NATIONAL COMMISSION ON AIDS

WORKING GROUP ON SOCIAL/HUMAN ISSUES

COPY

BE IT REMEMBERED THAT on the 10th day of July, 1990, at 8:30 a.m., the above-named group came on for discussion before LAURIE S. KOKORUDA, a Certified Shorthand Reporter in and for the State of Texas, at Dallas Public Library, 1515 Young Street at Ervay, City of Dallas, County of Dallas and State of Texas, whereupon the following proceedings were had:

1 P R O C E E D I N G S

2 REV. ALLEN: Good morning. This is

3 the Working Group on the Social and Human Issues

4 of the National Commission on AIDS. We are here

5 -- we are the Working Group of the National

6 Commission on AIDS on Human and Social Issues. We

7 are here looking at today the obstacles to care

8 and continuous care models.

9 I would ask June Osborn, the Chair of

10 the Commission, to say a few words about the

11 Commission itself. Then I'll explain some of the

12 background of the Working Group.

13 DR. OSBORN: Well, I'm pleased to

14 be able to be here and listen to the testimony

15 given to the Working Group today. The National

16 Commission on AIDS has three formats in which we

17 have tried to do our work.

18 Briefly, we are finishing -- coming

19 toward the end of our first year of our two year

20 assignment. The Commission was created by

21 Congress, an act of Congress in late 1988 and

22 fully constituted in August of '89, with the

23 charge to try and move the national concensus

24 about the epidemic and to be both reactive and

25 pro-active with respect to Congress and the

1 effectiveness so far as needed AIDS policies and
2 activities were concerned.
3 To do this, we have elected members,
4 three cabinet secretaries ex officio and in fact
5 one of our -- I'm sorry. Appointed members
6 appointed by -- ten by Congress and two by
7 president. One of those members is a member of
8 Congress so that our hearings in full commission
9 session more or less need to be conducted in
10 Washington most of the time. And, so every second
11 month, we have that kind of a meeting.
12 In alternative months, we have been
13 trying to visit around the country in what we call
14 site-visit sessions. And we actually try and get
15 a detailed sense of how a given region or a given
16 station of the epidemic is progressing.
17 This represents a third format in order
18 to try and take full advantage of the talents of
19 the commissioners which are extensive and varied.
20 We have broken ourselves into what's called small
21 working groups where specific themes can be
22 developed more fully than those other two rather
23 more formal structures allow.
24 So, this is, I think, the third or
25 fourth full meeting of what is called Small

1 Working Group on Human and Social Issues which
2 will then ultimately be reporting back to the full
3 Commission and so forth.
4 Therefore, I am pleased to be mostly a
5 listener since I am not technically a part of the
6 Working Group. And Reverend Scott Allen has been
7 leading that group and all of us that are here,
8 and we're looking forward to hearing from you
9 today about the facets of the theme that this
10 Group is trying to develop which Scott will be
11 talking more about. Thank you for your
12 hospitality.
13 REV. ALLEN: The Working Group felt
14 that it was important for us to look at continuum
15 of care and looking at testing and early
16 intervention. And so, we have tackled that
17 subject by having a hearing in Boston, dealing
18 with the issue and finding some information on
19 community-based organizations.
20 We looked at public health issues
21 yesterday; and now we're looking at obstacles to
22 care today. And then we're going to have another
23 meeting at the end of July in Seattle to continue
24 looking at the continuum of care models and then
25 hopefully to provide a report to the full

1 Commission in September.

2 Let me introduce to you the folks up

3 here. This on my far left is Maureen Byrnes.

4 She's the Executive Director of the National

5 Commission. Don Goldman is in private law

6 practice and the past president of the National

7 Hemophelia Foundation.

8 Harlon Dalton is Professor of Law at

9 Yale University and Editor of "AIDS in the Law".

10 Dr. Konigsberg is the Health Director in Kansas

11 and was a former health director at Boward County

12 in Florida.

13 And Eunice Diaz is from Southern

14 california and she has worked extensively with the

15 Spanish community and also is an Adjunct Professor

16 at University of Southern California in Family

17 Medicine. And Larry Kessler is the Executive

18 Director of the AIDS Action Committee in Boston.

19 So, we are here; and it's time for our

20 first presenter, Warren Buckingham.

21 MR. BUCKINGHAM: Good morning,

22 Reverend Allen and Dr. Osborn and the Commission.

23 It's a privilege to appear before you today.

24 You've been in Dallas several days. And even

25 though the New York Times is universally

1 recognized as the newspaper of record, those of
2 you who read the Times I hope have realized that
3 you are not in Calcutta.
4 As our society moves fully into the
5 second decade of the HIV disaster, it is timely
6 that we revisit the subject of barriers to care
7 and re-examine earlier notions about just what
8 constitutes an obstacle.
9 Many of the first identified
10 difficulties such as institutional homophobia are
11 still present in some communities and other old
12 barriers have fallen, but new ones seem to have
13 emerged with each change in the face of the
14 epidemic.
15 What has been constant over time as new
16 impediments have emerged is that they all can
17 logically be grouped under four broad headings.
18 Begging your pardon, especially Commissioner
19 Dalton, for the alliteration, I would like to
20 speak today of barriers that stem from
21 mythologies, morals, myopia and money. I will
22 provide one or two examples of the barriers in
23 each as a focus for your thinking and planning.
24 What might I mean by barriers which
25 originate in mythologies? Our society has a full

1 complement of preconceived notions about
2 subsegments of the larger whole and how they will
3 or will not act in response to certain
4 situations.
5 We hold, for example, nearly universally
6 to the belief that intravenous drugs users will
7 not care for themselves and for one another. That
8 is a wrong assumption that should be called into
9 question at every opportunity. Innovative pilot
10 projects in Newark and our drug-ravaged cities
11 have demonstrated that with minimal incentives, IV
12 drug users will, in fact, become active
13 participants in their own care and can be trained
14 for social and pratical support providers for
15 their peers.
16 What other myths color our perceptions
17 of who needs what and how they will get it? Far
18 too many of the well-meaning human care
19 professionals and volunteers responding to the
20 growing number of infants with HIV -- the over
21 majority of whom are African American or Hispanic
22 -- rip families assunder.
23 They do this because their myths tell
24 them that mothers who would prostitute themselves
25 or use illegal drugs are incapable of caring for

1 their infants. That is wrong, it is immoral and
2 it is ethno-elitist in a most offensive way.
3 We should instead be developing programs
4 which provide basic skills and support to mothers,
5 grandmothers, aunts and sisters who can deliver
6 care to children who have no business locked up in
7 hospitals or other institutions but should be at
8 home whenever possible and for as long as
9 possible.
10 The myth is also afoot in many cities
11 that the gay and lesbian community is financially
12 and physically spent and can no longer be the
13 voluntary backbone of the HIV response it was in
14 the first decade of AIDS.
15 We should not accept this legitimate
16 concern as accomplished fact but should instead be
17 feverishly developing innovative strategies to
18 keep that critical community at the center of AIDS
19 care. Part of that planning must include
20 identifying new alliances which can help spread
21 the burden.
22 Which leads me to the barriers stemming
23 from myopia. I cannot begin to number the legions
24 of people and groups here and across the country
25 that I've heard bemoan the fact that one group, or

1 another or one person or another, was sure to be
2 at least unhelpful if not downright hateful, or as
3 is sometimes alleged, "criminal", towards persons
4 with AIDS and those trying to care for them.
5 While the fact that people and
6 institutions have been hateful can never be
7 forgotten or ignored, I would also like to point
8 out that no organization asked to be part of the
9 AIDS response in this community -- from the
10 Salvation Army and United Way to proprietary
11 home-care agencies and nursing homes to monolithic
12 bureaucracies like the VA and Social Security --
13 has said no. We have definitely proven that it
14 doesn't hurt to ask.
15 I agree that we dare not become
16 complacent about our opponents, but would argue
17 that we need to be at least equally vigilant in
18 seeking out allies.
19 Four years ago in Dallas, pastoral care
20 response to AIDS was in the exclusive and
21 exhaustive hands of four members of the clergy.
22 Today, we have an AIDS Interfaith Network with
23 dozens of cooperating parishes providing Care
24 Teams and nearly one hundred rabbis, priests and
25 pastors available to meet both the spiritual and

1 temporal needs of persons affected by HIV.

2 The Metropolitan Community Church of
3 Dallas, with its roots and mission in the gay and
4 lesbian community, was neither ignored nor
5 excluded as the Interfaith Network developed but
6 was and is a full participant.

7 Organizations seeking to develop
8 services in the Hispanic or African American
9 communities must likewise recognize that many
10 valuable lessons have been learned by groups with
11 their origins in the gay and lesbian communities.

12 Our society's impaired vision is also
13 demonstrated in the fact that so few communities
14 are actively planning for the social and health
15 services that will be needed when AIDS reaches
16 third- and fourth-wave cities. Their failure to
17 prepare means these neglectful towns will forever
18 be in a reactive posture.

19 What this translates into in terms of
20 human care is that they miss the opportunity to
21 conserve lives and resources and that is being
22 conservative in the most caring and constructive
23 sense of the word. If we are not anticipatory as
24 a society or as institutions, how can we be such
25 in our dealings with men, women and children in

1 need?

2 If, on the other hand, our intent is to
3 identify all potential societal resources and
4 engage them in the AIDS struggle, we can translate
5 that at the service delivery level to helping
6 people identify current or potential resources for
7 their life situations and bringing them to bear on
8 fulfilling a plan of care.

9 And what of the role of morals in
10 raising up barriers to care? The obvious:
11 Assertion by zealots that AIDS is a more judgment
12 meted out in response to immoral behavior is old
13 pat and seems to be dissipating as the moral
14 stalwarts are brought up on morals charges.

15 What is less obvious, and more odious,
16 is the lingering fallout from these
17 pronouncements. The number of people adrift in
18 our society with deep wounds resulting from
19 immoral judgment they lay on themselves -- that I
20 am not worthy of help and deserve this death
21 sentence infection -- cannot be counted and dare
22 not be ignored.

23 Our challenge is to be a compassionate
24 and a moral society which listens for the silent
25 cries of these brothers and sisters of ours and

1 gently insists that they seek the care available
2 to them.
3 The way we resolve ethical dilemmas
4 around HIV services in this country epitomizes the
5 moral category of barriers. AZT in early
6 infection has proven effective in prolonging life
7 and improving the quality of life for persons who
8 receive it.
9 We have changed the labels on the
10 bottles to reflect that fact, and morally
11 mythologize that we have somehow made that aspect
12 of early intervention a reality for the masses.
13 We didn't appropriate the funds to pay for the
14 drug, though, so we've left the ultimate barrier
15 still in place.
16 That moral barrier which we have not had
17 to communal will to overcome promises early death
18 for thousands. Our righteousness can wreak havoc
19 on persons with HIV illness who also have
20 addiction disorders, and their numbers increase
21 hourly.
22 Competent and dedicated professionals do
23 all in their power to encourage these individuals
24 to overcome their addictions because it's the
25 moral thing to do. But what does society offer

1 beyond encouragement? Months-long waiting lists,
2 then miles-long waiting lines, for treatment.
3 Incarceration -- or more subtle punishments -- for
4 failure, and an artificial hierarchy of addictions
5 where some are deemed more deserving of treatment
6 than others. The moral failure is ours; the
7 barriers to overcome is theirs.
8 And now to the root of all barriers:
9 Money. Persons desperate for assistance need to
10 feel some sense of confidence that the agencies to
11 which they turn will be there tomorrow. Given the
12 current state of private and public funding for
13 HIV services, that assurance is often absent.
14 Not a week goes by when the press or the
15 national AIDS grapevine isn't full of talk of the
16 latest AIDS agency downsizing its operations or
17 closing its doors for good. We are foolish if we
18 assume that clients or potential clients are
19 unaware of these facts or if we assume that that
20 knowledge doesn't prevent people from coming
21 forward for care.
22 Whether it comes from the private sector
23 or from government, the majority of AIDS care
24 money is still called demonstration funding. This
25 is the second decade of the epidemic and many of

1 us are finished demonstrating. We have proven the
2 efficacy of our programs and are in need of stable
3 and reliable financial support.
4 This Commission has sought to help
5 remove that barrier by endorsing the Kennedy-Hatch
6 Care Act, and those of us in the field are
7 grateful. There is still room for funding which
8 encourages innovation, though, and creative
9 funders are desperately needed.
10 We could, for example, be given the
11 opportunity to train family members in the barrios
12 and ghettos of America to be home-care providers.
13 AIDS planners in city after city have thrown up
14 their hands in dispair at using traditional
15 sources to provide home care in these
16 neighborhood.
17 The easiest way over this barrier is to
18 train people already in the home to deliver the
19 home care. Many other creative solutions to
20 seemingly insurmountable barriers are out there
21 waiting to be financed.
22 You, and we, must continue to be
23 rigorous compaigners for adequate funding and
24 services in response to the people in our
25 community who are living with AIDS. We dare not

1 relax as there is a fifth and final obstacle out
2 there and it is the most frightening of all. In
3 my opinion, the greatest barrier and danger facing
4 this nation in the decade ahead is the growing
5 sense of malaise about this epidemic.
6 TIME Magazine, acting as though founder
7 Luce were still alive, has adopted as editorial
8 truth the reactionary contention that we are doing
9 too much about AIDS. Other publications and media
10 are already claiming this argument as their own.
11 Even more frightening is the fact that
12 numbers of young gay men are not reacting on the
13 lifesaving lessons learned in the last decade by
14 their older brothers and that heterosexual
15 adolescents aren't getting the message, aren't
16 hearing it, and aren't acting on it either. And
17 they are becoming infected and they are dying.
18 We are only doing too much if we are
19 willing to accept that doing no more condemns many
20 for the next generations to unnecessary death.
21 Thank you.
22 REV. ALLEN: Thank you, Bob. Are
23 there any questions? We have about five minutes
24 for dialogue here. Are there any questions for
25 Bob this morning?

1 DR. OSBORN: Not a question, just a
2 comment. That was exceptionally eloquently
3 presented.
4 REV. ALLEN: I have a question
5 then. Would you elaborate on the issue, the HRSA
6 and the Robert Johnson Foundation's money and what
7 you see your agency dealing with in the next year
8 or so in private funding.
9 I know being on the board of AIDS ARMS,
10 I'm very much aware of the precariousness of the
11 whole stability of the organizations around. So,
12 would you comment on that?
13 MR. BUCKINGHAM: Not just in
14 Dallas, but in other communities around the
15 country, this is a kind of a year of double
16 whammies.
17 Four years ago, the Robert Johnson
18 Foundation established nine AIDS demonstration
19 projects across the country. The AIDS ARMS
20 Network here in Dallas is one of those.
21 In subsequent years, all nine of those
22 cities and another thirteen or fourteen have
23 received Federal AIDS Service Demonstration
24 Funding from the Health Resources and Services
25 Administration.

1 This year the Robert Johnson Foundation
2 grants expire and the impact that will have on
3 Dallas numbers in the hundreds of thousands of
4 dollars. And there is no replacement funding out
5 there for that.
6 HRSA has extremely limited dollars for
7 renewal applications which are going to be very
8 competitive this year. And while I'm confident
9 that Dallas has its act together enough to submit
10 a successful application to HRSA, we already are
11 on notice that we will be getting less money
12 rather than more.
13 That's hard to take in a year when it's
14 expiring and our case loads are exploding.
15 REV. ALLEN: And we are not even
16 dealing with second city.
17 MR. BUCKINGHAM: No. Those are all
18 what would be called first place cities.
19 REV. ALLEN: Yeah.
20 MS. DIAZ: I was interested in your
21 comment on the need to expand home care.
22 MR. BUCKINGHAM: Yes.
23 MS. DIAZ: And I'd like to just
24 question you a little more about that. Who do you
25 think might take the leadership role in the

1 training and preparation of the large calvary of
2 people or army of people we will need to be able
3 to do this?

4 MR. BUCKINGHAM: Well, I think a
5 very effective partnership could be formed between
6 private and public sectors.

7 In Texas, for example, Primary Home Care
8 is a program administered by the Texas Department
9 of Human Services. And one of the few positive
10 aspects of the state's response to AIDS that I
11 have is that in this state, family members can be
12 reimbursed for providing primary home care.

13 In terms of training and preparation,
14 that's the barrier we aren't yet over. And I
15 think in every community of any size across this
16 country, the ideal institution to provide a
17 training would be the American Red Cross.

18 Years ago, they trained family members
19 how to care for a bed-bound parent, how to do a
20 bed bath, how to change the bed for the patient,
21 how to deal with incompetence, those kinds of
22 things. And in some cities -- Atlanta is one that
23 I know of -- the Red Cross has resuscitated and
24 brought up-to-date that curriculum and made it a
25 specific. And I'd love to see something like that

1 happening across the country.

2 MS. DIAZ: I want you to know that

3 some of us are working with the National Red Cross

4 to see that that becomes a reality because it

5 could apply throughout the whole United States

6 through their chapters.

7 MR. DALTON: I heard a rumor that

8 you were going to reduce your remarks today to

9 writing which seemed odd because you're such a

10 marvelous speaker. You're obviously marvelous

11 from the script.

12 Having reduced it to writing, I would

13 just urge you to put that in circulation because

14 you managed to say many things that I think I

15 thought about, but sure as hell have never been

16 able to put words around it and you've done

17 beautifully. And you should share that with

18 everybody.

19 MR. BUCKINGHAM: Thank you. I do

20 have copies for you.

21 MR. DALTON: But I didn't mean just

22 for us.

23 REV. ALLEN: Any other questions?

24 Larry.

25 MR. KESSLER: Buck, I'm interested

1 in, I guess, hearing about the relationship that
2 you and your board, your volunteers, your staff
3 and your agency have with your policy makers,
4 particularly in the State Capitol.
5 MR. BUCKINGHAM: Okay. I think
6 it's easier for me if I start at the local level
7 and work up to the state if I may.
8 We are extremely fortunate in that two
9 local elected officials, Roy Palmer and Dallas
10 County Commissioner Nancy Judy, serve on our
11 policy-making board of directors and both in that
12 forum and individually are a regular source of
13 what it's all about things politic.
14 The AIDS ARMS Network has no formal
15 legislative agenda, neither does it have any
16 direct connection with policy makers at the state
17 level. We are an active participant in the Texas
18 AIDS Network. I serve on the board of directors
19 of that agency and share their strategic planning
20 committee. And we are working hard to get that
21 organization postured to make some significant
22 impact in the next session for legislature.
23 Responsive to your question?
24 MR. KESSLER: Well, I think so in
25 part. I was just wondering, you know, what you've

1 done to cultivate the relationship with the
2 legislature and whether or not that's been
3 successful, helpful or whether a barrier is there
4 as well.
5 And one of the things that I'm aware of
6 is that Texas in general has been slow to respond
7 with dollars and resources and so on to this
8 epidemic, despite the fact that it's the third or
9 fourth leading state in terms of numbers.
10 MR. BUCKINGHAM: Yeah. Very
11 candidly, AIDS ARMS has not done as much as I feel
12 it could have and should have at this stage in its
13 corporate development to impact decision-making at
14 the state level. I think there's a role there for
15 us in the future; and we're moving toward it, but
16 most of our energies have been focused either
17 locally or nationally for the last three years.
18 We have had some success locally in
19 partnership with a number of other organizations
20 and getting pretty market increased in the cities'
21 commitment to AIDS services.
22 The state largely in response to more of
23 the legislative task force on AIDS in its last
24 session did enact a fairly substantial increase in
25 money for AIDS. It still is -- ended up being

1 about half of what folks thought was needed.
2 You're looking for thirty-five to thirty-six
3 million dollars and got eighteen for a two year
4 period of time. There's definitely more to be
5 done no question.
6 MR. KESSLER: Okay.
7 REV. ALLEN: I think we're going to
8 need to be moving along. Thank you. The next
9 panel: Eileen Carr of the Dallas Urban League;
10 Deliana Garcia, National Migrant Resources
11 Project, Austin, Texas; John Hannan, Positive AIDS
12 in Recovery, Dallas, Texas; Don Schmidt, Board
13 Member, AIDS Action Council, Person Living With
14 AIDS, New Mexico. We'll go in alphabetical order
15 with Eileen Carr.
16 MS. CARR: My name is Eileen Carr
17 and I work for the Dallas Urban League. And I'm
18 an outreach worker for the HIV Minority Prevention
19 Program.
20 First of all, I want to focus on the
21 needs of the African American community and then
22 we'll go on to the concerns because as we know,
23 there are many concerns and needs that create
24 barriers to HIV AIDS service within the African
25 American communities.

1 For instance, it is a denial and
2 ignorance that permeates the entire issue of HIV
3 AIDS individual and family care. And there's a
4 question that needs to be asked at this point:
5 Why? Why such a denial and this ignorance within
6 the African American communities?
7 And I want to, you know, point, you
8 know, a few questions towards you. For instance,
9 could it be because the African American community
10 feels the HIV infection and AIDS is another plot
11 against them? I mean could it be because they
12 feel they're being blamed again and again for
13 something that's negative? Or, you know, what
14 other reason that they have to feel this way?
15 Now, it is our belief that it's -- the
16 answer lies in who, what and how HIV/AIDS
17 prevention, intervention and services have been
18 presented within our community. We feel that
19 agencies need to know the African American
20 background and past and their present, what's
21 going on in their lives today.
22 Things similar to this have happened in
23 the past. Programs supposedly geared toward a
24 community have lacked community involvement and
25 cultural sensitivity. Agencies need to know --

1 are we on? I want to make sure you hear me.
2 Agencies need to know how to communicate
3 with the African American communities. For
4 example, how do you tell a single mother who's
5 only means of supporting her family is through the
6 use of sex and drugs and how do you tell her to
7 say no to sex and drugs? Her main concern is her
8 family's survival and that's through the means of
9 sex and drugs, the way she's going to, you know,
10 have her family supported.
11 And again, we just simply need agencies
12 to know that the African American communities'
13 cultural background and social experiences are
14 determining factors in service delivery. Again,
15 their community's cultural background and social
16 experiences.
17 Agencies can effectively address these
18 community needs by knowing and understanding that
19 all of the above are ways to racism and economics
20 and must be considered if programming is to be
21 viable.
22 Now, since I focused then on women, I
23 have another typical situation here. A woman with
24 an eighteen month year old child is in the
25 hospital dying of AIDS. The woman had not known

1 herself she was infected until her baby's birth.
2 When a woman is infected, there's a
3 fifty percent chance that the fetus will also be
4 infected. This woman is Catholic; therefore, she
5 is unable to use birth control. So, she has to
6 decide -- she's pregnant again. So, she has to
7 decide whether she wants an abortion; but where's
8 the money to come from for an abortion since she's
9 on medical assistance.
10 This awful situation is going to repeat
11 itself over and over again because it's estimated
12 that ten to fifty percent of those with AIDS by
13 the year 2000 will be poor women, women of color,
14 single head of household and teen mothers.
15 Indeed, no matter how much attention we want to
16 pay to this, the question of reproductive rights
17 for women with the AIDS virus will affect all of
18 us.
19 And another thing that is needed is more
20 support groups within African American communities
21 not only for the person with AIDS, but their
22 families as well. The African American community
23 at large seems to be nonsupported.
24 Now, let's say this is based on lack of
25 education; but I think it's simply based on not

1 understanding the education that's provided to
2 them. Agencies need to provide cultural-sensitive
3 and relevant educational information. That is to
4 say simply and I stress simply know how to relate
5 to the African American communities.
6 And it was also told to me by several
7 persons with AIDS that one can't get social
8 security if one doesn't have what they call
9 full-blown AIDS, one or more opportunistic
10 infections.
11 However, some stages of HIV and ARC,
12 they are unable to work. Again, they can't start
13 with social security until six months after
14 illness. Now, six months for a person with
15 full-blown AIDS can be and may be a lifetime.
16 Changes need to be made within this system to
17 ameliorate their plight.
18 And the issues of money. One client
19 stated that his AZT cost is over $300.00 a month.
20 He is already in the low-income bracket. He
21 doesn't have insurance and can't get insurance.
22 So, what is he supposed to do? What is anyone
23 supposed to do when faced with this dilemma?
24 And I want to focus a little on shelters
25 as well. Shelters need more services provided

1 within their facilities. Residents have no
2 transportation and they can't go to other places
3 for pre- and post-test counseling nor for
4 treatment.
5 What we need to do is train the staff at
6 the shelters to provide these services. Since
7 most of the shelters, especially in the Dallas
8 area, have clinics, the medical staff needs to be
9 educated about AIDS and the sensitivity needed of
10 the residents.
11 The shelter population need not only
12 agencies to cater to their health needs, but other
13 social needs as well. Residents' primary concern
14 is where their next meal is coming from or where
15 their next meal is going to be served, if anywhere
16 and also employment. Again --
17 REV. ALLEN: Excuse me, Eileen.
18 You have one more minute.
19 MS. CARR: Let me get this in. I
20 know it. Just as in the minorities, handle the
21 shelter population sensitivity and concern allows
22 agencies to reach them more effectively.
23 Also, I want to point out like
24 comprehensive AIDS services offered by the AIDS
25 ARMS Network and the AIDS Resource Center have two

1 barriers: Their location and lack of
2 accessibility. The organizations are the -- the
3 majority of these organizations are operated for
4 and by the white gay community. Minorities live
5 mainly in the southern section. These agencies
6 are located in North Dallas. We need a service
7 organization located in the minority communities
8 operated by culturally-sensitive understanding
9 minorities.
10 In conclusion, the African American
11 community needs continuing of service,
12 culturally-sensitive programs and staff to be at
13 the forefront of HIV/AIDS prevention and
14 intervention.
15 REV. ALLEN: Thank you. We'll have
16 all the panelists' opinions and then come back for
17 questions. And so, Ms. Garcia.
18 MS. GARCIA: My name is Deliana
19 Garcia. I go by Dell. I'd like to speak to you
20 about a national problem. Discussion of human and
21 social services needs for minority individuals
22 affected by HIV and AIDS often centers around
23 those members of our society marginalized by
24 poverty, racism, language differences and cultural
25 differences.

1 When discussing the needs of migrant and
2 seasonal farmworkers, these and the added factors
3 of a highly mobile lifestyle, absence of legal
4 protection, abysmal living conditions and
5 alienation from their temporary community must be
6 included.
7 This population of three to five million
8 people is composed of eighty-nine percent ethnic
9 and racial minorities. They labor in the most
10 dangerous industry in the nation with a
11 thirty-nine per one hundred thousand death rate
12 versus the national average of nine per one
13 hundred thousand.
14 They lack federal and state protection
15 for basic living and working conditions afforded
16 workers in other industries. They have a life
17 expectance of forty-nine years, and suffer from an
18 incredible assortment of chronic and
19 life-threatening health problems as a result of
20 their life circumstances such as chronic low-level
21 pesticide exposure.
22 You may already be aware of this
23 information, and it may appear to have no bearing
24 on the issue of HIV and AIDS in the farmworker
25 population; however, I'd like to share with you a

1 case study, a case that exemplifies all of the
2 ills and questions involved in confronting HIV
3 infection among migrant farmworkers.
4 Rosalia is a young woman of twenty-eight
5 years of age who has lived all of her life in the
6 unincorporated colonias of South Texas. No indoor
7 plumbing, no heating or cooling, a spigot out back
8 for drinking water and bathing, an outhouse next
9 to it for use by her family of eight.
10 In 1983, Rosie was looking forward to
11 the birth of her first child. Her young husband,
12 Saul, and she had worked the midwest migrant
13 stream together since childhood when both of their
14 families went north each year looking for work.
15 They continued to migrate even while Rosie was
16 pregnant because every pair of hands means greater
17 earnings when you are being paid by the bucket or
18 the box.
19 Prenatal care is hard enough to get when
20 you're stationary. When you're immobile and every
21 day is a working day, it's almost impossible to
22 obtain. Fortunately for them, they made it back
23 to Texas before the baby came. Rosie had started
24 to bleed sometime before she was due, and her
25 family had to travel to Galveston to get the

1 medical attention she needed.
2 She had to have a blood transfusion and
3 the baby had to spend two weeks in the hospital,
4 but they both survived. The family got back to
5 Weslaco just in time for the big freeze of that
6 year.
7 The freeze meant that there were no
8 crops, and consequently no work that spring.
9 Things between Rosie and Saul got very tense. He
10 began to spend more and more time away from home.
11 Doing what, Rosie wasn't sure, and wasn't sure
12 that she wanted to know.
13 He talked about having another baby, a
14 son; but sex wasn't very good and Rosie was
15 scared. She'd been taking those vitamin shots
16 from the woman down the road, but she didn't feel
17 very good.
18 A visit to a local migrant center after
19 a month long wait for an appointment resulted in
20 Rosie being seen by a caring, young doctor who was
21 astute enough to take a good medical history. He
22 said he needed to do some tests. A few days
23 later, he was trying to explain the results.
24 Rosie was HIV-positive.
25 This exemplifies the challenge to be

1 faced in trying to address both prevention and
2 treatmenmt of HIV infection and AIDS in the
3 migrant and seasonal farmworkers.
4 This group as a whole lacks access to
5 appropriate health education due to limited
6 services and language barriers. The Migrant
7 Health Program is only able to serve about
8 seventeen to twenty percent of the eligible
9 population it is mandated to serve.
10 Culturally acceptable behaviors such as
11 the frequenting of prostitutes and the sharing of
12 needles to inject vitamins and antibiotics (a
13 practice observed in a quarter of the population
14 and seen as a positive behavior) increase the
15 opportunity for infection.
16 All of this occurs in a rural
17 environment already suffering a deterioration of
18 medical services for its permanent residents. The
19 saga doesn't end here for Rosalia. She must still
20 confront the fact that the providers in the
21 various states to which she migrates refuse her
22 T-cell screening because they were unwilling to
23 take on the responsibility of ongoing case
24 management.
25 She also has to worry about the amount

1 of support her migrating family will be able to
2 offer when she can no longer work. She knows
3 there is no work available for her husband in the
4 economically-depressed Lower Rio Grande Valley if
5 he decides to get out of the migrant stream. And
6 once they are no longer migrants, eligible for
7 health care under that system, can the indigent
8 care system in their community provide a minimum
9 of help?
10 To keep from reinventing the wheel, the
11 Federal Government should utilize existing
12 organizations with recognized connections to the
13 farmworker population and demonstrated expertise
14 to disseminate funds for production of
15 migrant-specific material, to coordinate services
16 through the migrant health system and to extract
17 all relevant information derived from other
18 minority research for use by frontline providers.
19 Many barriers to this service are
20 inherent in the way funds are distributed. One
21 way to overcome this is to create a network of
22 case managers with state-wide responsibilities.
23 Armed with reciprocal agreements, they could then
24 ensure that an HIV-positive migrant farmworker and
25 migrant farmworkers with AIDS received care

1 without overly burdening the receiving states, who
2 only benefit from about three weeks of farmworker
3 laborer, but happens to be the site of the ailing
4 farmworker's medical crisis.
5 REV. ALLEN: You have about one
6 minute left.
7 MS. GARCIA: Okay. If these state
8 case managers had guaranteed access to all
9 services across the United States, a farmworker
10 from South Texas could be plugged into the
11 necessary services in a northern site without
12 anyone refusing to provide services for fear of
13 nonpayment or impossible care requirements.
14 A system designed to meet the needs of
15 special populations must consider the specific
16 characteristics of that population. It must keep
17 people like Rosie clearly in focus so as to
18 determine what will be effective change in
19 people's behavior.
20 In migrant and seasonal farmworkers, the
21 U.S. has a marvelous petrie dish to experiment
22 with answers. You have a group with a very low
23 seroprevalence rate of point five determined by
24 the CDC engaging in culturally-sanctioned
25 high-risk behaviors with a very low understanding

1 of the disease.

2 This hard-to-reach population offers a

3 unique opportunity to develop working models for

4 HIV prevention and treatment which could then be

5 adapted through use of other special populations.

6 Money for prevention must be spent now in order to

7 avert the widespread transmission of the HIV which

8 would result in the need for greater spending of

9 care in the future. Thank you.

10 REV. ALLEN: I appreciate both of

11 your sensitivities to the time factors so the

12 others can speak. Thank you very much. John

13 Hannan.

14 MR. HANNAN: Madam Chair Person,

15 Members of the National Commission on Acquired

16 Immune Deficiency Syndrome. Thank you for the

17 opportunity to voice my experience in living with

18 AIDS.

19 After my first three years of living

20 with the knowledge of having HIV and experiencing

21 my rampant fear of identification and

22 incarceration and lack of governmental support or

23 even acknowledgment of HIV, my life became so

24 unbearable that even increased use of drugs no

25 longer masked the emotional pain I was suffering.

1 In June of 1986 with the good fortunate
2 of having a comprehensive health insurance plan, I
3 was admitted into a substance abuse treatment at
4 Baylor Hospital in Dallas.
5 Once in treatment, I thought I was
6 finally in a safe and confidential environment
7 where I could openly discuss some of the issues
8 that for years I had been troubled by.
9 Among these were being gay in a society
10 that admonishes, and in most states, interprets
11 gay behavior as illegal, the fears of carrying the
12 HIV virus, the fear of dying, the fear of having
13 infected sexual and drug using partners and the
14 fear of disclosing my HIV status to my family and
15 friends.
16 It was in treatment that many of my
17 fears become reality as the medical director
18 suggested that for my safety, it would be better
19 if I did not discuss HIV. I confronted his
20 opinion and he stood firm. However, many other
21 staff members saw past the medical director's fear
22 and encouraged me to openly discuss everything
23 including HIV disease.
24 There was no AIDS education in place at
25 Baylor and hospital administration fumbled to

1 create an AIDS one-on-one for the patients. They
2 really fumbled when faced with how to enforce a
3 blood and body fluid isolation policy after I had
4 been in treatment for twenty-two days without
5 isolation precautions.
6 After staff members passed the buck for
7 several days, one morning at four a.m., two staff
8 nurses arrived in my shared room with a red
9 isolation sign, bags, sharp containers explaining
10 to my roommate that I had a blood disorder and
11 these precautions were necessary.
12 After he put two and two together, his
13 parents arrived on the scene to confront the
14 medical director about their son being in the same
15 room as someone with AIDS. They withdrew him from
16 treatment along with the threat of a lawsuit.
17 It was then that I could no longer hold
18 the emotional pain inside and I told all to the
19 remaining patient population. I was graced with
20 emotional support for the balance of my stay and
21 successfully completed treatment.
22 Forty days in treatment was time enough
23 to open many emotional wounds without much time
24 for healing. I was out of treatment and in search
25 of a safe place to discuss all: Gay, AIDS and

1 drug addiction.
2 I tried AIDS support groups; however,
3 there were people attending those groups that were
4 still using drugs. I got support in AA and NA;
5 but in those groups, I was asked to refrain from
6 talking of AIDS.
7 After several months of frustration and
8 finding others in my same predicament, I founded,
9 with the help of one of my therapists from Baylor,
10 Positive AIDS in Recovery or PAR. We adapted the
11 twelve steps of Alcoholics Anonymous to deal with
12 AIDS and addiction.
13 PAR, in addition to offering the support
14 group, established itself as an agency to offer
15 AIDS and substance abuse education and to secure
16 beds in drug treatment centers for people with HIV
17 disease.
18 During my seven years of living with HIV
19 disease, I have experienced more roadblocks than
20 just those centered around my substance abuse. I
21 have experienced being unable to obtain health
22 insurance after my HIV diagnosis. I have heard
23 the voices of Dallas County commissioners saying
24 if they want Pentamidine treatments and AZT, let
25 them go to San Francisco and get it.

1 I have been ill and without income
2 waiting six months for social security disability
3 payments to start. I have experienced closed
4 doors when applying for jobs. I have witnessed
5 housing discrimination, discrimination in hospital
6 emergency rooms and continued abuse by society in
7 general.
8 One can only imagine the pain inflicted
9 when a hospital chaplin enters the room of a
10 deceased person with AIDS and acknowledges only
11 the parents of that person and not the gay partner
12 of twelve years.
13 I have witnessed health care triage
14 decision biased by statements such as he's an
15 addict, she's a prostitute, let them lie. I have
16 seen funding, empathy and caring given
17 unconditionally to children with AIDS as they are
18 perceived to be innocent victims of the disease.
19 AIDS is a virus that attacks human
20 life. There is not a human living with HIV that
21 is more deserving or less deserving. We are all
22 children of our parents and of God. We are all
23 children with AIDS.
24 The solutions I see are as follows: We
25 as a society need to acknowledge AIDS as a disease

1 rather than a moralistic issue. The same with
2 substance abuse.
3 We need to create a long-term drug
4 rehabilitation lasting at least six months. There
5 needs to be a strictly enforced and high-quality
6 AIDS education track in all existing drug
7 treatment facilities whether they are for-profit
8 or not-for-profit centers. This could be done
9 through state licensure.
10 AIDS education needs to start among
11 school-aged children and adolescents. There is no
12 room for politics when it comes to education.
13 AIDS education needs to be based on medical
14 facts. These facts are that AIDS is transmitted
15 by homosexual sex, heterosexual sex, intravenously
16 and in vitro. The facts need to be taught and not
17 denied.
18 We need a national health insurance that
19 would enable every American the opportunity to
20 access our existing health care system.
21 REV. ALLEN: One minute.
22 MR. HANNAN: We do not have time to
23 wait for the system to change. We must adopt and
24 adapt quickly to access our existing health care
25 system and not place more burden on our public

1 health care system.

2 We must acknowledge that many people

3 infected with HIV are currently abusing drugs and

4 will die of AIDS an active addiction. While we

5 can hope for their treatment of substance abuse,

6 as long as our government is dependent on the

7 upward, economic movement of the South American

8 drug-producing countries, we cannot possibly

9 expect these drug addicts will ever see through

10 the darkness of addiction. Yet, we must provide

11 for them dignity with AIDS and with death.

12 I see the government response to AIDS in

13 Dallas and in the State of Texas as a mere shadow

14 to the response of our Federal Government. We've

15 lived through eight years of the Reagan

16 Administration not even whispering the word AIDS.

17 In 1989, ten years after the first case

18 of AIDS was recognized, the National Commission on

19 Acquired Immune Deficiency Syndrome was formed.

20 Today, I ask that this Commission take

21 back to Washington and to the President my voice

22 of hope for the future and discontentment with the

23 past. We in Texas need a better example set by

24 the Federal Government in dealing with the

25 humanness of AIDS. There is nothing soft or

1 gentle about living with this disease.

2 REV. ALLEN: Thank you. Don.

3 MR. SCHMIDT: Mr. Chairman, Dr.

4 Osborn, Members of the Commission, I'm very

5 pleased to be here with you today to provide my

6 testimony.

7 My name is Don Schmidt. I'm from

8 Albuquerque, New Mexico. I've lived with

9 symptomatic HIV disease since September of 1985

10 and was diagnosed with AIDS in October of 1987, I

11 guess making me what people call a long time

12 survivor. I would like to get that label later,

13 but I think it's here now.

14 I was a founder and the first executive

15 director of New Mexico AIDS Services, and I

16 currently serve on the Board of Directors and the

17 Public Policy Committee of the AIDS Action

18 Council.

19 Poor- and middle-income Americans have

20 faced serious barriers in accessing care since

21 long before any of us knew anything about HIV

22 disease. The ever increasing numbers of those of

23 us with AIDS and HIV is simply expanding the pool

24 of Americans requiring long-term care based on

25 their individual needs.

1 As I'm sure you know already and have
2 learned through your role as commissioners, it has
3 not been an American priority to adequately
4 address that even the most basic survival needs of
5 all Americans with disabilities.
6 Service providers, third party payers
7 and state and local laws and regulations all
8 create barriers to chronic care for those in
9 need.
10 Dr. Ruth Finklestein from the AIDS
11 Action Foundation assisted me in putting together
12 some real specific looks at barriers and access
13 problems which I've attached to my testimony for
14 you.
15 The AIDS/HIV epidemic has focused more
16 attention on these long-standing problems and has
17 made it clear that it's time for sweeping policy
18 and systemic changes in how America cares for its
19 most needy.
20 While barriers to care for people with
21 HIV and AIDS have caused untold suffering and
22 neglect for many, having to somehow try to address
23 our needs in spite of these barriers has prompted
24 the development of some creative new models of
25 effectively addressing the chronic care.

1 We now have the opportunity to
2 institutionalize these new and effective ways of
3 addressing chronic care throughout our society.
4 And I really think this is an opportunity not only
5 for how we treat people with AIDS, but all with
6 chronic care and needs.
7 We have the data showing not only the
8 success, but also the cost effectiveness of these
9 new ways of meeting human needs in our society.
10 These new models are compatible with The Denver
11 Principles which were written in 1983 as the
12 founding statement of the National Association of
13 People with AIDS.
14 I've enclosed a copy of those Denver
15 Principles because I always try to refer back.
16 Even at this point in the epidemic, I think they
17 hold up well in terms of what rights are, what we
18 need from providers, what we need from society.
19 These new models of care are based on
20 individualized client-centered care planning and
21 services implementation with a strong emphasis on
22 community-based and home-based services.
23 San Francisco provides us with probably
24 the best known such model in a major urban area.
25 New Mexico provides us with a model for such

1 services in a less urban area.
2 When I talk about care plan, I see four
3 component parts that need to be looked at for all
4 long-term care folks. That's ADL, Activities of
5 Daily Living. Housing, cooking cleaning,
6 shopping, personal care, etc. The things we all
7 must do to live in our society.
8 The second is informed medical
9 management and care based on individual needs; and
10 as we know, those vary so much back and forth
11 during a disease process with HIV. Third is
12 looking at the support system, that natural
13 support system and in what ways it needs to be
14 beefed up so that there is adequate support to
15 meet these needs.
16 And the fourth is the money, the
17 paperwork, etc., which is often times the
18 stumbling block to meet needs in care plans.
19 Instead of following the old costly and
20 clearly ineffective models of putting folks away
21 in various sorts of nursing homes and long-term
22 facilities, these new models of care help people
23 remain at home.
24 Specific client services are designed to
25 meet individual needs. The new models have shown

1 that family and friends supplemented as needed
2 with help provided by others, nonprofessional
3 others in most cases, can and do meet client needs
4 in a better way than either large or small
5 institutions. People prefer to be at home and can
6 remain there with these kind of support services.
7 Real quickly in my personal life right
8 now, my lover is also ill, much more ill than I am
9 at this point in time. And we deal with home
10 care. We have home-care services coming in. We
11 have nursing services coming in as needed. We do
12 IV's at home.
13 Now, paraprofessionals, these homemaker
14 people. Eighteen hours of care in the course of
15 the week is what we get from those folks. Two
16 nursing visits in a week with a good outpatient
17 and HIV clinic at our university hospital.
18 Without these services, Rick would have
19 been consistently in the hospital through this
20 whole period since he was last released on the 7th
21 of May. It's the only way to go, I think.
22 There are problems that really have to
23 be addressed in order to really institutionalize
24 this kind of model throughout the country. First,
25 we have to locate and establish homes for those

1 with chronic care needs who are homeless.
2 Then we have to understand that there
3 are not enough volunteers. This isn't a model
4 that's just funded and staffed by volunteers.
5 That does not work. If we're really going to go
6 to this new way of service, we've got to pay for
7 those homemaker services and in-home services for
8 all people with chronic care needs.
9 New Mexico's Coordinated Community
10 In-Home Care Program, which is a Medicaid Waiver
11 Program, models how to fund many of these services
12 for some folks with such needs. A complete
13 reversal of the whole reimbursement structures
14 which favor institutional over home-based care is
15 essential.
16 REV. ALLEN: Don, about one
17 minute.
18 MR. SCHMIDT: Okay. Moving now to
19 implement these changes in how we meet chronic
20 care needs is the smart thing to do, is the caring
21 thing to do, and it's the only cost-effective
22 thing to do. We as a society owe a great debt of
23 thanks to those communitity-based AIDS service
24 organizations and their volunteers, many from the
25 gay communities, who have so clearly shown us how

1 to be the caring people we all want to be.
2 Before I close, I want to raise one
3 other related but separate issue that we are all
4 much more comfortable not talking about. The
5 issue is dying with dignity.
6 AIDS has not alone prompted increased
7 focus on this issue, but it has been through the
8 context of AIDS that I have become more clear
9 about the barriers to dying with dignity.
10 My experience has taught me that some
11 people who are terminally ill make informed
12 decisions to practice voluntary euthanasia. It is
13 time for America to follow the lead of the
14 Netherlands, which has established strict
15 guidelines under which doctors may legally aid
16 patients in dying.
17 Thank you for your consideration in my
18 testimony and thank you for your ongoing
19 leadership in what's helping, I think, to make
20 America a more caring society for all of us.
21 Thank you.
22 REV. ALLEN: Thank you all. I
23 appreciate your input. As I stated, I have a
24 horrible job trying to be the timekeeper. And now
25 we can open up to the Commissioners to ask

1 questions and dialogue with all of you. Are there
2 any questions?
3 MS. DIAZ: Dell, I was very
4 interested in the concept that you had shared with
5 us about case management that would follow the
6 person -- impact in the family impacted by HIV.
7 Do you not think that that might, in
8 view of the situation with migrant families, need
9 to be more on a multi-state basis than just within
10 one state because of the frequency of people
11 moving stream into various states? I wonder what
12 ideas you may have in trying to do that beyond one
13 state.
14 MS. GARCIA: I mean in all states.
15 And so, that you would then create a quarter of
16 case managers who would have connections, a
17 network of connections as people went up and down
18 the streams.
19 While the streams are fairly set, they
20 vary in terms of crops and how the seasons are
21 going and who is going with what particular crop
22 and which farmers are doing well. And so, what
23 happens is that the state sees an influx of
24 farmworkers but not in the same places and not in
25 the same forms. So, it has to almost be at the

1 state level.

2 And I mean state by state to have one

3 because the way the money is set up right now,

4 those folks coming into the state unless they are

5 served by the federally funded 229, Migrant Health

6 Centers are relying on state services.

7 So, we have to be consistent with what's

8 going on in each of the states but try and provide

9 some connection from state to state travel.

10 MS. DIAZ: So, how would you

11 connect the various states? Through the state and

12 health departments or through the Migrant Center

13 Network?

14 MS. GARCIA: I think that I would

15 make it through the Migrant Center Network, but

16 that I would make sure that the state health

17 departments recognize that these case managers

18 needed to have access to their state health system

19 because they're going to be the only ones.

20 There are a lot of places that migrant

21 farmworkers go where there is only a

22 state-supported health clinic, you know, twenty,

23 thirty miles down the road in the nearest urban

24 center or these rural care places. So, it becomes

25 really difficult.

1 You need to have a state health care
2 system in place and then use that federally-funded
3 migrant system that could be seasonal. The
4 migrant health centers are only open three months
5 a year and your health department will be there
6 year-round so that it's not the startup and
7 shutdown part.
8 MS. DIAZ: Thank you.
9 REV. ALLEN: Any other questions?
10 Well, I have a couple of questions. Eileen, I'd
11 like to ask you some sharing of some of the
12 barriers in dealing within the black community
13 itself. Sensitivity of perhaps professionals such
14 as the clergy and all of us. It's not just black
15 clergy, but white clergy and so forth.
16 But in particular, I've had some
17 experience of dealing in that area and would like
18 your input as you deal with the Chamber of
19 Commerce, black Chamber of Commerce and others.
20 What type of sensitivity is there within the
21 community itself to sustain education and care?
22 MS. CARR: Like I mentioned in my
23 testimony, the African American community as a
24 whole is not very supportive. Because of the
25 questions that I mentioned, they think that this

1 is some type of plot against them and that if they
2 ignore the whole issue -- the clergy I'm speaking
3 of as well. If they just ignore the whole issue
4 that, you know, they won't be blamed for
5 anything.
6 And another thing that they just, you
7 know, feel like -- you would be surprised in the
8 black community or the African American community
9 that they still feel it's a white gay disease.
10 It's not something that's happening to us.
11 Until it hits them, you know, full
12 swing, you know, then perhaps a clergy would wake
13 up and support them because if you -- I don't know
14 if you know that much about African American
15 community, but we tend to go to the clergy as a
16 whole for support.
17 And they think, you know, well, hey, if
18 you're in any type of homosexual activity or any
19 -- they don't even know or even want to know that
20 there are other ways that you can get the disease
21 besides being a homosexual. They feel like you
22 should be out of the church as a whole.
23 We really need to educate the clergy so
24 they can know all about how to get AIDS and how to
25 support. I think it's just a matter of fear is

1 what I think.

2 REV. ALLEN: I have found a real

3 punitive tone to the clergy --

4 MS. GARCIA: From the clergy or to

5 the clergy?

6 REV. ALLEN: Excuse me. From the

7 clergy to individuals perhaps that bring your

8 testimony out in L.A. from gay individuals -- of

9 minority gay individuals that don't feel

10 comfortable in any world and then find that they

11 can't go home and that the family members and so

12 forth. And it's deeply disturbing to me. It's

13 with drugs as well.

14 Now that we are moving in this hardness

15 to individuals and we find that kind of mentally.

16 And it's very difficult to break that barrier. Do

17 you have any suggestions, and you can respond,

18 too, but have any suggestions on how to sensitize

19 folks to --

20 MS. CARR: Again, you have to know

21 the African American background. You have to know

22 they feel like they've been down all their lives,

23 especially the black male.

24 I mean a black male can't go up to his

25 family and say, you know, well, hey, I'm gay

1 because they have enough problems already. They
2 have enough problems trying to feed their family,
3 trying to find, you know, shelter for them.
4 So, I mean there are so many problems
5 that are going on economicwise as far as African
6 American community that it's very hard for a black
7 male to go to his family with those issues. I
8 mean they're trying to survive. There are other
9 things that are going on that's more important.
10 You have to know their background. You
11 have to like -- no person is stupid. You have to
12 maybe, you know, answer some of these things as
13 far as racism are concerned and then go on.
14 You think you're having a hard time.
15 I'm having a hard time, too, because I have to go
16 through all these different changes. All you did,
17 you know, in a white man's world, you don't
18 realize what's going on. Honey, I'm black. I
19 know what's going on.
20 So, you just have to, you know, just
21 face the issues for the background, the cultural
22 background and just work your way up through
23 that.
24 REV. ALLEN: Okay.
25 MS. GARCIA: And when you were

1 talking about not being able to go home, it made
2 me think of the fact that there were a lot of
3 people gay and drug using and of different ethnic
4 groups who came from rural backgrounds and went to
5 a major urban area and were infected by whatever
6 method and had their community there start to kind
7 of dissolve around them because they were not
8 entrenched in something that could provide them
9 with a safety net. And they'd like to go home to
10 rural communities that don't know how to deal with
11 gayness and don't know how to deal with drug use
12 and don't have the broad scope kind of let's get
13 hip social networks that you have in urban areas.
14 These are rural communities.
15 And not only then are they dealing with
16 their own and trying to let their own come home,
17 then the issue that we look at too is that if
18 they're in a rural community where they have
19 outsiders coming in, everybody gets blamed. The
20 migrants coming in get blamed. They are
21 outsiders. Kids who have gone away from living in
22 the rural areas and come back get blamed because
23 they have now become outsiders. So, there's
24 really no community for people to come back to.
25 REV. ALLEN: Thank you.

1 MR. DALTON: Eileen, I just wanted
2 to say needless to say, despite much of what you
3 had to say, your observations had to do with the
4 need for support groups within the African
5 American community.
6 And it was my good fortunate yesterday
7 to spend some time with a couple of men here in
8 Dallas with AIDS or HIV infection, both of whom
9 are participating in a support group that -- I
10 gather an African American support group that's
11 been in existence for about three months. And it
12 is truly growing. There's a tremendous need for
13 it. Word is getting around. And I understand
14 that plans are in the works to create a separate
15 group for women.
16 And what I'm saying is there is such a
17 need for this kind of support among people who are
18 especially sensitive to our community. You also
19 mentioned those needs for support groups for
20 parents and other family members. And you're
21 absolutely right.
22 And in one of these homes, I sort of met
23 the mother at the door and then she kind of
24 disappeared. And I did sort of wonder who was
25 there for her. I asked afterwards how she was for

1 her son and she's been terrific; but who's there
2 for her.
3 One thing that occurred to me as you and
4 Scott were talking back and forth in connection
5 with the church is that one quite real source of
6 support for family members is from the church and
7 that's dual. Ministers' wives or women's
8 associations within the church which after all are
9 the backbone of our church are a wonderful source
10 of providing support groups for families as well
11 as for people who are infected.
12 In my own town in New Haven,
13 Connecticutt, when we had trouble cracking the
14 black churches, it was the ministers' wives who
15 essentially got involved in the AIDS care business
16 and have done a tremendous job. I just offer
17 that.
18 MS. CARR: I'm happy for you
19 because I've gone to churches and I've asked and
20 I've asked. As a matter of fact, one of my
21 coworkers, Erica Thomas, she's asked for support
22 from the church and all the little -- and most
23 churches do have other organizations, women
24 organizations as well; but see, they feel if they
25 get involved, you know, well, someone's going to

1 find out that we're involved with this.
2 Now, we do have a care team that's
3 coming out of St. Luke Community United Methodist
4 Church; but it took them so long to come forward,
5 you know, to decide whether or not they wanted to
6 do that. But they have come forward and I think,
7 you know, that's great. And maybe, you know, that
8 could start something new for other churches to
9 just come forward and help their families.
10 MR. DALTON: I also just wanted to
11 say briefly that I always find it useful when
12 people talk of their own personal experiences as
13 John did, and as Don did a little bit. And you
14 may wonder whether it's helpful, but it's
15 tremendously helpful. That kind of detail is
16 useful for all of us.
17 For example, John, your comment about
18 your experiences in the hospital will be terribly
19 useful to me when talking with hospital types
20 about confidentiality and their sort of talking
21 about their systems and this and that. And I can
22 say wait a second, let me tell you a story. And
23 it's a wonderful way to break through a lot of the
24 BS, excuse the expression. And it's obviously
25 difficult sometimes to put your personal pain out

1 there on the table.

2 And, Don, you've done it many times, but

3 it still can't be easy. But it's helpful to us.

4 So, thank you.

5 REV. ALLEN: Larry.

6 MR. KESSLER: Eileen, I have two

7 suggestions in response to your comments. One is

8 a tactic that I've seen used with ministers in the

9 Boston area. When we try to get individual

10 pastors involved, they wouldn't respond; but when

11 we convinced them that maybe they could do it in a

12 large block, we started several.

13 About this time two years ago, summer of

14 '88, preparing them for a Sunday in November, so

15 that on a given Sunday, the Sunday right before

16 Thanksgiving, seventeen black and Hispanic

17 congregations all preached on AIDS.

18 And they found that a more comfortable

19 way to get into the community and felt safer doing

20 it because they didn't feel they'd get picked off

21 for raising an issue.

22 And the city participated, the mayor

23 visited as many of those churches as possible also

24 that Sunday morning. There was literature for all

25 the congregants. It seemed to work. It broke

1 that barrier that was there about not being in our
2 community.
3 Another suggestion I have about your own
4 community-based organizations, I agree with you.
5 I think they're necessary. One way to help bring
6 them about, however, I think is to get involved
7 with existing agencies as volunteers. That's a
8 great training ground. It's a good place to learn
9 the skills, to learn about AIDS, to learn about
10 the psychosocial issues.
11 And as we've gone around the country,
12 we've seen that actually happening where
13 communities of color have for a time joined some
14 of the groups that were perceived to be all
15 white. And generally, they're not all white; but
16 there is a perception.
17 And I know I yesterday visited some of
18 the clients that AIDS ARMS Network serves, and
19 many of the clients that I visited were black and
20 Hispanic. So, they are getting services.
21 And one way to build your own services
22 is to get the experience somewhere else, come back
23 with a cadre of people who have knowledge, have
24 picked up some concrete skills that can say now
25 let's do it ourselves. That's just a suggestion

1 that might work.

2 MS. GARCIA: Can I speak back to

3 you, Mr. Kessler?

4 MR. KESSLER: Sure.

5 MS. GARCIA: We're a national

6 organization. And I live in Austin and I do a lot

7 of work with our local community. And I had a

8 conversation yesterday with an AIDS group in

9 Austin that was gay-founded and predominantly

10 white and had done a great deal to expend itself.

11 But the conversation focused around

12 minorities that was going to come up through the

13 State of Texas. And they were saying what is it

14 that we can do to kind of create ourselves or

15 fashion ourselves in the appropriate model to go

16 after this money.

17 And after I kind of pulled myself up in

18 my chair and felt all my hair go straight for the

19 first time in its life, I stopped and said you

20 really have to look at it from the position of

21 your work being to empower others. That is not as

22 rapid as you might want it to see happen, but it

23 is our job. And as organization of individuals,

24 that should be our conscious.

25 And I offered the suggestion that they

1 look at roots that they could step into without
2 infringing on the CBO's that were trying to effect
3 their community. One, they have a good workplace
4 model, AIDS in the workplace, do that. Extend it
5 to all businesses and then look for black
6 businesses they can work with.
7 They have inroads in the gay community.
8 There are very few people in CBO's particularly
9 who feel that they can access gay minority
10 communities. And that was an interesting thing.
11 The other thing that I suggested though
12 is that they kind of reserve this sense of we can
13 do it better because we know how to do it and
14 we've been successful doing it and we can show you
15 how. As difficult as that is to overcome because
16 I feel that it is sincerely based in a desire to
17 do well and to have some action now, that they
18 back up and realize that they might be better
19 serving these organizations by providing technical
20 assistance.
21 Let us show you how to do the
22 statistical analysis. Let us show you how to
23 write a grant. Let us show you how to write a
24 grant report. Let's do your midyear report for
25 you. Let's do your end-of-the-year report for

1 you. We'll really show you how to tap dance and
2 we'll introduce you to the state health system and
3 to the Federal Government and to the CDC. We
4 won't hold on to those reins. We'll let you
5 figure it out and work it out and build that
6 political base of your own.
7 And out of expediency, we often lacked
8 that willingness to empower, you know. And people
9 want to stand around and argue. Well, if they
10 really were interested, they'd learn how to do
11 this themselves. And political negotiation is not
12 that easy to learn. So, that has to be something
13 that we encourage groups to focus on.
14 MR. KESSLER: I agree. I think
15 both sides have to be open to the possibilities.
16 And my third comment is, Don, I wanted to thank
17 you on behalf of the Commission, but also I think
18 on behalf of the country.
19 In the last five years, you have
20 traveled the breadth and depth of this country in
21 talking about the New Mexico model, really
22 bringing a perspective from people with AIDS.
23 You've been a really clear and articulate voice, a
24 very sane and reasonable voice that I find
25 extremely helpful. And I know all across the

1 country people have raised your name as someone
2 who has been incredibly articulate about
3 empowerment of people with AIDS and also
4 empowerment of the community-based models. And I
5 thank you.
6 MR. SCHMIDT: Thank you much.
7 REV. ALLEN: John, you had a
8 comment.
9 MR. HANNAN: I'd just like to
10 comment briefly on what you were talking about
11 with the gay organizations and wanting to maybe
12 restyle themselves to accommodate some
13 minorities.
14 You know, what we lived with as far as
15 grass roots organizations was basically eight
16 years of totally grass roots funding. And now
17 that there is some money trickling in from various
18 agencies, a lot of those grants are fashioned to
19 avoid being used by gay organizations or at least
20 the monies footnoted for certain types of use and
21 language.
22 And so, you know, as someone that has
23 been involved in the grass roots movement for a
24 long time and has fought, you know, terrifically,
25 I can understand exactly what the desire is to

1 change, to accommodate minorities and frankly to
2 not be real willing, okay, to offer grant writing
3 techniques. That's an art that is highly
4 cherished in funding circles.
5 MS. GARCIA: I get big bucks for
6 it, but what I'm trying to say is there are
7 organizations who, if they were smart, they'd
8 parlay that talent into saying we will write for
9 small groups and what you need to do is write us
10 in small dollars, fifteen hundred, three
11 thousand. Next one five thousand. We'll do your
12 statistic analysis. We'll do your grant writing.
13 And then if they've got six, eight of
14 those CBO's turning to them for TA even if it's
15 materials. I mean all of those things that can
16 fall under it, then that AIDS organization is now
17 bringing in eighteen thousand, thirty thousand
18 that they couldn't have counted on from -- except
19 for maybe one position, a position and a half.
20 But it is money that they can start to
21 develop to diversify their funding base. The
22 money now coming down from all sorts of
23 coalitions. And by God, they need to position
24 themselves well.
25 MR. HANNAN: I agree with that and

1 part of my testimony was about bringing the
2 humanness into AIDS. You know, it for so long has
3 been us against them in mentality everywhere. And
4 I think to -- you know, while we need to continue
5 the programs, you know, I don't see exactly that
6 -- there can't be care provided within the
7 existing organizations that are working. I mean
8 that's just --
9 REV. ALLEN: Let me -- Don was
10 next. This is very helpful to us. And we
11 appreciate all your input, your candidness; and we
12 want to encourage that. We're grateful for this
13 kind of dialogue.
14 MR. SCHMIDT: Real briefly, I asked
15 you to look at the mirrors here. I come from a
16 community with the highest population of nonwhite
17 folks in the state -- I mean the state with the
18 highest population. We have folks in need from
19 all communities.
20 And when you get down to it when you're
21 talking about client center care planning and
22 services, you build into that system and model
23 that the client comes first. That's where the
24 agenda is and sensitivity to his or her needs is
25 what it's all about.

1 And so, here we have the discussion
2 about is the money for supporting of those
3 services going to go to the gay organizations, the
4 mainstream organization, the organization of
5 color, etc.
6 Quite frankly, the answer is all of the
7 above and working together and doing needs-based
8 assessments and splitting the pies in fair ways to
9 communities which is different town to town to
10 town.
11 But what this mirrors is the same thing
12 we have in terms of long-term care needs for
13 people who are not people living with HIV. And we
14 have these barriers. Should the HIV money all go
15 to HIV specific communities? The reality is we
16 need national health care. We need new and
17 community and home-based ways of serving long-term
18 needs. And these barriers of not AIDS not -- HIV
19 not HIV of color pigmentless -- you know. Those
20 are artificial barriers and those are the big
21 barriers we're letting get in our way by being
22 combative, not cooperative.
23 REV. ALLEN: Eileen. I'd like to
24 say there are several Commissioners who would like
25 to participate in this.

1 MS. CARR: He basically said what I
2 wanted to say. You know, we're like talking about
3 what organization and what monies. And we've just
4 lost track of the people that actually have the
5 AIDS and have the disease.
6 The reason I brought that up was that
7 because I have had a person with AIDS to go to
8 some of the agencies over in what they call the
9 white gay community, and they have been turned
10 aside because their main concern is well, you
11 know, we need money.
12 And, you know, I think it's a money
13 thing. I'm not into this money game. My main
14 concern is helping. I don't care who has it.
15 Black, white, yellow, green. We need to start,
16 you know, focusing on helping the persons that
17 actually have the disease and as well as their
18 family and stop trying to, you know, like getting
19 more money than the next organization.
20 I want to bring this up another point.
21 When I was asked to come here from the Dallas
22 Urban League, I called the AIDS Resource Center.
23 I want to get it right. The AIDS Resource Center
24 to see about getting some information from them as
25 far as the black gays coming to them for help.

1 They in turn called I think his is Ted
2 and told him that I called up there saying I
3 didn't know anything about the AIDS epidemic. I
4 needed help from them. What? I didn't call over
5 there for that. I called over there to -- they
6 didn't even want to help me. They wanted to --
7 you know, why wasn't we invited, why wasn't we
8 invited to be here. I mean I don't care about the
9 popularity or the money and all this. We need to
10 focus on helping the persons that, you know, have
11 the infection.
12 MR. DALTON: Before you all clasp
13 in each others arms in agreement, I actually think
14 that this has been really quite useful and I want
15 to thank John for saying something really
16 difficult, but really very honest. I don't think
17 we're going to get to the point of Don's wonderful
18 millennium until we first acknowledge what are
19 some very real tensions and conflicts.
20 I don't think I've ever heard anyone put
21 it quite that way, John, the experience of
22 certainly gay and white and their inception and
23 having disgruntled volunteers and the money starts
24 flowing in and it's earmarked for these other
25 groups. And you have all a good game. Yet, you

1 want some of that money, too.
2 And once you sort of accept that, it's a
3 little easier, I think, for at least fledging
4 organizations to understand why you're being a
5 little bit resistant with that technical
6 assistance. I really appreciate your candor and
7 that was very useful to me.
8 You talked about empowerment that the
9 multi-cultural health coalition, that group that's
10 being formed here.
11 MR. SCHMIDT: The group Phil Morrow
12 started to form here.
13 MR. DALTON: Here exactly. That
14 group I trust will be guided by you and others'
15 wisdom about having empowerment in our communities
16 and being really, really the central feature of
17 what they do. The fact of the matter is that
18 these quotes from gay organizations that the first
19 generation of gay organizations really were very
20 helpful in empowering the gay community.
21 And I think that's almost as important
22 mostly the white gay community, but it's important
23 to remember that. And that's another reason why
24 it's hard for those organizations to sort of open
25 up because they have performed this very important

1 sort of cultural function quite apart from AIDS.
2 And it seems that we need to talk about those
3 kinds of things, get them out on the table. Maybe
4 not this table in this room, but it's to y'all to
5 keep having this conversation and not shy away
6 from the conflict, but sort of work through it.
7 REV. ALLEN: Charlie, do you have
8 something?
9 DR. KONIGSBERG: First of all, I
10 found this to be one of the most interesting and
11 useful and stimulating panels I think we've had in
12 any of our sessions. The fact that you talked to
13 each other was unusual and we ought to encourage
14 more of that. It was quite excellent.
15 I'm a state health official and being a
16 local health official and sometimes have been
17 quite concerned about the grant writing skills and
18 the accounting and accountability skills. Larry
19 Kessler and I have had this discussion before and
20 have become convinced that there needs to be some
21 sort of an effort on the part probably of a lot of
22 people, existing private organizations as well as
23 government, to try to work with these groups.
24 And it's not only the right thing to do,
25 I guess it has a practical side in that there's

1 the advocacy role. And very often, your groups
2 can do what we in government sometimes won't do
3 but sometimes can't do -- there were some
4 questions about that yesterday -- as well as the
5 types of service delivery the Government needs to
6 depend on the groups.
7 But somewhere along the line, I guess
8 what I'm really trying to say is that the
9 Commission probably needs to deal with that in
10 terms of one of our recommendations. If any of
11 you have a reaction to that, I would appreciate
12 it.
13 REV. ALLEN: In writing?
14 DR. KONIGSBERG: Yeah. Thank you.
15 MS. DIAZ: Just a brief comment
16 first to John. One of the things that we find
17 existing -- that is lacking throughout the country
18 and that is existing -- nonexistent is those
19 months of care within the drug rehabilitation and
20 drug communities that are specific to women.
21 And I'd just like to highlight that
22 because it was not mentioned in your presentation
23 specifically, but with an increasing number of
24 women who are HIV-infected and their offspring,
25 it's really important to review those models of

1 care. They're very women-specific.
2 To you ladies, I just enjoyed so much
3 the dialogue because for the last nine years, I
4 have been in frontlines of community organizations
5 both of whom you represent here today.
6 But I just would like to add one
7 thought. Coming from Los Angeles and having
8 worked with many efforts that initially started
9 within the white gay community, I found a
10 tremendous enrichment to what is now going on in
11 the Latino communities and the black communities
12 from actually having work side-by-side as partners
13 within organizations that started out of the white
14 gay community.
15 Give you an example: AIDS Project
16 Los Angeles is one of the largest organizations,
17 except for in New York, and it was our being there
18 from the very initiation of that organization,
19 being part of the board and working hand-in-hand
20 with our white gay men counterparts that led into
21 successful transfer of knowledge and experience,
22 as Larry has talked, into the Latino community
23 where now we have our community-based projects
24 that are each developing in a growing sense with
25 expertise similar areas.

1 When you talked about the need to
2 establish a model immediately in the black
3 community, I don't think that with the resources
4 you have you're able to start a model that will
5 encompass all the services in education, service
6 delivery and advocacy; but you may have to now
7 move that very, very slowly in partnership with
8 other organizations and then transfer that kind of
9 knowledge.
10 And I would just dare say unless you do
11 that, it's going to be very difficult to
12 immediately implement a model that is already
13 successful somewhere else.
14 MS. CARR: Please. You tell me how
15 because we have tried to work along with these
16 white gay organizations that are not being
17 responsive to us. You know, I can only speak for
18 Dallas. I don't speak for Los Angeles. You tell
19 me how to be a part of the board, how to be a part
20 of the committee. You know, if you show me how to
21 do it, I will go over there now and work along
22 with them.
23 MS. DIAZ: I will --
24 MS. CARR: Because I am not getting
25 that response here in Dallas.

1 REV. ALLEN: We're going to give
2 the next group a little more time here
3 considering. But just to close this out, I know
4 your frustration; however, on the AIDS ARMS
5 Network, there are minorities, there are people.
6 Phil Morrow was on there. And the AIDS ARMS
7 Network has really worked expanding minorities'
8 participation. And there is a frustration, and I
9 think the frustration is that there's not enough
10 money. It's not with each other as much as it is
11 with the fact that where is the resources.
12 MR. SCHMIDT: It's Government
13 divide and conquer here in Texas. And we're
14 falling into it. It's crisis.
15 REV. ALLEN: That's one thing that
16 I did not hear is the fact that what we're dealing
17 with is not a large enough pie. It's not that the
18 piece is here and bringing in.
19 MS. GARCIA: It's a long-held
20 tactic of this Government, and we are just seeing
21 it on a new front.
22 REV. ALLEN: Pitting one group
23 against another.
24 MS. GARCIA: Pitting one group
25 against the other. And the thing that -- you

1 know, I got lost in not being more appreciative of
2 the point, but if we could find some practical
3 ways to introduce groups into a coalition so that
4 the pie gets spread out.
5 MR. SCHMIDT: It's
6 client-centered. If we stayed that way, we'd
7 become a coalition as well.
8 MR. DALTON: Let me close the
9 account. I want to thank Larry Kessler for
10 starting this brouhaha out by mentioning and
11 sounding like an insensitive comment.
12 I do want to say though that one thing
13 I've learned in Boston is that the organization
14 that Larry heads, the white gay organization, has
15 among other things provided some of its money,
16 passed it on to Latin organizations, has, in fact,
17 elected not to compete with the newly started
18 organizations for money and has stepped out of the
19 way.
20 And those are some of the things that
21 need to be done with this small pie that we have.
22 I wanted to thank Larry for what, in fact, he has
23 done in Boston for people.
24 REV. ALLEN: Okay. We got to move
25 on. Thank you very much. I would like to say to

1 the next panel that as you come, you probably know
2 who you are, but Barbara Aranda-Naranjo, Robert
3 Dickson, Timothy Panzer and William Waybourn.
4 I would also like to say that as we
5 change over, I would like to keep the time of the
6 testimony at around six minutes so we can get into
7 the dialogue. But I would like to keep the
8 testimony time to six minutes a piece so we can
9 have more enriched dialogue than we had here.
10 So, we'll start and then have dialogue.
11 And we will just go again in alphabetical order.
12 Is Robert Dickson here? He wasn't scheduled until
13 one thirty. Is there somebody from one thirty
14 time that is here and would like to switch?
15 Let's go ahead and go. Barbara
16 Aranda-Naranjo, South Texas Children's AIDS
17 Center; Timothy Panzer, Valley AIDS Council,
18 Harlingen, Texas; and William Waybourn, Dallas Gay
19 Alliance. We will go ahead and start with -- I
20 guess we'll go ahead and start with it's Timothy
21 Panzer, then Barbara, and then William.
22 MR. PANZER: I think my testimony
23 is six minutes and twenty seconds.
24 REV. ALLEN: No slower.
25 MR. PANZER: I'll try to speed it

1 up. Reverend Allen, Dr. Osborn and members of the
2 Commission, I'm thankful for the opportunity to
3 provide this testimony and to present the
4 viewpoint of the community-based organizations
5 responding to the needs of persons with HIV living
6 in rural areas and small towns. Since 1988, I've
7 served as Director of the Valley AIDS Council, an
8 AIDS education and service organization in the
9 Lower Rio Grande Valley on the Texas-Mexico
10 border.
11 Our organization serves an area of over
12 forty-two hundred square miles with a population
13 of about seven hundred thousand. Approximately,
14 eighty-five percent of the area's population is
15 Hispanic and twenty-five percent of our residents
16 don't speak English with any fluency. Two of the
17 three poorest Standard Metropolitan Statistical
18 Areas in the United States are in our service
19 area.
20 According to a report released by the
21 University of Texas Valley/Border of Health Task
22 Force, at least fifty percent of the area
23 population is medically indigent. And even basic
24 data on many of our health care problems including
25 STD are unreliable because so many area residents

1 seek care in Mexico. The nearest major U.S. City,
2 San Antonio, is a five-hour drive away.
3 In this context, there have always been
4 problems with access to health care, especially
5 for persons with chronic disease. And it's in
6 this context that an increasing number of persons
7 with HIV and AIDS are struggling to find the
8 services they need to go on living.
9 In an area that desperately needs health
10 care resources for the poor, the health care
11 system -- and the word system really doesn't fit
12 here -- is grossly out of conformity with need.
13 The two largest cities in the area have
14 four hospitals, all of them private, for-profit
15 institutions. The only public hospital in the
16 region has extremely limited services and is
17 underfunded and understaffed. It has no emergency
18 room and no ICU. Its pharmacy's formulary does
19 not include many of the basic medications
20 indicated for patients with HIV. Outpatients do
21 not receive CD4 monitoring until they can pay for
22 the lab costs.
23 Access to outpatient care and early
24 intervention for persons with HIV is even more
25 limited, especially if the individual is

1 asymptomatic. Two of the three community/migrant
2 health centers in the area that are supposed to be
3 addressing the health care needs of our indigent
4 patients are currently not accepting new
5 patients. Even for those HIV patients already
6 under the care of the community health centers,
7 important preventive therapies such as aerosolized
8 Pentamidine are not available.
9 A handful of private physicians have
10 been providing primary care for the vast majority
11 of HIV patients in the area, including indigent
12 patients. However, the care that these physicians
13 can provide is limited when the person with HIV
14 cannot afford medications or required lab tests.
15 Because of the lack of outpatient
16 primary care service for poor persons with HIV,
17 patients seek care through emergency rooms and
18 experience more frequent hospitalization due to
19 improper outpatient management. An area like ours
20 can ill afford an overutilization of these scarce
21 and costly services.
22 Agencies providing counseling and
23 testing programs do little or no outreach to
24 at-risk populations. Without a support system of
25 early intervention and primary care for

1 HIV-positive individuals, testing programs have
2 few incentives to offer at-risk individuals to
3 find out their HIV status. Bad things happen to
4 people who find out they're HIV-positive.
5 Our agency provides both HIV prevention
6 services for the community and social services for
7 HIV and AIDS. While we rely heavily on volunteers
8 for the provision of many services, a rapidly
9 growing case load has stretched our volunteer
10 resources beyond our capacity. Our current
11 caseload of fifty clients represents a three
12 hundred percent increase in clients in less than a
13 year. And that other case management and service
14 delivery for these clients is time-consuming and
15 labor-intensive, especially due to the wide
16 geographic distribution of those in need.
17 Less than twenty-five percent of our
18 agency's clients have private health insurance.
19 To be Medicaid-eligible in Texas often means to
20 have a monthly income below the monthly cost of
21 your AZT and Pentamidine. Less than twenty
22 percent of our clients are currently
23 Medicaid-eligible, and almost none live long
24 enough to qualify for Medicare. That means that
25 over fifty percent of our clients are completely

1 medically indigent.

2 The Texas Department of Health

3 administers an AZT program to provide the drug for

4 medically indigent patients who are already

5 symptomatic, but this defeats current efforts to

6 initiate early intervention strategies. T-cell

7 monitoring is unavailable for the non-paying

8 patient.

9 To the institutional and financial

10 barriers I've already outlined, we must also add

11 more difficult to measure social, cultural and

12 language barriers that limit access to care in a

13 predominantly rural minority community.

14 What can be done to erode those barriers

15 to care? I'll divide my suggestions into two

16 categories: (1) solutions requiring significant

17 financing (at least initially), and (2) solutions

18 which require little or no financial investment.

19 In the first category, I believe that in

20 the short-term, our current human resources in

21 health care (both in the public and private

22 sectors) could better absorb an increasing burden

23 of HIV patient care if there were better back-up

24 systems, especially in terms of funding for

25 HIV-related medications, laboratory costs and

1 other hard cash items.
2 However, we must also have more
3 comprehensive outpatient primary care for the
4 poor. In an area like South Texas where the
5 majority of persons with HIV are indigent even
6 before they get sick, the provision of the
7 accessible outpatient primary care for the poor is
8 essential. Poor areas with significant numbers of
9 HIV-infected individuals cannot be served well by
10 profit-motivated institutions.
11 In the category of nonfinancial
12 solutions, there are a lot of "hearts and minds"
13 issues that must be confronted. Public health
14 officials and health care providers must be given
15 incentives to become pro-active. The
16 responsibility for HIV care must be shared in an
17 area where there are few specialists and a widely
18 dispersed population. This requires, however,
19 leadership and encouragement of the respected
20 peers of the health care providers themselves.
21 Some problems require, not more funding,
22 but more flexible funding which can be used to
23 target the unique problems of rural and small-town
24 communities.
25 I've presented the view from a

1 particularly unique region of America, but I
2 believe that our problems are shared by many other
3 nonurban areas in the U.S. And HIV, as you know,
4 is becoming an increasingly ruralized problem in
5 our country. Thank you for the opportunity to
6 speak with you today.
7 REV. ALLEN: Next on the list is
8 Barbara.
9 MS. ARANDA-NARANJO: Reverend
10 Allen, Madam Chair Person and members of the
11 Commission, thank you for the opportunity to share
12 my testimony. It comes from a multidisciplinary
13 team.
14 My name again is Barbara
15 Aranda-Naranjo. I'm a Registered Nurse. I'm a
16 member of a Multidisciplinary Care Team concerning
17 children and their families in South Texas. This
18 includes children that have acquired the disease
19 through sexual abuse, through transfusions.
20 Include in the majority are hemophiliacs and
21 parents who have acquired the infection through
22 high sexual activities, transfusions and IV drug
23 abuse.
24 I'd like to give just a philosophical
25 overview of the positive and negative responses of

1 people in our society towards this AIDS epidemic
2 and then share with you observations and
3 recommendations from multidisciplinary approach or
4 care of AIDS infected families.
5 Nine years ago, our country's physicians
6 identified a new disease, Acquired Immune
7 Deficiency Syndrome, better known today to all of
8 us as AIDS. This disease, now an epidemic in our
9 country, is changing the course of history for us
10 all. AIDS has and continues to devastate
11 families, communities, nations and the world.
12 Simultaneously, this epidemic has caused a variety
13 of positive and negative responses by people in
14 various communities.
15 Some of these positive responses are as
16 follows: People have united to create innovative
17 approachs to educate and prevent further spread of
18 the epidemic in their communities. There has been
19 a resurgence among scientists in the study of
20 infectious diseases in order to find drugs to
21 combat the HIV virus.
22 Physicians have taken innovative
23 approachs in their care for people living with
24 AIDS. Social workers, nurses and other health
25 care providers have formed multidisciplinary teams

1 in an effort to facilitate the needs of people
2 living with AIDS.
3 Local, state and federal government
4 agencies have responded passing legislation to
5 provide funding for the care of people living with
6 AIDS; perhaps not as timely as many who are
7 afflicted with the HIV virus would have liked, but
8 nevertheless, they did respond. Churches have
9 responded in many ways, one of which is to form
10 care teams for people living with AIDS.
11 There has always been, unfortunately,
12 devestating negative responses, many stemming from
13 discrimination against people living with AIDS.
14 According to retired Admiral James D. Watkins,
15 ex-chairman of this Commission, said, "the threat
16 of discrimination is the most significant obstacle
17 to progress" against the epidemic.
18 I will not enumerate the individual
19 community discrimination that has occurred in the
20 country. I think the press has covered these
21 incidents as they have occurred all too well.
22 These positive and negative responses continue to
23 occur simultaneously and the hope is that the
24 positive actions will prevail.
25 In reflecting on these responses, I am

1 reminded of the words written during the French
2 Revolution by Charles Dickens and I quote, "It was
3 the best of times. It was the worst of times. It
4 was the age of wisdom. It was the age of
5 foolishness. It was the epoch of belief. It was
6 the epoch of incredulity. It was the season of
7 light. It was the season of darkness. It was the
8 spring of hope. It was the winter of dispair. We
9 had everything before us. We have nothing before
10 us. We were all going direct to heaven. We were
11 all going direct the other way." This period was
12 much like our present.
13 While keeping these words in mind, I ask
14 even each of you and ask myself where are we today
15 in the AIDS epidemic? As I work with people in
16 various settings and families and observe the
17 struggle and the struggling unity of communities,
18 I want to say we're in the best of times.
19 When I observe people of every color,
20 ethnicity and creed come together for preventive
21 education programming or fundraisers, I want to
22 say we're in the best of times. When I see a
23 child able to attend school without
24 discrimination, I want to say we're in the best of
25 times.

1 Conversely, when I see an HIV-positive
2 pregnant drug-addicted mother who is giving birth
3 to her second child, I sadly say we're in the
4 worst of times. When I observe a couple who is
5 HIV-positive being turned away by their families,
6 I sadly say we're in the worst of times. When I
7 observe an HIV-positive homosexual not receiving
8 compassionate care from a health care provider, I
9 sadly say we're in the worst of times.
10 The reality is we're in the best and the
11 worst of times in the AIDS epidemic. On June
12 12th, 1990, the World Health Organization stated,
13 "The rapid spread of the AIDS virus in developing
14 countries means the disease will be more
15 widespread in the next century than previously
16 thought." The current projection is that up to
17 twenty million people will have been infected by
18 the year 2000. "Heterosexual transmission of the
19 disease is expected to rise substantially in
20 industrialized countries", said Michael Merson,
21 director of the organization's Global Program on
22 AIDS.
23 If there's to be a spring of hope in the
24 AIDS epidemic, the Government must continue to
25 fund existing multidisciplinary, effective health

1 care services for people living with AIDS. There
2 must also be community funding for community-based
3 organizations and consortiums. Funding can no
4 longer be on a year-to-year basis. Permanent
5 funding is desperately needed.
6 As the AIDS epidemic continues to
7 escalate in the United States and shifts from gay
8 men to heterosexuals and newborns, there is a
9 critical need for programs to be in place on a
10 permanent basis.
11 REV. ALLEN: Barbara, you have one
12 minute.
13 MS. ARANDA-NARANJO: I think I
14 would like to just shift to some of the
15 observations in that we have made as
16 multidisciplinary team working with their
17 families, their children in South Texas.
18 Drug abuse is one of the primary causes
19 of AIDS in families. Maternal illnesses affects
20 the health care of the child. Families with AIDS
21 are primarily from the lower socioeconomic
22 minority population. These families lack a number
23 of basic resources. Housing, food,
24 transportation, employment. These needs must
25 often be met simultaneously with their medical

1 needs.

2 Rural area physicians and other health

3 care workers lack familiarity with care of AIDS

4 patients. Families in rural South Texas often

5 must travel six to ten hours to clinic visits in

6 San Antonio. If you can imagine taking your child

7 from Boston to New York for a clinic visit, that's

8 about what it comes out.

9 Families need clinics where both

10 families and children can be seen at the same

11 clinic visit and as parents become disabled by the

12 HIV virus. So, the tenacity of medical

13 associations, social problem family requires a

14 multidisciplinary pyschosocial and community

15 networking.

16 And in closing, as we move into the next

17 decade of AIDS epidemic, coordinating

18 multidisciplinary care is a must have. Thank

19 you.

20 REV. ALLEN: Thank you. Thank you

21 for being sensitive to the time. And, Bob, you

22 arrived late and early. I tell you we are having

23 six minutes of testimony and then -- we're going

24 to have an entire panel obviously speak, and then

25 we'll come back for dialogue.

1 MR. DICKSON: I apologize for being
2 late. I was delayed somewhat. I'm sure that the
3 panel has had more than adequate testimony about
4 the incidence of AIDS and the problems that are in
5 that.
6 What I want to talk to you about is the
7 State of Texas' response from a standpoint of
8 alcohol and drug abuse, what the Texas Legislature
9 has directed us to do and what the response of the
10 --
11 REV. ALLEN: Excuse me, Bob. We're
12 going to try to turn up the mic a little and you
13 need to really get close if you can.
14 MR. DICKSON: Okay. How's that?
15 REV. ALLEN: Yes.
16 MR. DICKSON: The last session of
17 the Texas Legislature which ended last summer, the
18 state -- the 71st Legislature shaped our role in
19 responding to the AIDS problem from two ways:
20 One's through their appropriate sanction in which
21 they directed that a statewide HIV plan be adopted
22 and asked the Texas Commission on Alcohol and Drug
23 Abuse be the legislative agency to put the plan
24 together. I have a draft of the plans with me
25 which I'll leave with you. I'll talk about that

1 and make a couple of comments about it and then
2 leave it with you for yourself to review.
3 And then they passed a Bill 959 which
4 directs that TCADA, which is our agency, ensure
5 that licensed and funded facilities provide HIV
6 education for staff and clients. Also, it
7 required the prevention of referral to HIV
8 counseling and testing.
9 Specific rules to implement these will
10 be adopted in September 1990. HIV education is a
11 part of the current standards of our licensure
12 standards and our licensure department is
13 implementing the provision for referral of HIV
14 counseling and testing under the requirement for
15 medical services.
16 An additional requirement we have placed
17 on our funding contractors is that they provide
18 HIV assessment on every individual who enters the
19 program. I would like to elaborate that our
20 agency provides treatment services for what we
21 call medically-indigent clients, those that don't
22 have insurance, don't have the money to purchase
23 their own services. We license all treatment
24 facilities, however, both public and private.
25 We use federal funds in the following

1 ways: We use some of them for TCADA Staff, one
2 coordinator, four trainers, one administrative
3 tech. And their primary duties are for training
4 and funding all substance abuse programs and
5 program management of special HIV initiatives.
6 We have funded one counseling and
7 testing outreach program and we fund these jointly
8 with the Texas Department of Health. We have
9 worked closely with TDH on all substance abuse/HIV
10 issues and we provide frequent services for IV
11 drug users and other substance users at risk of
12 HIV.
13 We help put together the State Plan, as
14 I mentioned earlier, that's required by the
15 Legislature. It has been completed and submitted
16 to the Legislative Board this past March and is
17 currently in its final printing.
18 The Plan utilizes several different
19 agencies, each of which has some responsibility in
20 seeing clients that may have AIDS or be subject to
21 having AIDS. Besides our own agency, the Texas
22 Department of Corrections, the Bureau of Pardons
23 and Paroles, Texas Adult Probation Commission,
24 Texas Department of Mental Health and Mental
25 Retardation and several others.

1 And this Plan, which you can read at
2 your leisure, takes into consideration the
3 education outreach needs and what the current
4 activities are, what the ultimate needs are and
5 the goals, objectives. Also then takes into
6 account the AIDS counseling and testing, what
7 those current activities are, what the ultimate
8 needs are and what the goals and objectives are
9 for each one of these agencies affected.
10 REV. ALLEN: Bob, you have one more
11 minute.
12 MR. DICKSON: Let me go ahead and
13 point out that in surveys that we have done for
14 the State, we find that thirty-six percent of male
15 inmates have used needles to inject drugs and
16 twenty-two percent did so in the last thirty days
17 before being incarcerated.
18 Of needle-using inmates in TDC, only
19 about sixty-three percent rated their risk of
20 becoming infected with AIDS as very low or none;
21 and this is really a startling bit of
22 information.
23 Of inmates sharing needles within thirty
24 days of last incarceration, forty-nine percent
25 rated their risk as either very low or none.

1 About fourteen percent of the Texas youth in Texas
2 Youth Commission have used needles to inject drugs
3 and five percent did so their last thirty days
4 before being incarcerated.
5 Among the TCADA clients, ninety-six
6 percent of heroin addicts, seventy-seven percent
7 of amphetamine abusers, and thirty-five percent of
8 cocaine addicts reported needle use, placing them
9 at risk of spreading the virus.
10 There's a lot of other good data here.
11 Our research department has put together several
12 documents that I'm leaving with you for you to
13 read at your leisure.
14 I'll just read the titles to you very
15 quickly. Texas Survey of Substance Abuse Among
16 Adults, Substance Abuse Among Students and Texas
17 Secondary Schools, Substance Abuse Among Texas
18 Department of Corrections Inmates, and finally
19 Substance Abuse Among Youths Entering the Texas
20 Commission Facilities.
21 This is all good information.
22 Obviously, there's not time to go into here; but
23 I'll be happy to try to answer questions about
24 it.
25 REV. ALLEN: Thank you very much.

1 Mr. Waybourn.

2 MR. WAYBOURN: As the author of

3 Dallas is the Calcutta of the AIDS, I think I need

4 to clarify that remark. As you know, that

5 appeared in the New York Times. And immediately

6 after that remark appeared, I wrote the New York

7 Times a letter that I had unfairly characterized

8 the citizens' responses to this epidemic without

9 any personal knowledge of this endeavor. And

10 therefore, I want to apologize to the citizens of

11 Calcutta as I believe my remarks have showed

12 different remarks create different realities.

13 I don't want to dazzle you with a bunch

14 of specifics to justify why I was asked to speak

15 to you today on social services needed by people

16 affected with HIV/AIDS. But the organization I

17 represent, the Dallas Gay Alliance, provides

18 almost eighty percent of the direct services in

19 Dallas that involve food, shelter, medical

20 attention or financial assistance.

21 We accomplish that on a budget of just

22 over $1,000,000.00. We have received no

23 significant government grants and nearly seventy

24 percent of our funding comes in the form of small

25 contributions of $20.00 or less making us a very

1 strong grass roots organization.

2 We have, as I stated, learned that
3 different experiences create different realities,
4 and those who control the health care and social
5 services system obviously don't have to use it or
6 else it would have already been changed.

7 Our experience in attempting to gain
8 access to readily available health care and social
9 services has been cheated, circumvented and
10 misrepresented. It has created a sobering reality
11 that health care is indeed rationed in this
12 country.

13 Only the rich can afford it. Only the
14 employed can attain it. Only the educated can
15 exploit it. And those who need it are left
16 without it. Subsequently, they die faster. We
17 have put a price on living longer, but no one
18 really cared until AIDS came along.

19 Most of the indigent patients who depend
20 on the services of Dallas' only public hospital
21 are the second and third generational patients.
22 They were born into that system and they will die
23 into it. They don't know that many people can see
24 a private physician within hours if you have
25 insurance or money.

1 Not so with indigence. The same system
2 that says you don't have to pay enslaves you to
3 make you pay. Lengthy delays make you
4 unemployable. A lack of preventative care
5 guarantees your dependence, but then there's
6 always welfare.
7 AIDS did not create the difficulties
8 with the public health care system in Texas. It
9 only turned the lights on when nobody was home.
10 And as a middle-class white male, I must
11 say that I am ashamed that we have created such a
12 system of fraud, waste, and abuse. We owe an
13 apology to women, the elderly, the poor and people
14 of color who have no alternative to health care.
15 We have wasted billions of dollars and hundreds of
16 thousands of lives.
17 No where is the failure of the
18 government more evident than in the AIDS Clinical
19 Trials Group. There is none for adults in Texas.
20 And that's just the beginning of the inequities of
21 how poorly AIDS research and treatments are doing
22 not just in Texas, but in the United States.
23 Dallas' VA Hospital couldn't for nine
24 months get $20,000.00 to build a room to deliver
25 aerosolized Pentamidine treatments as a

1 preventative for pneumocystis pneumonia. Yet,
2 countless AIDS patients were given twenty-one day
3 in-hospital Pentamidine treatments after they got
4 pneumonia at an average cost of $10,000.00 each.
5 This is insane.
6 Seven years ago, a Texan, diagnosed with
7 AIDS could expect to receive all the inpatient,
8 outpatient and pharmaceutical benefits of
9 state-supported public hospitals. Now you can
10 only get into those public hospitals to die.
11 In these seven years, all of the public
12 hospitals in the eleven counties around Dallas and
13 Fort Worth have closed except Parkland and John
14 Peter Smith in Fort Worth. That means almost
15 three million people are without publicly-financed
16 health care. If you don't have insurance in
17 Texas, and a large percentage don't, you're going
18 to die a quicker and more painful death.
19 My organization, the Dallas Gay
20 Alliance, had to go to court to get a court order
21 to force Parkland to end its discriminatory
22 policies against persons with HIV because it
23 withheld readily available health care. Parkland
24 was ordered to end its waiting list AZT and was
25 ordered to deliver aerosolized Pentamidine as a

1 preventative for pneumonia.
2 But now the situation's only worse.
3 Emergency rooms have merely become waiting rooms.
4 Parkland's AIDS doctors see an average of sixty
5 patients a day and yet they're supposed to conduct
6 research in this environment.
7 New drugs are useless unless patients
8 can get them. The Dallas Gay Alliance opened
9 Nelson-Tebedo Clinic with a grant from the private
10 American Foundation for AIDS Research. We have
11 one full-time physician and three full-time
12 nurses.
13 Each week the NIH pays to fly scores of
14 HIV-positive patients to its headquarters near
15 Washington, D.C., ignoring locally-based
16 physicians in our own CRI. In our own backyard,
17 Parkland refuses to refer indigent AIDS patients
18 to our clinical trial.
19 Politics and medicine, as we have
20 learned, are indeed strange bedfellows; but AIDS
21 doesn't care about politics.
22 The U.S. Public Health Service official
23 in our city, who is charged with oversight and as
24 liaison to our agency, can't even find our
25 offices. Dallas has a member serving on this

1 panel, yet never once has he inquired as to our
2 program needs or objectives.
3 The public health care system in our
4 region of the country is a cesspool of
5 bureaucratic entanglement, criminal negligence,
6 backroom cronyism, incestuous nepotism and borders
7 upon fraud to taxpayers. Image is still more
8 important to Dallas than substance.
9 The AIDS industry is alive and well in
10 Dallas, while AIDS patients go begging for basic
11 local services such as food, shelter and
12 medicine. We see large encumbering and bloated
13 staffs that look good to the nation on PBS' AIDS
14 Quarterly. We can build sixty thousand dollar
15 toilets for the military, but AIDS patients can't
16 even get pots to piss in.
17 Two years ago, a blue-ribbon commission
18 comprised of a broad cross-section of community
19 leaders was formed to provide a comprehensive
20 strategy for fighting AIDS in Dallas County.
21 After an exhaustive six months of hearings and
22 meetings, an extensive set of recommendations on
23 how to deal with AIDS was released.
24 REV. ALLEN: You have about one
25 more minute.

1 MR. WAYBOURN: It is particularly
2 difficult now to comprehend how only one of those
3 more than one hundred recommendations was ever
4 adopted, and that was the appointment of yet
5 another board of health. And to ensure its
6 ineffectiveness, the county commissioners refused
7 to vote it any enforcement powers, no budget
8 appropriations and no staff.
9 Dallas is number one in gonorrhea,
10 number one in teenage pregnancy, one or two in
11 childhood measles deaths. And we have a higher
12 infant mortality rate than some third world
13 countries. Yet, federal and local officials think
14 nothing of wasting $550,000.00 on a useless
15 point-in-time HIV seroprevalence survey, a dollar
16 figure by the way that mirrors the entire city and
17 county budget for AIDS.
18 For years, Dallas County's
19 sexually-transmitted disease prevention education
20 efforts have been to corral persons with STDs,
21 give them a lecture, a shot of the penicillin, and
22 send them on their way. The problem with HIV is
23 that by the time you come in, the lecture doesn't
24 help anymore than a shot of penicillin.
25 And the school system is just as

1 negligent. Despite surveys that show teenagers to
2 be the next highest risk group, teachers in the
3 Dallas Independent School District can't discuss
4 condoms until students bring up the subject. If
5 "Just Say No" doesn't work, then why are we
6 withholding education that condemns teenagers to
7 death?
8 Dallas County's Health Department, is,
9 as its director told me a couple of years ago --
10 REV. ALLEN: You need to go ahead
11 and wrap it up.
12 MR. WAYBOURN: The reality of AIDS
13 requires us to be more pro-active not reactive.
14 The model of using community-based organizations,
15 many of them operated and funded by gay men and
16 lesbians, to buy time in the AIDS crisis is now
17 that time that has run out. We cannot sustain
18 such rapid growth with such governmental neglect
19 and political abuse.
20 It is immoral and unethical to withhold
21 readily available health care, treatment,
22 education, research or social services to anyone
23 and certainly, not because of inability to pay.
24 I would like to give you three simple
25 recommendations: Broaden research priorities,

1 support innovative clinical trials and expand
2 access to health care and social services. This
3 would not require an influx of millions of
4 dollars. Just a commitment to spend those dollars
5 wisely and that includes working directly with the
6 one group most responsible: Community-based
7 activists and their organizations.
8 I would submit this to those of you in
9 power. You cannot float half a ship. Thank you.
10 REV. ALLEN: Are there any
11 questions?
12 MR. GOLDMAN: I'd like my question
13 to Barbara. Would you let us know how you handle
14 the case management with your multidisciplinary
15 care teams particularly in the kind of areas
16 you're talking about where people have to travel
17 many hours and the community resources that have
18 to be dealt with may be very varied on home
19 community.
20 MS. ARANDA-NARANJO: I think first
21 off we are a demonstrating project funded by the
22 Texas Department of Health and Human Services
23 under the auspice of Maternal Child Health Care
24 for South Texas. And therefore, we do not turn
25 anyone away when they were coming to San Antonio

1 to the County Health System where we are situated
2 in our clinics.
3 We work very closely with the Valley
4 AIDS Council in South Texas in coordinating the
5 case management and care because we cannot do the
6 day-to-day care that the HIV-infected child and
7 his parents needs.
8 So, we try to find a physician --
9 sometimes we do -- who would see the day-to-day
10 care medically and we use the case management
11 system from the Valley AIDS Council to network the
12 case management.
13 When they come to San Antonio, it is a
14 struggle of case management over miles of
15 territory and it makes it very difficult because
16 many of the physicians are not familiar with the
17 care for these children and many times have to be
18 flown. And people use their total resources for
19 their other members of their family in trying to
20 have the child get the care he needs. It's
21 coordination across miles.
22 MR. GOLDMAN: Tim, I didn't mean
23 not direct it to you. I was just wondering if
24 there's any better way of coordinating the case
25 management in the kinds of areas that you're

1 dealing with and what recommendations you have.
2 MR. PANZER: I think it takes more
3 people to make a home visit. It may require an
4 hour or two hours drive to see. It is more labor
5 expensive.
6 We have been fortunate with the
7 pediatric cases to be able to work with the
8 demonstrating project which is basically the same
9 thing. They hold monthly clinics which can do a
10 lot of the more costly care for these patients.
11 However, those reserves are not available to the
12 adults; and that's been a problem.
13 Case management in our area had done a
14 lot over the telephone. And so, we have high
15 phone costs. Almost every town where our clients
16 are is a long-distance call.
17 MS. ARANDA-NARANJO: We do send a
18 team of new doctors, pyschologists once every two
19 months to do a routine visit on the children. And
20 many of them are hemophiliacs and there is a
21 center at one of the hospitals, private hospitals
22 where the hemophiliac children can come to see and
23 and they try to make the parents part of their
24 annual visits for the hemophiliac. We do just a
25 lot of footwork.

1 And each individual family is so
2 different based on is the parent infected or one
3 parent is infected, are the other children
4 infected because I think the other thing you have
5 to look at, too, quickly, is the culture. Have
6 one family have enough money from donations.
7 Well, not only did the parents come, but the other
8 kids came and the grandmother came and aunt came
9 and the sister came. We're like would you -- I
10 think that's another thing to keep in mind. Each
11 individual family is so different.
12 MR. PANZER: I just wanted to
13 mention one other thing in terms of case
14 management. We have in the past relied very
15 heavily on our buddy system in which we try to
16 decide a volunteer who lives in the same area as
17 the client and they then are kind of extended arms
18 as the case management system. That's going to
19 reach a capacity or it already has.
20 We need to start paying for services in
21 home care. That will be an extension of case
22 management and report back to a case manager on
23 any changes in the client's status. There is just
24 -- especially in rural communities and very poor
25 communities, there are few people who have the

1 time and resources to devote to that extent of
2 care for people who may be dying.
3 REV. ALLEN: Any questions?
4 Larry.
5 MR. KESSLER: Mr. Dickson, I have a
6 number of questions. We haven't heard a lot about
7 the state of those infected in Texas due to
8 addiction, and I was wondering if you had any
9 numbers or estimates of the rate of infection and
10 how many people are considered to be drug addicts
11 in the state or addicted.
12 MR. DICKSON: Yes, sir. I wish
13 that I had had a little more notice about this
14 hearing so I could prepare a little better. I
15 have volumes and --
16 REV. ALLEN: You need to speak in
17 the mic, Bob.
18 MR. DICKSON: About the incident of
19 HIV among drug abusers in Texas and we have a
20 number of concerns about some of the strengths and
21 labor and hope you'll be able to take some of
22 these concerns back to the Federal Government.
23 One of the big concerns we have is the
24 limitation of the HIV set aside to needle users
25 and we're finding that crack abusers are high-risk

1 for AIDS, high-risk among all abusing -- drug
2 users and alcohol abusing types. And we need to
3 be relieved of this, set aside for needles in your
4 planning and our allocation of treatment dollars
5 around the state.
6 One of the things that I certainly want
7 to bring to your attention is that currently our
8 last allocation of funds which occurred about two
9 weeks ago only took care of seventeen percent of
10 the need for treatment in the State of Texas among
11 the medically-indigent people.
12 It would take a hundred sixty-nine
13 million new dollars to take care of the present
14 need in Texas for alcohol and drug abusers. About
15 thirty-six to thirty-seven percent of these people
16 are alcohol abusers and the rest are drug
17 abusers. We consider all of those at high risk
18 for HIV.
19 MR. KESSLER: What is your waiting
20 time now for treatment?
21 MR. DICKSON: On any particular
22 day, we have about sixteen, fifteen, sixteen
23 people on the waiting list for treatment. And
24 this -- you know, the length of time varies
25 depending on the type of treatment, whether it's

1 outpatient or what. But I can safely say three to
2 four weeks is an average waiting period.
3 MR. KESSLER: Are clean needles
4 available across the counties?
5 MR. DICKSON: Yes, they are. We
6 don't make them available. They are.
7 MR. PANZER: Through whom are they
8 available?
9 MR. DICKSON: They're not
10 controlled in Texas.
11 MR. DALTON: You mean by that that
12 there is no paraphernalia law and no description?
13 MR. DICKSON: Paraphernalia laws,
14 but they don't control syringes. Anyone can walk
15 in a drug store and buy a syringe.
16 MR. DALTON: And needles, too?
17 MR. DICKSON: Yes.
18 MR. KESSLER: Is there any
19 education campaign about not sharing needles and
20 be choosy and so on that the state may be
21 conducting?
22 MR. DICKSON: Yes, sir. We are
23 doing that with all of our treatment programs, as
24 I mentioned in my comments. And we have one
25 program where we do outreach in the community in

1 the high-risk community. And one of the key
2 elements of this is education by not sharing
3 needles and by cleaning needles with Chlorox and
4 with anything else, trying to get them involved in
5 treatment programs.
6 MR. KESSLER: Is there any actual
7 description of bleach?
8 MR. DICKSON: No, sir. That was
9 forbidden by our government.
10 MR. KESSLER: What about condoms?
11 MR. DICKSON: No.
12 MR. KESSLER: That also was
13 forbidden.
14 MR. DICKSON: Yes, sir.
15 MR. KESSLER: Is your department
16 waging a campaign to change the mind of
17 legislators about those issues?
18 MR. DICKSON: I wouldn't go call it
19 a campaign, no.
20 MR. KESSLER: I didn't hear you.
21 MR. DICKSON: I would not call it a
22 campaign. We're using persuasion, but I think
23 campaign is the wrong way to go about it.
24 MR. DALTON: Sir, to follow up. I
25 was struck, as you no doubt intended us to be, by

1 the figures that you gave us at the end of your
2 testimony with respect to those people entering
3 your system who had used a needle within three
4 days of admission and in their own self-assessment
5 of their risk for HIV infection.
6 I guess I want to ask what you're going
7 to do about that.
8 MR. DICKSON: We are entering a
9 joint planning project with the criminal justice
10 system to bring an integrated treatment plan to
11 Texas Legislature for funding for a number of
12 reasons. One is just over recidivism of people
13 re-entering the Texas Criminal Justice System.
14 And we feel that a great deal of that recidivism
15 is underlinked by drug abuse and alcohol abuse.
16 Whether it's caused by that, may be problematical;
17 but it certainly is present among about eighty
18 percent of this clientele.
19 The states that have been successful in
20 the use of recidivism are the ones that have
21 integrated a treatment system into the prison --
22 pervasive prison and parole experience. There's
23 about less than a dozen of our states that can
24 claim some success in that.
25 We're studying that and we're going to

1 take what we feel will be applicable in Texas and
2 ask the Texas Legislature to fund a very ambitious
3 program to make treatment available within the
4 system as an integral part of the prison
5 experience rather than that later on where they
6 have the time and the money.
7 The Texas Legislature has only recently
8 awakened to the great need for alcohol and drug
9 abuse treatment among its citizens. So, while I
10 have to tell you that we're very far behind, I
11 must also at the same time tell you that the Texas
12 Legislature is rushing to catch up with this now.
13 And we have a great deal of interest
14 among the legislators to come up with such a plan
15 as I've just described because we feel like that
16 if we treat the alcohol and drug abuse among the
17 inmates, among the people in the criminal justice
18 system, which will include, of course, HIV
19 education and that type of thing, we feel we're
20 going to have a positive impact on the recidivism,
21 we're going to have a positive impact on reducing
22 alcohol and drug abuse among these people and
23 that's going to help reduce the spread of AIDS.
24 MR. DALTON: Okay.
25 REV. ALLEN: Any other questions?

1 MR. KESSLER: Well, I would only
2 suggest to Mr. Dickson that the -- I applaud your
3 efforts to work with those in prisons, but that's
4 a small number of people who are sharing needles.
5 And it may be stereotyping needle users in the
6 community to focus exclusively on those in prison
7 and also doing a service in terms of slowing the
8 spread of AIDS.
9 National statistics, you know, are
10 showing that the most drug users and needle
11 sharers in the workplace are not necessarily
12 having a record or criminal record and are not in
13 prison. That's the tip of the iceberg.
14 And we need to work with that group, but
15 we also need to work with those who are considered
16 model citizens who are subsequently also out there
17 sharing needles and having unsafe sex and may be
18 infected.
19 MR. DICKSON: Well, we certainly
20 agree with that. And the criminal justice
21 initiative is not the only initiative that we have
22 going. As I pointed out earlier in our needs
23 assessment, we've set a dollar figure on what it
24 would take to satisfy those needs. And we are
25 pushing to get that -- to get to a hundred percent

1 of certainly the medical it takes.
2 Along with this, we've required in all
3 of our treatment programs education about the HIV
4 and spread of AIDS and how to practice safe sex
5 and how to avoid this sort of thing and that type
6 of thing.
7 We're -- most of our budget currently is
8 dedicated to prevention and intervention of
9 treatment among the general public and not toward
10 the criminal justice system. Texas has -- in
11 addition to what we need to be doing in the
12 community and are trying to do, we have three
13 hundred fifty thousand people approximately on
14 probation in Texas. And that's an enormous amount
15 of people. We have forty thousand in prison and
16 another forty some odd thousand on parole. So,
17 that by itself is a big chore just to provide
18 services for that type of operation; but we're not
19 ignoring the general population. No.
20 MR. KESSLER: Do you have any ideas
21 how many of the forty thousand are infected and
22 how many have been diagnosed with AIDS?
23 MR. DICKSON: No, sir, I don't.
24 REV. ALLEN: Do you have a question
25 along that line? I have a question about the

1 confidentiality issues of individuals that are
2 HIV-infected. I know you're not the Texas
3 Department of Corrections, but I know the records
4 follow individuals and there's a lot of difficulty
5 there. Also in treatment centers. How do you
6 protect confidentiality in your area?
7 MR. DICKSON: We -- of course,
8 confidentiality is a big issue among alcohol and
9 drug abuse treatment facilities. Our standards
10 speak to that very strongly. Whether or not a
11 client has AIDS is treated with the same kind of
12 protection of confidentiality as their identity as
13 far as alcohol and drug abuse is concerned.
14 And within the program when we -- to
15 give you an example of our efforts that we've gone
16 to protect this, when we enter you into an
17 agreement with the Texas Department of Health to
18 provide the outreach services within some of our
19 treatment programs, CJ -- the Center for Disease
20 Control, CDC, had a requirement that in our
21 treatment programs one person, one counselor be
22 trained in AIDS and be identified as the AIDS
23 counselor. And what we were finding was that
24 people who went to see -- nobody would go see that
25 counselor.

1 And so, we prevailed on the Department
2 of Health and CDC to allow us to make each one of
3 the counselors of these programs an AIDS counselor
4 and train them all so that no one would know, have
5 any idea whether it be counseling about alcohol
6 and drug abuse or counseling about AIDS.
7 REV. ALLEN: One of the
8 difficulties to follow up on that before we leave
9 this subject is the problem with halfway houses --
10 and moving out of counselors, but moving along the
11 spectrum of health and recovery.
12 The difficulties of the HIV status
13 following and sometimes haunting the individual is
14 a deep concern of mine. Also that some halfway
15 houses are rejecting individuals that are
16 HIV-positive because it is on their probation and
17 so forth.
18 It seems to be a catch-22 if you're
19 trying to provide services in the city where a
20 halfway house will not respond to the individual.
21 Is there some -- we talked about this on the
22 legislative task force and so forth. And I
23 wondered if there's been any remedies to perhaps
24 restrictions on money or licensing and so forth
25 that would require halfway houses to do what

1 they're supposed to do?
2 MR. DICKSON: Our standards -- we
3 license all treatment facilities in Texas, GI
4 patients, halfway houses, whatever, be it public
5 or private. And our standards protect the health,
6 safety, civil rights and protection from abuse.
7 That's the core standards and those are not -- you
8 can't get away with it.
9 In other words, if there's a violation
10 of those, there's no aid available because we feel
11 those are most important. And civil rights is one
12 of those same as it is protecting our standards.
13 And I think what you're talking about is a civil
14 rights' issue. If the program is available for
15 the treatment of someone who has alcohol and drug
16 abuse, then it certainly is available even if that
17 person has AIDS.
18 That's not to say that there's not some
19 abuse of that. We don't operate, directly operate
20 treatment programs. We contract for it. All of
21 our services are private, not-for-profit
22 organizations.
23 REV. ALLEN: But out of that
24 contract, can you require them to do their job?
25 MR. DICKSON: Yes. We require them

1 to help and train in this. And I couldn't answer
2 you right now whether we require them to not turn
3 someone away for AIDS.
4 Obviously, any treatment facility has to
5 have the capability to refer someone on if they
6 don't have the capacity to treat that person. And
7 we try to give our people as much laxity as we can
8 in that, but that's something that I'd be happy to
9 look into.
10 REV. ALLEN: I would appreciate
11 that because it is very concerning. Individuals
12 that are in the midst of desire and recovery and
13 working at it find a system that locks them out.
14 They lock them in to the prison or lock them out
15 of the care and it doesn't make a lot of sense to
16 me.
17 And I know that, you know, you have a
18 difficult job on other fronts; but that is
19 something that this Commission we are very
20 sensitive to and we will be addressing prisons and
21 seeing the connection thereof. So, I just wanted
22 to share dialogue a little about what's happening
23 in Texas. Thank you, Bob.
24 MS. DIAZ: I just have a real quick
25 question for William. What percent of the clients

1 that are served by your agency have both substance
2 use problems and are also seeking services as gay
3 men at your agency and also about what percent
4 would you say are persons of color?
5 MR. WAYBOURN: If you can bear with
6 me just one minute, I could give you the exact
7 figures because Mr. Thomas is our Executive
8 Director and has our exact figures. If John could
9 get those figures.
10 I would like to make one other
11 clarification that came up on an earlier panel so
12 that you and Mr. Dalton or whatever won't leave
13 here with the wrong impression. We've worked
14 quite well with the Dallas Urban League and
15 indeed, they have attempted to be a subcontractor
16 to them.
17 The problem with Mrs. Carr when she
18 called was not only who she was, but more familiar
19 working without the commons and referring them.
20 And so, we don't give out figures over the phone
21 until we know what use of the figures will be.
22 And also, we have attempted -- we
23 believe in the right of self-determination. And
24 we have attempted to help several African
25 Americans and Spanish organizations get funded and

1 operate on their own.

2 We don't break out the IV drug abusers,
3 but we did have twenty point three percent African
4 American, six point eight percent Hispanic and
5 four point four eight percent women. And we have
6 a caseload this month of five hundred and
7 sixty-seven clients.

8 MS. DIAZ: HIV?

9 MR. WAYBOURN: Right.

10 MR. PANZER: I wanted to make a
11 quick comment on the discussion that happened in
12 the earlier panel about competing for funding. We
13 don't have that luxury in a rural area, and I
14 think that -- well, I know the minority of our
15 staff and we don't even have a white male on our
16 board.

17 So, I think that especially in rural
18 areas in small towns, funding that encourages the
19 fragmentation of services is very detrimental.
20 And I think that really the Commission should
21 think about that especially in terms of small
22 towns and rural areas.

23 And maybe Barbara can echo that; I don't
24 know. But we just don't have that luxury.

25 MR. ARANDA-NARANJO: I think that

1 children have made us look more that AIDS has
2 always been a family disease rather than it was a
3 gay homosexual or whatever. And it's always been
4 a family disease. And as the children are now the
5 effects of that, the tenacity of the need is going
6 to make you reach down.
7 That's the only way you'll be able to
8 cover the needs that these families have, both
9 medical and psychosocial. You're going to look
10 out to that consortium that's going to give you
11 the impetus to put your own agendas aside because
12 it's going to take a community consortium to deal
13 in the next decade as we see total families.
14 We have mother, father, two or three
15 children infected in San Antonio where you
16 probably have the lowest numbers in the country.
17 You can look up to New York and New Jersey and
18 California. I think it's going to be required to
19 put aside your agendas.
20 MR. PANZER: The services need to
21 be client-centered.
22 MS. ARANDA-NARANJO: And if you
23 don't get them, they'll still come. And move you
24 forward.
25 MR. DALTON: So I understand you,

1 are you saying that you think it's inappropriate
2 for funding agencies to specifically target, for
3 example, IV drug users with their finding or
4 women?
5 MR. PANZER: No, not at all; but I
6 think that the impact that -- that narrowly --
7 that's why I was talking about flexibility of
8 funding. Service funding that narrowly focuses on
9 the small target populations, the impact on
10 services in a rural and small-town community needs
11 to be looked at.
12 There will be organizations that will go
13 after that funding that may qualify and then you
14 start to have territoriality and fragmentation
15 services and it becomes detrimental to the overall
16 services in the passive community. We just don't
17 have that luxury in a small rural -- I don't know
18 if I've clarified that.
19 There does need to be targeted funding
20 for people, particularly groups at risk; but I
21 think that some funding tends to fragment
22 services. And the impact of that needs to be
23 considered in the design of the programs.
24 MR. DALTON: Thank you.
25 REV. ALLEN: I think we're ready

1 for a break.

2 DR. OSBORN: I just wanted to make
3 one last comment. I wanted to thank William
4 Waybourn for a very succinct and very usable
5 definition of the crisis in health care which I
6 hope you won't mind if I quote if I wrote it down
7 correctly.

8 You were saying that only the rich can
9 afford it, only the employed can obtain it and
10 only the educated can exploit it. I think that's
11 a wonderfully-put phrase which I certainly plan to
12 quote. So, thank you for that.

13 The other comment I feel inspired to
14 make and you hit a guilty nerve in me. So, I want
15 to apoligize here in Dallas to Ann Arbor,
16 Michigan, for not being able to spend as much time
17 as I would like in my own community. And by the
18 same token, I want to thank Dallas for lending us
19 the talents of Reverend Allen and the National
20 Commission's work.

21 I think most of us working side-by-side
22 in the distress of this epidemic can share one
23 thing if nothing else and that is we all wish we
24 could do more than we are able to do in any given
25 day.

1 And I -- to Ann Arbor, Michigan, I hope
2 they understand why I'm in Dallas and I hope you
3 understand why we are sometimes off somewhere else
4 when we'd like to be everywhere.
5 REV. ALLEN: Well, we are right on
6 time and we're going to have a break for fifteen
7 minutes.
8 (Short recess.)
9 REV. ALLEN: We're going to go
10 ahead and begin even if some of the Commissioners
11 are not here. I'd like to go ahead and introduce
12 the next panel. Janet Voorhees from the Mexico
13 HIV Services Planning Grant Director; Donna
14 Antoine-Perkins, HIV Services Planning Project,
15 Mississippi State Department of Health; Rebecca
16 Lomax, Associated Catholic Charities of New
17 Orleans, Louisiana. We will start with Janet and
18 then Donna and then Rebecca.
19 MS. VOORHEES: Mr. Chairperson, Dr.
20 Osborn and Members of the Commission, thank you
21 for asking me to be here to share my ideas. My
22 name is Janet Voorhees. I have been doing AIDS
23 service work for the last five years. I started
24 in inner-city Baltimore, but now I'm from rural
25 New Mexico and will be giving you my perspective

1 in New Mexico today.
2 I believe that the major systemic and
3 economic barriers in providing comprehensive and
4 compassionate HIV care, especially in the rural
5 states, fall in seven different categories. I
6 will try and give you a few personal examples as I
7 go along.
8 Health care professionals and
9 nonprofessionals who are undereducated and
10 undertrained and undersupported about the HIV
11 epidemic in general and about how to provide
12 specific HIV-related care and about their role in
13 providing that care.
14 Lack of insurance or underinsurance
15 among people with HIV disease. The lack of
16 creative coordination and linkages of services
17 among care providers in institutions. What I mean
18 by that, I'll give you an example.
19 In New Mexico right now, we're trying to
20 invite private physicians who don't want to be
21 identified in their offices as AIDS docs to come
22 to the public health clinics and reimburse them
23 through the new legislative appropriation. Also,
24 to do private sort of intimate partnerships.
25 I recall a man, who did not qualify for

1 hospice care because he didn't have a primary care
2 giver, who I worked a deal out with. He had no
3 home. We were able to a pay for him to go to a
4 motel. And the night clerk, if I guaranteed to
5 give him $5.00 a night and some He-man Chewing
6 Tobacco and a cup of coffee in the morning, would
7 look out for my patient and call me at night.
8 I see a lack of long-term chronic care
9 services, facilities and reimbursement
10 mechanisms. I see different standards of
11 eligibility among medical and social service
12 programs to people who are disabled and a big lack
13 of substance abuse, alcoholism and mental health
14 services, especially for poor people, especially
15 for people in prison.
16 In our entire state, there are six
17 public beds for people with alcoholism and
18 substance abuse problems period. I'm also
19 reminded -- I went to visit a friend, someone I've
20 known who's been HIV-positive for about four years
21 now in the detention center recently. He told me
22 that he had last been there eight months ago and
23 had left his words there. He engraved his
24 initials on them. And when he came back eight
25 months laters, the same ones were there. There's

1 no education in those services in that detention
2 center for HIV-positive people.
3 Also, I see a problem in the vast
4 distances between rural communities and primary
5 care services. And I think with the exception of
6 that barrier that all of the barriers that I see
7 prevade our entire health care system. And I use
8 that in quotes and are only exacerbated by HIV
9 disease.
10 I recently heard a spokesperson from the
11 Centers for Disease Control say that the future
12 for the HIV epidemic is now in the rural states.
13 And as a result of conducting statewide HIV Needs
14 Assessment and planning for HIV services this year
15 in New Mexico, I can assure you that the future of
16 the HIV epidemic has already arrived in our
17 state.
18 We're suffering through barriers of
19 perceptions, perceptions about where we are in the
20 epidemic and where we're going. Although we still
21 qualify by definition as a low-incidence state, in
22 May of this year, the New Mexico Health and
23 Environment Department held a special press
24 conference to announce that it is estimated that
25 twenty-five hundred to three thousand New Mexicans

1 are HIV-infected; and while the numbers of persons
2 diagnosed in New Mexico communities is lower than
3 that in larger cities, the rate per capita of AIDS
4 in Albuquerque is higher in Pittsburgh and
5 Detroit. The rate in Santa Fe exceeds the rates
6 in Los Angeles, Dallas and Washington, D.C.
7 These projections also informed us that
8 by 1992, eight hundred people will have been
9 diagnosed with AIDS in New Mexico, more than twice
10 as many people in the next year and a half as
11 we've had since we started counting in 1981.
12 We have the highest percentage of -- I
13 use this advisedly -- minorities in our state.
14 Although it has a rich cultural diversity of
15 Native Americans, Hispanics and Anglos, it's an
16 economically and very poor state. Per capita
17 income is in the lowest ten percent in the United
18 States. And our Medicaid reimbursement rate is
19 ranked fourth lowest in the country.
20 Physicians are currently being
21 reimbursed under the 1978 pay schedule. It means
22 that they are getting fifty-five cents on every
23 dollar of care that they deliver. So, many
24 private physicians and health care institutions
25 refuse to care for Medicaid patients and thus use

1 this as a straight-faced bonafide rationale for
2 not caring for HIV patients.
3 Due to the abundance of small employers
4 and self-employed individuals in our state, a high
5 percentage of the population has no health
6 insurance. It's estimated that more than
7 twenty-five percent of our population compared to
8 fifteen percent nationally is uninsured.
9 To shed some light on that problem in
10 particular, I want to give you a few statistics
11 from our University of New Mexico Hospital HIV
12 Clinic. Thirty-six new patients were admitted
13 HIV-positive symptomatic from January to April of
14 '90. Fifteen of those were indigent, ten are
15 self-pay patients. That means that seventy of the
16 new patients are uninsured. Self-pay generally
17 means little pay or no pay in our system.
18 Of the remaining eleven patients, four
19 were qualified for Medicaid, one receives Medicare
20 and six have private insurance. The self-pay
21 folks are charged approximately $500.00 for the
22 initial medical visit. The basic bare bones of
23 what their year of care can look like will amount
24 to about $10,000.00 a year including lab work,
25 Pentamidine prophylaxis, AZT and the physician's

1 fee.

2 If they go into the hospital once, an

3 average hospitalization of about $6,300.00 which

4 comes to $16,300.00. I'm not sure anyone I know

5 even the middle-income people can make

6 out-of-pocket expenses of $16,300.00.

7 I also wanted to make two points: One

8 is that in our Planning Project this year, we

9 discovered that New Mexico State's Correctional

10 System has signed a contract with an insurance

11 carrier that specifically excludes any kind of

12 services with symptomatic HIV disease. When I

13 asked the Medical Director what would happen to

14 people when they developed symptoms or became

15 seriously ill, he answered, they will leave prison

16 under a compassionate release provision.

17 It is mind-bogglig to consider the

18 economic, systemic and social barriers to

19 providing care and to receiving that care with

20 that tragic scenario.

21 And then finally, I think in our attempt

22 as health care professionals to serve the

23 expanding and changing population of HIV issues,

24 we must face the possibilities that we ourselves

25 may be the barriers.

1 The barriers are our delusions about the
2 HIV epidemic about who it is we're going to be
3 serving and who we are in it; our limited
4 expertise and care for people who have problems
5 with drug abuse, alcoholism or who are chronically
6 mentally ill; our conscious and unconscious
7 prejudices about ethnicity, race, gender, and
8 sexual preference; and our professional and
9 institutional isolation and arrogance is a big
10 problem for us. Finally, our naive grandiosity in
11 believing that our professional training has
12 prepared us for that panoply of human suffering.
13 I feel that we must continue to support
14 ourselves, our friends and our loved ones and our
15 colleagues to cultivate in continuing to allow the
16 HIV epidemic to open our hearts and our minds.
17 Thank you.
18 REV. ALLEN: Donna.
19 MS. ANTOINE-PERKINS: Good morning,
20 Reverend Allen, Dr. Osborn, Ms. Byrnes, and
21 members of the Commission.
22 In the great state of Mississippi, the
23 needs are high and resources are low for
24 combatting the HIV infection. The low economic
25 and educational levels in Mississippi in

1 socioeconomic status of the state, an
2 ever-widening gap between the health needs in
3 terms of HIV and existing resources to meet these
4 needs becomes glaringly visible.
5 During the past decade, the transmission
6 of the human immunodeficiency virus and the
7 development of related illnesses has emerged as a
8 serious public health crisis affecting Mississippi
9 residents.
10 For the period May 1989 through April
11 1990, Mississippi has had a case rate of seven
12 point three per one hundred thousand population
13 placing the state twenty-fifth among states for
14 AIDS case rates. Through June 1990, nine hundred
15 and eight cases of HIV infection have been
16 reported to the Mississippi Department of health.
17 Of these nine hundred and eight of HIV infection,
18 one hundred and thirty-two has subsequently been
19 reported to the department as AIDS cases.
20 AIDS in Mississippi parallels that on a
21 national scale. The majority of Mississippi cases
22 has occurred in adults ages twenty to forty-nine
23 years. Although all races have been affected,
24 trends both nationally and statewide indicate
25 increases in infection rates among minority

1 populations.
2 National estimates indicate there are
3 fifty to one hundred persons infected with the
4 virus for every AIDS case currently reported. By
5 applying the national estimates to Mississippi, an
6 estimated pool of approximately five thousand to
7 ten thousand individuals infected with the virus
8 may be established.
9 The expected trend of the epidemic in
10 Mississippi over the next three years is for
11 infection rates to move sharply upward. As many
12 as two hundred and twenty to two hundred and
13 thirty new cases in 1990, two hundred and sixty
14 new cases in 1991. And by the end of 1992, three
15 hundred and twenty-five new cases are expected.
16 Additionally, the percent of cases among nonwhites
17 has been increasing steadily and is expected to
18 continue in this trend.
19 Mississippi currently has two
20 residential facilities for persons living with
21 AIDS. One is in the city of Jackson which is the
22 Sandifer House and the other is located on the
23 Mississippi Gulf Coast. These are the two most
24 urban areas of the state and the two with the
25 highest incidence of infection.

1 The Mississippi PWA/HIV Coalition
2 operates these homes and is now negotiating to
3 purchase three more, one of which will be located
4 in North Mississippi.
5 The Mississippi PWA/HIV Coalition is
6 also assisting four clients per month with any of
7 the following: Rent, mortgage, utilities, etc.
8 It has been stated that many more individuals are
9 in need of assistance; but due to inadequate
10 funding, they are unable to provide this service
11 for the numbers in need of it. It is projected
12 that these figures will increase at much the same
13 rate as for temporary shelter.
14 According to officials at the
15 Mississippi Department of Mental Health, programs
16 funded by the state indicate that there are
17 approximately three hundred fifty-seven
18 residential primary treatment beds, a hundred
19 fifty-seven transitional treatment beds, forty
20 beds at the Mississippi State Hospital and
21 twenty-five at the East Mississippi State
22 Hospital.
23 HIV counseling and testing is not being
24 conducted at any of these facilities. Resources
25 are not available to provide this service.

1 However, alcohol and drug abuse officials state
2 that on occasion it has come to their attention
3 unofficially that they are treating HIV-infected
4 clients in their system.
5 Currently in the state, there are eleven
6 pediatric or medically-fragile foster care beds.
7 These beds are for children determined to be
8 medically-fragile. There are no children with
9 AIDS occupying these beds. However, the
10 Department has recently prepared a proposal to
11 increase the number of medically-fragile beds by
12 six which will include HIV-infected or AIDS
13 children.
14 Medically-fragile as defined in
15 Mississippi is one who requires daily care in
16 addition to routine child care, that is
17 approximately equivalent to care in a nursing
18 home, skilled nursing or SSI eligible or
19 enrolled. For example, requiring frequent
20 hospitalizations or is technologically-dependent.
21 Due to the progressive deterioration of
22 HIV-infected or AIDS mother's health, they may not
23 be able to actively participate in the care giving
24 of their children. Therefor, other means of
25 support are going to be needed.

1 The pediatric medically-fragile program
2 is not, given its present participating numbers,
3 going to meet the needs for the numbers of babies
4 projected over the next five years. Even with the
5 possibility of obtaining the six beds being
6 proposed, there will still be a tremendous
7 shortfall on beds needed to care for these
8 children.
9 Our state department of health currently
10 provides AZT to persons with HIV infection
11 providing they have an absolute CD4 cell count of
12 five hundred or less. The department currently
13 has twenty-three PWA's receiving AZT now and
14 thirty-six on the list.
15 Last week, we received word that
16 continued additions to the waiting list may no
17 longer be possible. I don't know what's worse; to
18 tell someone they are number twenty-seven on a
19 waiting list of thirty-six or to tell them we are
20 no longer accepting names for the waiting list.
21 Also, many of these individuals know
22 that there are a few ways to move up on this
23 waiting list. Either someone has qualified for
24 medical assistance or someone has died. The
25 program, however, does not cover the cost of

1 equipment necessary to administer some of the
2 medications.
3 Aside from the coverage provided by
4 Medicaid, the State of Mississippi currently
5 provides for no other methods of payment for
6 treatment and services for the HIV-infected AIDS
7 population. We are doing what we can, given the
8 resources we have; however, we cannot continue to
9 operate on limited financing and expect to meet
10 the needs of our citizens.
11 Our state and federal governments must
12 become more responsive financially if we are to
13 realistically battle and defeat this monster
14 called HIV. Thank you.
15 REV. ALLEN: Rebecca.
16 MS. LOMAX: Good morning, Ladies
17 and Gentlemen of the Commission. I want to thank
18 you for the opportunity of coming here to this
19 hearing today. I have met some of you privately,
20 but I find you as a collective body somewhat
21 intimidating.
22 I'd like to say first of all that I
23 don't pretend to be an AIDS expert, but I think I
24 have a very good grasp of the political and
25 economic issues that impede the delivery of a

1 continuum of care to people living with AIDS in my
2 state, Louisiana, New Orleans.
3 I hesitate to talk about political
4 issues because politicians tend to be a little
5 testy when I do, but you have to understand the
6 politics of my state and my city. Indeed,
7 probably the politics of the south to understand
8 the task that we face.
9 The expectation in some locations is
10 that groups will work together for the common
11 good. The expectation in Louisiana is that there
12 will be contentiousness, there will be
13 factionalism, there will be racism, there will be
14 sexism and there will be lots of secret meetings.
15 Our legislature just passed the most
16 restrictive anti-abortion bill in the nation. In
17 opposing an amendment which would allow for
18 abortion in case of incest, a state representative
19 said publicly and I quote, "Inbreeding is how we
20 get championship race horses". Need I state more
21 about the enlightened politics of my state?
22 Louisiana has created a classic catch-22
23 system with its Medicaid bill. A person who is
24 applying for benefits must apply for Supplemental
25 Security Income -- that's welfare -- and Social

1 Security disability at the same time. Any person
2 who receives SSI also receives Medicaid health
3 care coverage.
4 The maximum SSI paid in Louisiana is
5 $386.00 per month. The state allows an income
6 from all sources of $20.00 a month over SSI. That
7 means that a person who has a total income of
8 $406.00 or less retains Medicaid coverage. A
9 person with a total income of $407.00 loses their
10 Medicaid coverage.
11 Most people who have been employed and
12 paid into the Social Security system will receive
13 Social Security disability benefits in excess of
14 the four hundred and six dollar limit.
15 It is ironic that those people who have
16 never paid into the Social Security system fare
17 better than those who have. It is also ironic
18 that our state with its very low SSI limits is
19 actually putting people into the already
20 overburdened public health care system who could
21 continue to receive health care in the private
22 sector with Medicaid coverage. At any given point
23 in time, only about twenty percent of people
24 living with AIDS in Louisiana are covered by
25 Medicaid.

1 To the best of my knowledge, we have not
2 had a single person admitted to a nursing home.
3 We are either told that the beds are full or that
4 the staff lacks the expertise to deal with these
5 patients. We believe that Louisiana's Medicaid
6 reimbursement rate of $47.40 per day for skilled
7 nursing care has a lot to do with these refusals.
8 Those people who need this level of care often
9 must utilize expensive hospital beds because they
10 have go no place else to go.
11 Housing is a critical need in New
12 Orleans. Our housing stock is generally expensive
13 and substandard. Project Lazarus, owned by the
14 Archdiocese of New Orleans, is our city's only
15 dedicated house for people living with AIDS. It
16 was expanded last year from seven to thirteen beds
17 with the help of a renovation project grant from
18 the Health Resources and Services Administration.
19 We need the same range of housing
20 options for people living with AIDS as we do for
21 any group of people who may experience
22 deteriorating health. Apartments that can
23 accommodate walkers, wheelchairs, congregate
24 living, group homes. And it needs to be
25 subsidized because of our limited income.

1 We need home care and personal care
2 attendant services to help people stay in their
3 homes. And we need the flexibility to allow
4 people to move back and forth between those
5 arrangements as their needs change.
6 We have not been successful in working
7 with our local housing authority which is
8 considered and I quote troubled by HUD. And HUD
9 is having its own problems. They've had two
10 career HUD officials resign rather than move to
11 New Orleans.
12 There's something wrong with what we've
13 been doing with preventive education and how we've
14 been disseminating that information about HIV
15 through the media, and I don't know how to fix
16 it.
17 We're seeing the changing face of AIDS
18 in Louisiana. More minorities, more drug abusers,
19 their children, increased numbers in rural areas.
20 And we're providing in the words of the
21 grant-makers culturally-sensitive AIDS education
22 provided by minority leaders. But how effective
23 have we been when ten years into the epidemic, we
24 are still answering questions about toilet seats
25 and mosquitos.

1 Information indicates that newly
2 diagnosed cases of AIDS are declining in gay men.
3 We hear that this very information is being used
4 by our legislators to reduce funding.
5 Please do not misunderstand what I'm
6 about to say. I well understand the problems of
7 drug abuse in this country. I know the waste of
8 human life and the desperate need for effective
9 treatment. But every time I turn on the news, I
10 see coverage of the very real and present danger
11 of drug abuse and drug trafficking.
12 Perhaps it is that AIDS is becoming
13 almost too subtle for our media, maybe even for
14 the American public. It's carried on TV and the
15 written media as a special, a health problem of
16 the very few. Maybe it's still seen this way by
17 our policy-makers.
18 Where have all these people been while
19 we've been talking about the transmission of
20 demographics of this disease; or were we saying it
21 wrong so that they didn't hear us?
22 In August of 1989, the United States
23 Department of Health and Human Services announced
24 that early intervention of AZT can delay the onset
25 of AIDS in people who are HIV-positive, but we're

1 not seeing the numbers of HIV-positive people
2 asking for treatment that we anticipated. And
3 we're not experiencing a great increase in
4 requests for confidential counseling and testing.
5 Is it lack of information? Is it that
6 the information has been misinterpreted and people
7 think that AIDS is now curable? Is it denial?
8 Maybe information and education are again the
9 issue, but I believe that there are also other
10 considerations.
11 In our state, only one hundred and
12 eighteen people with monthly incomes of $1,047.00
13 or less receive AZT via HRSA grant that's
14 administered by the Department of Health and Human
15 Services.
16 The person who is employed and earning
17 approximately $1,100.00 a month -- that's an
18 annual income of $13,200.00 a year -- will not be
19 supported by this system of ours and cannot
20 qualify for this AZT.
21 AZT costs right now are a little over
22 $200.00 a month. How can a person who is earning
23 a little over a thousand dollars a month spend
24 one-fifth of that income on one prescription in a
25 city where the basics of life -- food, shelter,

1 utilities -- all of that are very expensive and at
2 a time when this person may need more than just
3 that one prescription?
4 Health insurance at least partially
5 reimburses prescription medication costs. But
6 many businesses and agencies cannot afford the
7 cost of traditional indemnity plans.
8 The Archdiocese of New Orleans employs
9 over seven thousand people. It offers its
10 employees a choice of HMO's but has dropped its
11 option for a traditional indemnity plan because of
12 the cost. The last cost quoted to the Archdiocese
13 in 1989 for an individual person was over $200.00
14 per month. For a family, it was over $600.00 a
15 month.
16 Our employed HIV person may not have
17 insurance coverage because his company may not be
18 able to afford insurance coverage or he may not be
19 able to afford the employee's share of that
20 coverage.
21 But what about the HIV person though who
22 is covered by health insurance? Why isn't he
23 receiving early intervention? It's so simple that
24 it's painful to those of us who have not been
25 through this before.

1 He doesn't want to obtain a preexisting
2 condition that might prevent his obtaining health
3 insurance should he change jobs. He wants to
4 prevent moving into the public sector of health
5 care. He wants to save his care for when he
6 really needs it, when he has AIDS.
7 The service needs are complex, and many
8 people with AIDS and HIV are new to the health and
9 social services system. They may be new to the
10 city drawn there because services are not
11 available in their hometown or their home state.
12 They need help knowing what services are available
13 and they need help assessing those services. They
14 need to have case management available to them.
15 I know that my time with you is very
16 brief, but I have one final point. Politics does
17 interfere with the delivery of services in our
18 state. But for Louisiana and for Mississippi and
19 for other states that are struggling hard to
20 rebuild shattered economies, the primary barrier
21 is inadequate economic systems.
22 I know that people who wrote the
23 criteria for the Department of Health's AZT
24 program. They were pioneers in AIDS, and they
25 understood the needs; but they had to make

1 critical decisions on the best use of limited
2 resources. They had to decide who could get into
3 the lifeboat.
4 My friends, without critical federal
5 funding from the Federal Government, states such
6 as ours will be making many more life-threatening
7 decisions. Thank you.
8 REV. ALLEN: Thank you. Any
9 questions from the Commissioners?
10 MR. DALTON: I have a question for
11 each of you actually. I'd like to thank the State
12 of Mississippi -- words I thought I'd never say --
13 for birthing a couple of our panelists and John
14 Hopkins University for a couple of careers.
15 Let me start with Ms. Lomax and move
16 backwards. You asked a rhetorical question. I
17 guess I'd like to have you answer it. You
18 observed that in the wake of publicity about
19 utility of AZT and early intervention and the
20 like, we aren't seeing an increase in people
21 looking for testing or coming forward.
22 You offered several possibilities for
23 why that might be, but I guess I wanted your best
24 judgment on that. Why is it that --
25 MS. LOMAX: I think I also said I

1 don't know how to answer the question.

2 MR. DALTON: Yeah, but I didn't

3 believe that.

4 MS. LOMAX: I think probably the

5 economy definitely in your states -- and

6 Mississippi is my home state, so I smile when she

7 was talking, too.

8 The economy definitely interferes with

9 the delivery of services. As long as people who

10 have the funds to distribute are having to decide

11 that the $13,200.00 a year you have to pay for

12 your own, I don't think we're going to have a lot

13 more people coming forward. That's pretax

14 dollars.

15 MR. DALTON: Thank you. For Ms.

16 Antoine, I wanted to ask you about substance abuse

17 services in Mississippi. In your remarks and in

18 your prepared statement, you gave us a sense of

19 the number of beds available, but no sense of what

20 the demand is. And I guess I was curious about

21 the extent to which drug treatment is available to

22 those who wish it in the State of Mississippi.

23 And secondly, as I understood, you said

24 that in the Department of Mental Health program,

25 the HIV counseling and testing is not being

1 conducted except perhaps informally in some
2 places. And I think you suggested that the
3 explanation given was cost. And I wanted to make
4 sure I heard that and register how appalling I
5 find that if it's true.
6 MS. ANTOINE-PERKINS: The demand
7 for treatment in terms of beds being occupied is
8 fairly high. These are beds that are funded by
9 the State Department of Mental Health. These are
10 not exclusive of private hospital beds out there.
11 These are public beds.
12 However, in talking with one of the --
13 the lady who is over the Division of Alcohol and
14 Drug Abuse is on my coalition for my planning
15 grant. There are no counseling and testing
16 services going on now in these programs; but she
17 is interested in looking at doing something with
18 this. However, her word is not the last word on
19 that.
20 MR. DALTON: Okay. Delicately
21 put.
22 MS. ANTOINE-PERKINS: Thank you.
23 I'm from Mississippi.
24 MR. DALTON: I see. Ms. Voorhees,
25 I trust you're getting paid by He-man Chewing

1 Tobacco Company for your plugs. I wanted to ask
2 you, you talked about previous linkages and you
3 gave us one example which is really very helpful
4 for me. And namely, how to deal with private
5 doctors who in their heart of hearts are willing
6 to help HIV patients, but don't want to become
7 known as the AIDS doctor. And you talked about
8 providing I guess space for them in the public
9 health facility, and which is something I hadn't
10 thought about.
11 I wonder if you have some other examples
12 of what you refer to as creative linkages.
13 MS. VOORHEES: Yeah. At this
14 point, we are starting an early intervention
15 program through the Health and Environment
16 Department. That's where the money was
17 approrpriated. I'm sorry. It was appropriated in
18 the Human Services Department and has been
19 subcontracted out to the Health and Environment
20 Department because Human Services couldn't do it.
21 There was someone creative enough to say I can't
22 do it. That's a new one for us.
23 And you also have at this point a
24 pastoral care training that has been extremely
25 successful in our state that is sponsored and

1 supported by the largest AIDS service organization
2 for people who are interested who are professional
3 pastors and also people who are coming from a
4 church perspective.
5 That partnership has been fostered by
6 the archdiocese and by the New Mexico Conference
7 of Churches working together with that AIDS
8 service organization. They saw that there was a
9 way in there that wasn't going to upset people to
10 begin with.
11 And, in fact, Don and I were talking
12 about this the other day. We think that this has
13 become now a mental health service to the
14 community. I wouldn't like to say push that in
15 terms of that's why we're doing it; but, in fact,
16 what we do is we treat groups of people who bond
17 with each other and also who then see HIV under a
18 microscope. And they're able to apply it to a
19 much larger picture.
20 MR. DALTON: I have one other. You
21 ended up with something I thought was provocative
22 and painful suggesting that we ourselves may be
23 the barriers to care. What I'd really like to ask
24 you is if you have some sense of ways in which
25 this Commission might find itself if we're not

1 careful being a barrier to care.

2 You might even would like to answer

3 that, but could you just give us more thoughts

4 about the way in which those of us who are

5 devoting all of our energies and time to working

6 with AIDS who in some ways get in the way of what

7 we're trying to accomplish.

8 MS. VOORHEES: Two things cross my

9 mind: One is that you as a group already are

10 doing something that I mentioned in terms of

11 cultivating leadership, being role models, being a

12 mixed salad that works quite well together.

13 That's really obvious in your presence yesterday

14 in that meeting. I was struck by how supportive

15 you are of each other and supportive you were.

16 And in your comments to people on these

17 panels who have been supportive in terms of what

18 you appreciate about what people are doing. So,

19 there you are as our role model.

20 And at the same time, that may be the

21 biggest danger. So many people who I know who

22 have done this over an extended period of time

23 have burned out in some way or another. Few of us

24 are able to actually admit that.

25 And I think someone mentioned this

1 morning the conversation that she was taking some
2 time off and wanting to come back to the
3 frontlines.
4 I would ask you all to keep doing your
5 own individual supportive work, your own
6 investigation. It's the only way that I can see
7 that other people can be affected when they feel
8 your presence. That's really a transformational
9 thing that happens to people when they know that
10 you take care of yourself and that you have the
11 courage to say when you're not.
12 DR. KONIGSBERG: Again, I would
13 like to complement this panel. We've had some
14 excellent testimony today.
15 I'd like to address a couple of
16 questions to Janet Voorhees. First of all, I
17 really am impressed with what you're doing in New
18 Mexico and being in a low -- quote low-incidence
19 state, Kansas, and relate to what you're
20 discussing. So, I may find some excuse to go to
21 New Mexico to get some consultation.
22 MS. VOORHEES: Please do.
23 DR. KONIGSBERG: I find it a
24 fascinating state.
25 One of things that is particularly

1 fascinating about New Mexico is the fact that it
2 is a tricultural state with the Native Americans,
3 Hispanics and Anglos.
4 Can you talk a little bit about any
5 special efforts that you've had with Native
6 Americans? That's the main concern that I have.
7 MS. VOORHEES: I hesitated how much
8 to go into Indian Health Service in my
9 presentation. I hesitated so much, I didn't say
10 it specifically.
11 DR. KONIGSBERG: Don't hesitate so
12 much.
13 MS. VOORHEES: Okay. It is very
14 difficult to explain the way that the Indian
15 Health Service works even when you ask Native
16 Americans. What we have done to answer your
17 question is on our planning grant, we have
18 specifically asked people from Indian Health
19 Service to join us as well as to do -- we've done
20 are sort of a mini version of what you're doing.
21 We go all around the state and ask people on the
22 reservations and from the pueblos to come and tell
23 us what their situations are.
24 What we find there is that because its
25 so rural, because it's such a tightly-knit society

1 when someone goes to get tested, they might run
2 into their aunt who exactly is the person drawing
3 the blood.
4 So, what we have done is to try and set
5 up an alternative transportation reimbursement
6 system where people can come to other regions to
7 get tested. That has helped actually. It's
8 increased the number of Native Americans
9 three-fold in the last year.
10 There is also now collaboration going on
11 between the Health and Environment Department and
12 IHS at the state level. And they're really
13 advocating it at the federal level to figure out
14 how to deal with situations like what happened
15 this year.
16 IHS did not release the money for AIDS
17 for the fiscal year that we are now in until May
18 1st. I guess that will never happen again. There
19 was enough of a stink made finally by enough
20 people. Those sorts of groups.
21 DR. KONIGSBERG: I was also
22 intrigued with your comment about the -- it takes
23 some courage to say that you can't do something in
24 public agencies which does take some courage. It
25 also takes some courage to say you can do it and I

1 guess the point is knowing when to say I can and
2 when to say someone else needs to. And that's a
3 tough decision. Thank you.
4 MS. DIAZ: Just one question for
5 Janet and one question for Rebecca. Janet, how do
6 you keep the enthusiasm in those that work around
7 you within the planning constraints of normal use
8 in the future that will need implementation at the
9 local level?
10 I kind of find myself torn with the
11 whole idea of the private projects, the planning
12 projects that really may show some hope down the
13 tunnel, but we're really not sure of how that will
14 all come together in terms of the dollars and
15 resources that are needed to implement these
16 plans. I just wanted to know if you could give us
17 a word of wisdom on that.
18 MS. VOORHEES: I wish I could.
19 It's the question that we've asked since we begun
20 these planning grants how to do something without
21 implementation, how to keep the continuum and how
22 to keep the momentum going.
23 I see it on three levels: One is
24 funding obviously; one is systems implementation.
25 But the other is consciousness-raising. We have

1 really had a good time in this last year. I hate
2 to say that. I actually struck it out of the
3 grant proposal because I know that will sound
4 rather Californian.
5 But, in fact, having people come
6 together and having national leaders -- you know,
7 June's with us last month. We have had other
8 people come nationally to give us a real shot in
9 the arm.
10 You all really do bring not only
11 authority and expertise, but you bring the feeling
12 to people, the experience to people that they are
13 important. And that's what we have tried to do in
14 this process is to remind people that they really
15 can come up with a solution for this.
16 When I saw these little faces in
17 February looking back at me at the first planning
18 symposium saying tell us what to do, I think I
19 need to go get another job. But what has happened
20 in the interim is that by not doing, by keeping
21 our hands away for a change, people have come up
22 with fabulous solutions to things and new
23 alliances.
24 MS. DIAZ: Thank you so much.
25 Rebecca. You didn't talk about what your agency

1 or program does. I'd just appreciate your
2 concentrating on describing the global situation
3 in New Orleans. But I know that you are one of
4 the few funded RWJ programs that is doing a really
5 tremendous job in Louisiana.
6 I happened to have been there in the
7 training of Hispanic ministers to address HIV in
8 congregations. And I hear so much about what
9 you're doing. In a capsule, could you tell us
10 what it is you're funded for?
11 MS. LOMAX: New Orleans AIDS
12 Project was originally funded as a consortium of
13 services in New Orleans by the Robert Johnson
14 Foundation. We received additional funding two
15 years ago from Health Resources Services
16 Administration. And at that time, we also
17 received a second RWJ grant, which is the one you
18 attended at the Regional AIDS Benefit Network.
19 We have spread out into portions of five
20 states providing training to ministers and to
21 congregations. In order to leverage the similar
22 resources that Scott was talking about earlier,
23 care teams to go into the home and support the
24 care givers and provide the supplementary
25 volunteers. It's been, I think, very successful.

1 It's been a rough job, too.
2 The New Orleans AIDS Project has funded
3 health education. It's funded primary care
4 services through Charity Hospital in New Orleans.
5 Health education services in our city right now
6 primarily are with no AIDS task force.
7 Our part of the project has been mental
8 health and case management services. So, that's
9 what we've tried to develop. We're all looking
10 now at where we're putting all of those to bid for
11 funding as this money runs out.
12 MS. DIAZ: Thank you.
13 REV. ALLEN: Any other questions?
14 All right. Well, thank you very much. We
15 appreciate your input. And I will like to make
16 one announcement before we break for lunch. There
17 is a sign-up sheet outside for public comments on
18 the blue tablet. And if you would like to make
19 public comments between three forty-five to four
20 fifteen. If we have enough time, each
21 presentation can be three minutes.
22 (Short recess.)
23 REV. ALLEN: I'd like for the next
24 panelists to come forward for the one thirty
25 testimony. Roslyn Cropper, Desire Narcotics and

1 Rehabilitation Center, New Orleans; Jean Derry,
2 Field Operations Division, Oklahoma Department of
3 Human Services; Paula Elerick Espinosa, Southwest
4 AIDS Committee; and Steve Hummel, Good Samaritan
5 Project, Kansas City, Missouri.
6 I'd like to begin with Jean Derry,
7 Roslyn, and Paula, and Steve.
8 MS. DERRY: I told you I'd be
9 back. My name is Jean Derry. I'm with the
10 Department of Human Services in Oklahoma City.
11 I'm the Department AIDS Coordinator. I'm just
12 proud to be here. Thank y'all for inviting me. I
13 shouldn't be here today. The person that should
14 be here today is a gentleman who was a dear friend
15 of mine, my mentor whose name is Tom Self, who is
16 the associate director of the Department of Human
17 Services.
18 Earlier in this past decade, he was
19 diagnosed with AIDS and put Oklahoma in an
20 extremely unique position. We had an official
21 very highly placed in our human services agency
22 who had access to the governor, to other public
23 agencies, who had AIDS who made AIDS very real to
24 people very quickly, who made it very difficult
25 for them to say, no, this is not important, this

1 is not real in Oklahoma.

2 Tom was astute enough and realized that

3 he wasn't going to be around forever. He coerced

4 out of me a commitment about a year and a half ago

5 that when he became too ill to continue to build

6 programs and to get people to work together in

7 Oklahoma that I would do that and I made that

8 commitment to him.

9 Tom did two very important things in

10 Oklahoma: One was he worked directly one-on-one

11 with PWA's who were having problems and

12 essentially was their case manager, whatever their

13 income base may have been, whether they were in

14 trouble with their employer, and were still

15 working or if they were trying to access Medicaid

16 benefits.

17 The other very important thing that Tom

18 did was talk with high level officials and speak

19 for persons with AIDS in Oklahoma. He gave us two

20 very -- he gave us kind of a mixed blessing in

21 that we got way ahead on a lot of things and we

22 fell very far behind in others.

23 Before Tom became unable to work, he

24 said, Jean, I want you to do two things. I want

25 you to develop a case management program and I

1 want you to develop a coalition of people in
2 Oklahoma to carry on what I've been doing. I
3 said, okay, that's easy.
4 The first thing I did was get on a plane
5 and come down here and spend a day with AIDS ARMS
6 and learned a great deal and then I have
7 replicated what they have done in a public agency
8 rather than in a private agency. We don't have
9 the look of AIDS ARMS, but we have the feel of
10 AIDS arms.
11 We opted not to provide that program
12 through Medicaid because of the economic
13 restrictions, financial restrictions. We instead
14 found extra monies through Title 20 programs,
15 social services block grants and have funded in
16 that manner. We have placed two case managers in
17 Tulsa and two in Oklahoma City who were
18 essentially dedicated to serve the persons in
19 those counties, which comprise about sixty to
20 seventy percent of our AIDS-diagnosed cases in
21 Oklahoma.
22 We had difficulties almost immediately
23 after they were placed with accessing nursing home
24 beds and long-term care in general. We have been
25 very fortunate in Oklahoma in that we have a Title

1 19 operating long-term care programs called NTMC,
2 Non-Technical Medical Care, and we have been able
3 to use this very creatively along with family and
4 friends and others to provide care.
5 Nursing home care continued to be needed
6 in Oklahoma. We couldn't get it. We eventually
7 made contact with the civil rights office here in
8 Dallas, the Regional Civil Rights Office, David
9 Winters, Ted Carl, and a representative of
10 Oklahoma. They did some investigating. They
11 talked with our Medicaid director.
12 There are still investigations I
13 understand to be done for nursing homes in Tulsa
14 that have been financially sanctioned. They have
15 had Medicaid monies withheld. They are appealing
16 that currently. We don't have obviously the
17 results of that appeal, but that will weigh
18 heavily where we do go in the immediate future
19 with access to nursing home beds.
20 We've talked a lot in the last couple of
21 days about this issue because I can throw this out
22 the window. It's been said in many ways. We've
23 talked about the need for national health care and
24 that's true. We need it. There's no doubt. The
25 reality is what we have. What the Federal

1 Government, and the state government puts a lot of
2 big bucks into is Medicaid.
3 I think what we've got to focus on at
4 this point is taking Medicaid and making it work
5 for as many people as we can as well as we can,
6 and I'm talking in terms of broadening the scope
7 of services as well as broadening the eligibility
8 criteria.
9 There's a lot of work to be done there,
10 and I think instead of pushing the river, I think
11 we can just ease the direction of the flow a
12 little bit and maybe take things that are already
13 moving and kind of direct which way they go. I
14 think that will be helpful to us.
15 The main things I wanted to talk about
16 today or I wanted to talk with you -- time goes
17 too fast. We have been able to use a lot of state
18 money and again we've used Title 20 money to
19 shore-up surfaces that were not able to provide
20 through the Title 19 program through Medicaid.
21 Again, Oklahoma is an institutional
22 state. Medicaid reimbursement drives the services
23 that we have. We would sure like to see some
24 changes in Medicaid reimbursement incentives.
25 We have been able to provide state money

1 for family members to provide NTMC rurally where
2 you can't find anybody else to provide it. We
3 would like to see Medicaid allow family members in
4 those circumstances to provide that. Medicaid
5 doesn't work well with this disease. It doesn't
6 work just real well with any disease. AIDS has
7 just highlighted the flaws and the apparent
8 weaknesses in that program.
9 And I'd be happy to answer any further
10 questions. Thank you.
11 REV. ALLEN: We will have dialogue
12 after all the testimony. Let's see. Paula
13 Elerick Espinosa.
14 MS. ESPINOSA: Before you start
15 timing me, I just wanted to thank each of you for
16 the interest you've taken not only in general but
17 by your questions here today. It's very
18 encouraging, as some of us said at lunch, to know
19 that we are being listened to.
20 REV. ALLEN: Now, how could I time
21 that? Okay.
22 MS. ESPINOSA: I'd like to thank
23 you for your dedication and efforts and more than
24 anything for allowing me to speak to you today. I
25 share with my colleagues here as well as in

1 El Paso and West Texas the belief that AIDS has
2 created opportunities for positive change in all
3 areas of society. That is the underlying theme
4 that keeps me going on a daily basis.
5 I come to you today from a border
6 community. El Paso and its sister city Juarez,
7 Mexico, represent the third largest metroplex in
8 Texas with a combined population of over two
9 million.
10 Barriers to development and delivery of
11 AIDS-related services in a border community are as
12 much a reflection of the challenges posed by the
13 stigmas associated with this disease as they are
14 symptoms of an overburdened health care delivery
15 system.
16 A local insurance carrier estimates that
17 as many as fifty percent of El Paso's population
18 may be without medical insurance. The reality in
19 a community with one of the lowest per capita
20 incomes in the nation, is that an overwhelming
21 number of citizens, in a city whose population is
22 seventy percent Hispanic, are under- or unemployed
23 and twenty-seven percent of our population of
24 seven hundred thousand live at the poverty level.
25 To understand barriers to AIDS patients,

1 one must understand how health care is utilized by
2 this indigent population. The county hospital,
3 Thomason, is not a last resort for medical
4 services of this disadvantaged population. It is
5 the first response to medical emergencies that
6 could have been avoided with preventive primary
7 care, treatment or social services.
8 The result of this dependence on
9 Thomason Hospital is an overburdened health care
10 system. Not only must Thomason care for a
11 majority of El Paso's population, it absorbs the
12 costs of caring for another unique population:
13 Undocumented workers from Central and South
14 America, primarily from Mexico.
15 A few weeks ago, an HIV-infected baby
16 was born in Thomason to an HIV drug abusing
17 Mexican woman all of eighteen years old. This
18 HIV-infected newborn is now in the custody of
19 Child Protective Services of the United States
20 Department of Health and Human Services. The
21 severity of this situation is underscored by the
22 recent approval by the board of directors at
23 Thomason Hospital to request a sixty-seven percent
24 tax increase from the county government.
25 Who will pay the bills and who will

1 provide the needed services? We have heard that
2 federal dollars are not guaranteed. But, in a
3 border community, a federally-impacted community,
4 solutions cannot fall solely on the shoulders of
5 already overextended taxpayers.
6 When we examine the needs for persons
7 who are HIV-infected, we are forced to take into
8 account the viability of our entire health care
9 infrastructure. In a global context, AIDS may be
10 the catalyst for creative restructuring of our
11 national health care system.
12 The single greatest barrier to social
13 services are the economic realities of this
14 community that I've outlined above. Additionally,
15 specific barriers to social services the persons
16 not only along the border face, but in the rural
17 areas we serve in West Texas and in Southern New
18 Mexico must also be discussed.
19 To leave out West Texas from these
20 proceedings would be to ignore the problems of two
21 point six million people residing in a hundred and
22 thirty-five square miles or roughly the land mass
23 of New York, New England, and part of
24 Pennsylvania. If we were our own state, and there
25 are rumors floating about succession, we would be

1 the fourth largest state.
2 One point six million of these people
3 reside in rural areas. For most of us, distance
4 is an abstract concept; but in West Texas, it is a
5 very real challenge.
6 Let me begin with barriers to social
7 services in the rural areas of West Texas. The
8 rural areas are characterized by traditional moral
9 values, and these communities are not very
10 tolerant of diversity directly affecting the
11 delivery of health care especially to HIV-infected
12 individuals.
13 In El Paso, as in the rural areas of
14 Texas, homophobia does still affect the quantity
15 and quality of social services available.
16 Dentists and private physicians are a rare
17 commodity. And when they are available,
18 homosexual men, in particular, are still very
19 reluctant to take advantage of these services.
20 In rural areas that extend from Van Horn
21 to Amarillo and Odessa, the isolation of AIDS
22 patients is more severe due to ignorance and
23 prejudice that has been not eliminated. Thirteen
24 counties in West Texas do not have a physician.
25 Diagnosis of AIDS cannot be done without a

1 physician and the communities then cannot prove
2 the needs for social services and funding.
3 Twenty-six counties do not have
4 hospitals. In counties that do, administrators
5 cannot take the risk of accepting AIDS patients
6 that may cost the hospital $70,000.00. Rural
7 hospitals already represent the increasing number
8 of failing hospitals. A consequence of
9 non-existent hospital or physician resources
10 obviously is the lack of social workers that go
11 along with that.
12 In rural areas, there is no such thing
13 as confidentiality. When your only support system
14 is the Texas Department of Health coordinator or
15 nurse, it is quite obvious you are sick or ill
16 when the TDH car pulls up to your house.
17 The "Coming Home" phenomenon or the
18 numbers of AIDS patients who return home are not
19 accounted for formally after being diagnosed
20 elsewhere. In El Paso, there are particular
21 barriers associated with culture, education, and
22 economics, in particular some culture items.
23 In the Hispanic and Mexican tradition,
24 the male insertive does not consider himself to be
25 homosexual. The homosexual in the act is the

1 passive male. The direct consequences are denial
2 of risk, of diagnosis, and complete resistance to
3 care.
4 Bisexuality has placed the entire family
5 structure, but in particular women and children,
6 at high risk for HIV infection because Hispanic
7 men, more commonly than their white counterparts,
8 will maintain a facade of heterosexuality while
9 secretly engaging in sex with men.
10 Homophobia in the Hispanic family also
11 leads to denial even if the route of transmission
12 was heterosexuality or IV drug abuse or substance
13 abuse. Certain communities are isolated from
14 information and services in particular in the
15 poorer areas and subsections of our city that are
16 separated from any kind of technology or health
17 services. In addition, the lack of
18 transportation, illiteracy and bilingualism pose
19 additional barriers.
20 El Paso has a staggering number of
21 teenage high school dropouts who remain isolated
22 from the social programs they desperately need and
23 we are already seeing how this will affect HIV
24 numbers.
25 In all of this, there are successes that

1 we shouldn't ignore. El Paso has had, like other
2 communities that have spoken here today, a
3 planning program that has been going for a year
4 now. We are coordinating services along with all
5 the other West Texas counties in Texas, that is,
6 Midland, Odessa, Harlingen, Lubbock, and
7 Amarillo.
8 But above everything, planning cannot be
9 done in a vacuum. Health care cannot be delivered
10 in a vacuum. And we were discussing at lunch
11 quite interestingly that when you discuss planning
12 for early intervention programs, one of the
13 responses you will get and one of the responses I
14 got from the physician at the HIV clinic is: What
15 will you do to ensure that this clinic does not go
16 under when you are sending us those newly
17 discovered patients through this early
18 intervention programs to the clinic. That is a
19 very real concern that we have.
20 The other real concern is that planning
21 can be done; but when there is no implementation,
22 it's probably going to be fruitless. And that
23 would be the final recommendation I would leave
24 with you. And that is that community-based
25 organizations experienced in providing services

1 must be granted the opportunity to establish
2 continuity with these successful programs.
3 Funding over longer periods of time is
4 imperative for long-term effectiveness in our
5 response to this epidemic. Because funding is
6 granted on a yearly basis, as you know, energy and
7 time must be focused every year with no guarantee
8 of sustained funding. This process is
9 unproductive and very stressful, and proven
10 programs can often lose very, very successful
11 grounds that they have made. Thank you.
12 REV. ALLEN: Steve.
13 MR. HUMMEL: Honorable Members of
14 the Commission: I'm the Executive Director of
15 Good Samaritan Project, Kansas City, Missouri's
16 largest AIDS Service Provider. At Good Samaritan
17 Project, we provide a wide range of social
18 services including volunteer programs, home health
19 care, emergency assistance and counseling. We
20 also have several education and prevention
21 programs and a National Teen education hotline
22 called Teens TAP (Teens Teaching AIDS
23 Prevention.). The number is 1-800-234-TEEN.
24 In the Metropolitan Kansas City area, we
25 have approximately twenty-five hundred cases of

1 AIDS and eight to ten thousand HIV-infected. At
2 the project, we currently serve five hundred
3 clients and project as many six hundred by
4 December of this year.
5 In Kansas City, we have four frontline
6 AIDS service organizations: Good Samaritan
7 Project, Kansas City Free Health Clinic, SAVE
8 Home - providing hospice and limited housing, and
9 Heartland AIDS Resource Council - a food market
10 for PWA's with AIDS.
11 Luckily, these organizations work
12 closely together, share resources, train
13 volunteers, and do some kind of fundraising. We
14 are also fortunate to have a city-wide AIDS
15 Council, whose mission is to provide leadership in
16 facilitating and advocating a planned and
17 coordinated response to the AIDS crisis in the
18 metropolitan area. Broad representation on the
19 AIDS Council of community leaders, including
20 corporations, foundations, United Way and
21 hospitals has begun to break down some barriers
22 that exist in Kansas City.
23 We are fortunate in the State of
24 Missouri to have a committed and active Bureau of
25 AIDS Prevention within our Health Department. In

1 1989, the Bureau of AIDS Prevention started a new
2 program called Care Coordination. The goal of
3 this program is to assist in the delivery of
4 services and facilitate access to entitlement
5 programs including a Medicaid waiver through case
6 management that employs the skills of social
7 workers and nurses.
8 In 1990, Good Samaritan Project signed
9 its first contract with the Bureau of AIDS
10 Prevention to become a satellite of the Care
11 Coordination program as a pilot project. If we
12 are successful, which I believe we will be, this
13 program will include other contracts with AIDS
14 service organizations across the state and
15 continue to grow as a project.
16 All of this may sound encouraging and it
17 is. Agencies in Kansas City, Missouri, work well
18 together and share the burden of the crisis. If
19 it wasn't for our ongoing lack of funding for care
20 services and expansion, continued education and
21 prevention, I might have little reason to be here
22 today.
23 There are four critical areas that must
24 have attention in the coming year if we're able to
25 maintain a level of quality services in our

1 community. These are: Social services, medical
2 services, education, and long-term care and
3 housing.
4 Good Samaritan has over the past twelve
5 months experienced a sharp increase in requests
6 for social service intervention. Great numbers of
7 clients seek emergency assistance for rent,
8 utilities, and medication. In the last eighteen
9 months, I've seen a disturbing new trend develop
10 which includes families with one or more infected
11 member, including children and single mothers with
12 one or more children.
13 Not only do these families have
14 extraodinary financial needs - two families in one
15 week had over $600.00 in utility shut-off
16 notices. And this is a common phenomenon for us,
17 but most need child care for all or part of the
18 day because their parent is ill or hospitalized or
19 one parent is overwhelmed by the needs of the
20 other ill spouse. We have no way to keep up with
21 these requests, and other social service agencies
22 in our community are as strapped for emergency
23 services and funds.
24 Currently, our case manager to client
25 ratio is one to a hundred and fifty. Standard

1 practice suggests one to thirty or forty-five. We
2 make do with volunteers, but have no choice to add
3 staff this year or begin turning clients away.
4 Additionally, we are seeing large
5 numbers of clients who have serious drug addiction
6 problems that compound HIV disease and in some
7 cases, supersedes HIV. For these clients, access
8 to treatment is often impossible if the desire for
9 treatment exists.
10 Our staff counselor is overwhelmed by
11 the huge needs for sensitive and informed mental
12 health services for over a hundred eighty-one of
13 our clients. Therapists who are trained and
14 affordable for outside referral are rare. We are
15 convinced that sensitive therapy is extremely
16 effective in stabilizing clients physically and
17 emotionally. Those clients who have professional
18 assistance are more able to meet the challenges of
19 HIV disease in many cases, find their physical
20 condition improved or stabilized over a period of
21 time.
22 In the area of medical needs, our most
23 critical problem is the lack of trained physicians
24 in private practice and in public health
25 institutions. Physicians in Kansas City who see

1 people with HIV disease have large caseloads and
2 long waits for new patients, some up to three or
3 four weeks.
4 Public hospitals and clinics are at
5 maximum capacity or lack trained doctors and
6 nurses to effectively treat the many
7 manifestations of HIV. Our clients struggle to
8 maintain health insurance premiums once they
9 become disabled or lose work and fear their level
10 of care will diminish once they are on Medicaid.
11 REV. ALLEN: Excuse me, Steve. So
12 we can have time for questions and answers, your
13 written testimony can be submitted into the record
14 and give you an opportunity for dialogue. I hate
15 to cut you off, but if you want to make your
16 closing remarks.
17 MR. HUMMEL: Sure. To close, each
18 service provided in Kansas City, Missouri,
19 recognize that unless we receive greater funding
20 in twelve to eighteen months, we will be forced to
21 draw the line and stop taking new clients.
22 After five years of service, funders
23 continue to work with suspicion that AIDS has
24 developed in Kansas City, although, this is
25 beginning now to change. I can only guess that

1 funds will be as usual, too little, too late to
2 respond to our crisis of need.
3 REV. ALLEN: Charlie.
4 DR. KONIGSBERG: A couple of points
5 and questions of Steve Hummel. I think it's
6 important to point out that there's a perception
7 that in the midwest, in fact, a lot of
8 midwesterners I think believe that AIDS is a
9 somebody else's problem. I think we may have
10 talked about this before. While I'm not sure I
11 totally agree with the case count, the fact is
12 that Kansas City, Missouri, looking at both
13 states, is not alone in this area and does have
14 many problems.
15 I wonder if you would elaborate a little
16 bit. One of the concerns that we as the Sante Fe
17 Tri-Regional was some way to pull together the
18 two-state area and there have been some
19 discussions about it.
20 For those of you not familiar with the
21 Kansas City metropolitan area, it does cover both
22 Kansas and Missouri. Kansas City, Missouri,
23 Kansas City, Kansas, which is Wyandotte County,
24 which is one of our highest case rate areas in
25 Kansas and Johnson County in Leavenworth also are

1 impacted from AIDS.
2 But it does raise a number of issues
3 that are difficult to deal with in terms of
4 planning a total service package across state
5 lines, across county lines, across city lines.
6 It's quite complex. And, Steve, do you want to
7 elaborate on that a little bit?
8 MR. HUMMEL: Well, I think there
9 traditionally has been a real separation in the
10 city between the Kansas side and the Missouri side
11 and I think that continues with the disease. The
12 AIDS counseling has made some efforts to bring
13 greater cooperation between health departments.
14 But the Kansas side is mostly suburban and very
15 wealthy and also has a real problem with denial
16 that the disease exists in that community, and as
17 well as hunger, homelessness, and other problems.
18 We serve about a hundred and fifty
19 clients on the Kansas side. We try to work with
20 the health department in that area, but many of
21 our clients end up moving across the state line to
22 access Care Coordination and Medicaid waiver
23 services. And this is very common that we'll end
24 up advising some of our clients to get across the
25 state line so that they are able get some of those

1 kind of services.

2 However, Kansas offers other public

3 funds that for some of our clients it's better for

4 them to move from Missouri to Kansas when they're

5 still physically capable to have access of those

6 funds.

7 DR. KONIGSBERG: Are those social

8 service funds as opposed to health funding?

9 MR. HUMMEL: Yeah, be it

10 entitlement programs.

11 DR. KONIGSBERG: That's what I

12 thought.

13 MR. HUMMEL: Right.

14 DR. KONIGSBERG: The case figures

15 that I have available to me on metropolitan Kansas

16 City are something over eight hundred including

17 the Kansas side. But the number of infected is as

18 you state and certainly would indicate that it

19 will be a continuing problem. Thank you.

20 MR. GOLDMAN: Jean, I was wondering

21 have you found that the civil rights investigation

22 and the results had any changes in attitude on the

23 part of nursing home and other attendant care

24 institutions to be more accepting?

25 MS. DERRY: No. It has changed the

1 manner in which they respond to our requests for
2 nursing home beds. They no longer say we're full
3 or they no longer say we don't take AIDS patients;
4 they say I'll have to get back to you on that.
5 And there was -- since you brought that
6 up, there was a comment made in the earlier panel
7 before lunch that they're a forty-seven dollar a
8 day rate was keeping nursing homes from providing
9 the care and that's not been our experience at
10 all. We established a hundred and twenty-eight
11 dollar a day rate which is three times our normal
12 rate for nursing home care just for AIDS patients
13 and got no takers.
14 The only facility we've been able to
15 place AIDS patients in took them at a forty dollar
16 a day rate and has shown that their cost is no
17 more great than their typical geriatric patients.
18 MR. GOLDMAN: Do you have any idea
19 or an explanation as to what their reluctance is?
20 Is it simply a matter of --
21 MS. DERRY: They have a number of
22 fears, mostly relating to loss of staff, loss of
23 residents. The facility that we have had sex
24 with -- sex with? Take that out of the record.
25 Success with.

1 (Laughter.)
2 REV. ALLEN: You have had what?
3 What did you say?
4 MS. DERRY: Well, you know, I've
5 got safe sex on the brain. We've had a lot more
6 safe sex than we have success. I better stop
7 while I'm ahead.
8 MR. DALTON: You just kept going
9 on.
10 MS. DERRY: What was the question?
11 MR. GOLDMAN: You were going to
12 elaborate on the perception of nursing homes and
13 why they were reluctant to take patients with
14 AIDS.
15 MS. DERRY: Okay. In the facility
16 we have had success with did call in their
17 residents and the families of the residents and
18 explained to them upfront we are going to accept
19 patients with AIDS. They called in their staff
20 and told their staff the same thing. They had one
21 employee who resigned. She came back one week
22 later and asked for her job back. They had no
23 residents leave.
24 They had no extensive costs above what
25 Medicaid would reimburse for. We offered to pay

1 with state funds, if necessary, additional charges
2 that they could document that would be pertinent
3 specifically to an AIDS patient and there were
4 none that I am aware of at this time.
5 So, we happen to have a very good
6 relationship with the AIDS Commission at our
7 Health Department and Department of Human
8 Services. And we have had the Health Department
9 out doing training at these nursing homes. We've
10 offered them every kind of service we can think
11 of. I don't know what to do next other than we
12 are waiting to see what the results of this
13 hearing are or the appeal.
14 MR. DALTON: Is there anything
15 different about the nursing home with which you
16 have had successes than the others other than that
17 fact that you're discussing?
18 MS. DERRY: Well, I guess what I
19 could describe as it's a small kind of mom-and-pop
20 operation as opposed to one of the large corporate
21 franchise kinds of facilities. They had a couple
22 of vacancies. It's not a new facility. They
23 didn't have a lot of huge overhead costs and so
24 forth, but their care was excellent. It was very
25 clean. All of the patients that we've placed

1 there have been very happy there. That's the
2 primary difference, I guess.
3 MS. ESPINOSA: I have a point on
4 that because we have a very similar situation
5 where we have one nursing home that has taken the
6 initiative and educated the family members, the
7 residents, as well as the staff for over a year
8 now.
9 And I, just from a personal opinion,
10 believe having talked to the administrator of that
11 nursing home as well as recently the administrator
12 of the nursing home that have refused, on every
13 day the reason changes to take a client with
14 AIDS.
15 It has a lot to do with the leadership
16 of the administrator. And one approach has been
17 to discuss with the administrator and the
18 successful nursing home making that program, an
19 education in-service program, a model for the rest
20 of the administrators and having her as the
21 administrator approach other administrators to get
22 this education done within their staff because it
23 is the law, and currently we're waiting for
24 corporate approval of that idea.
25 But I think what it boils down to is the

1 leadership of the individual nursing homes and how
2 willing they are to accept the inevitable.
3 MR. DALTON: What a wonderful idea,
4 using the nursing home that you have success with,
5 those administrators as trainers of other places.
6 MS. ESPINOSA: Yeah. It has to be
7 within the -- you know, the inside leadership, I
8 think. Because coming from the outside, I think
9 that's also another reason is we must appear to be
10 threatening to get on the phone, which I just did
11 out of desperation.
12 I said, all right, you want to play the
13 game, we'll play. If the only alternative we have
14 is to file a formal complaint, then we will do
15 so. And they have come back and said go right
16 ahead and that's where we're at.
17 MS. DERRY: If I may, the response
18 we have had to that very same kind of activity was
19 they -- the other nursing home administrators or
20 owners where this person had encouraged to
21 continue to take AIDS patients as if there's
22 anything they can do to help and, you know, in
23 other words, keep the monkey off their back.
24 MR. HUMMEL: I want to make a
25 comment on this. In Kansas City, we have the same

1 problem. We don't have nursing homes that takes
2 anyone except in St. Louis. There was a hundred
3 twelve referrals to long-term care from the state
4 that have been documented and only four of those
5 people were placed in a nursing home outside of
6 St. Louis that has four beds.
7 And at this point, several organizations
8 in the ACLU and a very large law firm in Kansas
9 City are looking at a class suit to be filed in
10 federal court and it's becoming a very real
11 possibility -- probability at this point because
12 we see this as the only way to finally change this
13 situation. Because we believe the same thing will
14 occur. One nursing home opens its doors, it
15 becomes the AIDS nursing home and it goes no
16 further than that.
17 DR. KONIGSBERG: I wanted to follow
18 up a little bit with the nursing home question
19 particularly to Ms. Espinosa and Jean Derry. I
20 guess one of my functions as the state health
21 official is to regulate nursing homes and
22 hospitals, which I guess my question is: Did that
23 enter into it at all in terms of that part of the
24 state government would be one question and then
25 could you elaborate a little as to exactly what

1 Hickfa's (phonetic) interest was and what rulings
2 they had to bring about some pressure to allow
3 access for persons with AIDS and HIV disease into
4 nursing homes?
5 MS. DERRY: Basically the policies
6 that Hickfa used related to the Medicaid
7 assurances that our department agreed to in
8 accepting Medicaid monies; and we, in turn, then
9 got those assurances from the facilities that we
10 contract with, that they would not discriminate
11 against any persons on the basis of race, sex,
12 handicap, etc.
13 We employed those policies in that. I'm
14 not sure about your question with the hospital and
15 nursing home regulations in that regard.
16 DR. KONIGSBERG: It was primarily
17 the nursing home that I was concerned about.
18 MS. DERRY: Okay.
19 MS. ESPINOSA: That would be
20 exactly the same policy structure we would follow
21 as well and that is the assurance that has been
22 agreed to. It's no different and our nursing
23 homes have signed that.
24 DR. KONIGSBERG: So that Hickfa was
25 then responsive and helpful in this regards.

1 MS. ESPINOSA: Well, he doesn't --
2 you're ahead of us in that sense. For us, that's
3 the next step, to see whether they will enforce
4 that or how far it's going to have to go before.
5 MS. DERRY: We most recently
6 received the letter from Hickfa to the Medicaid
7 directors laying out those procedures. Our
8 experience in Oklahoma, however, began back in
9 January or I suppose right after Christmas and
10 things seem to have been formalized at the federal
11 level since then.
12 DR. KONIGSBERG: Thank you.
13 MR. DALTON: A question for Paula
14 Elerick Espinosa. Anything about the story you
15 told about the hospital, Thomason Hospital, that
16 took the patients from Mexico. And then you
17 indicated that the county hospital board of
18 trustees had decided to ask for sixty-seven
19 percent increase in funding from the county. You
20 didn't indicate whether they had voted to increase
21 the funding sixty-seven percent.
22 You raised the question who's going to
23 pay for this. I guess my question is: What does
24 happen along the border when the counties along
25 the border wind up initially providing the

1 services for people coming across the border? How
2 does that lay itself out? I can't imagine that
3 those counties are inclined and capable of --
4 MS. ESPINOSA: No, it's
5 impossible. And this is just a recent
6 occurrence. This is
7 just -- everything is so recent that -- this is, I
8 think, last week that the request was made for
9 this increase.
10 In addition to that, the consequence
11 will be the shutting down of certain services
12 including nightshift, emergency room, which has a
13 direct impact on how we manage emergency
14 admissions for HIV infection and get them admitted
15 to the hospital and taken to alternative care.
16 But to answer your question, the county
17 cannot be responsible for the cost of the care
18 that Thomason ultimately has to deal with
19 because -- and it's only because this is very new
20 to us.
21 But years back, there was a lawsuit to
22 -- for the federal funding to be inputted into
23 this system because that's the only solution
24 really for that community and that may have to be
25 taken up again if this is going to be resolved.

1 In our city, there is a fed-up taxpayers
2 organization, I think, something similar to that,
3 that has just built a community cultural center,
4 an indian reservation cultural center, an old
5 theatre being renovated. People cannot give in
6 more. I mean that's really the bottom line. I
7 don't think it's an opposition to these things,
8 but it represents how overextended our tax base
9 is. It is so incredibly taxed already based on
10 what we are able to give.
11 And the solution I think is going to
12 have to be perhaps the county government getting
13 involved in putting the pressure on the Federal
14 Government to come to the table and get some
15 solutions because we can't turn anyone away. Or
16 maybe that's what it will lead to is turning
17 people away at the door at Thomason without --
18 MR. DALTON: And wait for them to
19 sue --
20 MS. ESPINOSA: Pardon?
21 MR. DALTON: And then waiting for
22 them to -- are you putting the burden on them to
23 sue the county?
24 MS. ESPINOSA: Maybe that's what's
25 going to have to happen because they're -- I know

1 that they're not in a position to vote and they
2 will tell you that they will not vote for any kind
3 of tax increase. It hasn't happened and it's not
4 going to happen. But now they're in a position
5 where they have to make a decision.
6 You can't turn away somebody from your
7 county hospital for assistance after a sixty-seven
8 percent increase. I mean if it had been a ten
9 percent increase, I think they probably would have
10 discussed it and compromised it. But this is a
11 pretty point-making figure and it's drawn all of
12 our attention.
13 And in El Paso, that's why I focused on
14 it. AIDS is just part of this entire system. If
15 our county hospital collapses, the next in line is
16 the Southwest AIDS Organization. That's
17 inevitable because we cannot go on supporting our
18 clients without that kind of assistance, without
19 that kind of care.
20 REV. ALLEN: I have a couple of
21 questions along that line. Are you aware or could
22 you explain to us about the relationship between
23 Juarez and El Paso and some of the health
24 initiatives that have been going on, who in the
25 health department are meeting together, and

1 talking about education, and so forth?
2 MS. ESPINOSA: There is a really
3 strong, probably the most national issue is the
4 coordination between both sides for TB control.
5 That's just a phenomenal problem. But along with
6 that comes the dialogue for other problems, one of
7 them being perhaps education for AIDS. That is
8 not happening yet. I think they've discussed it
9 in terms of problems, but there are so many other
10 problems. There's TB, the environment, water
11 sewage contamination. All of these issues sort of
12 take precedence, but yet the flow of AIDS is no
13 different. It crosses both ways.
14 The gay community in Mexico are
15 interfaced with our gay community and vice versa.
16 Just recently in the paper they had an article on
17 transvestite prostitutes, IV drug users along the
18 border. Juarez is, from my mother's house,
19 walking distance. From the University of Texas at
20 El Paso, the honor's office you look out into your
21 first generation Mexican/American student you look
22 out into Juarez, not of the United States. We are
23 one community. If that is what we can say, we are
24 one community and our problems are one. And yet,
25 the county government or the city government of

1 Mexico is very reluctant with respect to AIDS to
2 admitt to any problem.
3 And so, organizations in Mexico have
4 been forced to sort of take on the work for
5 clients who are HIV-infected without any
6 resources. And the few resources that they have
7 usually come from some collaboration on the
8 El Paso side.
9 And AIDS aside, all of these issues you
10 talk to someone involved in runaway youths and gay
11 youths and any kind of problem that they'll say to
12 you, what we need is initiatives to be able to
13 share our dollars, our programs or our dollars
14 through our programs.
15 If I can't go into Juarez and deal with
16 this problem, it's not going to be solved because
17 we just lose the ravel. It just continues. We
18 lose that link and the problem resurfaces. And if
19 this proves anything, this collaboration with TB,
20 it will be that in order to deal with AIDS along
21 the border it will require that kind of
22 partnership.
23 REV. ALLEN: Do you find a lot of
24 irrational hostility in El Paso and so forth?
25 What are you dealing with in that respect?

1 MS. ESPINOSA: I wouldn't
2 necessarily call it hostility, but I would say
3 that we are at a turning point in El Paso. We are
4 seventy percent Hispanic; and in the grassroots
5 organization that I belong to, the talk is, you
6 know, yes, tiempo, it's time that we start
7 empowering ourselves to take positions of power
8 and this is a Hispanic community.
9 And there is this tension in El Paso of
10 Hispanics being tired of not being able to make
11 the decisions that affect their lives. And the
12 political face of politics is changing and of
13 government. And so, there's that tension.
14 Hostility is not really a word I would
15 use. I think that as a community we get along
16 however. But when you talk about AIDS services,
17 we do -- there's the same tension you find in any
18 of the communities. There's territorial
19 defiances.
20 We are seeing as -- somebody else
21 accused another organization earlier today of
22 being a gay white male organization and yet the
23 reality is our caseload is primarily Hispanic, our
24 staff is primarily Hispanic, and we are not able
25 to defer sort of that territorial control to the

1 Hispanic leadership because they are unable to
2 deal with the homosexual population that they must
3 serve if they were going to deal effectively with
4 AIDS. So, there are tensions that are racially
5 based, but they're not necessarily hostile. They
6 do prevent the delivery of health care, though.
7 Recently we had a collaboration with one
8 of our foes who are now sort of one of our
9 partners in a grant writing session and I think
10 that that's -- it's becoming a reality that we're
11 going to have to work together if we're really
12 going to be effective in our community
13 REV. ALLEN: Okay. Anything else?
14 MS. DIAZ: Paula, are you working
15 with the border initiatives at all funded by CDC
16 for collaborative work between those border towns
17 here and border towns in Mexico?
18 MS. ESPINOSA: Well, we follow the
19 border initiatives that our health department is
20 taking as Reverend Allen asked with our issues.
21 But in terms -- and we've sort of created our own
22 initiatives with community-based organizations of
23 Juarez. Yes, in Juarez. And our organization has
24 interfaced with two organizations, one that does
25 outreach to gay prostitutes and the other that

1 does outreach to IV drug users and their wives and
2 families.
3 And what we do is come to the table to
4 discuss what we can do. We're limited. We can't
5 really even represent our organization because
6 that would be violating the law, but we can go as
7 individuals and say how can we help you to start a
8 program.
9 MS. DIAZ: You might be interested
10 that California recently held a first conference
11 between Mexico and California on AIDS. So, there
12 will be a full transcript and edited monograph and
13 I think it will be helpful to you.
14 MS. ESPINOSA: Very much so, yes,
15 yes. Thank you.
16 MS. DIAZ: Okay.
17 REV. ALLEN: Any other questions?
18 Thank you very much.
19 MS. ESPINOSA: Thank you.
20 REV. ALLEN: The next group of
21 individuals Henry Masters; Luis Fuentes; George
22 Buchanan, Director of North Texas Comprehensive
23 Hemophilia Center, Dallas; Don Maison, AIDS
24 Services of Dallas; and Ted Wisniewski. Do you
25 want to begin, Ted?

1 MR. WISNIEWSKI: Members of the
2 National Commission on AIDS, I would like to focus
3 on one concept related to our national response to
4 the AIDS/HIV epidemic, and that is, we need more
5 direction and we need it now.
6 I articulate this focus from the
7 perspective of our New Orleans and Louisiana AIDS
8 services configuration. We have been fortunate to
9 have captured virtually every source of federal
10 HIV-directed funding.
11 In some ways, we might be used as a case
12 study to examine what happens when these resources
13 are poured into an area without significant
14 interagency foresight and direction. Despite the
15 noble guidelines in grant RFP's and the best of
16 intentions on the part of project directors and
17 program staff, these grant initiatives cross
18 through an absolutely overwhelmed health care
19 system and service providing community.
20 Early intervention is perhaps the single
21 most important reason for our system's collapse, a
22 system built on multiple informal relationships
23 between community endeavors and health systems
24 programs.
25 Yet, perhaps our response to the demand

1 for early intervention can serve as a focal point
2 around which we can build the services
3 configuration that is meaningful, rational,
4 compassionate, and effective. We can only do this
5 if significant federal support and leadership is
6 forthcoming.
7 Six examples of why we need such
8 leadership are as follows: Number one, with
9 limited resources, we are currently struggling
10 with choices of quality versus quantity. Through
11 our previously developed structures and
12 community-based origins push us to uphold
13 quality. The research data, the medical system
14 and the public health tracking and treatment
15 recommendations pull us to manage quantity.
16 Secondly, this tension is further
17 exacerbated in impoverished areas where, quote,
18 hierarchy of needs, close quote, is a very real
19 experience. Federal initiatives that do not give
20 projects the authority or resources to work within
21 communities struggling for mere survival will
22 ultimately do very little to impact the epidemic.
23 Concretely, as mentioned this morning,
24 the pie is just not big enough. But even if
25 enlarged, we need your help in drawing the bold

1 lines. It is hard to imagine that we will be able
2 to continue, quote, demonstrate our service models
3 if significant dollars will need to be distributed
4 amongst a substantially enlarged number of
5 infected persons. From a national perspective,
6 help us tease out our most successful approaches
7 so that we might best target our limited funds.
8 Number three: The research is done and
9 the recommendations are very clear, but we have no
10 real way to provide early intervention. Our
11 current waiting period for persons to access
12 public care in Louisiana is greater than six
13 months.
14 The cost for AZT alone to treat next
15 year's expected population at our clinic is better
16 than double our current total clinic's operating
17 budget. The federal AZT support is only a small
18 fraction of what is needed, and the vast majority
19 of these patients are not disabled and thus do not
20 qualify for Medicaid.
21 Clearly, we need your leadership to work
22 with the pharmaceutical industry in lowering the
23 costs. We also need funding for massive volumes
24 of required T-cell studies. Priority should be
25 given to either changing federal Medicaids

1 disability regulations or, on the other hand,
2 expanding the AIDS definition to help finance
3 these costly care mechanisms that are now
4 recommended.
5 Fourth, though perhaps clustered in a
6 broad category of human services, medical health
7 care and psychosocial support services do not
8 usually always collaborate effectively. In having
9 to choose priorities, it is hard to imagine that
10 traditionally separate groups will find it easy to
11 work together. Plainly put, physicians and
12 hospitals need to be taught and reimbursed for
13 working with human service workers and community
14 organizations - and the reverse is also true.
15 Persons with skills to translate between such
16 diverse groups and systems should be sought and
17 promoted.
18 Fifth, even more specifically, we need
19 your guidance to assure that primary health care
20 services and case management services are managed
21 together; though their sites of service provision
22 will be inpatient and outpatient, hospital and
23 home, institution and community, primary health
24 care and case management must articulate a
25 conjoint purpose in response to the HIV epidemic.

1 Concretely, if out of hospital care is
2 our goal, we must include health care providers
3 and hospital administrators in the development and
4 administration of case management systems to make
5 sure that we move beyond mere community philosophy
6 to institutional nuts and bolts together.
7 Sixth, the administration of pediatric
8 and adult services response is duplicative locally
9 and irrational nationally. The sheer numbers of
10 infected persons and the dollars allocated really
11 call to question how we qualify ourselves as a
12 compassionate nation. Only through federal
13 leadership can our displaced biases be refocused
14 on a truly humane response.
15 In addition to the above six points, I
16 have offered some more detailed recommendations in
17 your packets that were previously submitted to
18 HRSA National Advisory Committee. Item number
19 1389 are particularly pertinent to our discussion
20 today. Thank you.
21 REV. ALLEN: Luis Fuentes.
22 MR. FUENTES: (Monologue in
23 Spanish.) Now my English is also sketchy. Good
24 afternoon. I just wanted to say really a very
25 important message. The language is a very

1 important thing we're going to address here.
2 My name is Luis Fuentes and I'm with a
3 group called AVES from Houston, and I'm going to
4 have to just basically side with my colleagues. I
5 think they've done a wonderful job bringing in the
6 problems.
7 So, I'm going to present a general
8 overview: The needs of agencies from the
9 Government. We need education. We need
10 services. We also need technical assistance.
11 There are no cooking recipes. We all
12 know that. There's no specific steps to follow.
13 I think like a family, a program needs to be
14 nurtured, needs to be guided, needs to be
15 educated, and disciplined if required.
16 Problem number one that I'm going to
17 express here is that sometimes we put a program
18 for Hispanics, we sometimes translate that into
19 Spanish and we think that it's appropriate for
20 those who do not speak English. Well, we might be
21 hearing the same label as Hispanics or Latinos,
22 but there is no unit in our community. We come
23 from different backgrounds, from different
24 countries. We got different lingos. We're very
25 different.

1 So, we need to let the target community
2 design their own program. They will accept it and
3 they will take it better under their wings. We
4 need to empower them. We got three different
5 groups within the Hispanic community. We've got
6 the newly arrived that doesn't have any commands
7 of the language, facing cultural shocks, and
8 socioeconomical differences.
9 We've got the dualistic individuals. I
10 think I'm going to label myself in that category
11 that we're trying to get acculturated with
12 command, but we still have very strong cultural
13 ties. And if we're talking about my mother, you
14 know, you better stop it because I'm not going to
15 tolerate that. So, that's the way, you know, my
16 Mexican heritage shows here. So, we have very
17 strong ties in traditional family and friends.
18 And then we have the A-traditional.
19 Okay. And I'm sure that the Hispanic community
20 and the whole Texas area is going to kill me for
21 this, but we label that within ourselves the
22 coconut, brown on the outside and white on the
23 inside by name only. Okay. Sometimes we make a
24 mistake of this individual as Latino or as
25 Hispanic and they do not have the ties to their

1 community because they've been fully
2 acculturated. More labels.
3 This areas needs to be specifically
4 addressed to design any kind of program or
5 education or health services. The solution for
6 this year is empowerment again. It is going to be
7 hard to work with some of these individuals and
8 ask me where our grassroots organization, but
9 allow us to design our own program. They will
10 accept it better and they will help you to promote
11 because that's their program.
12 You need to get participation from these
13 individuals. Insure their monies. We do need
14 money. I can hear the same song over and over
15 again. Top forties here. We need more money.
16 Okay. But this money should be directed to
17 minorities, directly to groups that are really
18 working in the community.
19 There are some -- and when you put
20 panels like this, do not just include a Hispanic
21 leader. Include members of that community.
22 Hispanic leaders sometimes we get so wrapped up in
23 our reporting and administrative requirements that
24 we lose touch with our community. We also need
25 technical assistance. A lot of times, we know how

1 to do the work; but we need help in planning.
2 Administrating and reporting.
3 Second problem: Always assume he or she
4 is bilingual; he or she speaks Spanish. We have
5 all this material in Spanish. Isn't that enough?
6 Well, we are assuming and you know what happens
7 when we assume. Not because you have a neighbor
8 or our maid who is a Hispanic individual, that
9 makes you an expert to rate another person as
10 bilingual and bicultural. You need to be
11 sensitive.
12 There are other cultural issues that we
13 need to address. AIDS does not stand alone. We
14 got sex roles; we got families; we got family
15 involvement; we got machismo; we got homosexuality
16 cultural perceptions. We have a lot of problems
17 that need to be addressed. It's not just Spanish
18 what we need. We need sensitivity and
19 biculturism.
20 Let me just give you a quick example
21 here. One of my clients went to a counselor. And
22 this individual counselor, this Hispanic lady, for
23 about an hour -- okay, and just to show you that
24 there's a lot of respect -- she didn't say
25 anything. She was just nodding and saying okay,

1 okay, okay. Just to find out that the -- after an
2 hour, this individual didn't understand a bit of
3 English at all. You call this sensitivity? And
4 this from a professional.
5 The solution, we need to hire
6 individuals -- we need to be selective. You need
7 to do some -- we need to do some search and
8 research. Don't just settle for just the token.
9 Not because you're Hispanic or you're brown or you
10 have brown hair or black hair. That does not make
11 an expert. And another thing: Degrees will not
12 help you if you're not sensitive enough. There is
13 a program in the area. That's all they need.
14 Well, let me tell you about this one
15 here. A greater number of agencies are getting
16 more and more involved in the fight against AIDS.
17 Why? Because there is more money. Okay. And
18 they are more powerful than small agencies. So,
19 they put much better, more complete with better
20 objectives and more evaluation than us. So, they
21 get the funding.
22 It's a lot easier for federal agencies
23 to fund some of their programs when we small
24 agencies do not have a track record. Well, how
25 are we going to get a track record if you don't

1 help us out?
2 They put beautiful reports, wonderful.
3 They manage to cover their reports very well. So,
4 you need to also watch the small underdog
5 agencies. We struggle and sometimes we collapse
6 and you see us as failures. So, you see. I'm
7 glad that we didn't fund them.
8 So, we try to work with large agencies;
9 but there is a lot of turf protection. And that
10 doesn't just happen in the Hispanic community.
11 That happens in any group of people.
12 REV. ALLEN: One more minute,
13 Luis.
14 MR. FUENTES: So, please become
15 watchdogs for the monies and the program. And
16 just to conclude, I want to just give you four key
17 words that I use myself. I practice what I
18 preach.
19 Observe. The language, the
20 discrimination, the politics, the education, the
21 culture, the shame, the guilt, the phobias, the
22 denial, the behavior, and all that. Observe,
23 watch.
24 And listen to the affected ones, to the
25 family, the loved ones, the community, the church,

1 the school, the children. Also listen to the
2 pain, the fear, the anger, their concerns.
3 Now, trust. Trust yourself first and
4 your ideals and then earn the trust of the
5 community. If you don't earn the trust of your
6 community, it's not going to work.
7 Now it's time to roll up your sleeves
8 and get to work. By observing the phobias, the
9 fears, by listening to the pain and the fear,
10 their pride and by earning their trust, only then
11 you can help. They'll tell you what they need.
12 And you can do one of three things just
13 to conclude. Get involved directly, provide
14 education or services. Get involved indirectly.
15 Help us in politics, advise and support. Or
16 kindly, please get out of the way. Muchas
17 Gracias.
18 REV. ALLEN: Thank you. George
19 Buchanan.
20 MR. BUCHANAN: My name is George R.
21 Buchanan. I'm a Professor of Pediatrics at the
22 University of Texas Southwestern Medical Center
23 here in Dallas. My specialty is Pediatric
24 Hematology-Oncology, and one of my particular
25 interests is hemophilia.

1 I direct the North Texas Comprehensive
2 Hemophilia Center which provides care to most
3 hemophiliacs in North Texas. As you know, many
4 thousands of hemophiliacs were infected with HIV
5 during the early 1980's and as such constitute a
6 large and unique group affected by this tragic
7 epidemic.
8 Hemophilia is an inherited condition
9 affecting one in seventy-five hundred males. It
10 is characterized by a delay in blood clotting
11 following minor injury. The treatment consists of
12 intravenous infusions, thirty or more times a
13 year, of a blood product that contains the missing
14 clotting factor.
15 During the 1970's, home infusion and
16 even self transfusion programs were initiated and
17 comprehensive treatment centers were developed to
18 assist these patients to lead more normal lives.
19 It became clear that hemophiliacs were capable of
20 having a normal life span and, moreover, that
21 their care was highly cost-effective.
22 However, tragedy struck in the early
23 1980's when the plasma pools used to produce
24 concentrate became infected with HIV. By the time
25 that HIV was identified as a cause of AIDS in

1 1984, more than twelve thousand of the twenty
2 thousand hemophiliacs in the United States were
3 infected with the virus. Over thirteen hundred
4 hemophiliacs have developed AIDS which is now the
5 leading cause of death in these patients.
6 Now, hemophiliacs certainly share with
7 other risk groups many of the medical and
8 psychosocial features of HIV infection. But this
9 population I think is unique. For instance, many
10 of these individuals are older children and
11 adolescents, an age when HIV infection
12 infrequently occurs in other risk populations.
13 Most are heterosexual in their orientation.
14 Hemophiliacs represent the entire
15 socioeconomic and cultural spectrum of citizens in
16 the United States. Most infected patients exhibit
17 no other high-risk behavioral characterisitcs
18 predisposing to HIV infection. Most importantly,
19 as a group, hemophiliacs are no longer at risk of
20 new HIV because of technical advances in virus
21 inactivation of the plasma concentrates.
22 Now, from my perspective here in North
23 Texas, I can speak firsthand about the tragedy of
24 HIV infection in hemophiliacs. Over two hundred
25 boys and men with hemophilia attend the North

1 Texas Comprehensive Hemophilia Center in Dallas.
2 Over eighty of these are infected with HIV and
3 sadly several have died of AIDS including a number
4 of patients whom I cared for, for more than a
5 decade.
6 The HIV epidemic is certainly a disaster
7 for every one, but especially so for these
8 patients and their families. I know the focus of
9 this Working Group is identification of the social
10 barriers encountered by these patients and I'd
11 like to briefly outline some of those specific to
12 the hemophilia population including economic
13 barriers, cultural barriers, psychosocial
14 barriers, barriers in the professional support
15 systems and briefly, geographic barriers.
16 The economic barriers for these patients
17 are overwhelming. The costs associated with
18 hemophilia care have quadrupled during the past
19 five years coincident with the development of
20 safer, fewer blood products devoid of HIV.
21 Hemophilia is now the most expensive of
22 all chronic medical conditions, with typical costs
23 of fifty to one hundred fifty thousand dollars per
24 year just for the blood products vital for life.
25 Even patients with excellent private insurance are

1 approaching their lifetime caps, creating worry
2 and uncertainty about future coverage.
3 Many hemophiliacs have become indigent
4 and face the stringent and often inconsistent
5 guidelines promulgated by Texas Medicaid. The
6 state agency charged to provide assistance to
7 families with chronically ill children including
8 hemophiliacs; that is, CIDC or Chronically Ill and
9 Disabled Children Services in Texas -- has been
10 woefully short of funds for coverage of hemophilia
11 and complications such as HIV infection.
12 Although a recent tax increase effective
13 just a couple of weeks ago is aimed to remedy this
14 problem in the short term, there is great
15 uncertainty whether this barrier can be
16 effectively reach in the future.
17 The State's Hemophilia Assistance
18 Program for adults is also grossly underfunded
19 with just $250,000.00 annually appropriated for
20 all hemophiliacs in the State of Texas. This is
21 hardly enough to provide meaningful assistance for
22 three or four patients much less the several
23 hundred who require health.
24 Moreover, the adult program covers only
25 the cost of blood products and does not provide

1 for assistance for AZT, immunologic testing,
2 hospital charges, etc.
3 Cultural barriers also exist for the
4 hemophilia population. These individuals often
5 have no one to talk to about their condition.
6 They can't go to their friends, neighbors,
7 teachers or associates and discuss openly their
8 fears and concerns.
9 What about support groups and
10 governmental agencies? Unfortunately for the
11 hemophlia population, most such groups focus
12 primarily or exclusively on the gay population or
13 other individuals such as intravenous drug users.
14 Moreover, until recently, most AIDS/HIV support
15 groups in Dallas and other communities have not
16 included children and adolescents and their
17 families.
18 Many of my patients with hemophilia and
19 HIV infection exhibit an intense anger toward the
20 gay community, in a sense blaming them if you will
21 for their new affliction. Therefore, it's
22 impossible it encourage these patients to
23 participate in support groups that include these
24 other patient populations.
25 Related to these cultural barriers are

1 several psychosexual ones. Most of our
2 HIV-infected patients are adolescents and young
3 adults and many of them are sexually active. The
4 transmission of HIV to their sexual partners is a
5 potential problem of great magnitude.
6 Several studies have shown that ten to
7 twenty percent of the sexual partners of
8 hemophiliacs are infected with HIV. And according
9 to the CDC, over fifty such sexual partners have
10 already developed AIDS; and on too many occasions,
11 the virus has been passed on to the unborn
12 children of hemophilia couples.
13 The need to counsel these patients and
14 inform them about the safest possible sexual
15 practices is readily apparent. The degree of
16 stress and anxiety faced by these patients has
17 been overwhelming resulting in problems in forming
18 and maintaining stable relationships.
19 Moreover, the advice that pregnancy be
20 avoided has added another dimension of stress in
21 these patients and their spouses who strongly
22 desire to have children of their own.
23 An additional barrier for these patients
24 and their loved ones relates to inadequacies in
25 the professional support systems available to

1 them. During the past twenty years, the main
2 health care providers for hemophiliacs have been
3 pediatric and adult hematologists like myself and
4 other professionals whose orientation has been
5 toward bleeding difficulties and muscoloskeletal
6 complications, not HIV.
7 Those of us who received our training in
8 hemophilia before the HIV epidemic were
9 ill-prepared to deal with complex psychosocial
10 issues in adolescents and young adults, human
11 sexuality, risk reduction, management of
12 infection, etc. This has put the patients and
13 their families in a really difficult situation,
14 since the doctors that they have counted on most
15 were ill-prepared to deal with their needs.
16 Now, fortunately, some progress is being
17 made in addressing the outstanding adequacies in
18 the professional support systems.
19 REV. ALLEN: About one minute.
20 MR. BUCHANAN: Okay. An infusion
21 of funds from the CDC and Office of Maternal Child
22 Health to the network of federally-funded
23 comprehensive hemophilia treatment centers has
24 been allocated for HIV education and risk
25 reduction. This initiative has allowed for an

1 assembly in centers such as ours of a team of
2 psychosocial professionals skilled at dealing with
3 HIV and at educating hematologists and other
4 classical hemophilia care providers about these
5 new and overwhelming problems.
6 The hemophilia centers have begun to
7 form effective linkages with community-based
8 organizations, governmental agencies and support
9 groups in order to bridge the knowledge and
10 service gaps.
11 The last barrier I wanted to mention is
12 geographic. In the two hundred thousand square
13 expanse of North Texas, many of our hemophilia
14 patients live on farms, ranches, and in small
15 towns many hundred miles away from Dallas. Many
16 of them, especially adults, remain in the closet
17 too afraid to be identified as a hemophiliac or to
18 be tested for HIV and often unaware of the dangers
19 in transmitting the virus. It's not feasible for
20 them to come to Dallas on a routine basis.
21 Fortunately, there is an effort underway
22 to begin to provide outreach to this patient
23 population. So, I think some progress is being
24 made.
25 And in my own opinion, in order to

1 eliminate some of the barriers that I have
2 addressed, we must address continued education to
3 the unique needs of the hemophiliacs.
4 And I believe that the highly successful
5 model programs for comprehensive hemophilia care
6 across the nation should be used as a structure to
7 expand HIV support and treatment programs. And I
8 think that providers of services to patients and
9 other risk groups could benefit greatly by
10 carefully examining the hemophilia model and
11 applying its multidisciplinary approaches to other
12 risk groups.
13 REV. ALLEN: Thank you. Before we
14 have the dialogue time, there are two individuals
15 that are not here at the moment that are scheduled
16 to be here. I believe Henry Masters and Don
17 Maison both are not here at this point. We are
18 going to go on and to do the dialogue time. And
19 perhaps, if they arrive later in this time frame,
20 we can have a chance to hear them.
21 I just wanted to be clear that we want
22 to be sensitive to those that we have scheduled.
23 Unfortunately, they're not here; but it's very
24 fortunate for us that you all are here. So, we
25 want to have the time for questions and answers at

1 this point. Are there any questions? Don.
2 MR. GOLDMAN: Thank you. Dr.
3 Wisniewski, you have referred to the needs for
4 additional funding and the inadequacies of the
5 systems that you're forced to operate under. To
6 what extent does your state and local communities
7 provide a reasonable response in your judgment to
8 the needs that you have?
9 MR. WISNIEWSKI: On the local
10 community level, the budget for public health in
11 local New Orleans is very small and in essense
12 funds a few programs that are HIV-directed
13 primarily through DC funds that go to prevention
14 and education.
15 Our whole setup in Louisiana and New
16 Orleans is that public health care is largely
17 funded by the state. So, you're really looking to
18 the state system for the level of support and
19 commitment.
20 The budget that we received from the
21 state -- the first budget that was allocated was
22 two years ago and that was at a level of
23 $870,000.00, with some willingness to pick up some
24 AZT costs. But the only planning and funding for
25 AIDS care really went to one place and that was

1 one clinic.

2 There has been no impetus to look at
3 funding services elsewhere. And, in fact, the
4 level of the budget has remained the same since.
5 So, we've been heavily dependent on the federal
6 grants and Robert W. Johnson grants which are
7 expiring this fall.

8 MR. GOLDMAN: Do you think it's
9 fair for different levels of governmental agencies
10 to expect that other levels of government agencies
11 will join with them in partnerships and that it's
12 reasonable for the Feds to expect that there will
13 be some state funding and vice versa and there
14 will be local contributions to the process as
15 well?

16 MR. WISNIEWSKI: It seems very
17 real, but I think you've heard some of the
18 testimony this morning from Ms. Lomax. The
19 reality for the projects and project directors and
20 people up on the frontlines is that that doesn't
21 exist. And besides our impetus from the bottom
22 up, we also need the federal push in a way to
23 ensure those kinds of partnerships in cooperation
24 if indeed it seems reasonable.

25 REV. ALLEN: Let's stop the

1 questioning since we just started it and go ahead
2 and have the testimony from Henry. It's good to
3 have you back. Henry is from Arkansas Department
4 of Health.
5 DR. MASTERS: Arkansas, as you
6 know, is a rural state. We have a population of
7 about two point four million. And one of my
8 concerns is that since the frustration is that, I
9 do not believe that we have the tools that are
10 necessary right now to adequately target a
11 specific population and to actually monitor the
12 infection in our state with HIV.
13 I'd just like to give you some
14 background overview and then express some of my
15 concerns with regards to barriers for effective
16 control and prevention of HIV in Arkansas. We
17 have had three hundred twenty-two Arkansans who
18 have been reported with AIDS since 1985.
19 Sixty-two percent of these people are already
20 dead. We have an estimated seventy-five to a
21 hundred persons who returned from other states and
22 are now residing in Arkansas.
23 The number of people, of course, in
24 Arkansas with HIV infection are expected to
25 increase. In fact, we estimate there are about

1 four thousand people currently living in our state
2 with HIV infection; and we expect this number to
3 increase to about seventy thousand by the next
4 eighteen months.
5 As of June 1990, we have had more than
6 seven hundred people reported to our health
7 department who have positive HIV antibody
8 serology. HIV antibody reporting in Arkansas is
9 required by law and has been required by the State
10 Board of Health since 1988.
11 We have five counties in our state that
12 contain thirty percent of our state's population,
13 but sixty percent of the AIDS cases.
14 We are in the early phase of the
15 epidemic. Recent analysis of sixteen thousand
16 four hundred ninety blood specimens that were
17 obtained during a blind HIV antibody survey of
18 child bearing women reveals a very low
19 seroprevalence rate of point zero five five
20 percent.
21 When we stratified these people who were
22 tested by race, white persons, nonwhite, we saw a
23 marked disproportionate impact on nonwhites in our
24 state as well as greater risk for infection.
25 Among nonwhite childbearing women, it was

1 twenty-one point four times greater than for white
2 women. And that's one of the highest levels that
3 I'm aware of.
4 During each successive decade -- and I
5 think it's extremely important that the Commission
6 understand the relationship between syphilis and
7 HIV infection because it has a very marked impact
8 on minority communities, particularly those in
9 Arkansas.
10 During the successive decades, the
11 annual incidence of syphilis in the United States
12 has steadily declined at about two percent per
13 year until about 1986 when we had a one percent
14 increase over the preceding year and that was
15 followed by twenty-six point eight percent
16 increase the year after that, 1987.
17 So, the syphilis in this country is
18 resurgent. In fact, I've calculated the
19 accumulated excess cases of syphilis from 1986
20 through 1988 and get a figure of around
21 eighty-eight thousand cases. In Arkansas,
22 syphilis morbidity, the resurgence of it, has
23 really paralleled that which is coming in the
24 United States as a whole.
25 I was looking at syphilis and HIV

1 infection in Arkansas to try to get a better
2 handle on where we should target our prevention
3 activities and what barriers there may be that
4 exist.
5 By analyzing fifteen thousand nine
6 hundred eighty-eight specimens in which the
7 physician who submitted the specimen requested HIV
8 antibody and syphilis serology, we found a very
9 high statistical association with syphilis and HIV
10 infection at least marked in the blood specimens.
11 We don't know if the infection of
12 syphilis is new or old however. P value is highly
13 significant. And we look at specimens obtained
14 from patients who use our public clinics, five
15 percent of our people who testified positive for
16 syphilis had also HIV infection. And when you
17 look at the people who had HIV infection,
18 twenty-eight percent had positive serology for
19 syphilis among our public.
20 Many of the risk behaviors that place a
21 person at risk for HIV infection are the same for
22 syphilis. And despite the availability -- and
23 this is what worries me. Despite the availability
24 of good diagnostic tools and curative medical
25 therapy for syphilis, it is still resurgent in

1 this country and in Arkansas. And the greatest
2 impact has been borne by nonwhites.
3 It's likely that unless the barriers to
4 effective control of the current syphilis epidemic
5 are identified and renewed that HIV infection
6 rates across the country will accelerate. And the
7 greatest impact is going to probably be felt by
8 the minority communities in this country.
9 REV. ALLEN: Henry, you have one
10 more minute.
11 DR. MASTERS: Okay. We are
12 operating right now with a very crude surveillance
13 system. And I think what we need to do is one of
14 the barriers at least for prevention is to be able
15 to identify target populations. Any time a state
16 like ours has a level of low seroprevalence rate
17 is discounted in terms of being in need of
18 resources.
19 I think that a better use might be made
20 of using, for example, surveillance techniques
21 that we utilize in our state. Inmates are
22 voluntarily tested. Most of them choose to be
23 tested and we also have a blinded study.
24 Inmate populations have about a -- an
25 AIDS case rate that is five times higher than the

1 general population. I think by seroprevalence
2 data possibly on inmates entering our system, that
3 we could perhaps gain better ideas of -- detect
4 better changes in prevalence over specific
5 geographic areas.
6 We have used this technique in the area
7 of tuberculosis and we were able to identify
8 geographic areas of our state, one county that had
9 a dramatic increase in tuberculosis.
10 The other problem that I want to
11 mention, and I've got probably ten seconds left,
12 is literacy. We have low levels of literacy in
13 Arkansas. The literature in the America Responds
14 to AIDS Campaign, one pamphlet entitled How You
15 Won't Get AIDS is targeted or has a readability
16 level of ninth grade.
17 Sixty-eight percent of the people who
18 are at high risk in our prison systems are reading
19 at the sixth grade level or below. I think we
20 desperately need appropriate educational materials
21 that are appropriate for people who have low
22 levels of literacy. Thank you.
23 REV. ALLEN: Thank you very much.
24 Now, for anymore questions from anyone on the
25 panel by the Commissioners?

1 MR. DALTON: First, just a brief
2 question for Dr. Masters. You indicated Arkansas
3 has had mandatory HIV reporting since 1988 I
4 believe.
5 DR. MASTERS: Yes.
6 MR. DALTON: Have there been any
7 attempts to study the impact of mandatory HIV
8 reporting as against the period prior to 1988 on
9 people coming forward for testing?
10 DR. KONIGSBERG: Is it with names
11 or without names?
12 DR. MASTERS: It is by name and
13 address. I have actually tried to look at it and
14 what I've done is using our state data base, all
15 the specimens that come to our lab for processing,
16 some of them are obviously coded. The names are
17 coded with alpha numeric codes or just a numeric
18 code.
19 And I looked at the seropositive rate
20 between specimens that we received over all
21 different codes versus those that were not coded
22 as far as I could tell. And there is a
23 statistically higher seropositivity rate among
24 specimens that are submitted coded in a fashion
25 that you cannot identify the individual.

1 Although we do have reporting by name
2 and address, if the specimen comes to us in a way
3 which we can't identify the individual, we still
4 go ahead and process the specimen and also we are
5 not able to contract tracing obviously. Partner
6 notification.
7 However, we do have two anonymous
8 testing sites in our state. And so, we have tried
9 to minimize the impact that mandatory reporting by
10 name and address might have. This was a law that
11 was passed in our state, but some of us were not
12 real happy about it. But apparently, people are
13 finding ways to be tested without identifying
14 themselves if they don't feel comfortable.
15 MR. DALTON: And you're simply
16 trying to change your views that those that go
17 through the anonymous system or find some other
18 way of being tested without being identified by
19 name and address tend to be more seropositive?
20 DR. MASTERS: Right.
21 Statistically, significant.
22 MR. DALTON: Okay. I've been
23 accused of prior to meet with the commission of
24 Dr. Beatty. And this is a wonderful panel for
25 that. So, we can sort of sit back and relax for a

1 second.

2 Actually, Dr. Wisniewski, in your

3 testimony or prepared remarks, your point four,

4 you talked about the need to somehow try to make

5 doctors more sensitive to psychosocial kinds of

6 issues. And complaining that physicians and

7 hospitals need to be taught and reimbursed for

8 working with human services organizations and the

9 reverse is also true.

10 And then persons who fail to translate

11 between such diverse groups should be sought and

12 promoted. I guess I wasn't sure what you meant by

13 that or sure what it would take to train doctors

14 to be sensitive to psychosocial issues to engage

15 in counseling and the like.

16 One way of putting the question to

17 doctors that, in fact, are retractable.

18 Certainly, in my experience, it's difficult not

19 only for someone other than myself in the legal

20 profession, but even for other doctors to get

21 doctors to come forward for in-service trained

22 even around the scientific aspect of AIDS, much

23 less the fact that those were -- Dr. Buchanan was

24 good enough to say that he and other doctors

25 involved in hemophilia were really kind of

1 blindsided by this new disease insofar as required
2 things like dealing with sexuality and
3 psychosocial things and the like.
4 I guess I wondered what can be done
5 about this problem.
6 MR. WISNIEWSKI: Certainly, this is
7 a problem that's being struggled with in many ways
8 in programs funded such as the ETC's are finding
9 that that is indeed true. I think we have to look
10 at a number of practical things that might be
11 brought to bear.
12 One that strikes me is that case
13 management systems do look at funding into
14 disciplinary teams, meetings between various
15 professionals; but in some systems, they don't
16 necessarily stipulate that they need to be
17 physicians.
18 If that were made to be a requirement,
19 both the physicians could be enticed somewhat by
20 that financial mechanism as well as just the
21 interchange that begins to happen when you put
22 that professional in a room with others I think
23 could be brought to bear.
24 Another issue I think is that we need to
25 look at how and to which group of physicians we

1 fund and give authority over some of the AIDS
2 programs. I'm impressed by what I see some of the
3 developments along primary care, general
4 practitioners, general internists, pediatricians
5 obstetricians, people who have some of the skills
6 that were mentioned. These are people that need
7 to be put in leadership positions for this
8 epidemic.
9 And I think these are within the
10 physician group translator types of people who can
11 educate their physician peers about some of these
12 very sensitive issues. A physician's going to
13 listen to a physician before they will listen to
14 somebody else. So, I think those are a couple of
15 ways of attacking the problem.
16 MR. DALTON: Though as I
17 understand, the hierarchy within the profession
18 you may not -- well, those may not be the people
19 at the top of the internal hierarchy.
20 MR. WISNIEWSKI: That may not be
21 true, that's right.
22 MR. DALTON: Dr. Buchanan, do you
23 have any thoughts about that?
24 MR. BUCHANAN: Didn't have anything
25 to add.

1 MS. DIAZ: I'd like to ask Dr.
2 Masters and Mr. Fuentes a little bit about your
3 last thought, Dr. Masters, regarding the American
4 Response to AIDS educational program.
5 You hit on a very interesting point
6 because not only is that appropriateness in the
7 literacy issues an issue that we have struggled
8 with in the minority communities, but also the
9 fact that many of these Mexicans really can be
10 impacted and creative with the kind of sensitivity
11 Wisniewski talked about in his remarks.
12 I'm just wondering if you could
13 elaborate as to some kind of thought you have.
14 It's interesting that a person with STD and AIDS
15 perked up your level. Is observing that kind of
16 thing as having an effective weapon for reaching
17 so many of our people, but I got a common thread
18 from both of you that you feel that the
19 communication to the targeted publics,
20 particularly minority communities, really needs to
21 be much more refined in terms of things you're
22 talking about.
23 And I'm wondering if you have some
24 thoughts and comments about that.
25 DR. MASTERS: Yes, I do. I got my

1 sensitivity to this issue while I was Medical
2 Director for Department of Corrections where so
3 many people are in the system. And when I saw the
4 literature for the America Response to AIDS
5 Campaign, I realized that many of those people
6 would not be able to understand it.
7 We have the technology right now to
8 mount a very aggressive campaign for people who
9 have low levels of literacy using portable
10 computers that have graphic animation, body of
11 interfaces. We could teach people about HIV
12 infection and other diseases, diabetes,
13 hypertension, etc., and do it in a way that they
14 would not even have to use a keyboard. They could
15 even touch the screen.
16 We could, if we wanted to, learn
17 something about the knowledge, attitudes and
18 beliefs of behavior of people who have low levels
19 of literacy. Virtually, nothing is done. And
20 it's very difficult to tailor education materials
21 when you have no data base from which to operate.
22 Right now at the Arkansas Department of
23 Health, I put together a task force that is
24 working on a project that would make at least
25 available to our inmates and our community health

1 center clients who also have low levels of
2 literacy a system by which they could learn.
3 And we would have a way of tracking
4 changes in their responses to questions over time
5 using computers that generate images that are
6 animated and audio. And I think that we need
7 assistance from other people in a project like
8 this. I think it's of importance since there are
9 so many people in this country who just are
10 functional illiterate.
11 MS. DIAZ: You're not aware that
12 the National Red Cross just completed a project on
13 HIV education for Hispanics that is just totally
14 visual, nonwords at all. So, you might want to
15 make contact while you are developing yours; but
16 it is something special.
17 MR. FUENTES: We deal mainly with
18 the preliterate and the illiterate and also
19 there's the population that my colleague was
20 talking about with individuals with a sixth grade
21 educational level or less even if they're English
22 speaking.
23 And we use a lot of cartoons. We use a
24 lot of photo stories. And we also kind of just
25 put the literature outside. We don't use

1 literature as the main tool. We go into their
2 homes. We go into this community groups. And we
3 do a lot of talks. And we just sit down and first
4 let's discuss it. Okay. Let's not put the
5 pamphlet between us. Okay. And I assure the
6 individual that, yes, you're going to get
7 something to take home and read.
8 Also, the terminology that we or the
9 lingo that we're used to using like homosexual,
10 bisexual. They don't understand it. If you call
11 them homosexual, they just call you that back,
12 okay, because they think it's a curse or something
13 nasty.
14 So, we have to simplify all this terms.
15 You know, for us HIV infection, oh, yeah,
16 everybody knows about it. Well, for them, it's
17 not. You have to just go back to the basics and
18 explain how the new system works and how the virus
19 is transmitted and also use stories from your own
20 community without names, of course. But, you
21 know, bring it home.
22 MS. DIAZ: Thank you.
23 MR. DALTON: Let me pursue where
24 you ended up in your remarks. You quite correctly
25 said it's appropriate for people who want to do

1 something about the AIDS go to the experts mainly
2 those who are directly affected. But I'm not sure
3 where to go from there.
4 Among other things, you said observe
5 many things including people's phobias. And I
6 guess my question is -- and then you came to the
7 helping sex. We should help by observing phobias
8 within your community or my community.
9 Since we have to do more than observe or
10 someone has to do more than observe, I'm just
11 curious what you would suggest are ways in which
12 we can deal with various phobias within our
13 community including homophobia.
14 MR. FUENTES: Well, the phobias are
15 going to be there. It's going to be very
16 difficult for us to break through this barriers.
17 The barriers are going to be there like it or
18 not. Same thing with revision. We work with a
19 bishop in the Houston area. You know, he -- I
20 have to respect his principles and he's going to
21 have to respect mine; but we work around this.
22 You know, be aware that the phobias are
23 going to be there. The homophobia and the AIDS
24 phobia in the community. So, you have to just
25 respect that and work around that particular

1 point.

2 MR. DALTON: I respect there are

3 sometimes ways of working around, agree to

4 disagree and moving on from there. I guess my

5 question though is: Do you see any way to, in

6 fact, alter some of the phobias?

7 MR. FUENTES: Well, just by being

8 there, by being a friend, we're -- you know, by

9 just not dwelling on it simply because in the

10 Hispanic community, you're not talking about -- or

11 from the Hispanic community point of view is that

12 sensitive issues, you don't talk about it. But

13 again, by respecting their points of view, by

14 being there regardless of their denial, you know,

15 slowly they're beginning to open up. But you

16 don't shove it down their throats.

17 It's just like, okay, we know that your

18 son is gay. But okay, let's not talk about it.

19 But I'm going to be here regardless. I'm going to

20 go to the hospital, call me any time; and I'll be

21 there.

22 And they're beginning to realize that

23 sexuality and AIDS is not the issue. Humanity and

24 morals is the issue. And you are the friend that

25 they need. And then before you know it, you got

1 them in your hand.

2 MR. DALTON: I guess I wanted to

3 ask a related question of George Buchanan. You

4 had mentioned that often times hemophiliacs don't

5 have support groups, people they can talk to about

6 what they're going through, and particularly, I

7 guess HIV-infected hemophiliacs. And then part

8 you said it was because many hemophiliacs are

9 angry with the gay community because they feel

10 that the latter are responsible for their

11 disease.

12 I think it doesn't necessarily have to

13 be the case. One of the things that struck me by

14 the commissions in the South of Georgia was that

15 there was support groups there that were

16 multiracial that involved hemophiliacs as well as

17 IV drug users as well as gay men and people who

18 were some combinations of those. Maybe that's

19 unusual. It certainly is much more uncommon and

20 likely effective that a system of support groups

21 is -- different support groups of different

22 people.

23 But I guess my question is: Have there

24 been efforts to your knowledge within the

25 hemophilia community in Texas to deal with that

1 particular set of understandable particular anger
2 and but nevertheless to move beyond or again is
3 that one of those things that you sort of accept
4 and work around?
5 MR. BUCHANAN: I'm not sure that we
6 accepted it or are happy about it, but we've made
7 some efforts working with our hemophilia
8 population to establish some linkages with them
9 and some of the local support groups that, you
10 know, usually are linked to one of the gay
11 agencies. We just had some difficulties in
12 getting agreement and willingness to go. And, you
13 know, a lot of these young men needed some help
14 and needed somebody to talk.
15 Where we have been successful I think
16 more in the last year or two is establishing
17 support groups in the center and in the local
18 chapter of the National Hemophilia Foundation.
19 That at least is effective for a smaller number of
20 patients and couples with that that are
21 effective.
22 But we have not been able to make any
23 progress like what you mentioned in Georgia. I
24 don't know what the lay of the land is in
25 Georgia.

1 MR. DALTON: I suspect -- I was
2 quite curious about Georgia. It may just be the
3 folks were all together and banded together
4 because there was no support for anyone other than
5 others who were also infected. That may be the
6 Quasimodo approach to support.
7 REV. ALLEN: Don, you had something
8 you wanted to say.
9 MR. GOLDMAN: Is there an adult
10 program?
11 MR. BUCHANAN: Yes, there is an
12 adult program.
13 MR. GOLDMAN: And that's where?
14 MR. BUCHANAN: It's also at our
15 institution?
16 MR. GOLDMAN: Which is?
17 MR. BUCHANAN: University of Texas
18 Southwestern Medical Center.
19 MR. GOLDMAN: Is that the same as
20 Parkland?
21 MR. BUCHANAN: Parkland is one of
22 the hospitals in that complex.
23 MR. GOLDMAN: Could you talk for a
24 moment about the transition and what the problems
25 are with the transmission between the children and

1 adult programs particularly in terms of the
2 economic and social barriers that are involved and
3 some of the funding patterns?
4 MR. BUCHANAN: Sure. I think it's
5 a good question. I think until recently, roughly
6 three years ago, we really didn't have too much of
7 an adult program. Adult hemophiliacs could come
8 to the center, but there wasn't a physician
9 particularly interested in it.
10 There wasn't a multidisciplinary program
11 like we had with children. That resulted, I
12 think, in part in a lot of hemophilia population
13 in North Texas among the adults being dispersed
14 among this or that private physician and this or
15 that clinic or institution and no real program.
16 Now, that has changed. We have received
17 funding now for a full-time adult hemophilia
18 coordinator who is interested in it now. So, that
19 now the transition -- it used to be a very
20 difficult and unwielding one for me and some of my
21 adolescent young adult patients who get used to
22 coming into our program for years and years and
23 felt comfortable with it. They felt that
24 sometimes they were being cast out to the wolves
25 when they turned twenty-one. And then

1 particularly, with HIV on top of that.
2 Now, instead of coming to pediatric
3 hemophilia program which also dealt with AIDS
4 education, now they were going to the county
5 hospital to the AIDS clinic for their HIV-related
6 care. And that's been changed fortunately.
7 So, I think that's better at least for
8 the patients in Dallas who identify themselves
9 with our hemophilia program. The problem is the
10 patients out there in Fort Worth and Amarillo and
11 Abilene and other cities in the distance. And
12 that's where we're still having some problems.
13 REV. ALLEN: Larry, you had a
14 question.
15 MR. KESSLER: My question is for
16 Mr. Fuentes. Considering the tension we've heard
17 about and we've seen all over the country actually
18 between some of the ethnic and racial groups
19 between the various levels of culture, cultural
20 groups and then the gay community, what's your
21 feeling about the impact of the pending
22 demonstration that I had read about last night at
23 the Cathedral in Houston?
24 I was trying to read between the lines
25 there and I got anxious about what that was going

1 to do, but I'd rather hear from what you think
2 it's going to do to the relationship between
3 Hispanics and the gay community in Houston and the
4 AIDS movement in general.
5 MR. DALTON: Larry, what is the
6 demonstration you're referring to?
7 MR. KESSLER: There's an Act-Up
8 demonstration at a Cathedral. And apparently,
9 Houston has a Hispanic bishop. I thought that was
10 sort of a very interesting dynamic, and it's
11 around AIDS, abortion, women's rights. And
12 there's a fourth issue, but I'm not sure what it
13 was.
14 MR. FUENTES: The Bishop San
15 Pedro. It's against him. He is also a board
16 member of the Greater Houston AIDS Alliance. And
17 this Act-Up Houston group is trying or -- were
18 asking for his removal.
19 And I think -- personally, I think it's
20 a move, a wrong move here because again he might
21 not be presenting the church views; but as an
22 individual, he's trying to build inroads into the
23 disease, into the fight against AIDS.
24 We have a lot of political problems as
25 probably everybody knows in Houston. And since we

1 got three main political bodies which is the city,
2 the county and now another one, the Alliance, it's
3 a lot of struggle between agencies, between
4 groups.
5 But I've been learning all along the way
6 and again, it's by observing what others are doing
7 and by learning their mistakes is like it or not,
8 we have to work together. We have to just, you
9 know, kind of just say, okay, you know, slap my
10 hand. I'm sorry. But let's go back and have at
11 it again.
12 We're working with the AIDS Foundation
13 with gay and lesbian Hispanic groups. We're
14 working with lesbian Latino groups which are very
15 -- they're kind of just it's not our problem type
16 attitude. But again, we have to work together.
17 There's no way that we're going to be able to pull
18 this alone.
19 And so, there's a lot of friction and we
20 have a lot of cultural barriers, a lot of cultural
21 differences; but I think again by observing, by
22 listening, you can very easily switch from one
23 track into another.
24 We got a powerful mind, and you don't
25 have to just design a program for Salvadorans or

1 design a program for Mexicans or Mexican
2 Americans. No. Just be careful when you're
3 addressing this population. You can use exactly
4 the same tool. Just make sure it is not offensive
5 to any of those individuals.
6 But how you present it, it's very
7 important. So, you got to be sensitive. You
8 know, Bishop San Pedro and myself have worked
9 together on a couple of programs already, believe
10 it or not. And I just go to church when one of
11 our clients dies. You know, I'm being honest.
12 And he called me up one time and he
13 said, well, let's do an educational program. And
14 here, I got all my condoms and lubricants and
15 syringes and bleach and all that. And then I got
16 to the church on a Sunday and I said okay, where
17 do I set up. And he said outside. Okay. And I
18 said fine.
19 You know, I was really thinking that it
20 was a miracle happening there and he was going to
21 let me do it inside the church. But again, you
22 have to work with the tools that you have. You
23 know, I was glad. I was outside the church. He
24 was inside. He was preaching morals. You know, I
25 was preaching, you know, protection now. And he

1 said okay.

2 MR. KESSLER: Sounds like a minor

3 miracle anyway. At least you got on the ground.

4 MR. FUENTES: He's a realistic

5 man. He knows that morals are not going to stop

6 it now. It's going to be a long-range job and

7 he's working on that. But I also tell him hey,

8 give me a chance. We need to stop it now. So,

9 let's work together in parallel. Let's not cross

10 the roads. It took us a while.

11 MR. KESSLER: But in terms of this

12 particular action, is it going to help move him?

13 Is it going to set back relationships or do you

14 think it's a wash?

15 MR. FUENTES: I don't think so. I

16 think this group -- first of all, Act-Up Houston

17 is very politial. It's not supported by the

18 community nor the gay community nor the general

19 community because on Sunday there was a

20 demonstration and we had a curing demonstration in

21 downtown Houston.

22 And our demonstration was about two

23 thousand people. And we were just asking, you

24 know, cure AIDS now. Allocate more funds. There

25 was two thousand people. On this Act-Up

1 demonstration to remove the bishop from the
2 alliance board, there was probably about ten
3 people that demonstrated. So, that tells you.
4 MR. KESSLER: You've already had
5 it. It's already occurred.
6 MR. FUENTES: Yes. It's over and I
7 don't think it's going to have any consequences.
8 DR. KONIGSBERG: It got a lot of TV
9 play. That was the main thrust of the story.
10 REV. ALLEN: Any other questions?
11 MR. DALTON: Just one last question
12 for Ted. You indicate in your testimony you said
13 early intervention is perhaps the single most
14 important reason for our systems collapse.
15 At our round table yesterday, one got
16 the impression that there is no early intervention
17 yet. I was curious what you meant by that
18 statement?
19 MR. WISNIEWSKI: I have a question
20 and comment to this work group as well regarding
21 early intervention. So, I'm glad you asked that.
22 In our program in New Orleans, we've
23 been doing, in essence, what is now recommended
24 since about 1987. But there's a sharp increase in
25 demand for those monitoring and beginning early

1 AZT treatments by a very large population.
2 It strikes me that the task that's just
3 ahead is to combine or take a good hard look at
4 what we've talked about today with what was
5 discussed yesterday. Because this, too, has got
6 to be worked out and it's got to be worked out
7 soon.
8 I guess my question or comment is and it
9 comes out of a sense of urgency not just to this
10 working group but to the whole commission. It
11 strikes me that perhaps we could have anticipated
12 this about a year ago.
13 It seems that the CDC data, the NIH
14 clinical data about the efficacy of the drugs and
15 some of the things we were learning through the
16 services demonstration projects, we probably could
17 have sat down and anticipated what we're living
18 with right now about a year ago.
19 And it seems that a real challenge to
20 you is to look at speeding up that kind of
21 interagency dialogue that needs to happen and
22 drawing frontline people who are experiencing that
23 frustration into helping translate federal
24 guidelines or initiatives into what's really
25 needing in terms of the program.

1 And I just wanted to encourage and push
2 this work group as well as the others into exactly
3 that kind of thinking and strategy.
4 REV. ALLEN: By any chance, do you
5 have something to say to that, Charlie?
6 DR. KONIGSBERG: I think that very
7 skillfully sums up perhaps the whole purpose for
8 the two days and I hope our report maybe when it
9 is written would kind of sum up on that note. You
10 know, we can make that case with a lot of federal
11 policies; but in very few cases had they done what
12 they did with HIV which is saying this is the
13 standard of care. There are other instances.
14 It's been done with, for example, the
15 second measle shot set the standard of care. And
16 I've used the same terms which is a strange one in
17 public health, but I've used it in clinical terms
18 and then not backing it up with the money to do
19 it.
20 That's small compared to this situation,
21 but I think that's a terribly important point.
22 REV. ALLEN: Any other questions?
23 If not, I have to remind you all that if you would
24 like to make comments during the
25 open-to-the-public comment time, please sign the

1 form in the back. Again, it's going to be three
2 minutes for each individual that would like to
3 state something. So, we'll take about a fifteen
4 minute break.
5 (Short recess.)
6 REV. ALLEN: I would like to make a
7 change in the schedule of the summaries of today's
8 proceedings. The Commissioners have asked Jeff to
9 put that in writing. And due to the airplane
10 schedules of the Commissioners, most of them are
11 going to have to leave right after the comments
12 from the public.
13 So, that's one change in the schedule,
14 first. And then Don is going to keep the time for
15 us for three minutes a person. That will be just
16 about the time allotted.
17 So, the first person on the list is
18 Margaret Gallimore.
19 MS. GALLIMORE: My name is Margaret
20 Gallimore. I'm the Director of the Mathis House.
21 I have been running the Mathis Hospice House,
22 whichever one you want to call it. I sent out for
23 my nonprofit and it came back hospice, not house,
24 what I originally named it after.
25 But my whole point in being here that I

1 know for a fact that I take care of PWA's in my
2 home that I rent to take care of the PWA's. I
3 have never had a grant. I do it on my own.
4 The organizations in Dallas -- if you
5 want me to name, I will name them -- I'm known for
6 names, and I will point the finger. But it is
7 true what the doctor who was sitting here in this
8 seat -- I couldn't see his face -- was saying. It
9 just revolved around just the gay community.
10 If you try and get into it -- I don't
11 discriminate because I have everyone. I take care
12 of black, green, purple, Hispanics. I've gone to
13 Houston. I took a film at my house to show them
14 there where and how to do it. And I flew back. I
15 don't get any funds.
16 Why is it taking them so much money for
17 Dallas to have all this funding, not other states
18 and the money and not be seen or not any have it
19 coming to me and I am the only person in that
20 house? The ones that's dying on my own.
21 So, whether the three minutes is up --
22 put me under a lot of pressure.
23 REV. ALLEN: We weren't going to
24 have comments, but if you didn't use up all your
25 three minutes, we can have comments.

1 MS. DIAZ: Do you have a licensed
2 hospice?
3 MS. GALLIMORE: Yes.
4 MS. DIAZ: How many beds?
5 MS. GALLIMORE: Six.
6 MS. DIAZ: Full?
7 MS. DIAZ: That is correct.
8 MS. DIAZ: How do you get your
9 referrals?
10 MS. GALLIMORE: Beg your pardon.
11 MS. DIAZ: How do you get your
12 referrals?
13 MS. GALLIMORE: From Parkland
14 Hospital. Well, now I'm going to have to call
15 names. In fact, this last past week, a good for
16 instance, a very bad situation came up.
17 And Buck Buckingham is the manager of
18 that agency, AIDS ARMS. The person that worked
19 there called the family. The guy hadn't died.
20 And they went and upset the family. The mother's
21 flying in here thinking that her son is dead and
22 the guy lived five days. But she called and asked
23 if the person wanted to go make funeral
24 arrangements, but didn't ask how the patient was.
25 So, I'm very upset about it. That's

1 cold-blooded.

2 MS. DIAZ: Do you serve primarily

3 blacks and Hispanics or all?

4 MS. GALLIMORE: No. I've always --

5 I've had less -- because that's what I'm saying.

6 I've had less blacks than anything. I've had

7 lawyers, doctors, designers, the whole nine

8 yards. One guy owned his own island. But when

9 everyone takes what he has, well, then he don't

10 have anything.

11 MS. DIAZ: How do you fund

12 yourself?

13 MS. GALLIMORE: Me. That's what

14 I'm telling you now. I've never had funding, but

15 I also don't get -- whenever you go to the

16 hospital or whenever I'm called there, Parkland

17 calls me, you don't cut off your nose to spite

18 your face. That's their only means of getting --

19 whether you're rich over here and you can afford

20 to go to a private doctor. Fine. You go to a

21 private doctor.

22 But one day, if you have the virus,

23 you're going to get sick and down and out. Just

24 because you're up and your friends may be

25 supporting you, when you get down where he can't

1 hound you anymore.
2 REV. ALLEN: Let me say this
3 Margaret, if you would like to submit written
4 statements to the Commission, they can be
5 incorporated. Unfortunately, the time is up; but
6 your input in the Commission is not -- if you
7 would like to write down your comments, it can be
8 submitted into the record.
9 MS. GALLIMORE: Are you going to
10 put it in his hand?
11 REV. ALLEN: Excuse me.
12 MS. GALLIMORE: Are you going to --
13 when I mail off things, that never get there or
14 just like the organization.
15 REV. ALLEN: It'll get there.
16 MS. GALLIMORE: I didn't get the
17 call. It was a volunteer. I said well, then you
18 should fire the volunteer.
19 REV. ALLEN: Well, submit the
20 testimony, whatever you would like, in writing. I
21 just wanted to be sensitive to the folks here that
22 have signed up to give them the equal amount of
23 time, but your comments can continue on and the
24 dialogue can continue on beyond this point.
25 MS. GALLIMORE: Thank you.

1 REV. ALLEN: Don Schmidt.
2 MR. SCHMIDT: I won't even use all
3 my three minutes. I just wanted to tell you -- I
4 want to talk a little bit about the conspiracy of
5 silence.
6 I believe the first time on your agenada
7 anywhere in this country that anyone talked about
8 the issues of dying with dignity in terms of
9 physician-assisted death was raised by me earlier
10 today.
11 I was really -- this was never raised to
12 the previous commission, never discussed in none
13 of their decisions. I felt it was appropriate to
14 raise it today because we have seen recent polls
15 in Time and Newsweek seeing that the majority of
16 Americans believe that those with terminal illness
17 may -- should have an access to physician
18 assistance in this area.
19 And I think the time is right to talk
20 about what we know has been a major issue for a
21 minority of those with terminal illness in this
22 country across the board. And clearly, in my
23 experience some folks choose voluntary
24 euthanasia.
25 I think you cannot avoid talking about

1 this. I believe if you're not going to do it in
2 this context of social and human services, I would
3 strongly encourage you to do it in bioethics
4 specific hearing at some point.
5 I would hope you don't get through the
6 rest of your year plus and avoid this issue. I
7 don't expect we're going to resolve it. We're
8 going to hear from the docs and the legal
9 barriers, but we need to get it on the table among
10 the other issues talked about in terms of barriers
11 because it is a barrier.
12 You're talking about living and dying
13 with AIDS. And it's a very significant barrier in
14 the process of dying from AIDS. Thank you.
15 REV. ALLEN: Gary Swisher.
16 MR. SWISHER: I wanted to thank you
17 for allowing me to take this time. I'm Gary
18 Swisher. I'm the Director of Health Services for
19 Oak Lawn Community Services here in Dallas.
20 Thanks for listening so compassionately
21 the last two days. I don't envy your position of
22 making recommendations and taking those back and
23 turning them to the powers that be.
24 There's an issue that I'd like to touch
25 on that -- actually, I'm going to be echoing what

1 you've heard from Ted. And I can't say Ted's last
2 name either.
3 But one of the issues is the lack of
4 leadership that we've seen. Now, HRSA has done
5 some very good things. They stepped over the
6 sides and worked hard to get RWJ and combined that
7 with one of our demonstration programs.
8 What I have not seen on the federal
9 level is the consortium and the sharing and the
10 coordination. Where is NIMH? Where's NIH? Where
11 is AmFar with their programs? Why are they not
12 taking what has been done in the last few years?
13 Demonstration programs have been
14 funded. They have been demonstrated. They have
15 been proven that they're effective. It's time not
16 to stop demonstrating, to implement those programs
17 and not create new demonstration programs for new
18 departments to be funded, to be tested all over
19 again.
20 I think you'll find that Texas itself is
21 a third world state in the way that we act
22 politically. And we are not the most progressive,
23 but we are also a very resourceful community. And
24 that's in the gay communities, the minority
25 communities, racial ethic minorities and all other

1 surface providers.

2 And what we have done is try to organize

3 and share and provide technical assistance among

4 ourselves and we have not seen it from anybody

5 else.

6 And there's an organization I'd like for

7 you to be aware of called Texas AIDS Network which

8 is a statewide body comprised of eight service

9 providers, coalition of PWA's, local and county

10 health departments and many, many, many interested

11 individuals that has done a lot of work on the

12 past two years to address the specific issue of

13 HIV education, funding and services.

14 And I think if more of the Federal

15 Government would look at what's being done on the

16 local level and following that example instead of

17 giving examples for the local level to follow, we

18 might be a little more progressive. Thank you.

19 MS. DIAZ: Thank you.

20 REV. ALLEN: Drew Dixon.

21 MR. DIXON: My name is Drew Dixon.

22 I'm with the Association for Retarded Citizens.

23 I'd like to ask that you consider

24 another barrier to the utilization of social and

25 human services as they relate to the HIV/AIDS

1 epidemic. And that barrier is cognitive
2 impairment.
3 We must begin to include people who are
4 mentally retarded and they have earned their
5 national prevention strategy.
6 But mental retardation is not like
7 having the mumps. It's not a case of either you
8 have it or you don't. An individual's level of
9 understanding must be matched with the range of
10 approaches.
11 Prevention programs cannot be successful
12 if, for example, they explain how to use a condom
13 and tell all the goodness of that if the listener
14 does not have a clue how to make change or take a
15 bus to the drug store to get a condom.
16 I put a side note that says it takes
17 cunning wiseness to find ways of having
18 unprotected same gender sex in congregate living
19 situations, but that it takes two geniuses to have
20 protected heterosexual contact in such
21 environments.
22 We've heard from a number of people
23 addressing the availability of programs and the
24 lack of availability of programs and support for
25 local minorities. I suggest that the minority

1 group of people who are mentally retarded cross
2 all ethnic and cultural boundaries.
3 A minority group that we think so little
4 of that we have historically isolated them in
5 institutions or if they do live in a community, we
6 place them in portable classrooms physically
7 separated from the main school or other segregated
8 settings.
9 Further, we maintain myths, dangerous
10 myths. Let us finally accept the fact that some
11 people who are mentally retarded enjoy a range of
12 activities that place them at risk of HIV
13 infection.
14 I understand that on the one hand, we
15 often will have a mother who'll say you're not
16 going to talk to my fourteen-year-old retarded
17 daughter about sex and drugs.
18 But I know on firsthand that we have
19 programs whom we're teaching fourteen-year-old
20 mothers who are mentally retarded how to care for
21 their child. Obviously, the answers will not be
22 easy but we must at least start asking the
23 question.
24 Being so limited in time, I've only
25 addressed the question of prevention. I hope that

1 in future hearings, you will consider complex
2 questions of how to provide services for people
3 who are mentally retarded or have other kinds of
4 impairment and are HIV-involved.
5 I, of course, assume that you already
6 have some ideas and plans to ensure the quality,
7 not quantity of life for the children who have
8 AIDS. It's important to note that it's been
9 estimated in the next four years, AIDS will be the
10 largest infectious cause of mental retardation in
11 children under the age of thirteen. Thank you
12 very much.
13 REV. ALLEN: Thank you. May
14 Pasquet.
15 MS. PASQUET: My name is May
16 Pasquet. I'm a Registered Nurse and I'm Director
17 of the Infectious Disease Clinic at John Peter
18 Smith Hospital in Tarrant County.
19 John Peter Smith Hospital is the leading
20 provider for indigent care in Tarrant County. I
21 would like to speak today in support of human
22 service organizations that pay a most important
23 role in the care of our patients.
24 Tarrant County has reported five hundred
25 and eighteen cases of AIDS as of last week. Four

1 years ago, a portion of our medicine clinic was
2 designated to provide outpatient care for patients
3 infected with the HIV virus. At that time, we saw
4 two to four patients per clinic per week and
5 followed a caseload of twelve patients.
6 Today, we limit forty-five patients per
7 clinic and provide care for a caseload of three
8 hundred and fifty patients. Men, women and
9 children. One hundred and forty-six of these
10 patients receive AZT, eighty-two receive
11 prophylactic Pentamidine and we average eight
12 patients in-house each day hospitalized for
13 AIDS-related infections.
14 The average daily cost for care in the
15 inpatient setting for a patient admitted with
16 AIDS-related diagnosis is $654.00. Compared to
17 another patient admitted with another diagnosis,
18 it is $443.00 per day.
19 Due to limits in inpatient beds, our
20 focus has been on outpatient care and the
21 prevention of inpatient initiation because of
22 limited funding in the public hospital. We have
23 somewhat succeeded in this prevention of multiple
24 hospitalizations for our patients through the
25 development of many programs like case management,

1 development of IV procedural labs where patients
2 can receive on an outpatient basis IV fluids,
3 blood transfusions and antibody therapy,
4 antifoamal therapy.
5 But along with many other organizations,
6 we're at a limit; and we are now requesting
7 additional tax dollars from our county
8 commissioners to continue to provide safe care.
9 But our limited success would not have
10 been possible without networking with many of the
11 agencies and organizations like those represented
12 here today.
13 The need in the hospital setting is
14 overwhelmed, but it does little good to provide
15 medical care if it is not safe and effective. It
16 does little good to provide medical care if funds
17 are not available for medication, if housing is
18 not available for the patient, if food is not
19 available or transportation to and from hospitals,
20 counseling and a support system for the patient.
21 It takes all agencies I believe working together
22 for the cause and that cause has to be the
23 patient.
24 People are available to provide what is
25 needed if funds were available for those to do

1 so. The commonality which I've heard by all
2 speakers today comes down to the need for
3 education, organization and money.
4 More patients have died of AIDS than
5 have died in the Vietnamese War. I don't wish to
6 sound melodramatic, but I believe it's time for
7 our local state and federal leaders to realize
8 that we're at war with a deadly enemy.
9 In our war efforts, we must be --
10 MR. GOLDMAN: Can you just close
11 up.
12 MS. PASQUET: Yes. Our war efforts
13 must be organized and confronted because daily we
14 are on the verge of losing the battle. And I
15 encourage this Commission to educate our leaders
16 before we lose the war. Thank you.
17 REV. ALLEN: Dan Rawlins.
18 RAWLINS: Hello, my name is Dan
19 Rawlins. I'm Co-Director for the TD -- Texas
20 Department of Mental Health Mental Retardation,
21 AIDS/HIV Prevention Training Project.
22 Keeping in mind there's no time giving
23 an introduction, I just want to say that my
24 background is in education and substance abuse and
25 for the last seven years has been working with HIV

1 education in one form or fashion or another.
2 I also don't want to wear any of the
3 hats that I have because I want to complain and
4 then I want to make an emotional appeal to you.
5 The first thing I want to say is that
6 you're a smart bunch of people; and I know that
7 when people come up to testify before you, you
8 take a lot of things into consideration.
9 When a state agency from Texas comes to
10 talk to you, they feel like they're on trial. And
11 the first thing they want to do is sing their own
12 priase about how wonderful they've done in their
13 efforts. I'm here to tell you that what we've
14 done, while it has been an effort, is not at all
15 wonderful and that there are still lots and lots
16 of things to do.
17 In September, we are facing a real
18 crisis with the 72nd meeting of the Legislature.
19 One of the people on the Legislative Task Force on
20 AIDS, as Reverend Allen is familiar with, is going
21 to be a person who leads the fight against any
22 kind of positive direction and AIDS education and
23 in health services. He will stop it at all
24 costs.
25 With that in mind, we have our own fight

1 here in Texas. What I ask on behalf of all
2 educators, all of us here in the audience and all
3 over Texas is that you try to help us by getting
4 the gags off nationally.
5 In other words, if you can stop
6 guidelines such as the one that came down from CDC
7 recently trying to tell us how to tell our people
8 in our special population what it is we can say
9 and what it is we can't say, if you can tell them
10 to offer us comprehensive rational and sane and
11 standardized guidelines for what needs to be done
12 out there, fine.
13 Failing that, tell them not to say
14 anything and let us fight our own fight because
15 what has happened to us makes it far more
16 complicated. When we can talk about condoms, we
17 need to talk about condoms. When we can talk
18 about disinfection, we need to talk about it. We
19 need to get bleach out to our outreach centers.
20 There's no point in having an outreach
21 center that tries to talk to the street addict if
22 you can't tell him how to prevent STD's and HIV.
23 They'll listen if we can sound real; and we can't
24 sound real if we say that there are only certain
25 things that we can do and certain things that we

1 can't do.

2 MR. GOLDMAN: Your time is up.

3 RAWLINS: Thank you very much.

4 REV. ALLEN: Earl Milton.

5 MR. MILTON: I'm Earl Milton,

6 Secretary Treasurer of True Health, Incorporated.

7 Our company, in conjunction with the local Dr.

8 Terry L. Pulse, placed thirty AIDS patients on our

9 product in a one hundred and eighty day test.

10 At the beginning of the test, sixteen of

11 the patients measured above the five ninety-nine

12 on the Walter Reid Scale which meant they had

13 full-blown AIDS. All of them had some decree of

14 AIDS. After a hundred and eighty days, none were

15 above a five.

16 At the start of the test, twelve of the

17 patients immune system was dead. At the end of

18 the test, only two still was nonfunctioning. At

19 the beginning of the test, seven were totally

20 functioning. At the end, nineteen were totaling

21 functioning.

22 Dr. Pulse released the results of this

23 at the Advanced Immune Discovery Symposium two and

24 a half weeks ago in San Francisco. Unfortunately,

25 the press was not present. He stated at that time

1 that seven of the patients are currently
2 negative.
3 My request to you is to assign someone
4 to look at our test, verify it and then help us
5 secure the funds to make this product available to
6 the AIDS population.
7 I would like to give you our newsletter
8 which shows the beginning and ending Walter Reid
9 Scale score for each of the patients in the upper
10 right-hand corner. And hopefully, on your flight
11 back, you can take a look at this. Thank you.
12 REV. ALLEN: Okay. Dennis James
13 Kidder.
14 MR. KIDDER: Again, my name is
15 Dennis James Kidder. I'm an independent
16 researcher who has been accumulating data over the
17 last three and a half years -- I'm an independent
18 researcher. I've been gathering evidence over the
19 last three and a half years. I have before me the
20 appeal that maintained the sodomy laws in the
21 State of Texas in 1983 for Baker vs. Wade.
22 Within this document are facts that you
23 people don't know, for reasons I do not know. I
24 have been trying to get to Mr. Bush, President
25 Reagan, the National Institute of Health, the AMA,

1 the Journal of American Medicine, our own Texas
2 Health Commissioner. I mean I can go on and on
3 and on.
4 I have visited with Parkland people. I
5 have been harassed by the Dallas Morning News
6 regarding my stories. I have been investigated by
7 the Secret Service regarding my proclamation.
8 And at this point in time, I am telling
9 you right now, you are dealing with a problem you
10 have no conception of. I have some handouts here
11 for you that are going to overwhelm you. I'm
12 going to let you digest them, review them,
13 annihilate them or re-present them to me for
14 explanation. That's at your own convenience.
15 These facts that I present before you
16 are based on the formation of all matters, the
17 essense of all life. And it goes from the
18 smallest of the small to the largest of the
19 large. And I'm talking about the parameters of
20 our universe and beyond.
21 I have resolved Einstein's Theory of
22 Relatively dealing with the form and force of
23 gravity. And I will just stop at this time and
24 let you review a couple of the things. If you
25 want a momentary explanation, I will give it.

1 REV. ALLEN: This is a part of your
2 three minutes.
3 MR. KIDDER: I understand. I have
4 information packets here for you. A lot of you
5 are humored by some of the little antecdotes and
6 jokes that prevail. There are people that are
7 dying.
8 There are several members of the gay
9 community I have tried to contact. I will not go
10 into their names. They have their own burdens to
11 bear. Your burden now is how to handle this
12 problem.
13 My profession at this time is to make
14 you understand one thing: We need the end of the
15 ignorance. We don't need the jokes. We don't
16 need the comedy. We don't need anything else, but
17 rational factual understanding and action.
18 Intervention prevention means one
19 thing: You stop it; you handle it, and you go no
20 farther. There will be casualities. There are
21 casualities. If we continue to joke, if we ride
22 our airplanes back to our a little offices and
23 don't do anything, yes, in fact, we have
24 problems. I am done.
25 REV. ALLEN: Okay. Emerson Emory.

1 MR. EMORY: My name is Emerson
2 Emory. I am a physician in the City of Dallas
3 practicing in the South Dallas area. That's where
4 my office is located.
5 I was somewhat concerned, first of all,
6 by the apparent secrecy of the visit of this
7 Commission to Dallas, Texas. It took me a little
8 doing to find out just what you were going to do
9 and where you were coming from.
10 Anyway, nevertheless, I am concerned
11 because daily I read that AIDS is increasing among
12 blacks in the United States. If that is true,
13 then I think that the black medical health care
14 people should be involved in some of it.
15 Instead, in the City of Dallas, and
16 perhaps this has been mentioned earlier -- I
17 wasn't here -- there is no treatment facilities
18 for blacks. Ninety percent of the black
19 population of this city lives south of Elm
20 Street. There is no treatment facility for blacks
21 in that particular ninety percent group.
22 The black physicians are somehow left
23 out of the whole thing of treatment or care of the
24 AIDS patients. So, I'll be very brief and say
25 that I hope that this Commission -- I don't know

1 how other cities are doing it, but I would hope
2 that you would involve the blacks who practice
3 medicine and other forms of health care in the
4 community in this particular problem which seems
5 to be increasing among my group. Thank you.
6 REV. ALLEN: Thank you. Bill
7 Hunt.
8 MR. HUNT: My name is Bill Hunt and
9 I'm Vice President of the Dallas Gay Alliance. I
10 would ask the media not to use my picture. I've
11 lost two jobs because I'm a person with AIDS and I
12 don't intend to lose the one I have now.
13 I wondered what it is that I could say
14 to this Commission to impress upon you the urgency
15 of the battle against AIDS. And for people like
16 myself who are told that they could die a year and
17 a half ago. I'm still here.
18 I have testified before our own city
19 council, before my county commissioners twice,
20 before our state legislature when we marched on
21 Austin.
22 Our county commissioners who denied two
23 weeks ago AIDS funding for AIDS prevention
24 information for gay men, who have denied AIDS
25 prevention information for teenagers despite the

1 fact that Dallas is number one in teenage
2 pregnancy in the United States and number one and
3 two in syphilis and gonorrhea in the United States
4 saying that this information will somehow
5 encourage them to have sex.
6 In 1987, '89, we begged for money for
7 this AIDS prevention information to no avail. It
8 will be this generation of teenagers who will die
9 of AIDS, will pay the price for our county
10 commissioners' ignorance.
11 The facts still remain that here in
12 Dallas and nationally that women with AIDS die
13 four times faster and that people of color die ten
14 times faster. Still, we have no prevention
15 programs in place directed at these groups.
16 The city and county of Dallas put
17 together a task force called the Community
18 Response to AIDS and studied AIDS in Dallas for
19 almost a year. That commission report, wonderful
20 in its recommendation, still sits on the shelf in
21 Dallas with one minor recommendation implemented
22 and none of the rest of them. The
23 Antidiscrimination Ordinance and Housing Public
24 accommodations was tabled by city council and
25 still sits on the table.

1 The Texas Legislature who studied AIDS
2 recommended $36,000,000.00 for AIDS funding for
3 this biennium. We got eighteen million over two
4 years. We waded through while the City of Dallas
5 did their Dallas seroprevalence survey which at
6 best is a snapshot of AIDS in Dallas. The
7 conclusion: It's not as bad as we thought. They
8 can't handle what we have already.
9 In Dallas last Tuesday, my friend Lupe
10 waited, waited in Parkland emergency room for
11 eleven hours. No beds. I'm sorry. Go home.
12 Take some asprin. It will break your fever. He
13 has pneumocystic pneumonia. It's preventable, its
14 treatable; but he will not be delivered --
15 Parkland Hospital will not deliver aerosolized
16 Pentamidine even though we sued them in court to
17 make them end the waiting list for AZT and for
18 Pentamidine.
19 Today, the AIDS clinic in Parkland will
20 not allow Parkland patients access to
21 Nelson-Tebedo Community Clinic Trials for
22 experimental drugs, even though they can't take
23 AZT, even though we would save the taxpayers
24 money, even though it would allow those people a
25 chance at life.

1 We're looking at you for leadership
2 because when you go home, this is what we have to
3 deal with here in Dallas.
4 MR. GOLDMAN: Sorry. Your three
5 minutes are up.
6 MR. HUNT: Thank you.
7 REV. ALLEN: It's unfortunate that
8 we couldn't dialogue with each one of you about
9 this.
10 We appreciate your persistence in
11 staying and being a part of this because we are
12 here and very sensitive to the needs of people
13 living with AIDS and very sensitive to our society
14 and how we deal with this. And it encourages us
15 that you are here saying we support you too.
16 We have gone around this country and
17 there has been a lot of participation, a lot of
18 frustration by those in the audience, by us. And
19 we take this task very seriously. And it's
20 painful to see the tragedy before us. And it is
21 awesome to think of the responsibility that we
22 have in dealing with this.
23 And we will be continuing to do the best
24 we can. And again, thank you for being here
25 because it means a great deal to us. So, thank

1 you.

2 (End of Proceedings.)

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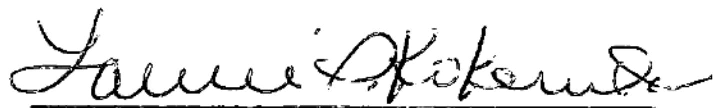
1 STATE OF TEXAS
2
3 COUNTY OF DALLAS
4
5 THIS IS TO CERTIFY THAT I, LAURIE S.
6 KOKORUDA, a Certified Shorthand Reporter in and
7 for Dallas County, Texas, reported in shorthand
8 and transcribed to the best of my ability the
9 proceedings had at the time and place set forth in
10 the caption hereof, and that the above and
11 foregoing 277 pages contain a full, true and
12 correct transcript of the said proceedings.
13 This the 19th day of July, 1990.
14
15
16 
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18 Certified Shorthand Reporter
19 in and for the State of Texas.
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