much to ponder. Thank you very much for your testimony. We shall take it to heart. Thank you and we now have this time for the opening comments from the public.

The first person is Barbara Wise from here in Seattle. And three minutes I assume --

MR. PRICE: It's Price.

MR. SCOTT ALLEN: Price. And Russel Price, you folks.

MR. PRICE: My wife is more accustomed to speaking than I am and so I would like, rather than to fill the transcript with a stream of expletives, to relinquish my three minutes to her. And if you want some information, you can turn off your little timer and let her say what she has to say.

MR. SCOTT ALLEN: We have a three-minute limit here. If you want to share it that's fine and if you want to submit anything in writing after the time limit --

MS. PRICE: If we are to submit something in writing, how would we get that to you?

MR. SCOTT ALLEN: Our Address is the National Council on AIDS, 1730 K Street Northwest, 8th Floor, Washington D.C. 20006

MS. PRICE: The first thing, I want to say that I'm not a member of ACT UP and I feel very appalled that this meeting was not advertised in our local lesbian gay newspaper. The only announcement we had was an article in the Post Intelligencer this morning and I got a call -- I don't get the morning paper -- I got a call from a woman that I do talks for, at 8:00 this morning telling me that this meeting was occurring today.

I did not get here until after lunch because I had some other things to take care of. One thing I would like to say is that I agree with all of the things the people

that have been speaking are saying.

However, I am a person living with AIDS; my husband is a person living with AIDS; our families are living with AIDS. And I guess the first thing I want to say is that to live with AIDS you have to have money, okay? You have to wait five months to get social security disability.

In the meantime, AIDS is supposed to be considered a -- I can't think of the word -- you are supposed to be disabled, automatically disabled, if you have AIDS, and if your doctor says you have it then you are supposed to get SSI.

I was not able to get SSI until the social security department declared me disabled nine months after I left my job because I had become disabled from AIDS. And then on top of that, my husband got sick in December and we were told that $696 a month is too much money for us to make in order to qualify for financial assistance, medical assistance without spend-down, and food stamps.

I have a family of four to support. The support level for a family of four is $683 a month. My rent is $650 a month. Because I make more than -- more than $683 a month -- I also receive money from my children for social security, that money is used to work what we call a spend-down -- my spend-down for six months was $2,020 or something that I had to come up with out of my own pocket,

out of less than $1,000 of income.

I'm very fortunate. I have a co-op plan in the City of Seattle. I worked for the City of Seattle for five years. However, in the last six months they have tried twice to get me off of their insurance rolls so that it's not costing them so much money for their other employees. They have notified me with less than 15 days notice that I have my insurance premium going up, and that they have new rules that I have to follow with the 29-month extension now.

They notified me with less than 20 days, less than 20 days notice that I have to submit my disability letter within 60 days of my disability notification, which I was going to fight back in January. I received this letter on July 7. So I'm a little upset.

The other thing is that social security disability, social security retirement, military, and veterans' benefits are considered unearned income. While my husband was working he was making between $800 and $900 a month. We were able to receive between grants for both of us between $100 and $150 a month and they helped us with food and rent.

If he made under $835 a month we were able to receive food stamps. We received medical coupons with no spend-down. And I think that is appalling. That if you

get sick and you're put on disability benefits that you pay into -- I paid for over 20 years. My parents paid. He's paid. He's self-employed, he had to pay double -- and yet we can't get medical without a spend-down.

The State of Washington is the best state in the United States to have AIDS because they have the Omnibus bill. They have the insurance continuation program. They have the AZT and POCANW and Aclavir programs that they pay for the medications for people who can't afford to pay for it.

And I think that the United States as a whole has to take stock and reprioritize their healthcare systems, their educational systems, the systems by which we place our moral values -- I have got all these little notes here.

And I guess what I'm trying to really say is that -- one of my final things I want to say is that we have a cast system. Okay? AIDS was recognized in the United States in the gay white male population. When it became apparent that people of color were being affected, these people were ignored. When it became apparent that women and children were affected, we were ignored as usual.

Healthcare for women in the United States and all over the world, we are second-class citizens. Dogs get better research and care than infected women and children

do. It's appalling.

And I guess another thing I want to say is that AIDS is not a selective disease. It's going to hit everywhere and everyone. And the systems that are in place are working temporarily right now, but unless you guys get in gear and get this thing together, people are just going to die because they are going to kill themselves because of their financial situation. They are going to die because they are not able to get medical care.

And we are not going to lay here and just let it happen. You are not dealing with uneducated people anymore. You are dealing with people who have college educations, who know how the system works, who have been put into the position of having to learn how the social and health systems work. And we are appalled that our people, our poor people, have been put through this tragedy. It is disgusting. And it's not acceptable, not to me or to anybody else I know.

And I wish that there were more people with AIDS in this room right now because they could tell you the same thing. And I go to support group meetings and I go to meetings for things, but I have a family to take care of too, so I'm not too politically active but I intend on becoming more politicallly active.

I have been doing AIDS education work for a year

and-a-half. We need to do something. It needs to be done quickly, needs to be analyzed quickly and has to happen soon.

MR. SCOTT ALLEN: We appreciate what you are saying. Reality is never far from us and we are extremely sensitive to your plight. We hear it and it always helps to hear it again. It's unfortunate to hear it again but we thank you for sharing this with us.

MS. OSBORN: Let me ask you -- you were eloquent and this is always quite helpful to use. We are a group of citizens trying to make the voices of people in your circumstances louder than the other ones would be. And so we can't promise to do what you have asked because we aren't in a position to do other than to communicate, but hearing from someone who speaks as beautifully as you have about the reality of that is something that is very meaningful to us and I wish you would take the opportunity to write to us as well, because I think your testimony is most useful, and thanks to both of you for taking the time to talk to us,

MS. PRICE: Thank you very much for listening.

MR. SCOTT ALLEN: Lisbeth Jardine.

MS. JARDINE: I likewise didn't hear about this meeting until I heard it on the radio. In this discussion of -- maybe I better give a little bit of background. I

was an AIDS working group coordinator at the University of Texas School of Public Health and coordinated several research projects and provided technical support to the Texas Legislature Task Force on AIDS. My education is -- I'm a native of Seattle by the way.

And I -- my academic education is a Masters Degree in History and Philosophy of the Health Sciences from the University of California, San Francisco. My thesis research was sort of an ideological analysis of alternative medicine and established medicine. I, in that thesis, more or less come out against the alternative therapies of medicine.

I heard some things in this meeting about alternative therapies and since the AIDS epidemic happened when I was between the time I was writing my thesis, I have looked at and heard about some of the alternative treatment that people in desperation have resorted to.

It's caused me to rethink my own feelings about how I rejected the alternative therapies. But I still think what I am hearing is too much of a dumping on bad and big science. What I think is at the root of more of the AIDS hysteria in this country is ignorance of the very basic concepts of science. And that goes across the whole range of legislators and religious fundamental groups.

When I try to describe some of my efforts in AIDS

education as I'm trying to get employed, I couch the terms of what we really have to do is deal with these alternative belief systems and the theories of disease causation and to join this a little bit -- I know I have a short time to say this -- with the social and the partnership theme and the social impact of AIDS.

I would urge the Commission to speak strongly on the need for basic science education at a very early stage in the American educational system. I'll just leave it at that. I could say is a lot more, but --

MR. SCOTT ALLEN: Thank you. I want to thank you all for your dedication to the cause. Many of you have been here all day long as we have, and it's been very helpful too for us to see your dedication, your concern, and your being here; it means a lot to us as we go about our tasks. This concludes our session for this day.

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(Whereupon the proceeedings concluded at the hour of 6:23 p.m.)

CERTIFICATE

STATE OF WASHINGTON)
)
County of King)

I, the undersigned Notary Public in and for the State of Washington, do hereby certify;

That the annexed and foregoing transcript of proceedings was taken stenographically before me and reduced to typewriting under my direction;

I further certify that all objections made at the time of said examination to my qualifications or the manner of taking such proceedings or to the conduct of any party have been noted by me upon each deposition;

I further certify that I am not a relative or an employee or attorney or counsel of any of the parties to said action, or a relative or employee of any such attorney or counsel, and that I am not financially interested in the said action or the outcome thereof;

I further certify that the transcript of proceedings as transcribed is a transcript of the testimony to the best of my ability.

IN WITNESS WHEREOF, I have hereunto set my hand and affirmed my official seal this 20th day of August 1990.

_____

Notary Public in and for the
State of Washington,
residing at Seattle, Washington.
My Commission expires 4-19-92.