NATIONAL COMMISSION ON AIDS

SOCIAL AND HUMAN ISSUES WORKING GROUP

SEATTLE, WASHINGTON

JULY 30, 1990

9:00 A.M.

VOLUME I

PAGES 1-171

COPY

VERLYN DECKERT, RPR
16442 - 13TH AVENUE SOUTHWEST
SEATTLE, WASHINGTON 98166
(206) 244-0678

COMMISSIONERS PRESENT

JAMES ALLEN

JOHN GOLDMAN

SCOTT ALLEN

JUNE OSBORN

HARLAN DALTON

EUNICE DIAZ

LARRY KESSLER

MARY BYRNES (Executive Director)

INDEX OF TESTIMONY

(Volume I)

(July 30, 1990 - 9:00 a.m.)

MR. SCOTT ALLEN: Good morning. This is the Working Group for the Social and Human Issues and we are here in Seattle to deal with some of the partnership issues that Seattle has been known for.

Let me introduce the Commissioners: To my far left is Larry Kessler from AIDS Action Committee in Boston; Eunice Diaz from the Los Angeles area and the Assocciate Professor at USC and she has worked extensively with the Hispanic community.

Harlan Dalton, Professor of Law at Yale and editor of AIDS in the Law; and Dr. June Osborn, the Chair of the National Commission, who is the Dean of the Public School of Health in Michigan, University of Michigan. I'm Scott Allen from Dallas.

This is John Goldman, a lawyer in private practice in New Jersy and former president of the National Hemophiliac Association, and Jim Allen from NAPO -- and what does NAPO stand for?

MR. JIM ALLEN: National AIDS Program Office.

MR. SCOTT ALLEN: From NAPO and working with the Secretary of Health; and Mary Byrnes is the Executive Director of the National Commission.

June, would you like to say a few words about the Commission as a whole and then I will be more specific about what we are here for.

MS. OSBORN: Well the National Commission on Aids was recruited by an act of Congress which was part of the first major AIDS legislation in late 1988. As it was designed by Congress, its considerable purpose was to be as independent as possible and to be responsible for both the executive and the legislative branches of government.

So of our 12 voting members, five were appointed by the Senate and five by the House and two by the President. And in addition, three cabinet secretaries are exofficio members or as it needs.

We have a two-year mandate. We began our work just slightly less than a year ago in the beginning of August, once all the appointments were made. And over the two years to follow, we are to be as proactive as well as reactive as we can be in guiding both the executive and the legislative branches of government on issues of national policy in an effort to bring that along and to improve and develop national consensus concerning the AIDS epidemic.

To do that, we have about three different forums of Commission activities. Because of the nature of our membership, one of our club voting members is a member of Congress and in addition, three cabinet secretaries are regularly in attendance at our full hearings. Therefore, most of those hearings we hold in Washington are on an every-other-month basis.

On alternate months we have been trying to do side visits in areas of the country which are prototypic of the features of some of the epidemic that we feel need a lot of attention and that's the second mode of activity.

And then a third represents the division into small working groups of members of the Commission to focus on particular issues in a variety of ways. This, as Scott Allen will say in just a minute, is the one vote and one of the largest working groups looking at human and social issues and has met in several locales around the country as a way of accumulating both the experience and the feelings of the people involved in the epidemic in different locales.

So I'm actually not a member of the working group but the kind of rich testimony that has been part of the activity makes it a privilege for me to be here and I'm glad that the Commission's been made so nicely welcome. Thank you.

MR. SCOTT ALLEN: Any Commissioner can come and we are very happy that June has joined us on several occasions. And let me explain to you what we are dealing with. We started out in Boston several months ago dealing with testing and early intervention, and had a round-table discussion and so forth in that meeting and felt like we needed to look at it further and to look at the continuum of care models and so forth.

So we decided to have a meeting in Dallas where we're dealing with continuum care models dealing with health folks and getting their perspective as well as community-based organizations and then looking at obstacles to care. And we had more of a reasonable approach, the balance playing to all of the crucial and excellent testimony.

3

And we felt like we needed to move on out here to the west and get some perspective from this area and look at partnerships, as we have heard so much about Seattle and the partnerships and how things have worked well together. And doing some background reading, it sounds very encouraging.

But of course, we want to hear from you all and want to hear what we can expect in the future. So we are very pleased at this time for you to come to help us out in this process and let us then begin with the first panel.

Jon Fuller is a Doctor from the Jesuit Urban Center, Boston, Massachusetts; and Gail Barouh, from Long Island Association for AIDS Care in Huntington, New York; David Woodring from the National Native American AIDS Prevention Center in California; and Linda Meredith, ACT UP Women's

Committee, Washington, D.C.

What do you say that we have six minutes and the timer will go off at six minutes and then you will have one minute to wrap up. So you will have seven minutes altogether and so be sensitive to the time so we can have a dialogue with you all at the end of your formal testimony. So let's begin with Jon Fuller.

MR. FULLER: Good morning. I appreciate your invitation to share some reflections on the pastoral needs of persons infected with HIV, to discuss barriers to the effective provision of that care, and to suggest ways in which the delivery of pastoral services might be improved.

I believe that the relationships that HIV-infected persons develop with their physicians and with their pastoral ministers are archetypical; both represent critical needs of the human person. Physicians and ministers have privileged access to one's relationship to some of the most primordial themes of human existence, including one's experience of and attitude toward pain, illness, loss and death, and of one's understanding of and relationship with the divine.

As an AIDS clinician in San Francisco and Boston, I have had many clients, often without formal religious affiliation, who have manifested an intense desire for contact with pastoral personnel to assist them in dealing with the spiritual challenges that HIV infection presents them.

Both of these roles need to be made available to a person who is struggling and suffering from this life-threatening illness, and in my experience it is as important for clients to be able to develop ongoing, long-term relationships with their pastoral providers as it is to do so with their clinicians. Both relationships are commitments that will hopefully be maintained through all stages of HIV-related illness, quite often including the client's death.

However, having described the central role that ministers should have in comprehensive AIDS care programs, it is no more reasonable to ask an unprepared physician to respond competently to an AIDS patient than it is to ask an untrained minister to deal well with the professional challenge and personal engagement that come with doing AIDS ministry.

I have heard of priests who have refused to see HIV-infected patients or have insisted on giving communion with gloves and mask on. One particularly poignant case of the damage that can be done by such ill-equiped ministers is forever burned into my memory.

A young man who was critically ill in an intensive care unit asked to see a priest in order that he might be anointed and receive communion. His lover at home was also struggling with the AIDS diagnosis.

The priest on call who came to see this young man told him that he would anoint him and give him communion, but only on the condition that he first renounce his longstanding relationship with his lover. Desperate to receive the sacraments in his failing state, he agreed.

Unexpectedly, his lover died at home that night, and this young man had to deal not only with the death of his partner, but with his own renounciation of their caring relationship that had been extracted from him under duress. Although this story occurred some seven years ago, I regret to say I've seen similar attitudes played out during this past year.

When several such unfortunate experiences occurred at San Francisco General Hospital where I trained as a resident, members of the nursing staff who knew that I was a seminarian would frequently approach me to ask for the names of priests who could provide better informed and more sensitive AIDS care.

I'm happy to say that many qualified persons made themselves generously available and that many persons at the AIDS epicenters have excellent track records in this regard.

The clinical pastoral educational programs at San

Francisco General, at St. Clare's, in Manhattan, and at Deaconess and the city hospitals in Boston are all examples of programs that not only provide superb care to their own clients, but also comprehensively train other ministers from around the country to carry on the excellent work being done in these institutions.

While I have described the real probability of the poorly equipped pastoral ministers, these are by far outstripped by the thousands of competent and committed individuals who provide pastoral assistance to HIV-infected persons on a daily basis in all parts of the country.

One patient I worked with at Boston City Hospital enjoys telling the story that he has a priest for a doctor, a Franciscan Sister as a client advocate at AIDS Action, a Franciscan Brother and a Sacred Heart Sister as buddies, and has a sister of Notre Dame de Namur as his nurse from the Boston Visiting Nurse Association.

Providing AIDS pastoral care presents some unique challenges, not all of which are due to the medical realities of this disease with which other providers must also contend. At least in my own church, many of those providing AIDS care do so under a considerable burden.

While some have been officially appointed to do part-time or full-time AIDS care and are financially supported for doing so, many others have entered this work as a second, third, or even fourth career and must personally bear the burden of getting themselves trained in the work and then must frequently support the volunteer hours that they give by other full-time work. Only very rarely is professional pastoral care financially supported through healthcare agencies or AIDS organizations.

I have heard ministers describe their experience of having to be discreet about doing AIDS ministry, either because they will be labeled as gay by their peers or superiors because of their interest in AIDS work or because they are concerned about putting themselves in delicate situations if in their work they privately encourage education about condoms to reduce HIV transmission or if they support bleach distribution or needle exchange programs for addicts.

Pastoral ministers frequently have to bear the burden of tremendous anger and resentment directed towards the churches of which they are a part. Many gay men express the feeling that they are only welcome in the church when they are sick and dying, and they want to be accepted and welcome in the church community when they are in good health as well.

Equally do Catholic positions regarding condom education and needle exchange programs increase the division between the church and AIDS groups, making it more difficult for individual pastoral providers to effectively overcome the resistance which can become built up toward an institutional church which many individual ministers represent.

Condom-throwing protests at the ordination in Boston several weeks ago are one example of the anger that is held by many towards the Catholic church and specifically towards its response to condom education.

But despite the fact that AIDS ministery may be fully supported, be cast under a cloud of suspicion, and can be burdened by relationships to the institutional church of which one is a part, it is also indisputable that a tremendous amount of competent pastoral care is being courageously provided at the grass-roots level. This work for many represents a vocation call that is rooted in a strong faith conviction that allows their work to thrive despite minimum financial or psychological supports.

Beyond the relationship that any individual has with his or her pastoral minister -- is that one minute? Let me move to my recommendations.

First, as models for the comprehensive care of HIV-infected persons are being developed and refined around the country, it is critical that pastoral providers be given their appropriate place on the AIDS care team.

Unless there is a consensus that comprehensive AIDS care programs should make a variety of pastoral services available to their clients, this aspect of care can never hope to compete with research and clinical care for space and dollars. And this has already happened at my own institution, financial support and physical space for providing this care will simply not be forthcoming.

A central role for ministers should exist not only in the inpatient setting where it has traditionally been supported even in the public health sector, but especially in the outpatient and home-care environments where patients frequently initiate and develop ongoing provider relationships and where the majority of HIV-related care is being provided.

Second, pastoral providers doing AIDS care usually work on a shoestring budget and have a difficult time making ends meet. This makes it difficult or impossible to pay tuition and conference fees for the professional development in the ongoing training that these workers need as much as any other other member of the AIDS care team.

Support for the training and development of these professionals, as has been partly accomplished through NIMH-funded grants, could go far to guarantee competent persons will be available when called upon to respond to the spiritual needs of these patients.

It is also critical that once they are trained, these ministers be given adequate opportunity to be refreshed and supported by one other -- I'm almost done -- as burnout can be extreme and individuals will need to leave this work after a few years if not properly supported.

It would be extremely helpful for this Commission to recommend that all professional ministerial training programs, both graduate school and hospital based, develop curricula in pastoral care specifically designed to prepare their trainees to constantly care for this population.

Finally, while small segments of scientific AIDS meetings, such as the International Conferences on AIDS, have been devoted to ethical and pastoral care issues, these are more frequently carried on in separate corridors and without facilitated diaglogue between ethicists, theologians, clinicians, and pastoral providers.

While many of the theological controversies that my own church deals with must ultimately be dealt with internally, increasing dialogue between policy makers, clinicians, theologians, and ethicists regarding the interface of moral theology and our developing understanding of the complex notion of the common good and public health could certainly be better facilitated as we struggle to deal with this expanding epidemic.

MR. SCOTT ALLEN: You almost did it. It always scares me. It's a hell of a long way, but thank you for trying to be sensitive. Gail is next. Gail Barouh.

MS. BAROUH: Good morning. My name is Gail Barouh, I'm the Executive Director of the Long Island Association for AIDS Care, or LIAAC. Today I'm here to talk to you about the --

MR. DALTON: Excuse me. But the reporter is going to go crazy if you don't slow down.

MS. BAROUH: Part of it is that I come from new York.

Today I'm here to talk to you about the surburban community-based spectrum on AIDS. Long Island is and has always been the nation's surburban area with the highest incidence of AIDS. The Centers for Disease Control on Long Island, Nassau and Suffolk Counties, which is LIAAC Territory Number 19, is at the top 25 cities with the highest incidence of AIDS.

Nassau and Suffolk Counties cover 1,200 square miles and have a population of 2.6 million. These 2.6 million are popularly thought of as white middle and upper middle class nuclear families who commute to good jobs, go to the beach in the summer, who park at least two cars in their garages. They better have two cars, because Long Island has almost no public transportation.

These simple facts lead us to look below the lows of surburban life. Transportation, housing, healthcare, even hunger are problems for a growing number of Long Islanders who don't have the income it takes to keep up. After all, drug abuse is also taking its toll.

Long Island has many minority populations, including Blacks and Hispanics and gays, who are living without much of the recognition and social support found in cities of comparative size. AIDS is a horrible way to get attention, but it's turning the focus on long overlooked members of the Long Island community.

An example of this, Blacks represent 7 percent of Long Island population but 27 percent live with AIDS. Hispanics are about 4 percent but 7 percent are AIDS cases. Gay men are estimated to be approximately 10 percent of the popupation but account for 35 percent of people with AIDS. A majority of Long Islanders AIDS cases relate to intravenous drug use. In fact, Nassau County ranks fifth in the nation for intravenous drug-related AIDS.

And there's more grim reality in surburbia. Our area has a large single population and a high divorce rate. We suspect that this is a partial explanation for our high number of people with AIDS, which is nearly three times the national average of 9 percent. Twenty-six percent of LIAAC caseload is female. Also 10 percent of all cases have had hetrosexual contact.

Among our teenagers, drugs, lifestyle, proliferation of runaways, sexual abuse, prostitution, and even intravenous steroid use are contributing to their growing risk of HIV infection. As the agency pushed ahead, providing client volunteer and prevention techniques, we encountered many barriers. Some we expected, others took us by suprise. Here are four obstacles we didn't expect.

6

We encountered continual fear, reluctance, and denial on the part of politicians, physicians, dentists, hospitals, long-term care institutions, to both working with and planning for people with AIDS.

In 1987, county-wide elections resulted in a Republican majority in Nassau but a democratic majority in Suffolk, the first in decades. This inter-island party, which left the county with a complete lack of government structure, led to real problems in trying to get them to work together on AIDS.

The Island PWA population has not naturally drawn together because of AIDS. Sometimes the common background of AIDS brings about a growing disparity of belonging among diverse groups as it has in many cities. On Long Island they are holding on to the old sterotypes such as homophobia, racism, sexism, and an intolerance towards the homeless and poor.

Finally, we have received little support from either the business community or other philanthropic foundations. Beyond small grants for specific projects, no other corporation or foundation has demonstrated much concern about AIDS on Long Island in terms of dollars or cents in education.

Following is an analysis of the various modes of transmission among the LIAAC clients. Forty-two percent intravenuous drug use, 35 percent gay, 10 percent hetrosexual, 7 percent bisexual, and 3 percent transfusion related, 2 percent children, 1 percent unknown origin. Of this total population, 28 percent are minority group members, 26 percent are women, and 11 percent come from a family in which more than one person has AIDS, usually a mother and a child.

Although much has to be done on state and local government levels, here are four recommendations for changes on a national level. Number one, consideration needs to be given to separate reporting procedures for surburban and rural areas with high incidence of AIDS.

Number two, the Centers for Disease Control should √ count all cases of HIV infection, not just cases of full-blown AIDS. Number three, surburban and rural areas have many people who are diagnosed and counted in the cities and then move home to the surburbs to live and receive treatment. This issue must be addressed. On Long Island, over a third of all cases are migration cases that were counted elsewhere.

And finally, the federal government should sponsor a pilot study focusing on surburban and rural areas outside of major cities to look at the changing face of the epidemic, for instance, increases of infection among women and multi-family members and with hetrosexual transmission. Thank you.

MR. SCOTT ALLEN: David.

MR. WOODRING: Mr. Chairman and Members of the Commission: Thank you very much for the opportunity to speak with you regarding the social and human needs of our first citizens who are infected and impacted by HIV.

CONFIDENTIALity

First and foremost are the issues surrounding confidentiality. Indian Health Services has tried to assure Native people that their records are kept private, yet we know that most of the workers in the area clinics are related to patients being serviced. This barrier begins with testing and continues through the medical and emotional care of the individual. Without better assurance of confidentiality, many Natives will not and cannot will seek treatment.

Given the accessability to alternate testing and treatment, many on reservation land have no means for transportation. In fact, many CHR's are not informed about alternatives and those who are informed fail to actively help individuals seek these services. Case management is something that none of my people understand.

In the urban setting, most Natives must seek help from already established AIDS service organizations, many of which have not been informed about the customs and living conditions and level of knowledge in the Native community.

Native people have no concept for long-term care and the choice of hospice doesn't exist. In those communities where HIV is a reality, the only thing that is consistent is the fear and denial of its existence. Many medicine men will not treat the HIV-infected people for fear of losing credibility within their community. Many Native people believe that as long as they deny this illness, that their community is unaffected.

Although Indian healthcare has made important strides with the Indian people, the facts show that BIA tribal government has done nothing in the way of service delivery or HIV education. Unlike other communities, there is no true community organizations. Church groups, Boy Scouts, Girl Scouts and the like are missing in the Indian community on reservations, and in the urban setting those community groups do not specifically serve Indian people.

More attention must be given to the elder and clan mothers of the tribe. Until this happens, AIDS will never be seriously recognized by Native people or thought to be the threat to the community that it is.

One of the reasons for this lack of attention is the subject of homosexuality. For generations the subject of homosexuality was never an issue, but now, HIV has seen the emergence of discrimination, abandonment, and isolation from our own people. Substance-abuse workers see no need to deal with HIV in their counseling because HIV is still "their" disease. This comes from lack of training on their part, but more importantly from the challenge each of them deal with on a day-to-day basis.

Many counselors, social workers, and CHR's feel that HIV could be more effectively dealt with by the recognized AIDS educators in the area. We must work diligently in our communities to mainstream AIDS services so the community can respond. Support groups do not exist in the Native community as a rule and those that do are built around alcohol abuse and recovery programs.

Everything connected with HIV falls on the shoulders of the AIDS educator. Those educators are challenged beyond belief. They are the area of education and emotional support, transportation for the patient, advocate for the patient, and many experience discimination because they too have been labeled.

Many Natives must drive 30 miles or more just to go shopping and many of them have no electricity or running water. Diets suffer and overall care becomes piecemeal at best. If the Natives get sick, they must either wait for their regularly scheduled appointment or be forced to sit sometimes for up to eight hours as a walk-in, many times suffering but not able to explain their problem because of confidentiality.

If we are to successfully meet the challenge of HIV in Native communities, we must all work together for one common goal. We must recognize the majority of Native children want to learn about HIV and this gives them a power that none of us ever had. This barrier is the greatest of all, for if we continue as we are now, Indian people will see an end to the seven generations and the circle will be broken. I thank you again for the opportunity to speak here.

MR. SCOTT ALLEN: Linda.

MS. MEREDITH: I think everyone knows that women as a group have less access to healthcare in this country for economic reasons. In addition to that, women choose not to access a system which recommends invasive medical procedures or abortion counseling rather than informed choices as the norm.

Lesbians face additional barriers because we have less frequent gynecological exams given the fact that we do not use contraceptives. And because of the discussion that occurs with doctors about that lack of need for contraception, we are often faced with homophobia in the medical environment as well. To avoid homophobia in the work place, many lesbians do not chose traditional employment with health insurance benefits or they may be self-employed.

Women are the fastest growing group in this country to be infected by HIV. Their numbers increased last year by 45 percent alone. The lack of access, either because of economic reasons or their refusal to access, has translated to a staggering fact: Women with AIDS survive 15 and-a-half weeks from diagnosis to death. The average white gay man lives 39 months.

true?

In order to combat these alarming trends, women with HIV infection must be able to access a CDC definition which informs them of their clinical manifestations of their disease, a legal, medical, and social services system which supports the needs of women with AIDS, an ACTG system which is committed to including women in the development of life-saving treatments, and safe-sex education designed to educate women, not to absolve their male sexual partners from responsibility.

Access to a CDC-defined diagnosis is critical for receiving Medicare, Medicaid, and SSI. Women are frequently denied access because the current definition of AIDS as established by CDC is based on ARC which has been defined and categorized in men. For example, chronic candida yeast in the mouth is a CDC-defined ORI but chronic vaginal candidiasis is not.

8

Individuals who qualify for SSI receive $463 a month, not an insignificant amount.7 You must have one of the diseases that's on the CDC list to immediately access these benefits. Since women's symptoms are not on the list, they must go through years of appeals and attorney's fees. Often they are dead or near death before they're able to qualify. Meanwhile, a man with thrush can promptly come in and receive his SSI check the following week.

I met a woman with AIDS. This woman, let's call her Ann, was sued 18 months ago for custody of her two children by the children's paternal grandmother. The grandmother sought custody because Ann was HIV-infected. Custody was awarded to the grandmother primarily because Ann refused to show up for the hearing. When I talked to Ann, she said she simply couldn't face the guilt and humiliation of showing up at the hearing.

Ann's only wish is to retain custody of her children before she dies. The Court intends to give her back her children back if she can only improve her living conditions. But to do that, you see, Ann needs the money AIDS related from SSI and Ann's cervical cancer is not on the official list of diseases.

For every case of hetrosexual AIDS transmission from an infected woman to a man, there are 12 cases of hetrosexual transmission from an infected man to a woman. It's unclear what biological or social mechanisms can account for this pattern and I don't see any interest in the CDC to tell us why.

♀→♀ H The CDC also refuses to investigate the probability of woman-to-woman transmission, even though a paper that ? was printed in Montreal by Denise Ribble describes 10 percent of women who were studied contracted HIV as a result of woman-to-woman sexual contact.

Women with HIV disease live in fear of a legal, medical, and social service system which offers punishment for, rather than assistance with, the special problems that they face.

At a recent ACTG meeting, a site coordinator who worked in Worcester, Massachusetts, told me of three women who had lost custody of their children because their anonynity was compromised when they accessed the ACTU there.

Affected women are often women of low socioeconomic groups who prioritize their survival by buying food, paying rent, caring for their children. Their personal healthcare is not on their list of priorities. Social services must be made available for women with AIDS, allowing them the resources to take care of their medical needs.

Let me tell you about a woman, I'll call her Marie, who enrolled in clinical trials at Montefiore Hospital in New York. During her enrollment Marie become pregnant. She was told that she could continue in the trial if only she would have an abortion. When the abortion was performed, Marie was also sterilized. She knew nothing of the fact that they intended to sterilize her. A lawsuit has been filed on her behalf by the Center for Constitutional Rights in New York. Is it any wonder that women with AIDS are afraid to enter these systems?

Only 5 percent of all persons enrolled in the ACTG system are women. Women are excluded from trials for a variety of reasons. First of all, before enrollment is granted, a woman must provide evidence of adequate birth control. While the concept of adequate is subjective, the interpretations at various sites are diverse.

An ACTG coordinator in the Bronx told me that almost any response is acceptable because they don't want to include women in their trials. A site coordinator in New Orleans told me that they have such rigid criteria that they specifically design those criteria to exclude most female applicants. The New Orleans site also told me that they refuse to admit individuals who are IVDUs and are not enrolled in a drug treatment program.

This philosophy presumes two things. First, that there are enough treatment programs to go around, and secondly, that IVDUs are irresponsible. Neither of these presumptions are true.

ACT UP chapters and others across the country have regular needle-exchange programs for people who want to obtain clean needles and to voluntarily dispose of dirty ones. This doesn't sound to me like behavior of people who have a death wish. It sounds to me like behavior of people who are trying to save their life.

9

Timing for blood collections during the pharmacokinetics phase of trials may be unnecessarily rigid, often requiring a 48-hour sample when children must be picked up from school or cared for in the hospital, often resulting in missed appointments and removal from protocols.

If NIH grant professionals can require institutional assets such as libraries and computers to receive federal funding, why can't they require the provision of primary care physicians, routine gynecological assessments, child care and transportation?

Finally, according to a study by Johns Hopkins, women do not believe they are at risk. More than 40 percent of the women that are now affected did not know that they had engaged in high-risk behavior. Safe-sex education is not reaching women in a way that is clear and believable or in a way that results in long-term behavioral changes.

The language used to describe safe sex for women sends a clear message of guilt. The majority of data on women's safe sex presented at the Sixth International Conference in San Francisco described the development of materials on the use of condoms in women. Excuse me, but the last time I checked, a condom fits on a penis.

Further, the increasing use of the term vertical transmission sends an incorrect message to women, that it is their responsibility for HIV infection to a newborn. What about horizontal transmission that occurred at the time of conception?

There is virtually no information on safe-sex guidelines for lesbians. The government's disinterest in this area, lesbian invisibility, and denial are all telling us that we are not at risk. This simply cannot be true since I know that lesbians share needles, sleep with men, and engage in sexual activities which may put us at risk.

Oppression is the absence of choice. For women with AIDS, the oppression kills. Something must be done immediately to give back the choice because in this case, choices save lives.

MR. SCOTT ALLEN: Thank you. You may have other parts of testimony in the dialogue. One of the things that we have done originally is not only have we interacted with you all, but we want you to interact with each other. So let's have an open time of questions and responses and feel free to jump in

MS. DIAZ: I have a question for Dr. Fuller. I was very interested in your concept of some type of academic certification for pastoral care related to AIDS, and that really hits home. I have concentrated a lot of my efforts during the last years working with pastoral groups who have seen the need for that.

I'd just like some thoughts on how you feel what could be done in an interdenominational type of venue so it just wouldn't be Catholics preparing their own for AIDS work, or what type of thing might be more of an interdenominational type of focus that could give us the certification or academic qualifications and might be done in that type of team spirit that you are talking about.

MR. FULLER: Well I think there are already a number of currently acceptable pastoral education national organizations that certify ministers from all denominations to ~~include the hospitals~~ here --

MS. DIAZ: Chaplins?

MR. FULLER: Chaplins, right. And many hospitals require a certification before they can take those persons on staff. So it's just a question of adding subject matter to the topics or CPE training required to be educating them now.

MS. DIAZ: I think the CPE program, at least what I'm acquainted with, really concentrates a lot on the inpatient provision of pastoral care and I like what you said in terms of focusing on outpatient and home-care services as well.

MR. FULLER: The second way that that structure is already in place is that many minister training programs, seminaries or graduate schools often have a Master Divinitive program, kind of a national basic certification for people in the pastor forum as a profession.

There is no national licensing board that are as a group as far as I'm aware, but many of these groups do meet on an interdenominational basis and can certainly share the concepts of including, for instance, education about working with addicts, the minority members, transmission of HIV infection, so that their ministers will feel comfortable working in an HIV setting.

MR. DALTON: I have actually three questions, so I can make them brief. Gail, I was struck by your testimony about how similar a lot of what you have said is to what we have heard from people talking about the problem with AIDS in rural America. In fact, you yourself drew the parallel and that was very useful for me.

In your recommendations, however, one of them was the CDC should count all cases of HIV infection and not simply cases of full-blown AIDS. My question, I guess, is whether you then would recommend mandatory reporting of people who have HIV?

MS. BAROUH: No, I would not recommend mandatory reporting. I think I was talking more along the lines with that women have such difficulty in being in the guidelines of full-blown HIV infection, which is the same problem that we have seen in Long Island, that the guidelines have not changed. We have many cases similar, of women who are declined from CDC because the doctors never assumed they have AIDS

MR. DALTON: I can understand, for example, arguing that opportunistic infections that affect only women should be entitled as a way for AIDS diagnosis or something less than full-blown AIDS should be entitled for federal entitlement or state entitlement. But I don't understand how you can say that --

MS. BAROUH: I think that's more along the lines of what I have been saying, that those changes have to be made. We have to report our cases to the state now on AIDS and ARC, using AIDS and ARC. And we have three to four ARC deaths per month. So we have three to four more ARC deaths per month and they are not getting any entitlements or other social benefits because they are not full-blown AIDS cases. Those procedures must be changed.

MR. DALTON: For David Woodring. You began your testimony about talking about this particular problem of confidentiality of the infected Native Americans because the person that you might be dealing with may be somebody you know very well and may be somebody we know.

I guess I'm wondering what can be done about that, because obviously there are drawbacks to having outsiders in the position of AIDS counselors for the very same reasons that you also pointed out in your testimony. What do you suggest?

MR. WOODRING: My file itself has a confidential tag on it but none of the other files do. It's not ultimately encouraged that you look at that file in the first place. A lot of times, like I say, if the patient comes in and is not on an appointment basis, then they sit there in the waiting room around everybody else, feeling bad, waiting to hopefully get seen. Most do get seen, but how much do they really get in care if it's 4:45 and they have been there all day long?

MR. DALTON: Thank you. And Linda Meredith, I think this is the first time we have heard the L word in any of our hearings, so I want to ask a little bit more about that. I appreciate your talking about other women with AIDS besides lesbians. But I would like to focus on a particular piece of -- and also the invisibility of lesbians. But another is obviously the interest in lesbians that make it clear that as a group you are at lower risk than personally any other imaginable group.

And yet, lesbians obviously are among those who are infected with the virus in part in that some lesbians do sleep with men and some lesbians do share needles. Where do we go with this? I mean, how do we sort of bring the visibility of the issue of lesbians affected with HIV and the problem of woman-to-woman transmission without at the same time putting you behind the eightball in a sense?

MS. MEREDITH: Well first of all, I think that there are a couple of ways that you can go about it. First of all, the CDC is not interested in investigating woman-to-woman transmission, and if somehow they could be encouraged to investigate whether or not various sexual behaviors among lesbians indeed do result in infection and to talk about that in literature, it might be good to put people into the mind set that that could happan.

Another thing, you know, there's a real taboo in the lesbian communities about talking about really what we do sexually. And if you admit that you have slept with a man, then, you know, people sort of ostracize you. So in some ways that has to be changed and the way that we sort of try and go about it in ACT UP is to host forums where 11 lesbians can come and sit down in a safe environment and really open up about what they do sexually. And I think when you get lesbians to talk about their sexual behavior, then they start to get it that some of those things also put them at risk for HIV.

MR. KESSLER: All four of you have alluded to the problems of stereo types, meaning discrimination. And I'm just wondering whether any or all of you might comment on what this Commission might do or say to help to break down some of those barriers. I was struck by that common theme.

I mean, it's not that we haven't heard it before, but that's the first time in my memory that all panelists at one time talked about these barriers, whether it be perception of gays, or if it involves pastoral, lesbians who have been with men, other problems in terms of communities, homophobia, increasing reservation in Native Americans, all of which are something that we have been seeing and hearing. But I'm wondering whether any or all of you want to comment on what this Commission might do, say, or recommend.

MR. WOODRING: One of the things I think that we could recommend, we need a national health policy in this country. We are not going to wake up Tuesday morning and do it, so why can't we make AIDS the vehicle to start that? Then we won't be worried about sterotypes if we have national health insurance. People, no matter how much you teach them, are still going to discriminate, if that's how they want to be.

MR. FULLER: One way that I could recommend among the various denominations is to specifically address the national organization that represents each of the churches and specifically encourage them not only to let AIDS education be more forthcoming in training programs, but also to make it a little bit of kind of ministry specifically needed right now, one that requires special training and special resources and be given a respect from the top down, not from the current situation where it's the grass roots who often find the resources to get into the ministry, so be sorted by policy and by materials.

MS. MEREDITH: Somewhere, people are going to have to stop passing the buck. We sat down with Dr. Felgee (phonetic) on Friday to talk to about him about some of these same issues, and we were told again that AIDS clinical trials was not where people should come for healthcare and that it wasn't his job and that it was totally from a scientific research.

So no one's doing it and everyone's passing the buck; it's not my job, it's not my job. We proposed to him to design trials which could be called something like the increase on longevity on women with AIDS when you compare them taking AZT alone to them taking AZT and having routine gynecological care.

I mean, why can't you sort of free associate a trial design that could open up access to social services that could open up access to routine healthcare for people? But people pass the buck. So somewhere we have to identify whose front it really is and then, you know, really make them accountable for that responsibility. Because what I hear from a lot people is, It's not my job.

MR. KESSLER: Dr. Fuller, I would like you to take your stole off and put your stethocope on. Do you want to comment on, I know you see a lot of poor individuals, a lot of women with AIDS. Do you want to comment on that?

MR. FULLER: I fully support the testimony, especially the ones, for instance, relating the relationship of homopathic environment to cervical cancer. It's certainly an opportunistic infection and should be labeled for women.

It's also true that I think the medical models, subspecialty models, that are developed for AIDS care centers has largely involved people from pulmonary medicine and infectious diseases and primary care.

And in our hospital in Boston, I find where one-third of our clients are women who have yet to develop a working relationship with a gynecologist and obstetrician. Women are coming in the hospital, are screened for HIV, and don't have any guaranteed follow-up in the HIV setting.

MR. GOLDMAN: To David, I'm just wondering to what extent are the problems that you are relating more generalized in terms of the inadequacy of the Native American healthcare system as opposed to dealing with issues involving AIDS and HIV?

12

MR. WOODRING: Well that starts the barrier, lack of communication and treatment, because most AIDS cases are systematized. Even though it has a good system and it does work, HIV has just brought it out even more. And we have Natives besides myself that have been in the hospital with AIDS. No one anywhere could get any kind of cooperation, any kind of understanding, and they told me each time to go in and talk to the dying. That seemed, as we all know, to bring a message home, talk to somebody that has this.

But out of the eight that have died in New Mexico, seven of those were not able to be embalmed and their families want them embalmed. But because the only people doing funeral work on Indian reservations were Indians who took off for other areas, seven of those bodies were not embalmed and now those people are coming in and their families are having deep trouble having to deal with that.

I think a lot of the things that HIV is showing us is the inadequacies that we have in the healthcare system anyway. I keep taking my care to Indian Health Service because I know there are more Natives that will need care and the doctors have to have experience. But I do have Medicaid and I could go anywhere I wanted to.

MR. GOLDMAN: Let me ask you a question, if I may. You talked about the, if I heard you correctly, the failure of some of the communities affected by AIDS and HIV infected to work effectively together and refrain from some of their discriminatory actions even with each other. What kind of suggestions do you have or how do you propose to get some more cooperation in that area?

MS. BAROUH: One of the changes, not changes, but one of the policies that we continue at LIAAC which has been very successful is to not segregate our support group services from people with AIDS.

Everybody has the common denominator that if they had AIDS they would want to be in a group support or the common denominator that if a loved one had AIDS they'd want to be in a support group. That politically has had a lot of problems with the minorities being provided places, such as hemophiliac organizations that are only for hemophiliacs with AIDS, and that follows suit. That's opened up and changed a lot of systems on line for us that we will not segregate our groups.

We also will not label our volunteers or our case managers to only work with people like themselves, which is part of the requirement of working for our agency if you want to volunteer. You go where you are needed, not necessarily -- I mean, there are some things that are just practical. Obviously, if somebody is Spanish speaking, they can volunteer to work with Spanish-speaking persons, but we are trying much more to have more of an integration in the community.

The biggest problem is that people with AIDS on Long Island really don't see that they have AIDS. Denial is just amazing. You can have people that have been sick for two years and they do not think that they have AIDS, which is something that we really came up with when we started the HIV forum, which is just information for people who are HIV positive. And we had people who were very, very sick showing up and saying, I just think I might be positive. So the denial problem is the biggest problem for us.

MR. JIM ALLEN: I have got a couple of questions. First, Gail Barouh, can you tell me in a little bit more detail, you indicated that it would be good to have additional statistics or epidemiological information about cases in surburban and rural areas. What is it that you need?

MS. BAROUGH: For us, we need not to be seen as part of New York City, which is our biggest problem. I think that a lot of rural and surburban areas are sort of lumped together with the major cities that have maybe a different profile. Certainly ours is a different profile than New York City has. It's the separateness we need more than anything, because we feel that that would sound out the individual problems of the communities, not just the problems of the whole state or surrounding cities

13

MR. JIM ALLEN: Let me suggest that that's the kind of information, rather than getting that from CDC, that you need to get that from the county health department and state health department.

Part of the problem with statistics that come out of a federal government agency like CDC is, first, it's compiled for the whole nation, you know, things get lumped. And secondly, because there is a chain of reporting from the individual physicians and clinics to the local health department, and then on to the state health department and then on to CDC, there's a loss of detail as you go up the chain.

In addition, the states sometimes put restrictions on what CDC can do. There may be some states that say, for example, I know we can work with CDC. The states will restrict us from publishing any kind of that information. So that I would challenge you, rather than lashing out at CDC that CDC is not doing anything, go to the county health department and state health department and force them to give you the level of detail and publish the kind of statistics you need.

MS. BAROUH: We are trying to get the state to look at us as a separate area right now. We are two counties that cooperated with the state in reporting procedures. That is a local problem that we have to deal with, I agree.

MR. JIM ALLEN: But if you can't get the cooperation at that level, there is no way by the time you get up --

MS. BAROUH: I just think it's important that the Commission as a whole understand. You are right, if we can't even get it from a local health department we are in a lot of trouble and a lot has to be dealt with on a local level.

MR. JIM ALLEN: I think the point is well taken by the Commission. The Commission needs to take a very clear position in terms of encouragement. We can tell the state and local health departments to not hide statistics, to make them readily apparent so that you can do the kind of local analysis that you need. Clearly, the data is very important to understand what is going on and to take appropriate actions. The point is very good.

Linda Meredith, let me ask you also, in terms of the epidemiologic investigation, what proof do you have? Why did you say the CDC is not interested in the female-to-female transmission?

MS. MEREDITH: Well, one thing is that it's just not on the reporting that they do. Okay? And the second thing is, I don't know of any study that specifically is designed to even say that the possibility of lesbians exist. People do hetrosexual studies on women all the time and they presume that it's a hetrosexual population when they haven't even asked the question. So that kind of invisibility of lesbians in general and our sexual practices in specific. Lesbians -- under the current CDC definition, they have no idea what's going on with lesbians nor do they really care.

MR. JIM ALLEN: Let me just back up and look at it from a different perspective. And first of all, I'd just like to know, have you talked with them directly or has anybody gone to them and laid out your concerns?

MS. MEREDITH: Well we talked to them in a demonstration in February that was about that whole issue of the CDC definition and about lesbians in particular. And it was in a very vocal way, it just didn't happen to be across a conference table.

MR. JIM ALLEN: Let me encourage you to do that also.

MS. MEREDITH: I don't see any sort of movement on the fact that they are going to change the definition. I just read a paper about the increased morbidity of women with HIV infection. And they talked about the fact that only 34.8 percent of the cases that they looked at fit into the CDC final diagnosis. And they didn't even tell us what happened to the rest of the people, nor did they like even intimate that they might be embarassed by the fact that over half of those people who had died did not fit in their definition. So --

MR. JIM ALLEN: They do review it and I have taken notes and I will go back and I will talk with them. But let me just reassure you that there is an awful lot of investigation that goes on very quietly. And you are

14

right, there aren't any large cohort studies where they recruit lesbians and follow that, because it would be extremely low payoff to have it.

On the other hand, for every case that is reported, we work very closely with state and local health departments to try to get out all the facts and information. And for any case that doesn't fall within acceptable -- for any case that doesn't fall within recognized risk factors, where there doesn't seem to be a means of probable infection, there are a whole series, pages and pages of questions of asking this person, to try to reevaluate. So it should show up in that kind of investigation to the extent that it's hapening occasionally.

MS. MEREDITH: If you look at the pie chart though, about 52 percent of women have high risk use. That separates us. Nine percent of women who are infected, you know, we don't know how they got it; as opposed to men, which I think is like 2 to 3 percent. So I mean, where's the fallout? What's happening? It's like triple for women.

MR. JIM ALLEN: My guess is it's a very high proportion that are in fact sexual transmission, but it's a situation where a woman will tell you that she's had lots of, you know, any number of different sexual partners, she doesn't know whether any were drug users or bisexual men, whatever. It's very difficult to get the level of detail.

I think the point is well taken and I will make sure I get it back to them. I would like to see you sit down and talk across the conference table though too.

MR. DALTON: At the risk of publicly putting you on the spot, I assume that Jim Allen would be willing to try to facilitate such a meeting?

MR. JIM ALLEN: Sure.

MR. SCOTT ALLEN: I have one question -- actually, I have several that will wait until the end. One of the issues that you didn't bring up and I would like for you to address is the proportion of women of color that are involved and the difficulty of racial barriers itself.

MS. MEREDITH: I think everybody knows that women of color constitute 72 percent of cases. I didn't feel that it was -- I don't want to address a specific issue of women of color, although I know some of them. I would prefer for a woman of color to sit down at this table and tell you about those, which is why it's not in my testimony. Although there are some changes that are just exacerbated by the fact that it's a woman and it also may be a Black or Hispanic woman, but she should tell you about that.

MR. SCOTT ALLEN: We have that testimony. But I wanted your opinion of how have you interacted within the circles, of how much sensitivity there is to individuals of color.

MS. MEREDITH: I'm thinking about the barriers to access that I described. I mean, sometimes people who are -- I don't want to stereotype this -- but sometimes people who are less well-educated or who do not have transportation to go from building to building to try to figure out the forms, to fill out the forms, cross the t's and dot the i's, are further denied access to a whole host of things that could be right there if they could just simply understand what they are. And so, you know, that has to do with low socioeconomic status.

It often frequently coincides with the fact that you are either Black or Hispanic. Because you don't have from square one the opportunities to educate yourself and to find out what is available to you. I really don't want to speak to that issue.

MR. SCOTT ALLEN: Okay. I have another one. David, I have a question for you about the individuals that leave the community and return and the family support systems. Do you find the families are rallying around the individuals, the family members?

And I hear there's a lot of ostracization from the tribe itself, but what about the family and also the spiritual needs of the Native American and where does that come into play and is that a basis of some type of support?

MR. WOODRING: Well, Right now, there's not much of the families rallying around. The basic immediate family where the person is actually physically living, they are. But they do not allow us even to know why they're there, what the problem is with that person. Because, like I said earlier, homosexuality was never an issue in our Indian communities, but now because of HIV a whole host of things are coming up.

Most of the families have wanted to respond. There have been some which just flat turned away. My family wanted me to be with them. I was the first Native in Oklahoma who tested positive with the virus and the way they had to deal with me was to send me out of the state.

Before that happened, while we were waiting for the test to come back to confirm that, everyone in the community knew what was going on. And my nieces and nephews, they quit going after a while to the grocery store because people would casually make a break from the line. So, that is also contributing to the lower life span of those who are HIV infected.

We testified a little bit earlier about it, but I don't think we really touched on it. When I was diagnosed with ARC, I was sicker than I was with the AIDS diagnosis simply because I didn't know how I'm going to live, pay my rent, food, where will I be able to live and have any kind of livelihood.

And there are many people in this country that have died who have died with ARC instead of AIDS. Like I said, you know, the small community groups that most communities have, that's not their people. And I tried to go out and talk to teenagers and I've personally talked to 6,000 this year already on AIDS. If this is the way we are going to have to develop and respond and depend on, we got big problems.

MR. SCOTT ALLEN: Well, thank you all. Any more questions? Thank you very much for participating and speaking to these issues.

The next panel is David Schulman. David Schulman is with the AIDS-HIV Discrimination Unit, City of Los Angeles; and Robert Greenwald with the AIDS Action Committe, Boston, dealing with housing I believe; and Veneita Porter, Planned Parenthood, San Francisco; and Sean Duque, with PWA, member of the Board of Life Foundation, Honolulu, Hawaii. Did I pronounce that right?

We will go in order of David Schulmanman, Robert Greenwald, Veneita Porter, and Sean Duque.

MR. SCHULMAN: I have seven minutes? I'll try to cover a number of different areas in my six minutes. First, I'm going to speak a little bit regarding what we in the City of Los Angeles have learned in dealing with AIDS discrimination itself.

A great deal has now been written about AIDS discrimination and I would like to refer you to the items that we included in our packet. But I would like to emphasize one point in particular that needs to react with a lot of the testimony that I will be offering this morning and that has to do with emphasizing the importance of combating the fear of epidemics itself, quite apart from the particular constellation of fears that are involved with HIV. We know about the issues regarding homophobias, fear of death and dying, fear of health dismissal.

But as I have dealt longer and longer with interaction in the law and the epidemic, I am more and more convinced that some of the lack of national leadership and the ways in which law has filled in the gaps has addressed a more primitive fear of social breakdown itself, and so to the degree to which lawyers and others can address this issue, which is somewhat independent of the fears connected to this particular disease, I think we will do a little bit better job.

I have attached a letter that my office sent to Edward Mercado who is the head of the office of Civil Rights for DHHS and I sent an exact same letter to Dr. Helen, encouraging DHHS to follow-up the hearing that was held, the workshop that was held last December, training National OSHA staff in AIDS discrimination techniques.

My collegues in New York and San Francisco and I assisted DHHS in putting this workshop together. There were not enough people attending, it was clear, because it was held in Washington and state, local, and federal agencies were not paying to get their people to Washington. I encouraged people then in follow-up letters and encouraged DHHS to fund regional programs.

We have invented the model; we know how to do it; we have the staff available. I'm prepared to donate my time again and so are my collegues in New York and San Francisco, but it takes the push and I think the push has to come from you to say, Let's get the knowledge out and implement that knowledge.

16

Next, I'd like to talk just a little bit about the private lawyer. Four years ago I was asked by the local Los Angeles County Bar Association to develop a training program for volunteer lawyers. Based on my experience on not having an overwhelming group of people responding to AIDS education, I thought if we had 20 attorneys attend we would be doing quite well; 80 attended.

And we had over 200 attorneys in the greater Los Angeles area, most of them from big city and ethnic corporations, wanting to deal with human beings a little bit in their legal practice and seeing the Bar's AIDS Hospice Lawyer Referral Service Program as a way for them to deal with human beings, let alone contribute a little bit of the legal expertise that can help eliminate a myriad of problems in some of the aspects in terms of access, in terms of entitlement, as well as relieving just some of the stresses and strains that anybody living a daily life has regarding legal problems, but which are exacerbated for people with HIV, landlord-tenant problems, debtor-creditor problems and the like

The Bar program -- there is a similar one in the San Francisco Bay area, and they are being replicated across the country -- but it is one example of the ways in which the private bar can step in and begin to model the kind of behavior that I suggested earlier, which is for attorneys to model behaviors of stability, behaviors of compassion and concern.

Related to that, there are more specific things that a private bar can do. I sit on the Los Angeles County Bar Association's Bioethics Committee. Not every bar association in the country has one, but we constructed an

AIDS subcommittee out of this and through the AIDS subcommittee we issued a pamphlet that is now being distributed through the AIDS service organizations regarding AIDS-related legal rights.

I'm sorry to say that the information in that pamphlet boiled down to one sentence which is, If you want to avoid AIDS discrimination problems, don't disclose your diagnosis to anyone. That, as painful as it is, stems from our experience in dealing with AIDS discrimination issues, and we clearly have to be involved in both ends of the situation.

We have to be constructed as a society where people can disclose and not be frightened or ostracized, but at the same time we need to be empowering people who have learned their diagnose to learn how to control the issues that are going to create AIDS discrimination matters.

In that regard, I'm going to comment for a moment relative to gynecologic training. One of the most disturbing AIDS discrimination cases I recently investigated in my capacity as head of the City Attorney AIDS-HIV Discrimination Unit was that of an individual, a hetrosexual woman, who wanted to throw away the condoms with her long-term boyfriend and so they went off to get tested.

She arranged for this testing to be at the local

Beverly Hills gynecologist. I asked her why a Beverly Hills gynecologist. She said, Because I figured those would be the kind who would really know how to counsel me.

Well she got her test results back from the Beverly Hills gynecologist over the phone with a hang-up and that led to her being sufficiently upset that she disclosed at work, when she might not otherwise have disclosed at work if she had received adequate counseling from the Beverly Hills gynecologist. And she disclosed this at work which led to workplace discrimination, so then she returned to my office to deal with it.

So there are a number of ways in which I think attorneys, despite the fact that we are the object of a lot of scorn in society, can embody. I think that Mr. Dalton's book relates with ways in which attorneys can serve a stablizing function, and some of the things that I have written are included in the packet that we have shared with all of you, some of the ways that attorneys can do this. And I think it's appropriate for the Commission to turn to the legal structure in things and begin to build on experiences.

In conclusion, I would like to talk about the third area, one that does not require me to speak with legal happening, but instead to another part of professional identity. I suggest that you direct your attention to the

Los Angeles County theme that I included, because I think it says it much better than I could in 45 seconds regarding the barriers to delivering chronic care well at home as long as what we impose upon our chronic care understanding is an acute-care based paradox.

17

And the longer I have worked with this idea, the more I'm convinced that our difficulty in delivering home-based care, be it HIV-related or related to any of the other kind of cares which have arisen in our culture, we are facing problems because we are trying to fit a round peg into a square hole.

And I think given the feedback I've gotten from that article, if you have a chance to work through a couple of the ideas suggested, it can help better facet some of the issues you are dealing with in delivering HIV-related services. Thank you.

MR. SCOTT ALLEN: Robert Greenwald.

MR. GREENWALD: Good morning. I'm going to talk about the housing needs of people with AIDS and the efforts being made to develop the broad continum of housing options. To begin with, I would like to point out two basic premises on which I base my work.

The first is that affordable and appropriate housing is essential for the health and well-being of people with AIDS and is necessary for the adequate provision of

HOUSING

home-based services.

The second is that the development of the continuum of housing options, that's housing options ranging from subsidized independent housing to congregate supervised residences, would not only save lives but would also save the government and taxpayers money.

Presently, it is estimated that 30 percent of people with AIDS are in an acute-care setting at any given time. In a city like Boston, for example, that's $1,400 a day at Boston City Hospital.

Some of this could be reduced as low as 50 percent if a continum of options existed. There are many documented cases of people that remain in hospitals well beyond the point in time that they are there for acute-care needs. They are there because there are no residential alternatives available.

Finally, just to point out, shelters are not an available alternative, not only in terms of the risk that they pose to people's health, but in Massachusetts, for example, it costs $800 to $900 per month per person to keep a person housed in a homeless shelter.

I would just like to give a few statistics which highlight the housing crisis that exists within the nation today. It is estimated that nationwide 30,000 people with AIDS are homeless. Fifteen percent of the homeless

1/2 % pwas?

population in the United States are HIV infected, although in high incidence cities like Boston it's estimated that 30 percent of our homeless population is HIV infected.

And finally, over 50 percent of people with AIDS that are not already homeless are what we consider in imminent danger of homelessness, which means that they are presently paying over 50 percent of income on rent.

In a city like Boston, the average person with AIDS on social security insurance or disability insurance receives approximately $525 a month to live on, in a city where rent for a one-bedroom apartment exceeds $500 a month.

In short, the homeless of tomorrow, the collapsing of our healthcare system, the dependency on acute-care setting, are to a large part created by today's failure to provide adequate housing for thousands of people with HIV infection.

I would just like to speak for a few minutes on the efforts we have undertaken for the AIDS continuum of housing, some of the problems we have encountered, and some of the solutions.

The first effort is in education. Education of government officials and housing professionals that AIDS is not only a medical issue. I can't tell you how many times I have submitted proposals for government housing to

HOUSING

both federal and state governments and received letters back saying, Sorry, this isn't appropriate here, here's information for funding on nursing homes. It's important that people understand when you talk about AIDS in housing, we are talking about more than just nursing homes.

NIMBY

Secondly, education of communities, education that AIDS is a community issue, that people with AIDS live in all communities, and that the concept of "Not In My Backyard" in terms of housing developments is just not acceptable.

In terms of improving access to housing and developing housing options, it's important to know that the majority of individuals and people with AIDS could live independently if affordable housing was available and services were provided through organizations like the service organizations.

18

Of the major programs which we could help to keep people living independently would be the Federal Section 8 Program. That's a program in which individuals are responsible to pay 25 percent of their income towards rent; the federal government pays the rest. That would actually be cheaper than shelters.

The problem is that presently waiting lists for Section 8 Programs in most cities exceed the life expectancy of people with AIDS. Secondly, the kind of selection procedures often require homelessness as a prerequisite to live in a shelter They do not in any way recognize the importance of homeless prevention. In effect, people with AIDS are being denied access to the Section 8 Program.

There are some solutions and I have attached testimony. Attachment C talks about the Rental Assistance Tenant Selection Procedures that we have adopted in the Commonwealth of Massachusetts for our state-run program. These are programs that recognize that people with serious medical conditions that are paying over 50 percent of their income on rent should be considered equal to people that are homeless and living in shelters. In other words, it's a homeless-prevention program.

The second, Attachment B, is an example of a set-aside proposal whereby we say because the waiting list is so long, to take a certain percentage of the certificates and put them aside in a special pool for people with special needs and conditions.

Attachment D is an example of a letter that was presented to HUD through our State Executive Office of Housing where HUD basically said, Do it if you want, but do it through local programs, not through federal programs.

Moving on, in terms of the development of support in supervised housing, we need to look at the traditional, major federally-funded programs for housing developments already existing within Section 8, the McKinney Act, and Section 202. These are programs that are designed to deal with the development of housing for special populations, housing for the homeless, et cetera.

HUD has basically denied us access to these programs and you can look at Attachment A. For example, a denial from HUD which was a combined effort between the Jewish Community Housing for the Elderly in Boston and the AIDS ACTION Committee where we together submitted an application to private developers for support housing for people with AIDS.

HUD Denials

HUD has basically denied access on four grounds; they have said that people with AIDS are not physically handicapped under the agency's definition of the term; they say that people with AIDS do not live long enough to qualify under the statutory definition of impairment; they say that the disease is not of such a nature that the ability to carry on daily functions would be improved by more suitable housing conditions; and finally, they said that there was a policy against permitting the development of housing for targeted populations.

Now I need to say, on the first three arguments these debates with HUD have been going on for years. We have been able to move them some. They are now saying that people with AIDS may be physically handicapped. What is unclear is whether they are saying there has to be another underlying physical handicap.

What we haven't been able to get them to move on is the concept of permitting housing development for target populations. In other words, they are telling AIDS service organizations, You develop housing through Section 202, but for handicapped populations in general. AIDS service organizations that are already stretched to the max do not have the capability to develop housing for handicapped individuals in general, so subsidies need to be set aside for people with AIDS.

HUD has, by the way, allowed development of housing for both the elderly and the mentally ill populations, which they have done by the use of waivers which they refused in the context of AIDS.

Finally, HUD has not adopted regulations that exist for initiated innovative program. They will not permit the development of housing on medical-care grounds, which is ridiculous in the concept of AIDS. They will not generally fund emergency or transitional housing. They only allow you to use chronological order to determine who gets housing.

And finally, they won't take initiative in terms of housing development money to set aside or give preference to programs that are going to develop housing for people with AIDS.

Attachment D is an example of Massachusetts attempting to set aside some of its federal funds to develop housing for people with AIDS. It's been going on for about a year and we still have not had approval in writing from HUD, although we are going forward on this project.

19

Finally, in conclusion for the Commission, I just want to say three things. First, that we strongly support The AIDS housing Opportunities Act which is a piece of legislation filed by Congressman McDermott in Washington D.C.; that we support efforts to move HUD in the direction to take some initiative on housing people with AIDS; and finally, that the Commission play a role in speaking out on the importance of the AIDS housing issue. Thank you.

MR. SCOTT ALLEN: Ms. Porter.

MS. PORTER: When Jason called me last week, I thought of Harlan and June and Eunice and Larry sitting up on the panel once again and hearing me go on about women, women of color, and children issues, so I'm going to do something like this: I'm going to suggest that preexisting conditions are a barrier in terms of most people with AIDS in this epidemic. If you happen to be poor, if you happen to be a person of color, if you happen to be a woman, that is a preexisting condition.

When we talk about sex, international access to healthcare, and early intervention, I suggest that we are really putting our mouths around a travesty that has nothing to do with women and healthcare.

Currently, I'm acting in the position of Director of Education for Planned Parenthood in San Francisco-Alameda. I felt that after nearly eight years in AIDS work, that one, I was burned out and tired; and two, I had been the precursor or the prefront in the women's caucus, where many of us sat across the table with CDC and other people and talked about the need for women to be included in trials.

This issue around women inclusive of trials in drug trials is not a new issue, it existed long before the AIDS and HIV diagnosis, that women suffer at an alarming rate of different kinds of cancers that are not currently under vertical study is something that we have lived with for a long time or died with for a long time.

The other thing I wanted a parallel for is that when we talk about discrimination, we need to talk about discrimination in at least a three or four tier system. When you talk about institutional discrimination, you have to talk about color and worker discrimination, and you have to talk about societial discrimination, and you have to talk about community and interpersonal discrimination.

And when you look at women or margined populations -- I hate that word -- you are looking at populations that navigate discrimination on a multifaceted system, that these are not just women who deal with the fact that coming out at work may be dangerous or coming out with a diagnosis in a workplace may be dangerous. These are people that certainly do not navigate the system and the way the system is now.

And the idea that we could allow these people or we could change one thing that would make early intervention possible, I think is amusing, but sort of a fatal way of looking at things.

I'd like to share the parallel that the civil rights movement and affirmative action laws that we have existed with since the '50s and '60s are a good example of how I think HIV discrimination is going to take effect; that currently, because of skin color or because of sexual preference, I still suffer in an interview in a job situation and in a graduate school program. And that reality is part of what many of us have grown up with.

I suggest that we have created a whole situation where HIV-infected people are going to have to live for generations with this same kind of legacy. I don't think you should assume that because a city or a state is heavily impacted by the HIV epidemic that people understand what the epidemic and discrimination does. I currently live in San Francisco. I ran the Human Rights Commission, AIDS Discrimination in New York State for two years before I moved to San Francisco.

I have firsthand knowledge of such things that the Long Island AIDS care giver talks about. We could not find an OB/GYN person or a dentist in Long Island who would willingly treat a woman or a person with AIDS who was HIV-infected and willing to admit it. It was an ongoing practice to tell people, especially if they were HIV, to not disclose their HIV status to their healthcare worker, and I cringe to say that.

I say that when we talk about discrimination, we have to look at that we are talking about the fact that something as simple as there are two national Conferences on pediatrics in AIDS currently, but there is no federal or national funding of women's in AIDS conference. I have been personally involved in three Women in AIDS Conference over the last six years and none of them have gotten any federal funding.

When we talk about discrimination, you can't assume that because people live in New York or Boston or San

Francisco, or Chicago, that they understand what discrimination does in their city or town. We currently still deal with employers in the City of San Francisco who just do such things as bring in their employees who they think may be gay and ask them to roll up their pant legs so that they can see see if there are lesions.

We currently still have the OB/GYN specialist who last year asked me if I was HIV infected. When I refused to tell him what my sero status was, I was asked to leave his office. This was in the City of New York. This was on Park Avenue.

My recommendation is that we support demographics and sero-prevelence studies that are based on a community model. We have the idea that in many cities that the demographics of the disease are switching. The demographics of disease may be switching in some of our cities, but in many of our cities it isn't.

In some cities, such as Seattle and other places around the country, the epidemic is still mainly gay white men, and if that's what the epidemic is, that's where the funding should be. But if the epidemic is in a city such as the Bronx or New York, where an increasing number of the population is women of color with HIV infection who are dying before they can get AIDS diagnosis, then let's look at the demographics and funding pattern of who we are funding in those particular communities.

The other thing is that you have to increase funding programs with dual diagnosis; that the idea that substance abuse and our lack of funding of substance abuse programs is not only attributing to the rise of HIV and IV drug users on a prevelant basis, but if we are not fighting on at least two fronts, that means substance and drug abuse as well as alcohol abuse and HIV infection, I think we are clearly not doing our job.

And just to conclude, whether or not any of us like to admit it, we can say all the things we'd love to say, but one really does make the movement here, and the buck really does stop here, and I think it's time for us to put our money where our mouths are. Thank you.

MR. SCOTT ALLEN: Mr. Duque.

MR. DUQUE: Very briefly, I would like to thank the Commission for the invitation to this hearing and I appreciate the gesture and the thoughtfulness for including a person living with AIDS and an Asian-Pacific Islander from Hawaii to this event. We in Hawaii sometimes feel left out of policymaking, especially when decisions that affect Hawaii are made here on the mainland without any input from anyone in our state.

Hawaii, which is made up of eight major islands, faces some of the same difficulties in regards to representation. Honolulu is the major city and the capital of Hawaii and is located on the Island of Oahu. Those on Oahu are constantly reminded to include those on the neighbor islands.

The cost factor of travel and long distance phone communication is sometimes overlooked, and it is sometimes simply convenient to convene meetings without the added burden of inviting and organizing outer-island participants.

Nonetheless, our entire state hungers for more participation. We invite organizations dealing with HIV Disease to consider Hawaii as their next conference site. We, in fact, open our arms to share with you our Aloha. Hawaii has a population of 1.097 million. Asian-Pacific Islanders make up 78.8 percent of the total.

In regards to HIV Disease, per 100,000 population Hawaii has the 8th highest annual rate nationwide for the last 12-month period from May '89 to April '90. Hawaii's Asian-Pacific Islanders represent the highest percent of the total cases per state with California and New York's Asian-Pacific Islanders ranking below that.

Hawaii is faced with a compound problem of illiteracy. One in five Islanders are illiterate and on most neighbor islands it's even worse, according to a survey.

One thing we all need to realize about illiteracy is that it directly affects children. Illiteracy begets illiteracy according to an artical. This presents difficulty in reaching these underserved populations.

By the way, the total number of AIDS cases does not reflect the huge numbers of HIV-positive individuals receiving medical care. That's a big major concern.

Henceforth, what kind of effect does illiteracy have on the dispersion of information and education about HIV Disease, and number two, its affect on medical care. Discussion of HIV disease to a few ethnic specific groups has provided me with an overwhelming surprise, that they have never had any HIV-disease education despite this being the 1990s.

Leadership must come from distinguished leaders and organizations. We are faced with a dilemma. Our government leaders find it very difficult to say the A word, AIDS. When will they realize that this disease is a major problem in our country, in our states, and in our cities and counties?

Despite this being an unpopular topic, facing the realities of its long-term effect must be addressed now. We can no longer play catch-up with this disease. In regards to AIDS, leaders must take an active role if we're to nip this disease in the bud.

This disease has and will continue to strain existing service providers. Medical care of HIV disease nationwide is being provided by only a handful of physicians, dentists, and medical units. Absence of efforts to promote more services by this sector is of major concern. I encourage this Commission to play a more active role in this effort and provide medical units with current medical updates. Our rural areas and neighboring islands are greatly taxed with a short supply of dedicated individuals.

To provide good comprehensive medical care, HIV clinics must learn the importance of management of patients versus focusing on treatment of symptoms. Summarizing patients past visits is essential in managing patients for continuity.

Patients are required to fill out so many applications for benefits. Much of the same information is required by various agencies such as DSSH, SSI, SSDI, Section 8 Programs, case management services, hospice services, and medical facilities. A consolidation of forms managed by one agency could eliminate the duplication of efforts. The Psychological and physical effects of AIDS is already taxing on patients, let alone the added torture of massive amounts of form filling.

Honolulu had the highest average of rental rates nationally, with Boston and New York rating second and third. We need you to influence HUD to change the Section 8 criteria. We have an average of 20 homeless AIDS patients per week. Homelessness among AIDS patients is the most major social service need in Hawaii.

We are also experiencing a flow of mainlanders moving to the islands because of the weather, et cetera, and many of them are not given their AIDS diagnosis in Hawaii, so we are even taxed more with the numbers of people. In fact, about -- we have a doubling of the amount of HIV infected, positive cases, versus the amount of AIDS cases itself.

Hawaii is experiencing major financial cutbacks. Our Department of Health AIDS Prevention Program which allocates funds for various service organizations is being cut by some 71 percent by CDC. There is a whole pack. We need for you folks to help us, get more involved with us, because it is going to drastically cut back our funds.

2

people respect the wisdom of leaders. We ask that you take a more active role in educating and convincing our government leaders in Hawaii about the growing effects of AIDS and its long-term consequences. Targeting ethnic specific community leaders, church leaders, social organization leaders, civic club leaders, student body leaders, private sector business leaders, communication, promotional, and production leaders are also very important.

We invite you, Dr. June Osborn, and also our nation's surgeon general to address our leaders in Hawaii. Don't forget, we are the 50th state in this great nation. I would like to thank you from the bottom of my heart for this opportunity.

In recommendations, we need Hawaii to be represented in these efforts. I think that we need to track HIV-positive individuals at the various stages of HIV, address the issue of illiteracy. We need more leadership from you folks to educate our government leaders to start saying the word AIDS and addressing the problem head-on.

We need to get more service providers. There's not enough, especially on our neighbor islands. Where do they go for medical care and psychological support, et cetera? We need to learn to manage patients and just not treat them.

We need especially to consolidate our forms, SSDI, SSI, DSSH, et cetera. It's a major burden on HIV individuals. We need you to get involved with HUD's Section 8 criteria, to change it. We need for you to help with the massive amount of cutbacks that we are experiencing. I would like to thank you from the bottom of my heart for this time and opportunity.

MR. SCOTT ALLEN: Thank you all for being sensitive to the time and if you have anything else for input, please feel free to join in the dialogue. Are there any questions from the Commissioners?

MR. KESSLER: I would just like to start with Mr. Schulman. I'm concerned about your bottom line in terms of your statement that you encourage people to not share the diagnosis and I'm wondering about what that does to the actual cases if people do not forthcome? What are the chances of their getting very far in a discrimination suit or whatever, if they are discharged, for instance, on grounds of, "Don't relate the diagnosis." What is your experience in that?

MR. SCHULMAN: When the advise is not to disclose, it is preventive discrimination and I will give you an illustration. When a discrimination case arises, there are a number of barriers to successfully litigate those cases that distinguish AIDS discrimination cases from similarily situated discrimination cases that arise from other issues, such as homophobia, racism, sexism, and the like.

Number one, the stress level for a person whose immune system is impaired distinguishes the level of stress of litigation from anybody else who is attempting to use the adversarial litigation systems of civil rights.

Secondly, there are confidentiality issues. A woman or Hispanic doesn't have the same needs to maintain the secretness of his or her identity in the same way that an HIV-infected person has an incentive to need to continue to hide his or her identiy while pursuing an AIDS discrimination case.

A real example is the Chalk case. That was the Orange County school teacher case. His case is one of the four or five most important cases in our system regarding HIV-related rights. His lawyer originally filed that case as a John Doe vs. Orange County School District case. Within hours after the case was filed, an Orange County Register reporter called up and asked, Would you like to confirm or deny that this is Vincent Chalk? And she said to the reporter, Well how did you find that out? The reporter said, Well it wasn't very difficult to figure out which male special-ed teacher who is delivering services to hearing-impaired children had just returned from a long medical leave of absence.

So these are difficult issues as well as the time frame involved with litigation. So one of the things I didn't talk about at all is that our units throughout the country and the kind of training we have tried to provide at the federal level emphasized early intervention and mediation of these cases.

3

For one thing, some number of these cases turn around when official looking government lawyers walk in and say, Read my lips; we are going to talk about causal transmission and the lack thereof. There are times when we can turn around cases that then efficiate the need for further adversarial proceedings.

Early intervention and education can really model good behavior and we have found a significant number of members of the businesses community wanting to find out how to avoid these cases. I have an increasing number of private attorneys calling me up saying, I have a client and we think we are going to have a problem, would you mind telling me how we can avoid these problems from occurring. I think that needs to be supported and that's a way of pointing towards some of the other strategies for eliminating AIDS discrimination.

But I would have to, as an attorney, tell any particular client that, Forget your human needs, forget your psychological and emotional needs. If you want to make sure that this doesn't explode in your face in the workplace, don't tell anybody. That has to continue to be my advice.

MR. GOLDMAN: I would like to ask the question of all panelists, particularly those having experience in the discrimination area. The first act of this Commission shortly after it was formed in August of 1989 was to refer to the passage of the ADA. Passage of anti-ADA was the major recommendation of the Watkins' Commission. The ADA is now defunct and we are all thankful and happy that that happened.

I was wondering if from your perspective, if you would suggest to us, now that that recommendation is being fulfilled, what recommendations you think this Commission might make to the areas of discrimination in the post-ADA era, and whoever wants to go first.

MS. PORTER: I think the ADA is going to be a very strong puppet unless we have background, unless we have enforcement unions nationwide to enforce the ADA. And some of those who did do discrimination work were not exactly thrilled when the feds showed up last year on federal HIV-discrimination landscape.

One, because that certain federal office hasn't had nurturing specifically to HIV until recently. They have had no special hearing or administrative procedures which speak of HIV cases, which can take up to two years, and there's been no administrative hearing process to deal -- which is a public process -- to deal specifically with confidentiality matters.

I think the need for enforcement is baseline to any effective law, that when we talk about civil rights or human rights or discrimination, and across the board, whether it has to do with race or religion, we know that human rights commissions across the country are handicapped by lack of funding.

You should look at not creating any monster when we talk about the ADA. Unless we have an adequate funding mechanism and an adequate penalizing mechanism, I think it is going to be an ineffective tool.

MR. SCHULMAN: Our experience in Los Angeles has been real interesting in distinction to the experience of New York and San Francisco in that while each of us have been able to accomplish certain things and have been hindered by other things, by situating our enforcement unit within the City Attorney's Office rather than separately housed in a human rights commission as in the case of New York and San Francisco, one of the things we have been able to observe is the mainstreaming effect of our enforcement strategies; that when enforcement officers come from the City Attorney's Office of Los Angeles, we are received differently in some context than human rights commission officials would be received.

And what I'd like to do is -- I don't mean that as a criticism of situating these enforcement strategies in human rights commissions -- but to use that anecdote as a way of illustrating further components, the need for creative enforcement strategies, for meaningful enforcement strategies.

And I want to reiterate my point from my main testimony, which is that the means and the lessons learned have been garnered and dispelled. You funded site studies of all units. You then funded a national AIDS Discrimination Training Workshop with a model strategy program that was eased out and written down.

But you have now got to get those of us who know how to take those things out to the hinterland. And I can't ask my folks to have a bake sale and fly me up here every time and neither can the others who are doing these things on a shoestring.

You have got to bring federal resources and ask us to then teach your federal people how AIDS discrimination enforcement and physical handicapped enforcement is different than other forms of enforcement and how other forms of civil rights enforcement can benefit from the lessons that we have been learning more recently.

I would like to tag onto that one other related comment and that is, at the local level we found that by being in city hall and being in the City Attorney's Office, we have been able to reach white gay males very well and have not reached African and racially-based communities very well in the Los Angeles area.

The Bar Association therefore brought together a bunch of community-based leaders from ethnic and racially identified communities and said, We have got a nice conference table, we have got some mailing list supplies, support staff, how would you like to use us.

What's emerging out of that is planning for a People Of Color AIDS Conference in the Los Angeles region. It's kind of tragic to my mind that that didn't happen long ago, but I don't think this would even be happening now had not the Bar recognized that it had certain limitations and needed to turn to those communities and provide some resources which say, Go for it.

As the head of the AIDS Discrimination Unit, I'm in a similar position where I'm now turning to the heads of those organizations and saying, I need to learn from you. I have the expertise, would you please bring me out and let's engage ourselves in dialogue and figure out ways to strengthen those interrelationships, because those have to be pursued and strengthened as well.

So the minute we take the law and we apply it to communities that already perceive themselves as being disinherited and are perceived by others as being disinherited, I couldn't agree more when Veneita Porter said, we have layers upon layers of this that we need to break through.

But I want to close by saying that a lot of the baseline information and strategies are there. You now need to strengthen our capacities to get that out and train others to do it.

MR. SCOTT ALLEN: We want to stay pretty close to time so can we have just one response.

MS. DIAZ: One question for Sean. You have such a multi-ethnic population within the state of Hawaii. I wonder if you have seen in your work and that of your peer educators and advocates for AIDS causes, any difference in the way that various communities are confronting AIDS. I'm talking about Japanese, Chinese, Thai, Laotian.

I was impressed by a visit this past year to the Hawaii Immigrations Center that had an AIDS education program, trying to preface that it is a specialized program of outreach to each of those communities. Have you seen any difference in the multipopulations that you serve?

MR. DUQUE: In Hawaii, people who are working through the immigration program are getting some education regarding HIV disease.

MS. DIAZ: That is federally funded though?

MR. DUQUE: Right. But then there's that group of citizens, who are citizens now, who are not hooked into those programs that are not reciving education. And as I would like to reiterate, that the HIV population among Asian-Pacific Islanders in Hawaii is the highest in the nation per state. Many of the ethnic Pacific organizations that I have gone as an Asian to, many of them have never received any HIV education at all, despite this being the 1990s.

MS. DIAZ: Is that a problem of culture?

MR. DUQUE: In Hawaii it's a combination of all of those things, and denial. There is also, the Asian-Pacific Islanders have a tendency to think they don't want to shame the family and all of these cultural aspects.

MR. DALTON: I was thinking I knew all there was about housing and I discovered otherwise, as Robert Greenwald described, and I thank you for your forum.

Dave, since we're kind of short on time, at the break I want to talk to you, being you didn't testify or write about co-workers with AIDS.

5

MS. PORTER: I would like to add that we've looked at institutionalizing the idea of multilingual programs, but it doesn't do us any good if we are creating programs that are culturally sensitive and ethnic inclusive if we have not created funding for the combination of those programs. Whenever we create a demonstration model or a new program, I think it should be a recommendation that a portion of that funding, whether it is demographically generated or whether it's locally generated, needs to be set aside for multilingual development, whatever the multilingual cultures are within that community, whether they be Spanish or whether there be any another language or two languages.

But if we don't create programs that from the start create a multilingual and cultural sensitivity, then we will always do what we are doing now which is to back up and say, Why aren't people with color getting this message. Because we are not existing, we are not creating new role models so that people of color do get these messages.

And it strikes me as odd even today that in certain places, in San Francisco General, I still only see one person of color speaking Spanish. I see the same thing when I go to other hospitals, that it takes me -- at 11:00 at night it takes me sometimes hours to find somebody on staff who can speak -- who is a multilingual Spanish-speaking person in a teaching hospital and I think we need to look at that, that this is probably the general rule as opposed to the exception.

MR. KESSLER: This is exactly the topic that we talked about, Mr. Schulman, while we were in Los Angeles in January and I wondered if you are able to comment, are we making any progress?

MR. SCHULMAN: The City of Los Angeles, I think you heard Dave Johnson who is the city's AIDS coordinator, say that the city was just not responsive for delivering health services because the county has been advised not to to do that. I don't think there's been a lot of development since January, frankly. And they just lost a lawsuit regarding -- a federal lawsuit, regarding alleging that the districts were not representative of populations in LA County, but they have set aside $4 million to fight that federal decision, so I think that's primarily more of the same.

MR. SCOTT ALLEN: Thank you all for sharing the views with us. The next panel, Nancy Campbell, Executive Director of Northwest AIDS Foundation and Catlin Fullwood, Executive Director of the People of Color against AIDS network. The first presentataion will be Nancy Campbell.

MS. CAMPBELL: Good morning. Thank you. I'm Nancy Campbell, Executive Director of the Northwest AIDS Foundation. I would like to talk to you briefly about four issues.

First, I would like to tell you little bit of the model of service delivery that we use in Seattle-King County. Second, I'd like to comment on the demographics of AIDS in the Northwest because it is different from what you see on the East Coast as well as the West Coast.

I would also like to address the need for continuing education for the gay and bisexual male community and I'd also like to talk a little bit about the funding situation here in the northwest.

This is the first time ever it's been said I don't project. Is that better?

Just briefly, the Northwest Aids Foundation is an AIDS service organization. We are a bit different from some of the other organizations that are labeled foundations in that we do raise money through our walk and give that away to other organizations, but we also fund a whole continuum of care of services that I will talk a little bit about.

We also provide direct services to the case management services here in King County in Seattle, which are provided by two organizations, the Foundation as well as Harborview Medical Center. And then finally, we do provide prevention AIDS education services for gay bisexual users.

We are an organization like many others that started our roots in the gay and bisexual community, although today as the epidemic has changed, corrosponding conditions have changed as well.

In Seattle we provide care services through what we call a continuum of care. The Northwest Aids Foundation is a lead agency. The Robert Wood Johnson Foundation and HRSA provided early demonstration funding through the Seattle-King County Department of Public Health to several organizations based in the community, subcontracting these services through the Northwest AIDS Foundation. So the way we have divied up the pot in terms of services has been designed to avoid duplication and to make sure that we cover all the need for services.

6

The Foundation being a lead agency, we see our role in terms of care services to continue to look out at community-based organizations to see if there is a new need that develops.

For example, we have a few organizations that will talk a little bit about the Seattle Treatment Exchange Program which is now providing programs specifically for the HIV positives. We didn't have that early on in Seattle. We saw this as a need and we support that organization. We do not provide a lot of programs ourselves, but we do try to generally look throughout the community to try and find ways to fund those programs.

Our programs that we have in the continuum of care that the Foundation is responsible for, again, just the care service is the case management. I think we have a strong model of case management. Again, we limited that program to two agencies, trying to not have duplication and to keep our resources focused.

We also provide practical support. The Chicken Soup Brigade subcontracts to provide transportation services, cooking, shopping, meal delivery, all of those kinds of support.

We have two other agencies in the continuum that provide emotional support, one is one-on-one services, Shanti. The other is the Seattle AIDS Support Group which you will visit tomorrow and that's a group setting.

We also have legal assistance in our continuum which is a volunteer program for attorneys. We use all volunteer attorneys to help with legal issues, with wills, and that kind of legal assistance.

We even have massage therapy. We are probably the only state which actually has dollars funding massage. We think that's an important aspect of taking care of people living with AIDS.

We also have an unusual housing program. That program will be discussed in detail later on so I won't focus on it now, but let me say this: I think we are unusual in that we have worked better with governmental entities than anywhere else I have seen in the country.

Our Seattle Housing Authority, again, we have a broader continuum of housing services because we have cooperative and good relationships. We have an emergency rent program that the Foundation supplies for people throughout the state, because in many areas of the state we do not have programs up and running that provide emergency grants to people living with AIDS. Most of our services, however, are limited to the county only.

We have information about treatment options that comes through the Seattle Treatment Exchange Program which is a new member of the continuum of care. And finally, we have another whole spectrum of educational services of which we provide just one focus, that is for the gay and bisexual community.

There are many, many other organizations, including ones Catlin will be talking to you about, such as the People of Color Against AIDS Network, Project Aries, the MOD Project, Catch On. There are many, many ways that we have sort of broken up the educational camp among different organizations. Again, the focus being we don't want to position services, so we try very hard to develop organizations that can speak to certain communities well and effectively and we try not to overlap, but we work cooperatively together.

I think that is the essence of the success of the Seattle-King County model of prevention, education, and care services; that we do work together, we work cooperatively. I think people work very hard.

Catlin and I, we get calls from around the country saying, What's your key to success? And we respond to that, a large factor is that we have a wonderful, mutual relationship with our health department. Our health department is the lead agency for all of our services and some of the community-based organizations subcontract for lead functions. But that is one of the significant differences about Seattle-King County and I think the State of Washington, having worked in other states.

I don't know how you replicate that. But I can't emphasize to you enough that what is different is that it's cooperation, we all come to the table to work on issues together. And a lot of that is the result of the leadership that we happen to have here in our health department.

I'd like to move on very briefly to the demographics of AIDS in the Northwest because they are a bit different and yet show some of the same trends as in other parts of the country. Our projections, of course they have changed as everyone else has around the county.

We are seeing a smaller increase in the number of cases, but we are seeing a greater increase in the number of people who are living with AIDS. We are seeing our caseloads double approximately every 18 months. So I

7

think that's fairly consistent with what you have heard from other parts of the country.

We have a projected increase in cases of AIDS in the state from about 2,500 in 1989 to about 6,800 in 1993. Those numbers include people who have died, people who are currently living, as well as projections for the unreported cases. What that means here in King County for that same demographics is that about 1,900 people, cases actually in '89, to about 5,000 or a little bit over in 1993.

For people living with AIDS only in Washington State, in 1989 we had a little over 1,500 people living with AIDS and by the end of 1993 we will have approximately 4,300 people living with AIDS.

So that gives you some sense of the scope here. It is nothing like some of the first-wave cities. Yet we are seeing the same trends in terms of the rapid increase of number of cases and that is particarly stressing to us who provide care services at this time in the community.

Having said that, I think it's important to know that the face of AIDS is changing in Seattle-King County as it is throughout the country. Our AIDS diagnoses among communities of color from 1982 to 1985 were 9 percent. By 1989, 14 percent of the new diagnoses were among people of color.

You can compare that to about 10 percent of our population here in King County being people of color. So you can see the overrepresentation which is, of course, a concern to us. Between 1982 and 1985 we had four women and children diagnosed with AIDS in King County, a big difference from the East Coast.

MR. SCOTT ALLEN: Would you find of wrap up so we can have some dialogue.

MS. CAMPBELL: Sure. So you get a sense that we don't have as many people here with women and children being the problem as they are in other parts of the country. Our epidemic still is overwhelmingly gay and bisexual men, which is a little bit different again from other parts of the country. We have roughly 92 percent of the people right now who need care services in terms of gay and bisexual men.

I think if we have a concern here, it is that we are seeing, as in other parts of the country, a change in the trend of not being able to get services for education prevention for the gay and bisexual population.

Here in King County we have seen a dramatic increase, over 200 percent increase, in the numbers of STD cases in the gay and bisexual male population. We are very concerned that we do something about that trend, and yet we don't have education dollars or prevention dollars to deal with that problem.

Last, I will just conclude that what is the greatest concern perhaps to us is when we look at the budget today and look at the services, we have got a great problem here. The problem is the funds are not going to be there to keep pace with this.

We have about $9.3 million coming into this county for AIDS. About $2.2 million of those by 1992 will be going away due to Robert Wood Johnson and HRSA cuts, other cuts. That develops by way of dollars to 25 percent decrease in our funding. At the same time that every 18 months our caseloads are doubling.

That's a dramatic amount of dollars, even though it may sound small comparatively to other communities, for us to raise in this community. We are doing everything we can to creatively raise the private dollars, but it is certainly a challenge for all of us.

So if we have an answer here, it's that's we have a system that works well and a system that to date has been effective at least in care giving. We still have many gaps in prevention and education, but the reality is, we simply do not have the dollars and do not see that those dollars will continue to be here to maintain that continuity of care that we have today.

MR. SCOTT ALLEN: Thank you very much. Catlin.

MS. FULLWOOD: Good morning. The People of Color Against AIDS Network multiracial AIDS education and prevention coalition serving Washington State was founded in 1987 by people of color who were concerned by the lack of prevention activity and service provisions to communities of color, including the Black African-American, Latino-Hispanic, American Indian, Alaskan Native, and Asian-Pacific Islander communities.

We realize that AIDS is caused by a mere virus but the impact in our community is exacerbated by the socially constructed phenomena of racism, homophobia, gender discrimination, poverty, lack of access to opportunity, employment, education, and the despair and hopelessness that leads to the enslavement of many segments of our communities, to drug and alcohol abuse and violence.

In order to deal with AIDS in our communities, we must first ultimately tackle these even more overwhelming and intricately embedded issues, not on a case-by-case basis, because that only works for one, not for the many; but through the painstaking and frustrating process of coalition building and institutional change.

We need community organizing and the development of partnerships are critcal to coalition building and effecting that change. Through training, education, public information, campaigns, developing community leadership, and educating minority community-based organizations and groups with the issues of AIDS, we can change the attitude, break through the denial, and utilize the cultural mores that enhance our people's ability to protect themselves, their loved ones, and their community against the epidemic of AIDS and fear.

This investment is something that we have worked hard to develop, because we believe that it's critical that our communities have the opportunity for self-determination, self respect, compassion, understanding, and the development of power and ways necessary to effectively build a climate in which we can fight the fire.

Currently in Washington State we are working to bring people together, people of color together, concerned about AIDS and the health and well-being of our communities.

By building coalitions against lines of racism, gender clash, and sexual orientation we have established the Minority Second Coalition on AIDS in Spokane, the Pierce County Minority Health Coalition, the Washington State Latino AIDS Coalition, The Asian AIDS Council, the Spokane Collaboration Education Project which is comprised of ten minority community-based organizations, and Spokane Community Clinic Project which involves six community clinics which serve primarily communities of color.

These coalitions provide voice for people of color statewide, they eliminate the validity of claims from the public sector that we just couldn't find any people of color who were interested in AIDS, and they provide mechanisms for insurance input and involvement of people of color in the development of provision of services and care, not run by one, but all of us.

We also work with the six regional networks in the health department throughout the state. Spokane is working within the AIDS service of primary care communities to encourage racial diversity and hiring practices and service provision.

Dealing with issues of racial inequities and inequalities is a difficult position. We find ourselves oftentimes with the position of being the conscience for a movement. It's a difficult role to play within the AIDS services community, within the general community, as well as within our own communities confronting homophobia among people of color.

It's not good enough to say that we serve everyone. It's not good enough to say that our programs are open to all. If we don't specifically design our programs in such a way that they reach out into the community, that they become part of the community, and the community becomes part of them, they are not as functional as they need to be.

Coupled with our efforts to ensure access representation and inclusion is the essential work of stopping the progression of the disease through education and prevention activity, focusing on risk reduction and behavioral change. Spokane uses community-based education and outreach as well as peer education to reach people where they are.

In communities of color, as in the majority of communities, much of the average behavior is clandestine, behind closed doors and unnamed or named differently, i.e., gay versus sex with men, so that a singular outreach strategy will only reach the most physical and obvious adverse population.

In our communities it is just as likely that we will reach at-risk people at church functions, at the barber and beauty shop, at the WICs program, in jail or work release, and topless clubs, in minor camps, in the social clubs, at the food bank, at the pow wow, or other community events, at the kind of local community gathering where people are together and where information flows.

Spokane has established 165 distribution sites in Seattle. At bars, small businesses, libraries, pool halls, where people can pick up information about AIDS as well as condoms and bleach and teach packets. These community settings are points of access for information and services for people within our community. Spokane has nine community-based education and outreach workers in Seattle, Tacoma, and Yakima who target educate the poor and involve people engaging in potentially high-risk behavior.

From these relationships, Spokane workers identified volunteers, potential trainers, and peer educators who are hired, trained, and placed in the community to reach their friends and circle of acquaintances with risk reduction information, peer to peer. The involvement and empowering of the targeted population is a key component of behavioral change because sexual practices and drug-using customs will be most effectively influenced and sustained by peers.

To ensure ongoing access to services for people of color who are HIV infected, Spokane has developed a formal physical linkage with service providers. The community-based services liason works between the care system and the community to identify those in need of a service and to ensure that the service is actually meeting the needs of the community. This formal relationship validates the service in the eyes of the community members and helps to mystify a complex and intimidating system.

In Seattle-King County we have one of the most sophiscated and effective systems of care in the Country.

This must be continued and resources must be allocated for that continuation. At the same time, the system must continue the commitment to diversity, to developing legal criteria that ensure access to instructing staff and programs that adequately reflect the diversity and meet the needs of those that need to be served.

Seattle-King County has an opportunity that the epicenters of the disease did not have. We can stop the spread of infection through primary prevention which we define as targeted education and risk reduction as well as community organization and mobilization. If we do not take this opportunity, we will have made a conscious decision to let the disease spread, to stand by and watch the devestation of our communities.

In Seattle, in 1988, twice as many as black babies died as white babies and we ask ourselves why. In Seattle in 1990 we have a potential of an explosion of HIV infection among young people of color involved in IV drug use, crack cocaine use, trading sex for drugs, with increasing rates of gonorrhea and syphlis.

The time to mobilize is now. As we face decreasing resources and dwindling interests as the disease is more and more defined as one of the poor, the disenfranchised, and the addicted. In 1995, the people of color will comprise 30 to 50 percent of the cases in the City of

Seattle or the state. We won't have to ask why, we will know why. Because we have decided that people of color were expendable. We don't have to let that happen here. We have a cure for AIDS, prevention.

MR. SCOTT ALLEN: Any questions?

MS. DIAZ: Catlin, I'm acquainted with the efforts of your organization over the last four years, as well as that you have participated in multi-ethnic racial conferences that you have done, including representatives of the Native American multi-tribe groups.

And I just would like for you to give us a better feeling of how it is to negotiate differences between those groups to form a coalition, because we don't find a lot of examples of what your organization stands for.

I have got to stay that here in this country it's a very, very unusual happening that brings people together to negotiate their differences around the area of how to approach and confront AIDS in a very positive and constructive coalition. Could you just briefly tell us how you have done it.

MS. FULLWOOD: I think that when we began in 1987, we were a project of the American Friends Service Committee which is also a multiracial, multicultural organization, so we began our organizing in that way.

Also, the realization that we were such a small part of the population, 10 to 12 percent of the population. We were either going to work together to get resources or we were going to work against each other to ensure that none of us had any resources. So we managed to bring people to the table.

I think the other thing that was very important for us in successful coalition building was that we were able to access money through the Minority AIDS Initiative, through the State, from CDC, that gave people money to take on AIDS as a programmatic issue.

We subcontracted the Seattle Urban League, the Indian Health Board, the Washington South Asian Council, programs out in the valley, and we have been able to say to people, Here are some resources to do. Not just out of good will because we know it needs to be done, but also to build something within our programs that's going to be everlasting and ongoing.

It continues to be a struggle and people continue to fight with each other and, you know, sometimes getting to the table around AIDS, the only issue that we can get to the table is grants.

MS. Diaz: And I think it's the staff of such ethnic racial diversity that keeps a coalition of such sort nourished and supported.

MS. FULLWOOD: I think that really helps because what the community see are the staff, and when they see themselves represented they realize that this is a place where they can come and have a voice, they can have a say.

MS. DIAZ: Thank you.

MR. GOLDMAN: Along the same lines, one of the reasons that I think the working group chose to come to Seattle was its national reputation as a community in partnership, cooperation, the coalition was working as well if not better than anywhere else in the country. And from all I have heard and seen and read, all of you should feel good about the wonderful work that you have done here in Seattle.

But my question is, to what extent is what's happening in Seattle replicable anywhere else? To what extent does it also rely upon what I have heard about in other areas, about a reputation of people in Seattle being caring people, being people who value from a social perspective the idea of cooperating, cooperating within the social community, where cooperation in the expected thing and selfishness is sort of not the expected thing. And there's a whole kind of societal attitude that probably goes back for some historical reasons that I don't fully understand, and it seems to be just in Seattle and not necessarily other communities.

But on the other hand, those other communities, as you well know, I mean, the gay communities are fighting the Black communities are fighting the Hispanic communities, and they spend as much money fighting each other as they do fighting the disease, and it's frustrating to see.

What I have been able to hear here is terrific and I'm just wondering, is this something that's unique or is it something that there are things that can be replicated and that we can look at and see?

MS. CAMPBELL: I think there are things that can be replicated. There is a uniqueness here, it is not just from AIDS. I came from other states and other areas and Washington State is a caring and compassionate state, it's not just Seattle.

However, what Catlin was just talking about in terms of coalition building, all of those organizations trying to work together, I think what Catlin mentioned is we have instruction, we don't just teach goodwill, we have money. Each of us as lead agencies, Catlin's organization, the Foundation and others, are conduits for the dollars.

In other words, HRSA, all the federal dollars, all the state dollars, all come to our health department but then they run through me for certain continuing care services; they run through Catlin for certain education services. And the result is we have a reason to want to work together and we all end up working with the health department. So I think it's essential that it's structured that way.

The other one is the relationship between public sector government and private nonprofits. I think, again, you can structure that somewhat with how you fund. And the way we have funded here is by having dollars be centralized and by then having them go -- over 50 percent of the dollars that come in to our health department are community based. There is an ethic that the community-based organizations know their constituents, and can work best with those constitutents, and I think that's something that everybody needs to look at, is what Catlin was talking about in terms of developing a community response. That's when you get an effective responsive to AIDS.

11 MS. FULLWOOD: I think also that this whole system of divide and conquer is one that is institutionally embedded within the fabric of this country and has a great deal to do with racism or sexism or whatever discrimination we are dealing with. And I think that, again, what Nancy has said, about the spirit of cooperation has started at the top and has managed to filter down and then it has managed to come up out of the community as well.

If that spirt of cooperation does not exist at the top, if at the top it has been decided that it is in the best interests of someone that people should fight among themselves for dollars and they should compete over everything and that there not be any forum for coming to the table and discussing differences as well as similiarities, then that's apparent what you are going to have within the services.

MR. DALTON: I want to pursue the conversation but first a small question. If Dr. Fuller were here, he'd want to know whether part of your partnerships in Seattle includes spiritual service.

MS. CAMPBELL: Yes, they do. For example, in our housing program, acumen in the community has been incredible. They have opened and continue to open group homes for us. I think Catlin has the same thing in terms of education prevention, so do we. I got a call the other day from one of the diocese saying, I have a plan, I would just like some cooperation.

MR. DALTON: I guess my question is, do you structure that in or if it's the by-product of an act.

MS. CAMPBELL: No. We go out and we solicit. That's part of community organizing. We go out and work with those groups and we ask them and we give them opportunities to join us and we keep working with them. If they aren't interested, we keep dogging them.

MR. DALTON: Back to the main question of whether or not what is happening in Seattle can be replicated, I have a bit of a sinking feeling as I listen to both of your testimonies, because it does seem to me that your happy coincidence may be local character or culture together with wonderful timing, not being the first wave but also not being so late that people don't care about AIDS but being somewhere in-between.

As you pointed out, Nancy -- I appreciate the candor -- you need to be in a position of having money to give out, sort of a swage of bruised feelings, and Eunice looked over at me and said, That's right, money sometimes helps for bringing folks together.

Also, a question about some of the local government. You spoke, Nancy, very feelingly about -- both of you in fact -- about your relationship with the local health department and local housing agency. Maybe some of that is structural as you are suggesting, but also some of this may be the luck of the draw. I don't think every local public -- I'm not sure -- tell me how this could be replicated without all of these events running in.

MS. CAMPBELL: I think it can be replicated. I think you can look at San Francisco or any first-wave cities and say, We've got to sit down and plan now because this thing didn't happen just by a fluke. This is a community, because of being the second wave, did lay claim.

We came up with, what are our goals, what are our assumptions and it has been a planned process and continues to be. We're planning for other parts of King County right now, we don't do this randomly.

I think you can do it in any community but there has to be a vested player, as Catlin said, a player at the top who will say this is a joint planning process; there is no government telling the community what to do; this is a planning process where we will work as partners at all levels and I think that's the difference.

And I think any community can sit down and do the same thing if they really have a bottom line of caring about people living with AIDS and preventing further infection.

MS. OSBORN: There is no one here from San Francisco to talk to that and, in fact, that is kind of like the second effort in the first wave if you like, doing very much what you are describing, so I think that's a nice validation of that.

MS. CAMPBELL: I'm aware of that and I think that will work. I think they have such knowledge about what they need in their community, but it comes from their saying, We must do this is and there you've got the authorization that you need.

MR. DALTON: I would ask an additional separate question or related question. You, in response to Eunice, talked about the internal coalition in Spokane which is terribly important and I agree with Eunice, that I don't see a whole lot of that coalition building among different people of color.

However, I'm also interested in coalition building between Spokane as an elective and other people's involvement in AIDS and healthcare dealing in Seattle. My experience with coalition building between people of color and the dominant society is that oftentimes it's not on terms of some equality.

Secondly, oftentimes people confuse reliances with friendships and so that -- anyway, I guess I would like to hear you speak a little bit about the difficulties and the possibilities and the up-side of the actual practice of building coalitions between people with color and dominant society.

MS. FULLWOOD: I think this has not been a simple process. This is not a pleasant process. This is an agonizing process, you know, and I think it's an ongoing process. I think one of our greatest challenges is in not allowing our organization to become tokenized.

We're asked, Okay, Spokane here, speak on behalf of people the world over, no matter what race, you know, or ethnic diversity notwithstanding, and we fight that constantly and we say, No, no no. You come talk to us and we'll facilitate your conversations with other minority community groups, with other leaders from the different communities of color, but we will not speak on behalf of.

I think that there are times when we are really considered a thorn in the side. I think that there are times when people get sick of us talking about affirmative action and diversity and access to programs for bad clients and people who don't keep their appointments, and people who aren't going to be successful, you know, and I think that this is an ongoing challenge.

We have seen, however, since we began in 1987 when almost all of the AIDS programs were almost totally white in terms of staff, program focus, educational materials, everything, and we have seen a vast change in that, you know, with the Foundation. The hiring has been much more diverse in terms of the services that are available.

I notice there are some programs that move much more slowly than others and it's just an ongoing commitment to making that kind of change and to taking that risk.

MR. SCOTT ALLEN: Larry, you have a question and Jim.

MR. KESSLER: I have two questions. The first one is actually a statistical one. It seems to me, looking at your figures, that you actually have a larger number of people living with AIDS proportionately than any other part of the country in terms of the mortality rate.

MS. CAMPBELL: Our mortality rate has been dropping and I think it is because we do have good care services here, so that doesn't suprise me, Larry. I can't compare it because I'm not familiar with other parts of the country.

MR. KESSLER: Well in other parts of the country this disease seems to be runing 55 percent --

MS. CAMPBELL: We are lower than that.

MR. KESSLER: -- at any one time with those diagnoses and you look like 60 to 65 percent.

MS. CAMPBELL: We have, I think, the last actual report that came out -- of course that was after that, it was down to about 47 percent, so we are better than that. And I think some of that, again, is because we have had good services.

MR. KESSLER: Well the second question is probably tricky for you but it's not meant to trick either one of you. But, one of the things that we have been trying to do is we have been going around the country and really defining leadership and coming up with a model of what others can learn from and benefit from. Would you each care to comment on how you would define leadership.

MS. CAMPBELL: That's an easy one for me, Larry, because I think there's a real difference and more importantly, I think we blend extremely well. The difference between leadership and managment is a manager does things right and a leadership leader does the right thing.

And what Catlin was talking about, it's not all pleasant, it's not all fun. Sometimes you happen to rub a whole lot of groups the wrong way, including each other and that's doing the right thing. That's getting out there and saying, Wait a minute, we do have some institutional-like problems here, whether it's homophobia, racism, or whatever.

And this disease brings up every issue you could probably bring up. I mean, it brings it up and makes everybody's gut churn and so we get all of that targeted at us and we have to be willing to take that on. If the epidemic has helped us with anything, it's helped us move forward in some of these areas that are so difficult and challenging, teaching all of us to let go of our judgment on all different levels.

13

MS. FULLWOOD: I think that for me, with education of color, leadership is usually defined as five or six men. And what we are finding in leadership is that leadership is that a woman who has AIDS, an addict and prostitute for 20 years who now has been in recovery for three years and goes out there in the street every day, she says, To save some lives.

This guy who was a dope pusher is now a peer educator, people on recovery on my staff do outreach to gay and bisexual men of color and put their own identity out on the line.

I think it's the person within the black church, the Pentecostal church is willing to get up in the pulpit and say that this not a response from God; that this has nothing to do with God; what has to do with God is caring and compassion for those within our congregation who are suffering with this disease. That's the kind of leadership that we are seeing emerge because of the work that we have been allowed to do.

MR. KESSLER: I really congratulate the both of you and all your staff, the programs, all the volunteers that work with you. You are an exciting model for the rest of the country and I hope the greater Seattle area and State of Washington appreciate it. Thank you.

MS. CAMPBELL: I think we have to thank our board of directors and all the volunteers, because that's what makes these program work, and we have some incredible volunteer support, and it does come from all over the state.

MR. SCOTT ALLEN: I have got two questions, both of you. First, I would like to reiterate what Larry said in terms of congratulations in terms of what you have accomplished. This is tremendous.

I think the term that you, Nancy, were the one that said it a few minutes ago, partnership in planning. I think that is the very key concept. Can you briefly describe for me, one, is this a multifaceted or multi-pronged partnership you are planning, and two, how much of it was government instigated, whether by local health department, state health department, or other units of government. How much came from the community itself?

MS. CAMPBELL: I think the direction sometimes comes from the community. I mean, we often say we think there is a need here and then that starts the ball rolling. It will identify a gap in services from a community perspective and let's look at this.

But the biggest planning process has been led by the health department, and it was long and all of us were involved and there were many iterations and many groups came forward and said, You missed things, blatantly missed whole areas. And this thing was rewritten many times because of that.

But I think most of the leadership at this point, knowing that we have only had a health department -- state health department for a year, so I'm not critizing them when I say they have not been a leader in planning; they didn't exist.

So I think the leadership in planning, at least in this county, has come from local health departments. That may change in the future, it's already starting to a bit. But we also in community-based level do planning as well. It's not from one level from my perspective.

MS. FULLWOOD: Well I think that Nancy's right, being that people came and banged at the door of the Foundation in 1987 and said, How about people of color? And it was said, Well, you know, it's not on the agenda right now; we are focusing on the community that's most clearly affected but you are welcome to take it on if you like.

I think that's the kind of thing that emerges from the community and then we find ourselves in a position of all having to sit down and say, Now what exactly does this mean in terms of ensuring continuation of services and ensuring the continuation of primary prevention activity.

MR. JIM ALLEN: My second question goes to the funding issue, and you as well as other speakers before you have talked about funds that have come from HRSA, from the Centers for Disease Control, NIDA funds and so on, and come out to community-based organizations as well as to and through health departments.

One, those funds in actual sence aren't being cut,

14

that the the amount of federal dollars continues to go up annually. When you look at this distribution around the country and the dollars versus the need, there is in effect a cut and any given area may see a decrease in funds as programs are phased out, requirements change, and so on.

The federal bureaucracy does put forward a budget annually that finally winds it way through, presented by the President to Congress. Congress then acts on it, increases, decreases, changes. What has been the response and how much have all of you gone to your senators and congressmen and let them know what the need is? What has been the response factor on that?

MS. CAMPBELL: The Foundation takes a role in that we put money into it, and that's unusual, because most organizations aren't in a position to do that. We put money into it by the Seattle Action Council as well as spending a lot of time in D.C.

We have had a good response. We have on certain issues, substantive issues, like with the ADA, had to hit a few people over the head. A couple have turned around and they are becoming much more sensitive to the AIDS issue because we have dealt with them. We have really made ourselves very, very painful to them at times.

I can't say that I think it's had a great change in terms of the actual budget. I think it's a change, for example, that Brock Adams, one of our senators, got $30 million for AZT. I think Jim McDermott, one of our representatives, running a housing bill getting AIDS housing rolled into the Omnibus Housing Act is remarkable. And that happens because we have been out there and what we do is we send out letters to all the organizations and we all march together with the same message. So, has it been effective? Yes, I think so. Has it been effective enough? No.

MS. FULLWOOD: I think that our efforts to mobilize communities of color around this kind of legislation and public policy action has taken longer. And we bring in people like Nancy or like people from the health department to talk about needle exchange or to talk about the need for additional resources and try to get people fired up enough to contact their legislators about yet one more issue.

And I think that something for us, like working with the National Minority AIDS Council and being more involved in the national level has sort of taken a second position to our efforts within our community. But I think that it will be certainly be a focus for us as we face our challenges and our cuts in the next few years.

MS. CAMPBELL: I think that's no different for us though. We have only recently been able to be in a position where we really could start to deal with the federal agenda. I mean, as a young organization you just don't have much time. You're running all the time.

MR. SCOTT ALLEN: Thank you very much. Many times when you travel around in communities, you bring us hope, and as we are here today you are bringing us hope and we sure do appreciate your testimony. Thank you. We have going to have a break for about ten minutes.

(A recess was taken.)

MR. SCOTT ALLEN: Let's go ahead and begin. We have got two Commissioners absent. We will have two panelists, Jeffrey Sakuma, he's the Coordinator, Community Health Services, Group Health Cooperative; and Margo Bykonen, AIDS Outpatient Coordinator for the Swedish Hospital in Seattle.

MR. SAKUMA: I will go first. Real briefly, my history with the Case Management Program is that I am the past Director of Services for the Northwest AIDS Foundation -- and you met Nancy earlier -- and I'm curently in a position with Group Health Cooperative which is our local health maintenance organization in the area.

And, actually, that's very timely to the topic here, and that's community partnerships in providing AIDS case management services in the Seattle-King County area. And

Margo will be talking from the Swedish Hospital Medical Center where she is employed. The person who is missing here today is someone representing Harborview Medical Center. Pam Ryan could not make it, but Harborview is the other major player in our case management system.

15 What I would like to do is go over five different areas here initially. First is sort of the history of how case management developed and that is extremely important to knowing how we exist today.

I will briefly talk about the model of case management that we utilize and then I will talk about the two key elements that are important to the functioning of the case management system, and that is centralization and linkages.

And lastly, I will talk about some of the challenges that we face and hopefully learn from the areas that we still are puzzeled about and will hopefully give you some ideas about ways that you can help us resolve those issues perhaps.

First of all, case management developed at the very grass roots in this area. Basically, what we're talking about is one person in one clinic who saw a need and began helping people access some services that were either existing or nonexisting in the area and that was the early '80s.

In 1985, case managemeant became much more formalized in the area with the actual hiring of AIDS social workers, one at Harborview Medical Center which is our local county hospital and one at the Northwest AIDS Foundation. And those positions are funded with local funds, city funds and Harborview funds.

Both of the programs at that time, the two social workers, basically got together and decided that they were going to use a similar model in the case management and that model was one that was adapted from our local Division on Aging and that was a model used providing case management services to the frail elderly in their home and in the community.

In 1986, it was that model that sort of became the cornerstone of our Robert Wood Johnson Foundation proposal and at that time, as Catlin and Nancy pointed out earlier, many, many people sat around a table and sort of came up with a model of a continuum of what was called the Continuum of Care Services.

And what they decided at that time was that case management was going to be the hub of those services and that with new case managers, they were going to try to develop a continuum of care where case managers knew about those services and helped people access those services.

So there are two important points in looking at the history of case management in this area. First of all, the two models, the two programs, that initially were developed were developed off of the same model. The second point, was early on in the service delivery in this area, case management was decided upon as being the hub of services from which all of the services would center around.

The model that we currently use, as I pointed out, is one that's basically used for the frail elderly, and that was one where functional assessments were done on people who were in need of services, finding out both their healthcare needs as well as social needs. From that, care plans were developed and that is a plan where both the patient and the social worker sit down and decide on what needs to be done and who does what.

And then from that care plan, the actual services are implemented by the social worker or by the client or through other service providers and then finally ending with the termination of the case. And that usually occurs and still usually occurs at the death of a client.

Something that has become a very important piece of the model is what we call case finding and that is that it is not merely a case of people coming to us asking for services, but it's also a point that we need to go out and find people who are eligible for services.

At Harborview, this is done through the social workers going through all the medical charts and contacting physicians who are working with specific patients and saying, Hey, how about this person? What is happening here? Would they need case management services?

At the Foundation it occurs a couple of ways, one which Margo will talk more about, the other being outreach service. And that is where we have outreach workers, going out into the community, out into the street, and finding out if people are in fact elibigle for case management service and try to bring them into the service.

Case management in this area is mostly restricted at this point to Class IV diagnosed individuals. And most people start case management at the point of disability, not point of diagnosis necessarily. Sometimes those are 16 both one and the same, but oftentimes what happens is a person will come down with a initial case of PCP or recover fairly quickly and decide to go back to work.

Where case management usually begins is at that point when the person decides that they are no longer able to work or that there are other issues in their lives that clearly affect their daily function, and that is where case management comes in.

The focus of case management are in three main areas. One is to need to refer the clients to the appropriate service providers in the community and making sure that link occurs. The second is teaching clients, and this is becoming a much more important aspect of case management, teaching clients about how the systems operate so that they can be their own advocate in accessing services. And I think that as the numbers of cases grow the teaching model will probably become more and more important to us.

Lastly, is as the advocate to the client and that's where we actually help clients do the necessary paperwork, whatever, and act as a representive if need be.

The main point of -- one of the main things the older case management system brought together is centralization. That was what I said earlier on, is that we are going to centralize case management. In other words, the health department was not going to provide this organization funding, this organization funding, this organization funding, this organization funding, to do case management services. We were going to the lead agency model that Nancy talked about.

Case management happens in two places. It happens at Harborview and they currently a have contractual relationship with the University Hospital AIDS Clinic where they have an out-station case manager there. But for the most part, they have four social workers working at Harborview itself.

At the Northwest AIDS Foundation, they have inhouse social workers on staff as well as have two contracted relationships, one with a case management program in East King County which is separated by Lake Washington from the city, and we have an out-station case manager there two days a week.

And also, the other one is with a program that I am now a part of and that's with Group Health Cooperative, the local HMO. Now that system being a closed system in the sense that they provide all the healthcare related services, and the Northwest AIDS Foundation contracts money directly to the HMO, and they provide their case management services as a part of their home healthcare social work program.

MR. SCOTT ALLEN: Could you kind of wrap it up so we can have some dialogue time here.

MR. SAKUMA: Centralization is the key in that everybody continues working off the same model; that as you subcontract, you mandate your model; and also that it cuts down on implication because it gives people a definition of who their client population is.

The other key element that I would like to talk more about is the community linkage; that in order for an effective case management model that incorporates the community and has community partnerships, you need those linkages and they need to be formed. It's not just me saying that you are going to be my contact.

Written work agreements are a very important piece of the equation. That's the foundation. That means having some very, very formal relationships with healthcare providers, and at Harborview where the healthcare provision is always a part of the program, it's having very good relationships with the community-based agencies.

Lastly, the challenges for us is in isolated case manager in the future, that as we out-station and as we try to reach hard-to-reach populations, we will need to continue out-stations and through that, process the fear of isolation of the case managers.

The second need is the growing need of the HIV-positive nonclassified population and when it isn't and when it is appropriate to provide them with case management services, also for populations where HIV is not their primary issue in coming into us.

And lastly, is the whole financing of the case management system as we move into more cases with higher healthcare costs and more needs for crisis intervention, will the case management get lost in the shuffle? Thank you.

MR. SCOTT ALLEN: Margo.

MS. BYKONEN: I'm here to talk a little bit about

Swedish Hospital, a private, nonprofit, large facility, 650 bed facility, which has established a case management service. 17 Although we don't provide case management directly, we do conferences with foundations who provide that service for us and today I'm just going to review how we got that system set up.

It was difficult initially or not real difficult but it was a challenge in trying to match the social service community organization with a traditional medical model in the hospital and how they managed to communicate our needs to each other and make sure that there was a system process in place so that no one was going to be missing.

Early in 1987, the hospital itself, the administrators, were seeing an increased number of people with HIV coming in a system and there wasn't a designated person who knew a lot about the services in the community. The Robert Wood Johnson funding process was under way, we had a representative there, and also our discharges planning model, which is comprised of nursing individuals were not aware of different programs out there in the community or the changes that happen on a pretty quick basis around this community. There's always new programs being developed.

So my role was started in June of 1987, and initially it was to be the liason person to the community, to be the person that the physicians would associate their clients with and I had to do a lot of marketing with physicians. But before I did that, I needed to define what my role was going to be.

And initially, I thought that I was going to be able to be the case manager for everybody with AIDS who walked into Swedish Hospital and follow through on everything that they needed. And hundreds of people literally knocked out that part of my role and I realized I could not do that. We needed to be the one to give good medical care and we would not be able to do all these things and meet all the needs of the people.

We spent about a year tuning up the case managment model with the Northwest Aids Foundation. I defined my role as the initial assessment for people with Class IV information referral and troubleshooting for people who would not get services through the Northwest Aids Foundation and there have been people that do not want to be associated with the foundations in the community for whatever reason, so I become a troubleshooter for those individuals.

I advocate for the people with AIDS in the hospital system with those types of systems in the hospital which sometimes can be very overwhelming. And last but not least, I represent the hospital in the community-organization process from a medical model, telling them where there's gaps that we are seeing and seeing if we can as a community develop some programs to meet those needs.

To try and communicate what was going on, how we had worked this out with the Foundation, each month I got an updated list of all our clients which are affiliated with Swedish Hospital. Case managers, when they open a case get a release of information to do that and each Monday morning I let the Foundation know who's been admitted into the hospital and who's going home.

People from the Foundation come over and sit in our discharge rounds, are part of our interdisciplinary team in getting people out of the hospital. They can bring a lot of information to us. They have seen people sometimes before they ever entered the hospital system. They know who their support systems are out there, are they on any disability, who is there to help them with meals, those basic needs we sometimes don't know from seeing people in the hospital, so that they bring that information in to us.

We also at Swedish Hospital have a home-care hospice organization that oftentimes is involved in our clients who are going home and the Northwest AIDS Foundation is updated each week as to who they are going to be talking about in rounds. Physicians are present oftentimes in those rounds and the case management from the Foundation can participate any time in those rounds also.

I think the clarification of roles has been really helpful in trying to establish a working relationship with the Foundation. Early connection of services has been very helpful for us. We have our lengths of stay at around 7.8 days, which is, I think, pretty good for most communities.

I think that as housing is becoming more of a crunch -- we had some housing available early on that's still there -- but as there are more vying for those needs, we are seeing lengthier stays. Sometimes When there is a housing crunch, hospital stays go up, so housing is certainly a priority, either housing that has attendant care or there is also a big need for housing with skilled nursing available.

18

Because we are not a public hospital -- we are not similar to Harborview. Harborview has an AIDS clinic; they have a physician and practitioners right there -- one of my challenges is that I'm trying to provide information to all the physicians on staff at Swedish and trying to increase physicians who maybe are not having a heavy case load of HIV to take a few individuals per month or more, whatever they feel comfortable with, using some of the doctors that have more expertise as more of a consultant.

And so my role has also been to escalate the prevention project plus test people who are positive and so they need to seek a primary physician. Sometimes individuals will call me and I will link them up with physicians who take people with AIDS.

And we have an HIV pharmacist in the hospital and between the two of us we now print an AIDS update for the physicians and it goes out to more than 1,000 physicians, because I can't answer all those phone calls and give the same information 100 times. And that's been a very helpful tool in communicating with over 1,000 physicians that we have on staff at Swedish.

In terms of the future -- I will just kind of wrap it up -- my current concern is I haven't said enough about how the people live in the hospital when they don't have a place to go that's appropriate. And we are not about to discharge people into the community that don't have a safe discharge plan, so they stay in the hospital, whether we write off the cost of their stay or we don't bill for those services or whatever. They are going to live up there and take up that bed and continue to receive the high level of care the hospital can provide.

Housing for women and for children, we are starting to see an increased number of this in the community.

Also, we are seeing a larger number of people with dual diagnosis, psychiatric-mental health or drug dependency and HIV, and those individuals are a different population in trying case management and those are needs we need to address.

And I'm very concerned. We rely on the Foundation to do a lot of follow-through for us. At the Foundation, hopefully everything is working smoothly. The case manager will come in and meet the person in the hospital before they go home, there is that linkage that they have agreed to service us. And I don't want to see the budget so strapped that these caseloads of individual case managers are doubled or tripled so that they cannot provide the level of case management that they are doing.

I think that they are doing a big service keeping people out of the hospital, keeping track of individuals as they are out there in the community. And if they have 100 clients in a caseload versus 35 or whatever the standard is right now, that linkage is not going to happen and people are going to end up back in the hospital for crisis volunteering. I appreciate the opportunity to talk to you and to answer any questions you may have.

MR. SCOTT ALLEN: Thank you. Are there any questions?

MR. KESSLER: I may have missed this, but what's your current census in the hospital or the average census, and of that number, how many do you think are there because of hospice?

MS. BYKONEN: Our statistical report from April -- April 1st through June 30th, we had 148 admissions into the hospital, average stay for 7.68 days for that quarter. We had three people of the 148 that stayed in the hospital 36 to 48 days, and so I would think that those were out there laying, waiting for the bed. The majority of people are in the hospital for a week to ten days.

We have an outpatient clinic that does a lot of IVM so that it does shorten up the hospital stays where people are able to leave the hospital after a week and continue two weeks of treatment as an outpatient and not need to be a patient in the hospital if they are medically stable and can be discharged.

MR. GOLDMAN: I was just curious as to how the case management is coordinated between the Foundation as to the contact, particularly outpatient care, of how the case management is coordinated between the Foundation on one hand and the hospital on the other hand to avoid to a certain extent, and probably to a certain amount, and I understand perhaps even some sharing of case management, at least in terms of outpatient-inpatient. How is that handled in terms of outpatient care to shorten

19

coordination as well as duplication of case management?

MS. BYKONEN: One of the things I have seen change over the last few years since I have been doing this job, I think physicians appreciate more what the Foundation can do with their clients. And the case managers at the Foundation seeing a problem, feel more comfortable calling a physician directly and don't need to go through me if they are seeing a problem. So they are compensating at home, they don't need to call me sometimes if they want to troubleshoot.

The Foundation also hired a nurse liason person in the last year, I believe, which has been very helpful. It seems like the various nurses with the various hospitals were serving that role for a long time, if the case manager just thought something was going on or sometimes things were being missed because they weren't medically trained, they were social services people that may or may not have had exerience in a hospital or medical circumstances. So they have a nurse liason person that is able to go out and see a person at home and call a physician and give them professional assistance.

MR. SAKUMA: Currently, the roles are fairly well-defined between what Margo does and what the case managers do. Margo usually, when a person comes in who she is not clear is being followed by a case manager, she will go in and do a case finding on that individual and see if there is need of case management services.

At that point she will make a referral over to us and so we enter into the picture at the same time that discharge planning staff is entering into the picture.

The discharge planning staff are primarily responsibile for making sure that the person's home-care needs are being met and then it's the case managers who follow through and make sure that's continued once discharge planning pulls out and the person is in fact discharged.

Margo at that point pulls out and so does not become involved unless the person has specific issues in terms of hospital stay or over their physician specifically, in which case they may go back to her, but at that point case management has been taken over by the Foundation.

MR. GOLDMAN: So you don't have much of a role in terms of outpatients coming back needing IV therapy, things of that nature?

MS. BYOKEN: Counseling is provided for outpatients, for IV contamination, whatever, things of that nature, whatever medication the person might need. If the person is over there for therapy and the person is not doing well, they are not able to get into their appointments, transportation problems, whatever, sometimes they will call me.

They don't know who the case manager is and sometimes they will call me and say, I'm worried about this person, and I will coordinate with the case manager. Sometimes I will just arrange for transportation for the patient to come back through and I will call the case manager. We do communicate informally. We call each other frequently.

MR. DALTON: Jeff, do I understand correctly that the hospital-based case managers are assigned from other people who have full-blown needs?

MR. SAKUMA: Right. The programs that exist, the one at the Harborview Medical center, currently both that program and the one in the Foundation currently have Class IV elgibility criteria.

MR. DALTON: And I think I heard you say in your concluding remarks that case management was threatened. Do you think this is -- or is considered being provided by hospital-based case management to people who do not have an AIDS --

MR. SAKUMA: As far as hospital based, Harborview has a clinic and social workers work out of that clinic. So it's an outpatient clinic and the Foundation is not, of course, hospital based at all.

What we are trying to look at is, again, what we are seeing is a group of individuals that are coming in whose needs are as great as many of the people that we used to see with a Class IV diagnosis. However, their needs center around their addiction, they center around their mental health diagnoses, and so therefore, the question is -- and yet they are not Class IV, they are HIV infected, possibly Class II.

20

And the issue becomes, how do you provide those people, those individuals, the case management services they need. Now, our first thought of course is to access the existing systems that deal with addiction and that deal with mental health. Mental health is somewhat easier. The sort of drug-alcohol system is a little more difficult.

And having sort of the type of case management where you actually follow and monitor a person over time, at this point in time doesn't exist within those systems as it does within the AIDS case management system. So people often refer over to that, because they know that at least if they have AIDS case managment, then they are going to have someone that has a lot of follow-through.

That becomes sort of a dilemma. So how do you open up those services or do you open up those services to be inclusive of those individuals? At what point do you open that up to everybody? And at what point, therefore, do we become overwhelmed with numbers and our caseload changes?

MS. BYKONEN: I also see a lot of people that physicians are sending over to my office who are HIV positive, no Class IV, yet they need AZT therapy, they have issues with insurance continuation. Those are the types of troubleshooting problems that I will solve, try and solve with that client. And then they can call me as they develop because they have not the appropriate relationship with the Foundation at that particular time. So I see a lot of people in my office who fit that kind of criteria.

MR. DALTON: What happens to people who don't have the proper -- it sounds like you are working a little beyond your proper boundaries, trying to -- you know, there's only 24 hours in a day. What happens to other people who don't meet that?

MS. BYKONEN: The physicians that are part of that, any time I'm working with those physicians, they know I'm available to do some of those things. Also, putting it back on the physicians -- although it's a delicate balance not to overwhelm them -- saying, These are the forms to give to the patient population, give it to clients to fill out and tell them to give it to their insurance company, or this is the number for the AZT program. Giving them some of those things so maybe the office assistants can do baseline paperwork, work that doesn't take a long time.

It's not, Here, I want you to help apply for disabilities.

We found that physicians are feeling like there's enough support for them in a social service area that they are more willing to take on the challenge of primary care for people with HIV.

MR. SAKUMA: The other important piece of any case management system is those individuals that are fighting sort of the baseline advocacy services. In some programs they are called financial advocates, in others just advocates. Whatever you call them, those are the individuals that sort of perform a lot of the paperwork and hopefully deal with individuals who do not have a continuing level of need, who sort of may assist them on a one-time basis. They come in and go out of the system fairly quickly and that becomes a fairly important piece of case management system.

MR. SCOTT ALLEN: Any other questions? I have a question concerning volunteers or use of volunteers. When you have people that are less sick and the possibility of having someone cordinate their care and the social structure, do you have that in place systematically?

MR. SAKUMA: At the Foundation right now we are in the process of relooking at the whole program in terms of volunteer usage. Again, something that has occurred in this area is that money came down for case management from the very beginning. So we are dealing with a lot of HRSA funds, city funds, and state funds, so therefore we are in the process of providing a staffed service for much of the time.

Now we are looking at the growth continuing, but probably not the funding at the same rate. So our process is different from other parts of the country where volunteers have started a service and then you add in the paid staff. We did the opposite; we had the funding initially. We built it into the system and now we are looking at this system and how to incorporate volunteers into that system.

MR. SCOTT ALLEN: Well, thank you very much. We appreciate that. The next panel is Robert Wood, AIDS Medical Director from the Prevention Project, Seattle-King County Department of Public Health; Charlton Clay, Assistant Coordinator, Seattle Needle Exchange, Community AIDS Services Unit; and Dave Purchase, Coordinator of the Tacoma Needle Exchange.

Again, we have a six-minute testimony and then you have one minute and so that's seven minutes in all and then we will have dialogue. We may have lots of dialogue.

MR. WOOD: Charlton Clay just went out to have a cigarette and I don't know exactly when we are going to start.

MR. SCOTT ALLEN: You may go ahead and start.

MR. WOOD: I'm Dr. Bob Wood, Director of the AIDS Control Program for the Seattle-King County Department of Public Health and also Chairman for the Governor's Advisory Council on AIDS for the State of Washington.

And I'm aware that you are trying to focus on partnerships and care, and I think that some of the programs that we have developed for the AIDS control, IV drug users, substance abusers, are good examples of how partnerships can be effective.

I thought I might just walk you in the first couple of minutes through the development of our programs targeting this population. The Department of Public Health has obviously existed for a long time in Seattle. Although Seattle is only about 100 years old, I'm not really sure how long the Department of Public Health has existed, but shortly over 100 years. We just published a centennial booklet.

An earlier part of the Department than the AIDS Control Program has been the King County Division of Alcohol and Substance Abuse Services which has for a long time had the responsibility of coordinating AIDS control programs, not AIDS control programs but rather drug control programs, developing various treatment programs, running one of the only detox programs in the state, particularly methadone maintenance programs.

And I think we have a problem that is common probably in many other states, and that is that there are scarcities of such programs in many parts of the state, and we find people migrating to Seattle for methadone maintenance, for example. The whole Olympia Peninsula has no maintenance program and there are only four counties in the state that have a methadone maintenance program.

But back in 1983-1984, the Department established an AIDS Control Program, I think one of the earlier cities to do so. And at about the same time the Northwest AIDS Foundation, who I believe you heard from earlier this morning, was established and I was involved in their origin.

In 1985 we applied to the Centers for Disease Control for some of the first moneys to actually develop disease control demonstration projects, and although we initially targeted gay men because that's the predominant pool of infected people in the Northwest, we were aware in our peripheral vision that IV drug users were going to be major parts of our equation and needed to have programs targeting those as early as possible.

Shortly after we got the money from the Centers for Disease Control, the Alcohol-Drug Abuse Institute at the University of Washington approached us and asked if we'd be interested in using some of our CDC money to fund some demographic surveys of IV drug users.

And so, not only had we begun working with the Northwest AIDS Foundation and already with the King County Division of Alcohol and Substance Abuse Services, but the University of Washington became a part of the overall pool of people interested in the adverse populations.

And shortly thereafter, People of Color Against AIDS Network, whom you heard from as well this morning, developed and became important allies for us as we were thinking about IV drug users, because a high proportion of our IV drug users here locally are people of color.

In 1987 a number of us got together and scratched our heads and said, What kinds of programs should we develop for IV drug users. And we thought perhaps one of the best ways to arrive at the answer to that question was to establish a regional conference, including administrators, treatment program staff, people from the treatment agencies, from the research establishments, and basically convene everyone who new anything about AIDS and IV drug use, drug use in general, and bring in experts from around the country such as John Nugeyer from San Francisco and others.

And we held a conference that lasted a day and-a-half. The first day was basically learning what we could learn that was already known in places like New York and San Francisco and the second half-day was devoted to a series of workshops to begin thinking about what we wanted to push through in Seattle, and some of the things had occurred, such as the development of AIDS brochures and pamphlets and posters targeting IV drug users.

And in 1985, the AIDS Council in Testing was added to our programs and to multiple clinics around the county as part of the Department of Public Health's activities and we were beginning to educate drug treatment program staff.

But the workshop basically concluded that in addition to what we had already in place, that the next most important step for us to take was to hire CHILDS, have community outreach workers, to have them out on the streets as had been done in San Francisco and was being done in New York City.

And that in addition, we should be distributing little bottles of bleach with condoms and information about how to use that sort of equipment to control AIDS with IV drug users, sterilizing the needles.

In 1988 we got money from the state. Along with the State AIDS Omnibus legislation about $9 million came which was split up to the various regions in the state and some of that money was used to employ counselors and testers and educators in the jail where a high proportion of drug users find their way eventually, and in addition, moneys were given to drug treatment programs so that more education and counseling and testing could be offered at the site where people were receiving treatment.

But we realized that only about one out of six drug treatment -- or people who were using IV drugs would find their way into treatment in any given year, according to the statistics from the CDC, and so we sought moneys from the National Institute on Drug Abuse to do both the research and intervention program which included both enhancements of our CHILDS program which was already under way by that time and the development of community organizational approaches, particularly in the Rainier Valley portion of Seattle where IV drug users tend not to be so much on the streets but more involved in apartments and various kinds of family situations.

That's one minute left? Okay. And then in March, to throw another actor into the equation, ACT UP, maybe the ultimate actor, decided that we ought to have a needle exchange program in Seattle. Dave Purchase is here from Tacoma and he will tell how it actually got going in Tacoma.

But we have one of our own in Seattle and perhaps the only city that I know of that has a partnership between the local chapter of ACT UP and the Department of Public

Health. ACT UP decided that since Tacoma had a program and if British Columbia, Vancouver and Victoria both, adopted programs, and Portland was soon to have a needle exchange program, that we should have a program here as well.

And it probably wouldn't have worked if there hadn't been the fertile soil in the communities around us. But as well, I think there was fertile soil in the Department of Public Health. I already had been convinced as the director of the AIDS Control Program that a needle exchange program at least ought to be given a college try.

Stockholm and Montreal and I think to some extent Washington International AIDS meetings had made a point, at least the perceptions about their downsides weren't being worn out, that there were in fact some potential benefits that would be measurable.

And so we began our program in March of 1989. The Deparment took it over in April of '89 and I won't tell you very much more about it because Charlton will actually tell you how the program operates, and Dave Purchase will tell you how the Tacoma Program operates, but I'll be glad to answer questions.

MR. SCOTT ALLEN: Thank you very much for your sensitivity to the time and there will be limits of time, six-minute time frame and then one minute time to wrap up.

And then we will have lots of time for interaction.

MR. CLAY: My name is Charleton Clay and I have two positions that involves working with IV drug users. The first is that I am coordinator for the research project here in Seattle which is doing research in outreach to people who use IV drugs with sexual partners.

The second position is a half-time coordinating position with the Seattle-King County Needle Exchange, and I think probably the reason that I was asked to speak is because I work directly with the needle exchange and I have worked directly on the street.

And I think probably I should start with just giving you a little background to the local Seattle-King County Needle Exchange. As Bob mentioned to you, it was started by ACT UP, and in March of 1989 ACT UP approached the Seattle Health Department, City Council, and other officials saying that they had the intention of starting a needle exchange. They did so, and with help from the health department. ACT UP spoke with the chief of police who guaranteed that he was not interested in harassing the people who were doing the exchanges or the people who were coming up to use the table.

So as a result of the political groundwork, the needle exchange here began without any fanfare and was soon established for people who use IV drugs. On May 15 of 1989, the health department took over the needle exchange from ACT UP approximately two months after it began.

I will just tell you a little bit about the operation of the needle exchange. I'm not sure how familiar you are with that. But we operate 20 hours a week, approximately. We do about 15,000 needles per month. We are open six days a week.

The materials from the needle exchange are very simple. We have a card table down in the street and we have chairs. We have bleached condoms and information and syringes. We also rely on a lot of volunteer help from ACT UP and there's probably about 40 hours of volunteer help per week at our table. So there is always one health department person there and then at least two volunteers.

Sometimes needles go into the syringe containers so fast and furious it's hard to keep up with it. We offer one-for-one exchange, that's one needle for one needle and there's no limit right now of the number of needle exchanges within a month.

We provide information and referral to drug treatment, provide HIV testing and counseling, referral to social services, and referral to medical care. We are a user-friendly needle exchange. This is a Dave Purchase term. And that term means the exchange is non messy, quick and simple.

The evaluation of our needle exchange is only just beginning. But the needle exchange appears to be both direct, positive, and highly appreciated for HIV intervention, yet introduced for people who use IV drugs.

The fact that 60 to 80 people come to the needle exchange in a two-hour shift on a single afternoon is a strong argument that the people on IV drugs do indeed care about their health.

No other intervention that I know of receives as high a degree of volunteer participation as the needle exchange. From the health outreach perspective, an exchange table invites a mere presence on the street, attracts people with a physical circumference for AIDS education and bleach and condoms can be freely given during the exchange.

From the standpoint of public relations, the exchange table creates a street-level contact that opens the possibilities for an unprecedented zone of trust between those with an AIDS education message and people who use IV drugs.

One consequence is that the syringe exchange is perpetually linked to conversation exchange and that many people feel comfortable enough that once they exchange a syringe, you can also exchange talk. And therefore, once people get comfortable enough with the table workers and the staff, they also begin to express genuine personal and social concerns relating either directly or indirectly to their IV drug use.

In other words, I'm saying that the zone of trust created by a needle exchange table often expands the allowable range of both meaningful statements and questions between health-outreach people and those who are using the table.

If a person can trade a needle with impunity, he or she might also trade an opinion, observation, or frustration. And with growing trust between table workers and users of the table, topics about AIDS, sex, drugs, police, as well as feelings of distrust, frustration, and anger come to the fore. More and more people use our table as a resource and referral to other social services, including drug, alcohol treatment, shelter, and welfare.

One thing I want to stress as a tool of AIDS prevention, the very practability of a clean syringe should be appreciated and can't be emphasized enough. We mark our needles at our particular exchange with a green or red magic marker and that let's us know that when we pass out a syringe and we get one of those back, that it came from the table.

Of the syringes that we've handed out with our mark on them, about 85 percent of those that come back have our mark on them. And that band becomes a visible link to the needle exchange table which in itself becomes a link to AIDS prevention.

So there's got to be cognitively some link to safe needle use when people use one of our syringes. Exchanging a dirty syringe for a clean one provides people with a physical tool through which they might preserve their present and future health.

In terms of intervention, the benefit of the needle exchange is that it affords people the chance to change their behavior before they necessarily change their knowledge or attitudes about AIDS. And that's one thing that's very important about a needle exchange. It takes a a much lower threshold of common sense to want to use a sharp syringe, even wanting a cleaner syringe with bleach, because people don't want to be poking themselves with something dull. People are coming up and exchanging their syringes enmass.

The mere presence of the syringe exchange may suggest to people who use IV drugs that if AIDS is important enough to justify a radical shift in official policy, then it must be worth thinking about in terms of behavior change.

One communicable disease investigator who works in the King County jail also told me that people that he interviewed didn't necessarily know that they should be concerned about AIDS, but they knew all about the needle exchange and how to use it.

The needle exchange novelty may wear off seeing that it's a rather incongruent fixture within the context that possessing a syringe is played against the costs of possible legal percusions in being caught. And right now, one of the main problems we have in the needle exchange hear in Seattle is the police department, and they have in general been, as far as the chief of police is concerned, sympathetic and agreeable.

But on the street we pass out syringes as a prophylactic tool, but once it crosses our table and someone else has it for the purpose of using drugs, then it becomes drug paraphernalia and the police have been known to take them away from them quite frequently.

So at the needle exchange table is where the difficult war on drugs and the battle against AIDS converge and the two issues are sort of at loggerheads about how to fight this war.

So I just want to emphasize also that I think work is being done right now to better the relationships with the police and to make things run a little more smoothly for anyone wanting to use our table.

MR. SCOTT ALLEN: Dave.

MR. PURCHASE: Thank you. In April of '88, a Pierce County Health Department put what for us was our first bleach and teach, IV-oriented junkie outreach worker on the street and at that same time there was a notion that we could have a needle exchange as well.

I had conversations originally with Terry Reid from the health department and there was a lifelong friend of mine who happened to be a county councilman at that time, Dennis Flannagan, and basically what we did in Tacoma, we began in a sense the way folks in San Francisco ended up doing what they called the Mae West model, which is Mae West apparently always found it better to beg forgiveness than to ask permission.

So, our approach was that this is what we have got to do. We know you and the chief of police or mayor, whatever, you have got to do whatever you got to do. As things turned out in Tacoma, there were a number of public officials who do not get the credit they deserve who had much more to lose than I did. Hell, what were they were going to do, fire me?

These are folks that stuck their neck out. The chief of police chose not to enforce the misdemeanor laws for syringes, viewing it that the greater issue was the public health. The mayor took the heat from the reporters, so did a couple of councilmen, Skinner, and several others, and instead of having been what at one time was a reasonable vote would have been like a splash-in-the-pan media event and the trial would have been used as an educational experience. Instead, what we have is the opportunity to continue the program. And we became captives of a device of our creation.

And as a result, the study started the very next month. We started the first week in August of '88. By the end of that month there were interviews on the street, photographers on the street. By December of '88, the health department had already had an educational session. In January of 1989 they voted to fund the program part-time.

A month ago they voted to substantially increase that funding and by the end of -- currently, what we have now is a van. We do exchanges and AIDS prevention at three locations. One of them is the pharmacy in the health department and this is for people who are paranoid to come out into the street or those who would be stopped because of drug loitering laws because they can't be seen in this neighborhood anymore, just exchanges are done there. But the AIDS prevention information and referrals to treatment, that sort of thing, go on at the other two locations.

We hope by the end of the year to have a fixed location and a fourth location and that probably will be as close to, in a sense, saturating our market as we can do in our county. We do HIV testing on-site, TB testing on-site. Before or at least after we have a fixed location, we'll go ahead and do STD testing.

We provide food, provide clothing, especially in the wintertime. And have become, as Charlton was explaining, in a sense we are also the social services that are offered to junkies and dopers and that's a wonderful position to me, and we do street doctoring -- don't tell the lawyers.

We provide referrals for just about any imaginable need that these folks have. And, you know, these are folks that are fine with us. I have never net a junkie yet who didn't know at one time during the day that he ought to quite. We don't have to tell them. Of course, they may have one time during the day when they think it's the best thing that ever happened to them too.

But up until the treatment filled up, basically we became the largest referral source for drug abuse treatment in town. Right now we have the same problem as everybody else, this whole war on drugs is a $7.9 billion popstand, and to shoot it with a $2 million propaganda just isn't going to work and there aren't treatment slots available.

But before that, we were referring 30 to 50 folks a month into treatment. I mean, that -- there is the data which I understand has been faxed to you and the latest was what amounts to our biggest survey now is -- currently we have a publication that while I'm not supposed to tell you what it says, I'll see that you get one. And it goes along with all the other studies ever done. We do provide risk reduction.

Having a syringe exchange and not having a syringe exchange, there is a demonstrable difference in the interruption of the transmission of the virus that can occur. It is a viable thing to do. It does work. And we do change behavior but we're not perfect. We are talking about behavior where folks do share and still share, sure. But we manage to reduce the incidence of sharing. What we are not good at yet is changing our sexual behavior, but I don't know anybody else who has been able to do that, and that's a tough nut to chew on.

And the hope is that when we have some more confidential area, which will come from fixed site offices and the standard paraphernalia of social services, that we will be able to do private intervention in sexual practices of the folks that we work with.

In terms of needle exchanges in general, there just isn't any medical or scientific or epidemological reason why there shouldn't be a syringe exchange program in every appropriate population in every place in this world. That's just a scientific fact.

And you know, I mean, sometimes I'm asked, Why Tacoma? And the question really isn't why not Tacoma; it's why not 500 other cities and 10,000 more people? I mean, our junkies and our young people are dying. Now if this virus was transmitted by the steering wheel of a BMW, it may be we would respond differently. But the fact of the matter is, they are dying, dying at our expense. They are all somebody's children.

6

Public health is either for everybody or we use the 30 percent a year plan. Ignorance, not counting some darker motives, probably is the primary reason why this isn't occurring, although one of the reasons that the population in general is so ignorant is because of lack of leadership at the federal level.

We got this guy, his middle name is Czar, who says that some things work and things that don't work are needle exchanges, and he cites unofficial research as his reason for making that kind of statement. That's a bunch of -- this is supposed to be an educated fellow. Understand what I'm saying? So, we have to tackle that. I mean, it's an inexpensive, effective method to prevent the death of people that live in our cities. It's as simple as that. Thank you.

MR. SCOTT ALLEN: Are there any questions?

MR. GOLDMAN: I have a couple of question. In the State of Washington, is the sale of needles and syringes prohibited by law? Is a prescription required? The patterns differ from state to state. Would somebody tell me just quickly what the situation is in the State of Washington.

MR. WOOD: You're to have a prescription in order to be able to require a needle. A pharmacist quite frequently provides needles to people without prescriptions but --

MR. SCOTT ALLEN: Excuse me. Could you use the microphone so the reporter can hear.

MR. WOOD: Pharmacists quite frequently provide needles to patrons without prescriptions but they may do that in a fairly judgmental and arbitrary fashion. We get reports that most IV drug users in fact get their needles from pharmacists, and an argument has been made by one of the council members that it actually might be more effective than a needle exchange to further liberalize the laws so needles are more easily accessible.

But pharmacies don't want having those kinds of clients in their store hanging around, waiting for needles. So the pharmacy board has agreed that they should enforce the letter of the law. On the other hand, they really don't.

MR. GOLDMAN: The second question here, how long is the current waiting list for drug treatment in Seattle, Tacoma, or other parts of Washington for withdrawal and do you have any data on how many slots you would need in order to provide care for those who are actively seeking treatment at the present time?

MR. WOOD: I will speak for Seattle. We don't have a good system to tell us how long the waiting list is. A little bit depends on how you define treatment on demand. We do have a detox unit which claims that people can get in within 24-48 hours for the most part, but I'm not sure that detox is what I could call treatment.

On the other hand, we know of people that are waiting for long periods of time to get into treatment, and without funding there's a real problem getting in. But the problem is we don't have even a good sense of telling us how big that problem is. Maybe in Tacoma you have.

MR. PURCHASE: A syringe exchange is a misdemeanor -- not exchange, excuse me -- but paraphernalia; a year, a day, and $1,000. But we just won a court case in Superior Court on every legal point. While that's not case law for the State of Washington, it goes to that it's understandable law in the State of Washington, so doing AIDS prevention with syringes is legal.

We can get folks in detox in Tacoma in one to three days. That's a five to ten day detox period and it takes them then at least three weeks to three months to get into longer treatment after that. So sometimes we house them in the meantime and more often than not they go back to where they came from, which is the street.

MR. GOLDMAN: One last question. In many parts of the country the leading opposition to the program for needle exchange has come from within the minority community. And I'm wondering how the minority communities in Seattle and Tacoma have reacted to the needle exchange program to gain their support or counter opposition if that's been the case?

MR. PURCHASE: Well I'm just going to reach out into the blue, and there's a limit to what I can say about that. The problem here is that it seems to me that in that particular instance, you know, that white may be right and that's a tough one to deal with.

7

And we have from some of the churches and from some of the leadership in the African-American communities some opposition, but it's not to the point where it's stopped the program, and one of our future sites will be in a predominantly black neighborhood.

MR. WOOD: The chair of the city council last year, and our current mayor who was on the city council last year, are both black and both supportive of the program and we have a county council member, a black member as well, who has been strongly supportive of the program and trying to urge us forward on this and other kinds of programs that people might consider controversial.

I spoke that there was already fertile soil for the establishment of a needle exchange program, but I think that it's important to know the Tacoma News Tribune did a series of surveys of community members and found that the majority of people in Tacoma -- which we would think of them in Seattle as sort of a biased community -- in fact, were in favor of the establishment of needle exchange programs.

Our press here locally have had editorials favoring needle exchange programs and recently we took city or county moneys to establish another branch of our needle exchange program outside of the City of Seattle in a county community where we perceived a major problem.

We initially had some problems with the police but actually the press were quite supportive, and although there was a small petition that was raised, a number of organizations we went to seemed to us were as much in support of needle exchange programs as they were opposed to the needle exchange programs.

So I think there is in general in the Northwest a lot of feeling that needle exchange programs are an appropriate form of public health and I think that helped us to establish programs here.

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

MR. DALTON: A series of questions. I must say I feel like a man landing on the moon in respect to this issue. The idea a needle exchange would be done in Seattle with no fanfare is bizarre. The idea that in Tacoma the place where people who feel most at risk go to change their needles is in the health department pharmacy was bizarre.

But be that as it may, following that up with a question, what is the ratio of breakdown of IV drug users in Seattle and Tacoma and what is the racial breakdown of people who take advantage of the two needle exchange programs?

MR. PURCHASE: Our clientele are just about half white and half people of color. And the vast majority, I mean, 90 some odd percent of people of color are black and the population of the city is 12 percent, I believe.

MR. DALTON: But the population of IV drug users as best you know of people of color as against white is what?

MR. PURCHASE: Not quite as high as our exchange rate. In treatment it's about -- runs between 35 and 40 percent and we are seeing almost half.

MR. DALTON: What about out of treatment? For example, my home town, currently New Haven, Conneticut, the population in treatment, 70 percent are white, addicted overall are 70 percent black, so comparitive treatment may not reflect the population.

MR. PURCHASE: And I don't know anybody who can tell you accurately, in fact, how many junkies we have, let alone any breakdown. Everybody has kind of a vested interest in what number they come up with.

MR. DALTON: My question is whether or not the needle exchange program is seeing an appropriate percentage of junkies, to use your phrase, who are Black and Latino. That is, whether the sort of fear in this zone of safety or zone of -- it's a nice phrase -- zone of trust, whether the zone of trust is the same for all groups restricted to needle exchanges.

You have described a lovely concept of this table, sort of a counseling relating to an exchange table, and certainly the idea of a needle exchange on the street running a table sounds so much more promising than in a government building in downdown Manhattan where the government runs a program.

But I do wonder how effective even the table on the street is when a block away or two blocks away or maybe around the corner the police are taking away people's needles. But I also understand a misdemeanor, but maybe taking away not only people's needles but their liberty as well. That's a potential.

8

So I'm wondering -- and it may mean that the different addicts view their risk differently, of being arrested for possession, of wanting red-marked needles. Would you respond to that?

MR. CLAY: I don't know the percentage for the ethnic ratio breakdown in Seattle-King County, throughout Seattle-King County. For use of the table, about half are white, about 80 percent of them are male, 75 to 80 percent. About 30 percent of them are black and then the rest are Latino, Asian, and it breaks down from there.

Where our table is located is pretty -- the area is demographically pretty mixed and I do think that from -- it's likely from statistics that we have from a drug loitering bill that was passed in Tacoma awhile back, that the arrest rate for people of color is much higher than it is for whites.

And it may also be true that in Seattle as you extrapolate, that people of color are having their syringes taken at a higher rate by police than whites. I can't say that for sure, there is really no way for me to know. But I do feel like it reaches proportionately from the area where it's now situated, a high number of people of color, although I think that those statistics can be improved even more with change of location and with more people of color staffing our table.

MR. WOOD: Two issues that your question raises. One, do our programs saturate the need? And I would submit that probably the Tacoma program goes further in that direction than ours does. Tacoma has two outlets in a smaller population of estimated, I guess, 3,000 IV drug users.

We have one outlet downtown and just established another in the county for an estimated 12,000 IV drug users. So I think partly what we're seeing at the needle exchange site depends a little bit on where it happens to be located, as Charlton was saying.

The population doesn't travel very far and that's the second issue. And that is that most of the studies that have been done, particularly in England, and I think the Amsterdam study, suggest that you can't have one needle exchange for a large population that's spread out over a large geographic area. Most people won't travel more than a mile or two.

Gerry Stimson's work I think suggests that you really have to have needle exchange programs all over the place in order to effectively blanket the community. Because people -- they do care, but they don't care that much that they are going to go a great deal out of their way in order to get a needle. That's a common perception we have to battle with the opponents who say, Gee, aren't you going to be attracting people to our area where you have a needle exchange program? It's a perception, but it's based on fact.

MR. DALTON: Final question, I guess Dave and Charlton in particular. If you eliminate paraphernalia laws and eliminate restrictions on prescriptions for needles, would you prefer an option of -- both in an ideal world -- but which would be more effective, a needle exchange program or simply eliminating restrictions on people's ability to acquire needles from pharmacies? Assume you both had jobs in either of these areas.

MR. PURCHASE: With all due respect, this kind of question doesn't need answering because the real answer is to do both.

I mean, you have like Bob is alluding to, we have different cultural populations that are IV drug users. What we're trying to do is to stop a virus here so what we do is avoid transmission that might occur. And allowing unlimited access to syringes is one of the methods just like needle exchange is a method, just one of the methods of AIDS prevention. So I wouldn't want to make an obvious choice there. I go for both.

MR. CLAY: I would answer in the same way.

MR. SCOTT ALLEN: Larry, you had a question?

MR. KESSLER: Do you have any data on the sero problems among the people who are either users in the state and also as those who are using needing exchange programs?

MR. WOOD: We have looked at five different populations of needle users in Seattle. People in detox, people in several drug treatment programs, people that we have recruited for money off the street to participate in the early stages of the Alcohol-Drug Abuse studies that Charlton was involved in, people in our own AIDS prevention project which tends to target more gay men, although we have seen over a 1,000 IV drug users there as well.

And seroprevelence rates vary between 5 and 10 percent and have stayed in that range since 1987 when we began looking at those populations. So I can't claim that needle exchanges or CHILDS or bleach distribution has accomplished that stabilization, but at least we are not seeing the rapidly escalating sero prevelence rate that has been described in New York and the East Coast.

MR. PURCHASE: I think ours are roughly comparable.

And again, it varies to populations. Overall, the guess is we are about three percent. Folks on the street presumably at the greatest risk, perhaps up to 11 percent with daily shooters.

MR. KESSLER: This is a question or actually an opportunity for Dave and Charlton. Like I say, occasionally we have at least a deputy from William R. Bennett's office call on us and it might be an opportunity as close as you may ever come to saying something to him. What would you like to say?

MR. PURCHASE: Resign.

MR. KESSLER: I was going to say 25 words or less.

MR. CLAY: I second that.

MR. KESSLER: Let the record show. Robert, do you want to add anything?

MR. WOOD: Publicly?

MR. PURCHASE: I really, aside from the flip answer, what is there to say? Clearly, the information coming out of that office is driven by reasons other than truth. So what do you? How do you educate somebody like that who knows better anyway, I assume, or else the guy is a total bozo. And there are lots of other people involved in this sort of thing and lives are at stake.

Unfortunately, if you let it die, and I don't think it's no secret that the folks who have some access to leadership in the media and public and that sort of thing have much political worth, and I don't read that junk in the Constitution.

MS. OSBORN: Let me maybe just get you to comment on something that is very congruent to what you just said. In listening to the data, from Europe in particular, I have been struck that every time this kind of an opportunity was offered to people who were using drugs, the demand or request or urgent need for primary care became almost an instant lack, obvious lack, even in the European healthcare systems.

That was something that I was wondering about as you were talking, because you're clearly trying to substitute in this a variety of ways and as you said, you are the total provider of what you can do.

But have you found that to be -- it almost sounds, in listening to your presentation, if that's almost a disincentive to do it because you get so overwhelmed in terms of people wanting care, to have themselves better. How have you have dealt with that?

MR. PURCHASE: Well, we fill the slots and then there aren't any slots left and one of my co-workers takes them home. It's quite literally the case. Junkies routinely, when like ER staffers or medical personnel are reviewed and asked who would they most like to see coming into the

ER room and who would they least like to treat, junkies are always last. They are notoriously abused by the medical system so when they come across folks like us that they perceive they can trust and that have some access to this great world, the stuff just piles up on us.

I suppose in the longest run, June, to answer the question, is that for myself, someday I'll have seen too much and I won't look anymore, but that day hasn't come yet.

And the other thing about treatment, if we look at drug treatment, what we have, nationally we have a capacity to treat maybe 15 percent, maybe 20 percent, maybe 25 percent of all people who we think need treatment. Well that's a wonderful position to be in if you're a physician. I mean, you always have waiting lists. Nobody's going to ask you how newly effective you are because you have always got clients and you can always say, The treatment didn't fail, the client failed treatment.

The only fact of the matter is, we have about 15 percent to 20 percent, and these are Don's figures, Don Des Jarlais, given instances of treatment will be effective maybe one in five times. I mean, we don't know how to do good drug treatment, not in the same way we would approach, I don't know, flu or some other health

10

problem, you know. We take guns to a health problem. The war on drugs, it's quite likely, will turn out to be a war on the victims rather than the perpetrator. So we just do what we can.

MR. WOOD: If you are getting more at the primary care as aside from the drug treatment needs of this population, I think our perception is that they do have major primary care needs.

And we have been fortunate again in pulling the community together to apply for the type of healthcare delivery assistance programs that seek to link primary care and drug treatment programs together, and we are presently trying to operationalize that. But we are hoping that will help us be better in terms of servicing the healthcare needs of this population.

MR. SCOTT ALLEN: Did you want to make comment?

MR. CLAY: I was just going to say again, emphasize that as far as access to primary care, of course it's very, very difficult for people out on the street. But again, the needle exchange does provide at least the entry level trust, a place where they can begin to feel comfortable with healthcare providers at some level, and that just doesn't happen in places as easily without treatment people or it doesn't happen to all of the treatment IV drug users.

MR. SCOTT ALLEN: I want to make one brief comment. I had three questions but I will cut it down to one question in the interest of time. The comment is that in terms of needle exchange programs and even bleach distribution programs, it's important to recognize that while there is an administrative position, there is also a congressional position. Every single piece of funding legislation that has come out has prohibited needle exchanges and many of them have also prohibited block grants, in particular bleach distribution. It's not just enough to say the administrators don't allow it.

Question for you: One of the concerns that many of the opponents of needle exchange have is that it's going to recruite new users. Charlton, you described your program, that it was a one-on-one exchange. Somebody has to come in with the initial equipment, first of all.

Do either of you have information on recruitment of new users under this exchange program as to what's been the impact? How do people obtain their first equipment? You know, if they have got to have something, do they then want to come in and exchange? And what can we do to better stop first use? Have you worked with the use of it with the dealers in the area?

MR. CLAY: I think that's a moot point because never has someone who has never used come up to the table and wanted a syringe. That just doesn't happen.

MR. SCOTT ALLEN: We need to get that point out.

MR. CLAY: I mean, we've had people come up and joke, but no, no, no, it just doesn't happen, so it's a moot point. And I think that it again is part of the whole scare around drugs and it's perpetuated at the level of the federal government, by the Czar. I would hope that that information can get out and that you as a panel will help enlighten this nation about the problems. But that really is not one of the problems in our needle exchange.

MR. WOOD: There are really three misperceptions I think that inhibit these programs. One is that it will encourage new use and I think the message has been stated in all the papers that I have seen, that no new users are being reported in any of the programs anywhere in the world.

Another misperception is that it will increase drug use. Matter of fact, one of the studies seemed to suggest that, if anything, drug use decreases in these populations.

And the third one is that will attract users to a specific site. Again, there are no data that support that whatsoever. It's just the opposite as a matter of fact. You have to have an exchange program where the users are because they won't come to you. They won't come to a

11

distant spot.

MR. PURCHASE: Our average folk person is male, 33 and-a-half years old, has been injecting drugs for eight years, has been using drugs for fourteen years. It's just these are folks on the street who their addiction, disease, or compulsion, by whatever term, has them right at the edge of existence, just them, their habit, and the next day.

We don't see -- in fact, we don't even see many young folks out there that are involved in exchanges. We work with the run away and the throw-away kids, but they are not in a sense our customers as far as exchange is concerned.

As far as people using their first syringe, that's invaribly shared. Somebody turns somebody else on with the outfit, the rig, the syringe that they have handy.

As far as intervening and that, as I understand it, again from Don, there is enough evidence to indicate that intervention at first injection, at first use of injectable substance might be effective, but prevention in this country isn't set up to allow prevention workers to do anything but work for abstinence.

And so while it's conceivable outreach workers can work at that sort of thing, there isn't a mechanism for that. The idea of prevention is always to be 80 percent effective, which is exactly the percentage we have anyway.

MR. SCOTT ALLEN: The worst part about this is that I never get to ask any questions. I just have one. You talk about 68 percent in favor of needle exchange, yet only four counties in this state are willing to have treatment facilities and it seems very inconsistent to me, since I understand it's up to the county to have treatment in the county. So you have only four. Why? I'm really confused about that, it sounds inconsistent.

MR. WOOD: These were 68 percent of the people in one county that had it already. It wasn't a statewide survey.

MR. SCOTT ALLEN: Oh, they already had it. One of the obstacles is treatment geographically in the state, right?

MR. WOOD: That refers to methadone maintenance and methadone detox programs, not to drug-related outpatient, et cetera.

MR. SCOTT ALLEN: Oh, well, thank you very much. It's been very helpful to us.

(The lunch recess was taken.)