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NATIONAL COMMISSION

ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

HOUSING ISSUES AND THE HIV EPIDEMIC

VOLUME I

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VOLUME I

Monday, March 2, 1992

9:05 a.m.

The Copley Plaza Hotel
138 St. James Avenue
Boston, Massachusetts 02116

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P R O C E E D I N G S

CHAIRMAN OSBORN: We are very pleased to be in Boston, and I am going to proceed immediately to turn the microphone over to Larry Kessler for some opening remarks in the first of our two days of hearings on the issue of housing. Larry.

MR. KESSLER: Thank you, Dr. Osborn. Good morning, fellow commissioners and good morning members of the public and the press. Over the next two days, the commission will attempt to look at the issue of housing, housing for people with AIDS, housing for people with HIV disease. In the past, we have looked at the issues of education, health care access, research, homelessness, teens, adolescents with AIDS and so on, and this particular site visit is a combination of hearings and site visits in which we will explore some of the models and the needs that people with AIDS need in our society.

It is going to become clearer, I think, over the next two days that the intersection between early intervention, primary care, home care relates very directly to the state of a person's housing condition. That their health condition and their housing condition are interfaced and interlocked. We hope to hear some very vibrant testimony from our guests around the country as well as from here in Boston, but also hear from people with AIDS, some of whom have been fortunate to be placed in housing and others who are still looking for housing. In the two afternoon sessions, we will also have a chance to meet with many people with AIDS in a variety of settings from shelters to independent living situations to congregate living and to hospice, that level of care.

My expectation is that we will try as closely as possible to stay on schedule because our schedule will affect the schedules of other people if we fall too far behind. So please adhere to the schedule as outlined in the book and everything should work pretty well. On behalf of the city and on AIDS Action, I want to extend that welcome to you all, and it's nice to have you here. We're proud of the kinds of things we've been able to do in Boston, and we're also proud to have visitors from other cities that have also created exciting programs, all of which need to be duplicated and replicated all across this county, and that will happen when we have the commitment we need from the federal government, from the states, from the cities, and from the private sector.

So with that in mind, why don't we begin, and June, do you want to introduce our first presenter?

CHAIRMAN OSBORN: I think what I'll do is introduce the whole panel initially so that everybody knows who is speaking, and I will ask you, if you would, to present in sequence, and then we'll have a good opportunity for interactive discussion with the commissioners after all of your presentations. That way I think it will make a good coherent whole. So let me say that the first panel will be Judith Kurland, Commissioner, Department of Health and Hospitals in Boston here; Robert Greenwald, Chief Policy and Legal Advisor for the AIDS Action Committee of Boston; and Betsy Lieberman, who is the Executive Director of the AIDS Housing of Washington in Seattle, Washington. Welcome to you all, and we are eager to hear what you have to tell us. Thank you.

MR. KURLAND: Thank you very much. I'm Judith Kurland, Commissioner of Health and Hospitals for the city of Boston, and along with many other people who are welcoming you, I'd like to welcome you on behalf of the city and on behalf of public health advocates.

I will tell you some things that you already know. It is often said that AIDS has shown us the strengths and the weaknesses of the health care system, and I think that is what you have come to talk to us about today. When AIDS was first identified, the health care system, the acute medical care system in the United States, I think, responded in the way that we do well, which is to gear up and to disseminate information quickly and to rush for cures. And we tend to do that rather well in the United States when it comes to acute medical care.

What we do not do so well is to think about the attendant issues and the attendant problems that surround public health issues. AIDS is not the only issue where that is true. We could look at something like lead point poisoning or infant mortality where the non-acute medical care issues are as important as the acute medical care issues, but we don't have the same kind of system nor I would argue the same kind of commitment to addressing those issues. I'd also like to point out something that we should never forget, which is that our need for housing and supported housing for people living with AIDS is actually a function of our success.

People are living with AIDS, and in many cases we did not expect that to be the case when AIDS was first identified ten years ago. So we shouldn't forget it. We should be mindful of it and actually be grateful for the opportunity to solve this problem. In Boston, we are, as Larry Kessler said, rather proud of what we have been able to do and what we're committed to doing. Tomorrow the mayor of the city, who has convened almost all the resources of the city to try to address the issue of providing supported housing for people with AIDS, will talk to you about what we've been able to do, and some of the frustrations we as a city have in trying to solve this problem, particularly with trying to solve the problem without major national support and input.

But I'd like to talk to you now as the public health commissioner and as the head of two hospitals in the city about the need for housing for our patients and for a need for continuum of care. I am the Commissioner of Health and Hospitals. That means I'm the head of the Public Health Department but also of two hospitals, Boston City Hospital, an acute hospital, and Mattapan Hospital, which used to be a chronic disease hospital and is now a sub-acute hospital with a major AIDS emphasis. Boston City Hospital, like public hospitals all over the country, we see a disproportionate share of people living with AIDS.

We have massive treatment programs. We have community based treatment programs. We have a network of care with neighborhood health centers. We have done an extraordinary job in educating primary care physicians to care for people with AIDS. But we face the frustration of knowing that you cannot send someone home with medicine that needs to be refrigerated when that person doesn't have a home or a refrigerator or an outlet in which to plug a refrigerator even were we to give it to him.

We face the frustration of knowing that people lose their jobs because of their AIDS status, sometimes lose their ability to cope, sometimes lose their families, and don't have a supportive network to care for them. We face the frustration of getting people through an acute episode, getting them back on their feet, and knowing that we cannot send them back to a place where someone is going to help take care of them. We face the frustration of knowing that we have home therapies, good home health care therapies so that people do not need to be kept in hospitals, either acute or sub-acute hospitals, but knowing that these home therapies either require individual competence when a person is either weak or sometimes neurologically impaired, or require a partner or someone there to help, and these people often don't have anyone there to help.

The public process required under the Ryan White CARE Act, which was to have citywide planning and organization was a very successful one. And Boston has been identified as probably having the best process in the country. Now that's in part because the Boston AIDS Consortium, an already existing organization, a consortium of lots of agencies that we merely asked to expand itself to do the planning for us. But we did a wonderful community-wide planning effort, and 22 people testified before the Hearing on AIDS and Homelessness. Two of those people were people living with AIDS who were homeless.

And what that process pointed out was that when the planning effort came to us as a city and as a public health department with recommendations about what needed to be done under Title I, housing was one of the top issues identified. A lot of people expected that there would be more clinical issues, but housing was identified, again because we have been successful, because people are living with AIDS.

The city, as I said, has a rather massive effort. With some irony, the mayor identified 501 units. That's, in part, because the federal government had only identified 500 units to be built nationally, and I think we wanted to make a point that in a city of this size, a city of only 600,000 people, there is a need for at least 501 units in this city alone and to talk about a national goal of 500, we thought, needed to be pointed out for what it was.

But it's going to be hard to get to that without massive federal help and without all the cooperation of the entire community. I would like to talk about three kinds of programs that we think need to be provided and then talk to you a little bit about some models that we think are useful. The first, of course, is the area of AIDS and homelessness. We have a program Health Care for the Homeless. Health Care for the Homeless was started not because of AIDS at all but because of the growing homeless problem in cities all across the United States.

Health Care for the Homeless, however, cares for about 360 people now who have HIV disease, about 80 living with AIDS, over 200 with symptomatic HIV disease, and about another 80 with asymptomatic HIV disease. That's 360 people that are homeless who have AIDS or HIV disease. Those people all should have homes. They should all have either supported living or independent living depending on their health status. It is a major problem because AIDS often makes people homeless. They lose their benefits. They lose their jobs. They sometimes lose their families and therefore people who before were thriving, employed and able to take care of themselves become homeless because of the fact of their AIDS. That needs to be addressed, and it needs to be addressed quickly and comprehensively.

Secondly, in Boston again we have a program called CAP, Children with AIDS Program, and it started after the mayor went to New York and was talking with the then-mayor of New York Ed Koch, and they were talking about AIDS, and Mayor Koch talked about the border babies in New York, and our mayor came back here and said do we have border babies, and we were fortunate that we didn't. But the health officials said to him that we would soon. And he said, no, he didn't expect that we would have border babies in Boston. He wanted us to find a way to house them. And so at Boston City Hospital, we built an apartment within the hospital for children living with AIDS.

But it's still in a hospital, and that is not the best thing for children, and so I'm happy to tell you that with some funds from the McKinney fund, we are going to build a house in Mattapan on our Mattapan campus in a residential neighborhood, a house and a home for children living with AIDS. But I should tell you that there are practically no operating funds for that house. We are saving the federal government and the state government millions of dollars by not having these children be border babies, and yet there really isn't any money on the federal level and a pittance on the state level to support this program that is better, more humane, more decent, and truthfully a lot cheaper. So we're doing the right thing, and it would save the federal and state governments lots of money, and yet there is really no money for operating costs.

And that needs to be addressed because in this country we have seen the AIDS epidemic become like the AIDS epidemic all around the world and increasingly becoming a disease of children. And we have to make sure those children are supported.

The third area I want to talk about is families because it is becoming increasingly a disease of children because more women are getting AIDS and they are living with their children or they are both living with AIDS but there are practically no supports. There is no housing presently for families for women and children living with AIDS. And we need to do something about that because there certainly cannot be any kind of single room occupancy for families or with children living with AIDS. And we need to develop those models.

I'd like to suggest to you that we do not have to be brilliant to figure this out. We actually have some wonderful models from our history and presently that we ought to look at. Because the issue of people living with AIDS is that they often go from independence to dependence back to independence, people go from strength to weakness back to strength, and so what we want is a kind of flexibility in our housing, that I would argue exists in a lot of housing for the elderly, congregate housing, housing that has support services available in a complex or available nearby, but doesn't have to be in every room at every time.

And a lot of models of housing for the elderly, strong robust elderly are living in the same place with more frail elderly, and it is the whole continuum of services that is available as you need it, when you need it, but only when you need it, and it is not a bad model for us to think about.

The other tragic model we need to think about is what you do for families when the middle generation is lost. We're certainly seeing this in East Africa where the elderly are left and the children are left, and people of childbearing age are dying.

And so we need to figure out what you do to help support families and keep them intact so long as you can, but also think about what you do when children are left. And again we have some very tragic models, but they are useful to look at. Following the Holocaust in Europe in the mid-'40s and following major holocausts around the world when children are left abandoned, and sometimes models have been developed where children can live supported with their family members who are still alive but sometimes with more group services that we need to think about and we need to look at.

And what we need to often do is think about how children can be taken care of during the day and returned to either foster care or to extended families with great support because these extended families are often grandparents who are taking care of their own children who have AIDS and need to take care of their grandchildren. But we don't have to invent things from scratch. There are nice models. We don't have to be, I would argue, particularly brilliant. What we have to be is committed. What we have to do is recognize that we have succeeded in keeping people alive with AIDS. The very program that I mentioned, the CAP program, when we started the Children with AIDS Program, the likelihood was that a child born with HIV disease would not live beyond 18 months. That was the expectation. That's what we were prepared for.

I'm happy to tell you that we have seven year olds in our CAP program, and I expect that these seven year olds will be 17 year olds, and that's the kind of planning and thought that needs to go into housing and not just housing, of course, but transportation and schooling and lots of things we need to think about. But as tough as times are and as much as we need to do, we need to constantly remind ourselves that this is a wonderful problem we have to face because these children are seven and they've made it to seven, and they're relatively robust, and we need to prepare a better future for them and a decent life. Thank you.

CHAIRMAN OSBORN: Thank you very much.

MR. GREENWALD: Good morning. My name is Robert Greenwald from the AIDS Action Committee of Massachusetts. I want to thank you for the opportunity to present to you once again concerning efforts being made to create housing for people living with HIV disease. I have some good news and some bad news to report to you since I last presented to the commission on housing issues on July 30, 1990 in Seattle. As to the good news, there are more people interested in and working on the development of housing options for people living with HIV disease than ever before.

AIDS housing providers have continued to move forward to meet the challenge of both increasing access to already existing housing programs as well as to creating new housing programs to meet the specific needs of housing of people with AIDS. We have had some successes. In Massachusetts we have developed an AIDS rental subsidy program, which is the cornerstone of our AIDS homelessness prevention efforts. We have 30 rental certificates which subsidize individuals with AIDS rents who can no longer afford their apartments without financial assistance. Ultimately, by giving people the certificates they can remain in their apartments and avoiding homelessness and the ensuing acute care hospitalizations that result due to homelessness.

We have also developed a subsidized housing unit program as private nonprofit housing directors in Massachusetts have agreed to set aside subsidized housing units for people with AIDS. With the subsidized units, we have been able to house individuals with HIV disease who are already homeless. One such client that we interviewed two weeks ago had been hospitalized five times in the year prior to us finding him subsidized housing. In the 18 months that he's been living in subsidized housing, he has not been hospitalized.

And this is not an atypical result. Many of the clients that we have worked with assert that finding affordable and appropriate housing has been the most significant factor in improving their health and wellbeing. We have developed a housing program with the capacity to house five children with AIDS as Commissioner Kurland talked about. Shortly, capacity will double to ten. We have 24 hour supervised housing for ten people with AIDS with central nervous system disorder. We have 28 rooms for people with AIDS with a history of substance abuse and homelessness. The residence is supervised 24 hours a day and two meals are provided.

We have a skilled nursing facility for 18 people with AIDS. You will be having site visits this afternoon and tomorrow afternoon so you can visit these places. In short, both the state and the city have increasingly recognized the importance of the AIDS housing issue. On the federal level, Congress has also taken some important steps. In 1991, Congress appropriated funds for 500 units of 811 housing. 811 housing is designed specifically to house people with disabilities that need support services.

Congress also appropriated $50 million under the National Affordable Housing Act, specifically the housing opportunities for people with AIDS provisions, to house and develop specific programs for people with AIDS. On the local, state and national level, some progress has been made. As to the bad news, even in a state with many community based organizations interested in developing and supporting AIDS housing and with city and state officials willing to put some resources into AIDS housing, we are falling even further behind in terms of meeting need.

While we have the capacity to house ten children with AIDS by the end of 1992, we will have over 200 children in need of such services. While we have a skilled nursing facility for 18, hundreds will need access. In fact, the number of HIV positive people that are homeless in the Commonwealth of Massachusetts is increasing rapidly. In the city of Boston, it is estimated that 30 percent of our homeless population is HIV infected. Approximately 50 percent of all people with AIDS in Massachusetts are either homeless or in imminent danger of homelessness and by federal guidelines, that means that over 50 percent are paying. Those that still have housing are paying more than 50 percent of their income on rent.

It is estimated that 30 percent of all people with AIDS in acute care hospitals at any given time in Massachusetts are in acute care hospitals because no community-based residential program is available for them. So in other words, we're paying $1400 a day to keep somebody housed at Boston City Hospital rather than developing affordable housing for people with AIDS. In Massachusetts, and it's painful to recognize that we are doing better than most states, while we may successfully house hundreds, thousands are in need.

There is an acute shortage of housing resources available for creating housing for people with AIDS. And this is largely the result of the fact that the Federal

Office of Housing and Urban Development has literally ignored the AIDS housing crisis. HUD, in effect, the largest single landlord, the largest housing provider, and housing developer in the country, has resisted all efforts by community based organizations, cities, states and Congress to meet the housing needs of people living with HIV 30 disease.

In an internal HUD memo, HUD listed the AIDS program 31st priority out of 33. With the 500 unit Section 811 set-aside, when it was established by Congress in 1991, grant awards have yet to be announced. On January 16, 1992, six weeks ago, HUD announced that funds for the AIDS housing part of the National Affordable Housing Act could not be released until 1993. This is the case despite the fact that final regulations have already been drafted and approved for much larger and more complicated programs.

After this commission's hearing was announced, HUD changed its position and how has announced that they will release the AIDS housing funds by June of 1992. That's good news. However, at the same time, the President's 1993 budget was released which included no request for continued funding for the AIDS housing act. Leadership has not even been a question. Every step of the way HUD has strongly resisted housing for people with AIDS. Ultimately, you name the program, and HUD has denied us access. When the state requested that HUD create a Massachusetts based rental subsidy set-aside program -- that's the certificate program for homeless prevention -- using federal resources already allocated to Massachusetts, HUD refused.

Instead, the state created a much smaller program using state resources. When Jewish Community Housing of Massachusetts applied for Section 811 housing -- that's the housing for people that need support services -- to develop housing for people with AIDS, HUD denied them access. HUD stated that people with AIDS don't meet their definition of handicapped or disabled, people with AIDS don't live long enough to qualify under HUD's statutory definition of impairment. The disease according to HUD is not of such a nature that the ability to carry on daily functions would be improved by more suitable housing.

Finally, when the state requested that HUD allow them to use federal funds for developing 65 long-term AIDS housing units, HUD refused. The state had worked on this program for three years with HUD's knowledge and approval. Service providers hired staff to develop the services. The state had agreed to contribute $1 million in service money to provide services to these housing programs since HUD won't fund services. At the last minute, HUD came up with their latest reason for denying the development of AIDS housing. HUD asserted that they have a policy against permitting the development of housing for targeted populations although it has been done for other disability groups in the past.

HUD, after tremendous pressure, allowed us to go forward with the housing program as long as it was billed as housing for those suffering from immunological disorders of a degenerative nature, not AIDS. In short, HUD has attempted to thwart AIDS housing development across the country with one arbitrary and capricious ruling after another. The only AIDS housing projects to go forward using HUD resources are the following: those that have either sued or threatened to sue HUD, those that have agreed to make major compromises which significantly diluted the effectiveness of the program, and finally those that have gone forward using HUD resources without HUD approval of knowledge of who the program was specifically designed to house.

In other words, we do have some AIDS housing programs funded by HUD, but the people did not specify that it was housing for people with AIDS. And this brings me to the final part of my presentation which is really a call for help from the commission and basically everyone here today. We must get HUD to move AIDS from a 31st priority out of 33 to a top priority. The federal government must help to support AIDS housing. HUD must give us access to traditional programs and adopt regulations and guidelines to meet the specific housing needs of people with AIDS.

Not only do we want them to put the money out for the AIDS Housing Act and the 500 set aside units, we need to have access to the billions of dollars of HUD housing programs if we are ever going to meet the housing needs of people with AIDS. The new Shelter Plus Care Program, for example, which the administration is touting as the program that should be used to house people with AIDS, was not designed to successfully house people with AIDS. It requires that you be homeless to be eligible. Homelessness kills people with AIDS. We must provide assistance prior to homelessness.

It requires that the applicant, the service provider, or the provider of housing provide equal matching funds for services since HUD won't fund services. Providing a million dollars for bricks and mortar with no service dollars is useless to most agencies trying to build AIDS housing. HUD's unwillingness to fund services attached to housing must end. Ultimately, again, HUD will not fund AIDS specific housing under Shelter Plus Care or any other housing program.

As an attorney, I must tell you that HUD's arguments as to why AIDS specific housing is violative of the federal law is most specious. HUD cites Section 504. Section 504 is the federal anti-discrimination law which states that an otherwise qualified individual may not be denied access to housing solely by the reason of his or her handicap. An individual who is not HIV infected is not otherwise qualified for the specialized AIDS related services AIDS housing projects are by their nature intended to serve. No deaf, blind, wheelchair bound, mentally ill or other disabled person would because of their disability be subject to exclusion.

Most compelling, the United States Supreme Court case in 1987, Trainer found there is nothing in Section 504 that requires that any benefit extended to one category of handicapped persons also be extended to all other categories of handicapped persons. HUD can and must permit AIDS specific housing. HUD must allow for changes in tenant selection procedures and tenant selection procedures basically rank order of priority for getting into HUD housing under federal guidelines. HUD must recognize that individuals with terminal or acute medical conditions need access prior to homelessness and that long waiting lists basically preclude access.

In Massachusetts, we have done tenant selection procedure revisions, and they have taken place. They have helped people with AIDS gain access to housing programs. They have worked. HUD must change its policy of denying that AIDS is a disability, and all that HUD needs to do is to look to all the other federal programs to see that AIDS is a disability and therefore people with AIDS should be eligible for 811 and other disabled housing programs.

Ultimately, and finally, HUD must begin to work with AIDS service providers and experts to develop all of these new programs. HUD officials are the first to admit that they don't know AIDS. They must allow us to work with them to develop successful programs. When I met HUD officials three weeks ago concerning the AIDS Housing Act, no clear plan for working together was developed. When we suggested that we work with them on the regulations, they said to do so violates HUD policy. They suggested that we should submit our thoughts to them but gave no indication that they had any intention of seeking our or any other AIDS service providers assistance. There is no law against us working together, and I publicly implore HUD to seek out AIDS service providers assistance in developing AIDS housing programs. Thank you

CHAIRMAN OSBORN: Thank you very much. Betsy.

MS. LIEBERMAN: Thank you. My name is Betsy Lieberman, and I'm Executive Director of AIDS Housing of Washington. AIDS Housing of Washington is a nonprofit organization that has just completed construction of the first new skilled nursing facility and day health program for people with AIDS in the United States. The building -- unfortunately, it's the only building -- stands as a clear testament of commitment, courage, and generosity of over 5,000 individuals, corporations, foundations and government funders responding to the crisis in long-term care for persons with AIDS.

Seattle-King County has a cumulative total of about 2100 cases. We rank about 20th in the United States in terms of total number of cases with the total number of infected individuals in the community over 10,000. What has set Seattle apart has been its ability to provide comprehensive AIDS services and the commitment of our health department and community-based providers to work collaboratively in developing a non-duplicative continuum of services.

We have a community that in 1983 when we had only ten cases of AIDS in Seattle came together, the city, the health department, and took the first steps to establish an AIDS project and develop a strategic planning process to address the media and the long-term care needs for persons with AIDS in housing, prevention, education, case management, medical care and support services. At that time, it was designated that we would have two lead agencies: our health department, the Seattle-King County Department of Public Health, and the Northwest AIDS Foundation, which was our community based umbrella AIDS organization.

These lead agencies have had the responsibility for facilitating planning, coordinating, development and standards for services and generating and allocating funds for these services. One of the original premises that came out of the planning process which was funded originally by the Robert

Wood Johnson Foundation under an AIDS health services grant was that case management services should be available for all persons with AIDS, that there should be developed multiple options and types of care available, and support for a strong volunteer system.

When you ask people with AIDS what they need in terms of housing, people with AIDS will say as many different things as all of us in this room, and at different times in the illness we will need different types of housing. There is not one solution. For housing, the goal is always going to be to try to keep people in their own homes, but as we heard from the two other persons testifying today, often people don't have homes, their homes may not be appropriate, and we don't have the resources to pay for the services that will keep people at home.

And the secondary plan was to develop a range of housing to meet people, to be able to care for persons with AIDS at different stages of the HIV disease from emergency housing to transitional to permanent independent living and to provide 24 hour care. In 1992, much like Boston, Seattle has a diverse continuum of housing which only meets a portion of the need. Housing is the biggest unmet need for people with AIDS throughout the United States in terms of services.

Seattle has a vouchered emergency housing program in motels and shelters that funds people for up to two to three weeks. We have 20 units of transitional housing which is housing for persons with HIV/AIDS for up to three months. And we have a series of independent housing. We are one of the few communities that has 90 dedicated HUD Section 8 certificates, which is the widest, the program that has the greatest demand because it allows people to remain in their own homes and it subsidizes the rent. We also have set up a process of expedited placement for persons with AIDS in both the Seattle and the county housing authorities.

We have four six-bedroom homes that are shared living houses run by religious organizations. Three have resident managers. And we have eight apartments in another church-owned low income housing project. And we also have two six-bedroom houses that have 24 hour care, skilled nursing care, that are operated by an organization called Rose Hedge, which is a nonprofit agency, which has served over 150 individuals since it opened in June of 1988.

The referral and advocacy for all these housing placements are coordinated through the Northwest AIDS

Foundation. Bailey Bouchet House, the skilled nursing facility and day health program developed by AIDS Housing of Washington, celebrated its community dedication on January 12 of this year with over 2500 people attending and presentations by Dr. June Osborn and the mayor of Seattle, Norm Rice, among others.

A copy of the commemorative report for this project is in front of you. A 12 page edition of this report was distributed with the morning and evening papers in Seattle the day after the dedication to really make people in the community aware of what people have done together. The opening of Bailey Bouchet House in May of this year will complete the housing continuum. Construction of the 35 bed residence was completed in January, and it will accept its first residents in May. The project encountered an unanticipated three month delay in opening as a result of a decision a year ago to change the operators of the facility from the Sisters of Providence in Washington to Virginia Mason Medical Center.

The change was precipitated by the inability of the board of directors of the Sisters of Providence and AIDS Housing to agree on the person best qualified to serve as the administrator. Bailey Bouchet House represents a very remarkable community effort which began in 1987 with the Robert Wood Johnson Foundation funded planning grant to the health department. This planning effort included the major hospitals, the city, county and state governments, the Northwest AIDS Foundation, and other community-based agencies, people living with AIDS, and others working in home care, long-term care and hospice.

Out of this planning effort came a series of recommendations that provided the founding of AIDS Housing of Washington in May of 1988 and the criteria for the development of Bailey-Bouchet House. The reasons we did this project was primarily because there was a shortage of licensed skilled nursing beds in our community. Our nursing homes were operating at 98 percent capacity and the number of beds we had in the community were based on a population of 65 and over. And the inability of nursing facilities to provide an appropriate level of care for persons with AIDS led to the committee's recommendation to develop a stand-alone facility which would assure the delivery of a broad scope of long-term care services, including 24 hour IV therapy, subacute care, skilled nursing care and hospice.

The spectrum of services allows the facility to provide flexibility in care and be able to respond to the changing and continually fluctuating needs of persons with AIDS. When I first started working on this project in 1988, the life expectancy in Seattle from diagnosis to death was 13 months from AIDS and now it's over two years, and we wanted to be able to build a project that would meet the care needs in 1992 and would meet the care needs in 1995 and would be able to be flexible in the year 2000.

The level of nursing care in Bailey-Bouchet house will be equivalent to that of a hospital at one third the cost. We are talking about $300 a day versus $900 a day. We had to go through the certificate of need process and get skilled nursing beds to assure the viability of the facility through reimbursement from Medicaid and Medicare for ongoing services. The day health program in the project has been approved for reimbursement through the Washington State Medicaid AIDS Waiver Program.

But success of this project has required surmounting a series of unforeseeable obstacles. I mean I think if I had known what I was getting into when I started this, I'm not sure I would have gone forward. We had to go to our Washington state legislature and get two separate bills passed that allowed the Department of Social and Health Services to reimburse for the nursing hours and nursing supplies required to provide care in the facility. I mean it was hours of time down in Olympia, our legislative office, and getting support and help from our corporate sponsors and corporate supporters. We had to respond to a legal challenge for siting of the facility that tied up the project for nine months in the city hearing examiner's office, the city council, and superior court.

That was after we had gone to the city and found an empty site that was zoned appropriately to allow this project to be built outright. We had to raise over $6.3 million for construction from over 5000 individual donors, participation by 50 local and national foundations and corporations, as well as grants from the city, county, state and federal government. Another example of the efficacy of community planning in Seattle has been that once Bailey-Bouchet opens its doors in May, Rose Hedge, which currently provides 24 hour care for people with AIDS, will lower the level of care it provides in the two six-bedroom house to assisted living for persons with AIDS with dementia complex or dual diagnosis of HIV and mental illness or substance abuse.

These individuals are the hardest to house and might otherwise fall through the cracks. Strategic planning and program evaluation has been the cornerstones of our comprehensive housing development for persons with AIDS in Seattle. There will be an evaluation done at Bailey-Bouchet House on the impact of the services, cognitive function and quality of life for the residents, and the cost effectiveness as well as evaluation of specific pharmaceutical combinations and treatment choices. The evaluation is funded by a grant from a demonstration grant from HRSA, the Health Resources Services Administration, given to three HIV sub-acute facilities nationally.

We hope that this ongoing evaluation will assist others in the country in being able to develop similar projects. In 1991, AIDS Housing of Washington received a grant from the Robert Wood Johnson Foundation to develop a manual on how to develop residential facilities for people with AIDS. The manual addressed the primary issues that we encounter in housing and program development and will include information on residential facilities and licensing requirements from across the United States. This manual will be available next January through AIDS Housing of Washington.

Over the past year, I and my colleague, Donald Chamberlain, have had the blessing of visiting AIDS residential projects in San Francisco, Los Angeles, South Florida, both Miami and the Palm Beach and Fort Lauderdale areas, New York, Boston, and most recently Puerto Rico. I want to make some general comments about those projects.

Almost none of the projects we visited were developed by experienced health care providers, but have come instead from the ingenuity and creativity of dedicated AIDS activists or AIDS service providers. We have met more heroes in small communities and neighborhoods in this country that are pulling together projects that are just unbelievable with no resources. There is no community in the country that we have visited where the availability of housing resources even approaches the need. Residential projects often operate in isolation from each other. We discovered in the state of Oregon alone there were seven small facilities and most of them had never even heard of each other.

Even when well connected with other, some of them are well connected with other AIDS organizations, but some are there doing their own thing. Lastly, the greatest obstacle in housing is not always finding the funds for acquisition and construction but rather obtaining funding and reimbursement to cover the ongoing services. It's not just the HUD programs where they're not funding the services but routinely in many states the construction monies are available, but no one funds the service component. In the state of Florida, we discovered that they have this great licensure called congregate living facilities for people with AIDS and they have a lot of requirements connected to facility development, and there is not even one dollar appropriated by the state to cover the cost of supporting the people in the housing.

Adequate reimbursement for non-institutional services is the key element in keeping people with AIDS out of the hospital and in their own homes and community. In closing, I want to urge the commission to work with the Department of HUD, Housing and Urban Development, and Health and Human Services to develop programs which will fund both the development costs and ongoing services in housing. I sat for two years as a reviewer for HRSA for 1610(b) construction program that funded over 50 projects nationally for intermediate, acute and long-term care services. It funded construction dollars and was able to leverage a lot of community dollars, and that program was not refunded this past year.

I also urge the commission to fund and implement evaluation and technical assistance components in these programs so that we can support each other to develop housing and services, and we can learn from each other's experiences and to increase funding for housing. It's the greatest unmet need in the spectrum of AIDS care. Thank you for the opportunity to speak to all of you.

CHAIRMAN OSBORN: Let me, I'm sure, on behalf of all the commissioners thank all three of you for very powerful testimony. I'm glad to say that we have some time now to interact and get a chance to ask questions and to bring out some of the points more fully that you made so succinctly. Commissioner Goldman.

MR. GOLDMAN: Thank you. I have a few questions, different ones for different ones of you. Ms. Kurland, Mr. Greenwald in his testimony estimated that 30 percent of the persons with AIDS who were currently in hospitals could, in fact, be cared for at a less intensive and less costly facility. Do you concur with that figure? Do you have an alternate figure? And how does that compare with your general hospital population generally?

MR. KURLAND: I concur with the figure. I think he also used a similar 30 percent for homeless people who have HIV disease. I think that it is very hard for an honest and decent discharge planner or caretaker to discharge a person from a hospital or chronic disease facility to no place or to a place that he or she knows is inadequate. It happens sometimes, but people tend not to do that sometimes for decent reasons and sometimes for liability ones.

But I think that it is not an unreasonable estimate in terms of the numbers. And, of course, the cost of caring for somebody in acute care or even a subacute care facility compared to home care of supported housing is extraordinary. So I think it compares reasonably with what we're experiencing. And how does it compare with the rest of the hospital population? Well, forgive my cynicism, but I think the hospital population, that is in terms of people that could be elsewhere but aren't elsewhere, not counting AIDS, depends on what the demand is.

If there is a demand for hospital beds, then you have a lower percentage of people who could be elsewhere, and if you have a low demand for hospital beds, you have a higher percentage of people who could be discharged to other kinds of facilities. I think that is what our experience has shown. But I think AIDS is different. I think for the most part for a whole host of reasons, good and bad, people would like to discharge people with HIV disease from hospitals, and there I think it's much more a function of where they can go.

MR. GOLDMAN: And Mr. Greenwald, would you compare and contrast the way that, at least your experience, HUD treats people with HIV disease and programs devoted to HIV disease as compared to persons in programs with comparably disabling conditions? And I'd like to ask Ms. Lieberman, given your past experience in dealing with the elderly, the kinds of programs and facilities that you are advocating for persons with AIDS and HIV infection, are they, in fact, available at least to a greater degree or to some degree with the elderly, and are there lessons to be learned from that, and are those programs available, and why aren't they available for persons with AIDS if they're available for the elderly?

MR. GREENWALD: Basically we know that HUD has allowed disease specific housing to be built historically.

We know that there are houses for people that have mental illness. There are housing programs for people based on blindness, et cetera. So that in terms of just general terms, I know, is true. In terms of how cooperative HUD is, for example, in terms of working with these other populations, I can't really comment on that, but I know in terms of our programs and us trying to work with HUD, we've basically been completely unsuccessful.

MS. LIEBERMAN: In terms of elderly, the development of long-term care and housing services for older adults is similar to those for people with AIDS except that we're dealing with a much more compact time line. Most people with AIDS end up in a nursing facility for an average of between 30 days and six weeks, and most older adults end up in nursing homes for 24 plus months who end up there. And so it's a very different kind of population that has a lot more acute episodes that needs a lot more skilled nursing care, and you need to develop a system that has the ability to be responsive to those needs.

We also have a system that funds, I mean Medicare for both its pluses and minuses has over the years evolved to funding in many states a host of community-based programs that it's not doing in other communities. And for many people with AIDS, as the other people have testified, you are talking about a population that is my age that doesn't, hasn't set aside money and resources to pay for housing and services when it gets older and sick. And so we have both lessons to learn but we need to provide the resources to be able to take those lessons and fund them at the community level.

MR. GOLDMAN: But there are services available to provide reimbursement for non-institutional services, for many in non-institutional services, for the elderly in various communities --

MS. LIEBERMAN: Yes.

MR. GOLDMAN: -- that at least are not available to persons with AIDS and HIV infection?

MS. LIEBERMAN: Right. Right. And so we just need to put those mechanisms in place to cover the cost of services. In the state of Florida, we met many programs that were receiving in residential programs $20 a day to care. These are people needing congregate care. So they are getting meals. They're getting activities of daily living support. They're getting supervision. And the project is receiving

$20 a day to do all that, the room and board costs and the service costs.

And in the state of Washington, our nursing home reimbursement gives you $1.62 a day for raw food costs, and that's what they're feeding people in nursing homes. And have you ever tried to feed someone with AIDS who needs 3,000 calories a day on $1.62? I mean I'm not sure how you could go ahead and do that.

CHAIRMAN OSBORN: Commissioner Dalton, Rogers, Diaz, in that order.

MR. DALTON: Commissioner Kurland, I am truly impressed by what the city of Boston has done with respect to developing a continuum of services, housing services for people with AIDS. And so I want you to hear my comments in that light, and I genuinely mean that. But I was a little concerned as I listened to your testimony specifically with reference to children and families. I heard you describe a facility that is going to open in Mattapan. I believe you said at some point would have space available for five children, I believe. Later we heard from Mr. Greenwald that ten children. But he also suggested that the need currently is for housing for 200 children, not for ten.

You also, as I recall your testimony, indicated that you had money for the facility but not for programming. And you talked about the need to sort of develop models for meeting the needs of children, but it sounds to me as if the needs of children are present today. Similarly, with respect to families, your testimony was very sort of future oriented. You said we need to begin to think about how to do this, that and the other. I assume if there are 200 children in need of housing today, there are families living with HIV disease today in need of care, and as you yourself said the models are available, at least serviceable models are available. We don't need to be all that creative.

And so I guess I want you to help us --

MR. KURLAND: Sure.

MR. DALTON: -- figure out why in a city that does care, in a city which has developed expertise, and in a city in which government and volunteer organizations all latched on this problem of housing, why even here is it so difficult to provide both physical facilities and programming for people living with HIV?

MR. KURLAND: I think there are several things. One is I do want to clarify. We have five residential slots for children. We're going to go to ten. But our hope is that children will not have to live in a home, I mean in our group home. The intent and the push of both Boston and the Commonwealth has been to provide for children to stay in their homes or with extended families or in appropriate family settings and not to have them in group living or in any kind of institutional setting no matter how homelike that institutional setting might be.

So when we decided to build the home in Mattapan, we are doubling the size of our residential capacity, but we actually did not want to build a home for 25 or 100 children because then that's the number of children that would fill it and not be taken care of with families in homes, with extended families and appropriate foster care. We have been fortunate in Massachusetts that we have had no problem finding high level foster care. People that have never been participating as foster parents have been when they understood that children had AIDS and we've actually been very successful and very fortunate.

The home also has a day program, though, so that we have a day care program to take children living with AIDS during the day so their families can get support. We try to keep the families involved in the care of the children. As I said, a lot of these parents often have AIDS themselves and so when they're healthy, they have a greater responsibility and role in taking care of their children, and when they're not, they either revert to a residential program or to extended family or to foster care.

But the whole intent was to have this not be the primary provider for most of the children in the Commonwealth. In terms of the disparity of numbers, right now there have been 101 children diagnosed with AIDS in the Commonwealth. I think the 200 is probably a projection because --

MR. GREENWALD: By the end of 1992 I think is the projection that there will be 200.

MR. KURLAND: Okay. Yeah. I think there have been 101. There are besides the Boston City Hospital program, there is a program called STAR, which is run by a private provider at a community health center that's a wonderful program. Also, a day program. That was a long answer to a relatively short question. But it is not our intent to become a separate residential facility for all children with AIDS. We still believe that children with AIDS like most children thrive and do best when they're with family and friends or a permanent foster care system if they lose their family. But we didn't want to become a permanent orphanage.

MR. DALTON: Thank you. And that wasn't too long of an answer. I mean it really does speak to the underlying concern. I wanted to ask you a specific follow-up which has to do with foster care. You said you had no trouble getting high level foster care. I take it you're talking about unrelated foster care and unrelated homes, and I guess I wanted to ask you what has the Commonwealth done or what has the city done to make it possible for kin, for related people, to provide foster care? Are there mechanisms for funding family members to take in children, for example?

MR. KURLAND: There is a mechanism, and our intent -- that's why I talked about sort of the bookend generation of grandparents taking care of their children and also taking care of their grandchildren. We have a very aggressive program, and so does the STAR program attempt to try to keep family involved. And it does tend to end up to be grandparents. That's for the most part who it is. And the same subsidies that are available to non-related foster parents are available to foster parents. But you also mentioned the point about money for construction and not money for services.

And I think my two colleagues here have pointed that out very, very strongly. That there is often money for bricks and mortar because the one time expenditure and people can point to it and put their names on it and plaques on it, and there is often money for one time planning, and listening to Betsy, I was reminded there is a Robert Wood Johnson one-time grant, there's Title I one time grant, there's McKinney one time construction. And if we as a nation are going to recognize that actually the wonderful thing that people are living with AIDS, then we need to think about permanent support for services that continue beyond one time construction or one time planning.

Most of the planning that has gone on in this community has been without any outside support other than what the city and the private organizations have brought to it, and certainly in terms of support services to keep people healthy and alive, those are much, much weaker than construction grants.

CHAIRMAN OSBORN: Dr. Rogers.

DR. ROGERS: Thank you. That was very elegant testimony. A couple questions. One for Mr. Greenwald and then one for Commissioner Kurland. We have in front of us, Mr. Greenwald, an elegant chart showing that HUD has been successful in reducing what it was putting into housing from a high of what looks like about $32 million to 4 million since '78 despite this tragic advance of people who need housing. If you were us, what could be most compelling in us talking to HUD? That's part of the question.

The other is just in my naivete, can HUD not only fund bricks and mortar but actually fund ongoing costs of housing?

MR. GREENWALD: There are some programs for which HUD is allowed to provide services. I think some of it would take HUD going to Congress and really pushing for in terms of particularly of AIDS specific housing the need to develop housing with services. I mean --

DR. ROGERS: How could we persuade them of the error of their ways at the moment?

MR. GREENWALD: Well, again, as I said, I mean we're 31st out of 33 so we have a long way to go. I think it's going to take some pressure to have it move up in priority.

DR. ROGERS: What pressure would be most effective? What would you like us to see us do?

MR. GREENWALD: I think calling public attention to the issue would be very helpful. I mean I have to say that some of the past commission reports, for example, have been very helpful to us on the local and community level in organizing. We have the commission reports to show to our legislators, to bring to our Congress people. So I think a concerted effort by both city, state, and national officials in trying to push HUD into taking the issue of AIDS housing seriously would be very helpful to us.

DR. ROGERS: Okay. Thank you. Commissioner Kurland, you've been so good at developing housing in Boston, how do you get around the NIMBY syndrome that is absolutely blocked us in New York City? The NIMBY syndrome for those of you who don't know is Not in My Back Yard -- successful in blocking almost all AIDS housing for a decade in New York City.

MR. KURLAND: Well, first I'll praise us and then I'll tell you where we haven't succeeded. I think that we've been successful in Boston because of Larry Kessler and Mayor Flynn, and the Multicultural AIDS Consortium.

DR. ROGERS: Were you put up to that?

MR. KURLAND: I'm sorry?

DR. ROGERS: I say were you put up to that?

MR. KURLAND: No, no, I was not.

(Laughter.)

MR. KURLAND: I think we're successful because they have been in the forefront of showing the human face of AIDS. I mean I think that we have to be careful of undue pride, but I think in Boston we are proud of the fact that we from the beginning saw the human face of AIDS, and I think that we realized that these are our brothers, our sons, our cousins and now our daughters and sisters and our children.

We're not always wonderful, but we work very hard at that, and I think that there is an understanding and compassion, but also a sense that this is us, and we're all in this together. So I think that has helped. We are also fortunate in some of our neighborhoods. I point out that Mattapan is a wonderful welcoming neighborhood. When we had a community meeting to do siting of the Children with AIDS Program in Mattapan, and Mattapan is a middle class black community for those of you who are not from Boston, the people that came out did not come out to say not in my neighborhood, and they did not come out to say don't put those children here. They came out and said can we help you care for these children? Can we do something?

I mean it was extraordinary. So I think the city has tried hard to make sure that people understand that this is all of us together, and I do think that there are particular neighborhoods that are wonderfully welcoming. But there are people that are less attractive than others. So the Department of Health and Hospitals, that is my own department, using Title I funds has a program for homeless people with AIDS who are still active drug users. And we've located that at our facility on an island in Boston Harbor because we thought we would never get it sited if we didn't do it ourselves.

These are people who are still active drug users, and that's a very frightening population to most people. And so we've done this in our own facility. I think we have to recognize that sometimes you need to have one success, and I do think this will be a success, and once we have a success, it will be easier to locate in somebody's neighborhood. But we're not always able to do it. I do think we've been very successful, but I don't think that we've got it down perfectly.

DR. ROGERS: Thank you.

CHAIRMAN OSBORN: Commissioner Diaz, Commissioner Johnson, Commissioner Goldman.

MS. DIAZ: Just two issues I think that some of you have peripherally mentioned, but your last response answered somewhat. Responding to the needs of those that may be dually diagnosed or that do have substance abuse problems, I am concerned that the issue particularly in minority communities gets to the very heart of what you're saying: where we're going to be able to find housing facilities that meet the needs of a growing population that is infected that are also substance users. And even including the possibility of having to house young people, young children, with their mothers while they're in recovery and while housing needs are also being met. So I was very pleased to know that these are in your plans. But I tell you around the country we are finding increasing difficulty in establishing housing that accommodates the needs of people that are not only HIV infected but are also substance users, and the particular desire sometimes of being able to provide housing needs transcended beyond just finding a housing facility but that of dealing with the substance abuse problem supersedes the housing needs. And I wonder if any of you have comments regarding that as a first issue?

MR. KURLAND: I think the notion of keeping people in their homes helps you overcome this almost entirely because they're already here. Right. So my neighbor is substance abusing, and then has HIV, he lived next to me when he was substance abusing before he had it, so if you can retain people in their homes, that's the easiest way to do siting because they're already sited. I think it becomes when you get to new facilities, particularly for homeless population, that the issue of substance abuse is an important one. But I also think that we have to recognize that there are substance abusers amongst us, and that this is also another epidemic, and if we don't address that as an epidemic that needs to be treated with the same kind of compassion, we're making a big mistake. But again I think that the notion of preventing homelessness is probably the single-most important thing to do.

MS. LIEBERMAN: One of the biggest issues that I've seen in visiting a lot of projects is whether the person with AIDS or HIV infection is going to be required to become clean or sober. And most residential facilities that's one of the criteria that we'll take you in our project as long as you've been through treatment or you're willing to be sober. There is a project in San Francisco, the Peter Claiborne House, that is run by the archdiocese. It's been in existence for three years, and sobriety and being clean is not a requirement of the housing and it's caring for people for quite a long time now who have been, who still are actively using drugs. And that's been a really difficult thing for especially some of the drug abuse and alcohol abuse providers in this country is how do they -- they've been trying to push sobriety for so many years, and how do you reconcile that in a population that may have a terminal illness. And I think it's the biggest challenge we have in housing for people with AIDS.

MS. DIAZ: My next brief concern is for you, Betsy. You just finished an evaluation of housing programs throughout the country and Puerto Rico. I'm concerned that the representation on the panel here so far this morning is from two very moving cities who have gotten out there.

MS. LIEBERMAN: Right.

MS. DIAZ: Particularly I know the programs in Seattle better than I do in Boston. You've had a great deal of community organization and push and political support to do what you represented here today. What about those smaller communities in mid-America where there are going to be housing needs but increasingly faceless epidemic in which people have not come forth with concrete numbers and community push that you have represented here today? How do they begin to mobilize? What did you see in any of these places that might give us a clue as to this?

MS. LIEBERMAN: Well, the biggest issue that we haven't seen a lot of successes in is that we need some of the more traditional housing providers to step forward and be willing to house people with AIDS within other types of housing, whether it's for mentally ill or people with substance histories, and there's been a very major reluctance among housing providers to take that on. It's like what Robert said, we don't know how to care for people with AIDS. That's the big excuse, but in most of those small communities, they don't have the AIDS Action Council, they don't have the Northwest AIDS Foundation, and they don't have that kind of support. And the people are doing this, people are housing people who have been personally touched with AIDS.

I mean someone has lost a relative to AIDS and opens their house up to two or three people, but there really needs to be some leadership provided among the housing, authorities, among the other non-profit housing organizations to house people with AIDS within other kinds of housing.

CHAIRMAN OSBORN: Commissioner Johnson.

MR. JOHNSON: Well, anyone of you can answer this because I just wanted to know how the housing situation works. I've been hearing it over and over again, but nobody has explained the procedure and then what happens when you actually get into the house. Is that that somebody cares for you, you cook your own meals, what happens once this situation, once you get in the house?

MR. GREENWALD: Well, I would start to say the goal for our housing development efforts has really been to develop a broad continuum of housing options. So in some instances the only thing a person really needs is a certificate that makes housing affordable. So because they have AIDS and are disabled, they can't afford an apartment in a city like Boston. So in some instances, our only job really is to get the person into affordable housing. And then sort of as you move along the continuum in terms of people's needs increasing, we then try to put the services into the housing that are required.

So in some instances, it's independent housing but as needed we'll bring in visiting nurses or we'll have meals delivered, or we'll provide transportation services so a person can get from their subsidized apartment to their medical appointments, and then as you move along the continuum, you're moving towards some housing programs that are 24 hour supervised, three meals a day provided, you know laundry service. I mean every service you could think of is built into the housing, and it really depends upon what the needs of the individual client are as to which particular type of housing the person would move into. And then finally I would just add that our goal really is -- and, I think, Betsy, you talked about it -- to try to have the programs be as broad as possible so that we can keep the individuals in place and then bring the services in as they are needed.

MR. JOHNSON: Go ahead.

MS. LIEBERMAN: I was going to try -- in Seattle, we have a somewhat more organized system. We have case managers. About 95 percent of all our cases of AIDS once they get diagnosed or end up in the hospital get a case manager, either through the Northwest AIDS Foundation or through one of the major hospitals. And that person, who mostly are social workers, work with the person with AIDS or

HIV infection, to try to help them wind their way through the maze of services because it is incredibly confusing. And in bigger cities like Los Angeles, you know, people can live in Los Angeles like you do and live 80 miles from, you know, the service provider, at one end of the county or the other end of the county.

But in Seattle the person would go through their case manager who helps them identify what kind of services they're eligible for, how they can get Social Security disability if they're eligible for it, how they can access medical care. And then like Robert said, helps them figure out what kind of housing is available and what kind of housing they are eligible for. And people often don't get what they want. I mean that's one of the challenges. As Robert said very eloquently the biggest, what people want most is to stay in their own homes. And there just are not enough resources available, Section 8 certificates or rent subsidy programs, that allow people to do that. And so people fall between the cracks.

MR. JOHNSON: So you still have to provide, even if they stay in their own home, you still have to care for them in their own home?

MS. LIEBERMAN: Right.

MR. JOHNSON: Is that right?

MS. LIEBERMAN: And we don't have a reimbursement mechanism that pays for 24 hour home care. So what you see happening with a person with AIDS, unless they have a lot of money or really good insurance, is that the state Medicaid office or the Office on AIDS will pick up maybe six, seven hours of care a day, and then the rest of the care is met by family members or volunteers if they have that. And as we're seeing cases increasing, we're seeing a decrease in the number of volunteer hours available to provide that kind of service. So people are making do with not enough resources.

MR. JOHNSON: And my last question is do you have an estimate in cost either by year or probably by day what this care is going to cost once they actually get in the house because that's important, too? So is there any numbers? I mean by your studies?

MS. LIEBERMAN: What we've seen -- right -- what we've seen in different parts of the country, and it really varies a lot depending on the housing costs, to just provide housing with some basic services, assistance with activities of daily living, some help with cleaning and bathing and a couple meals a day, that can range in cost from the low side of about $50 a day on up to about $100 a day. And then once you start needing nursing services on top of that, you're looking at 150 to $300 a day for a person with AIDS to keep them in the community. So it's a lot of money, but compared to someone in a hospital say at $900 or $1000 a day, it's, you know, one of the best kept secrets we have in health care. The people are not funding it. They're not even funding at that minimal level.

MR. KURLAND: When Dr. Rogers asked about one of the things we could push, I think one of the things we could push is the real opportunity costs. I mean to keep someone in a subacute hospital might be $200,000 a year, an acute care hospital maybe $500,000 a year. We're talking about maybe 25,000 to keep somebody in a home. Years ago, there was one of these perfect cases of a family that wanted to keep its severely retarded child home and care for it, but Medicaid wouldn't pay for it whereas if the child were institutionalized Medicaid would have paid for it at about 100 times the cost.

And so the then president made an exception but didn't change the rule. So that it's still harder to keep somebody at home. This is a similar one. If HHS would look at its Medicaid budget, sitting down with HUD, and figure out we're going to save it on this side, and that's what I argue about the Children with AIDS Program, we're going to save it on this side. Why should we pocket the savings? Why not transfer a piece of it to the support of people in a more humane and healthier environment? So the money is going to be spent, and more will be spent if people have to be institutionalized instead of being taken care of in their homes.

CHAIRMAN OSBORN: Commissioner Goldman. Jim Allen.

MR. GOLDMAN: I'd like to ask particularly Ms. Kurland and Ms. Lieberman, who have been in cities that have successfully done, and I think what you said before was so key. If you have a bureaucracy that is set up to consider their own so-called department in isolation from the other departments, then if HUD can save money, even if it costs HHS ten times as much, it wins. That's an insane system, but if that's the way the bureaucracy is established, and that is the way that the program, the incentives of the bureaucrats involved in the program are set up, then I guess that's what ends up happening.

This commission has recommended in response to that a national plan, and that it cut across cabinet lines, and it avoid having those kinds of problems in dealing, so that the issues that Mr. Greenwald talked about -- for example, we have enough problems within HHS and different definitions of disability for CDC and SSA purposes, I gather now we have a different definition of disability for HUD purposes, and I'm not sure whether or not they've ever communicated with HHS at all about the definition one way or the other. And we run around with 17 different definitions, and you deal with issues that require the intercession of both HHS, HUD and Justice and no mechanism in order to provide any coordination in policies between them.

But my question to the two of you is in two cities that have made it work, what is it in your cities that have allowed you, I mean sitting here on the issue of housing, somebody from the health and hospitals setting in Boston. That is, in itself, remarkable, it seems to me. How have you done? What has been the magic ingredient in Boston that has allowed that to happen, and what's been the major ingredient in Seattle that's allowed that to happen and how can we clone those situations to occur in the rest of the country?

MR. KURLAND: I think one of the reasons you see people from the health field, health and hospitals in this case, but other places, is because that's where people first got involved with AIDS because it was seen as a public health and as a medical condition so the kind of, I think, expertise and interest on the bureaucratic side and on the government side was the health departments. I think in the community it often came from gay and lesbian organizations and now greatly expanded. But on the government side, on the service provider side, it was often health because that was the first thing we could do was care for people.

In Boston, it is also the case that when homelessness really began with the decrease in federal aid, Mayor Flynn asked the Department of Health and Hospitals to take responsibility for opening and running the city's shelters. So health and hospitals is also responsible for the public homeless programs in the city of Boston. That may be another reason.

But I would also argue it's because we know how much money is being spent that could be spent more fruitfully. And on the public side, I think that's there -- and forgive my bias -- I think there is always a willingness to say you don't have to spend it on my medical services. I'd rather that you spend it over here at a local level. I think that on a local level -- again, I have a very strong bias. We're constantly squeezed, and I think we're always trying to get more for the whole and we're always trying to make sure that we can provide more services with limited means.

So I would be very happy to have less money come in to take care of people who don't need to be in a hospital bed if that money could be available to take care of the same people where they need to be taken care of. I hate it when it's just taken away from us and not replaced. I think that actually leads to what is a partial solution. I mean Ryan White gives us a mechanism to do community-wide planning. It might be -- and I'm thinking with my mouth -- but it might be appropriate for the Ryan White mechanism fully funded -- fully funded -- to get in a sense more than advisory. I would actually argue control over the federal resources going to AIDS in a community.

So that a locality that undergoes this extensive community planning process required by Ryan White Title I could then think about the best way to use all of the funds, federal and state, coming into a community through a very broad community process. Then we could do the tradeoffs. We could say let's not pay for people $300,000 a year to stay in a hospital bed when really for 25 or even 50, they could stay in their homes.

MS. LIEBERMAN: What's made, I guess, the success in Seattle has been a somewhat enlightened city government from our current mayor, Mayor Rice, to our previous mayor, Charles Royer, and the relatively enlightened health department that could see the writing on the wall in 1983 when we had our first ten cases and with some pressure from the gay and lesbian community. But Seattle has always had at least in the 13 years that I've lived there and worked in community health had an experience of trying to develop a cooperative process.

The thing that has held us in the best available situation has been pulling all the players together when we had our first few cases, and involving our state Medicaid office, the city, county, the AIDS organizations, and people in the hospitals sitting down together to say together what can we do? We're one of the few communities that has gone ahead with a number of licensed facilities. We don't have a state income tax in Washington state and we don't have a particularly enlightened state government, but we just sort of involved them and said you have to help us find a way to make existing licensure work.

And that by sitting in the same room with them from the on-start, they couldn't, you know we didn't set up an adversarial situation. So I think that's what's really made the big difference.

CHAIRMAN OSBORN: Dr. Allen, and then Commissioner Dalton.

DR. ALLEN: I would like to thank you all for some extremely rich testimony and discussion back and forth. I'd like to pick up on a couple of points, mostly from Ms. Lieberman, but mentioned by others, and that is the difficulty in coordination. You mentioned the Oregon example which is a state very different from certainly those along the eastern seaboard that have been heavily affected. What can we do or what ought to be in place at the state level or at county or municipal levels to try to provide that kind of coordination to assure that all service providers are linked with each other, that hospitals have access to the social arrangements that are out there? It seems to me that we're missing some real opportunities here, and I'd like to hear about models or the kind of arrangements that might be made, and do we need additional programs authorized at the state or federal level, again being cognizant of all the problems of trying to get federal programs authorized and funded on a continuing basis? But I'd like to hear your responses to that.

MS. LIEBERMAN: Well, it's interesting. I actually, my degree is in health planning and administration from the School of Public Health at the University of Michigan. But I am somewhat of an enigma as a planning type in the sense that I don't believe in doing planning for planning sake. And the tension that my colleagues have, you know, addressed is very clearly that we need to fund the planning, but we need to fund the actual services in the housing that go with the planning, and we need to put some resources into helping communities develop a plan in housing that includes a diverse number of providers. And in housing particularly, we need to look beyond our AIDS service organizations because most of those organizations don't have the experience to do actual development, and it's not a putdown of the AIDS service organizations, but the same thing happened in Seattle when we identified the need to develop housing. The Northwest AIDS Foundation, which is a very successful AIDS organization that does case management and AIDS education and fund-raising and coordination, just felt intimidated by taking on housing and construction.

And when I sat on the HRSA review committee, we used to review proposals from everything from little three person community based agencies in Arkansas and Texas to UCLA, to Montefiore Hospital, and it was like comparing apples and oranges. And we need to provide the technical assistance to those communities and those organizations so that they can actually do housing development, and that they can work within their own systems to support that because it's not, you know, it's not an easy thing building housing or renovating housing. It requires a very different kind of level of skills than doing case management and doing education. And so I think that's some of what's really missing in the system is providing the resources to support people doing that with experienced housing developers in their own communities.

MR. GREENWALD: I think the only thing that I would add to that in the same way that on the community based level that AIDS service providers need to educate housing developers on developing appropriate housing for people with AIDS while housing providers educate AIDS service people on how to develop housing, we also need to see the same cross-fertilization in terms of government. So, for example, in Massachusetts, we've really pushed our executive Office of Communities and Development, which is the state housing office to work closely with the Department of Public Health, which funds the service dollars to put out joint proposals and to work together to educate each other on how to attach, again, the bricks and mortar to the service dollars. So it really needs to happen on every single level.

MR. KURLAND: I do think that there are some means. Drs. Mason and Roper and Harmon, I think, are pushing very, very hard at the federal level to require collaboration and participation. There is a public health impact statement that they're considering which is in a sense nobody can go to the Public Health Service for money until they've gone through the local health authority to get comment on it. I think one of the ways is to require it. That it will happen when it's required, when people cannot just fund exquisite little projects for a year or three, which will then fall apart when the funding is withdrawn. And that there needs to be a plan for continuity.

I think when it's required, it will be required. I think what these cities have shown is that with the appropriate leadership, usually from the mayor, in other cities not always, but often from the mayor pulling together the city agencies and requiring them to plan together something happened. I think the federal government needs to be required to do that, and needs to require the states to do it with localities.

CHAIRMAN OSBORN: Harlon Dalton and David Rogers.

MR. DALTON: One invitation and two questions. Commissioner Kurland, earlier when you were tossing around bouquets in explaining why you've had the success you've had in Boston, you mentioned the mayor, you mentioned Larry Kessler, and you started to mention something else that began with Multicultural AIDS--

MR. KURLAND: Multicultural AIDS Coalition.

MR. DALTON: I just wanted to give you a chance to say it.

MR. KURLAND: Thank you.

MR. DALTON: I think it's sort of hard for organizations in a city with a 300 pound gorilla to sometimes get the kind of attention they deserve. Larry Kessler is never, I mean he's always willing to kind of share the credit and blame, I suppose, but I'm just acutely aware that we're here in Boston. One of the commissioners is the executive director of AIDS Action. We've got a panelist from AIDS Action, and that's not the only game in town, and Larry would be the first to say it. But I think we need to acknowledge that.

My questions -- I assume you don't mind in the slightest.

MR. KESSLER: You're doing fine so far.

(Laughter.)

MR. DALTON: The question is pretty good, too. I guess I want to ask the panelists to sort of push beyond what you've said thus far. We've been told that it's important to draw experienced housing providers into the business of building AIDS housing, and I guess the question is how? Why have, who are these experienced housing providers who aren't providing AIDS housing? Why haven't they provided it and how can we get them to? That's one set of questions.

And the other is we've heard that it's important to have funding for ongoing programming. Even if you get the facility, how are you going to provide services whether in the home, that is in the person's own apartment or house or in some sort of a group home? How do we do that? Within government, for example, whose role is it to provide sustaining, ongoing programming and how can we make that happen?

MR. GREENWALD: Well, in terms of getting the non-AIDS specific housing providers involved in this issue, I have to tell you that once the Executive Office of Communities and Development and the Department of Public Health put out a proposal that would have funded housing development for 15 years with subsidies plus service dollars, they were banging down the doors to develop housing for people with AIDS. It was then really up to us to start screening and seeing if these really were appropriate housing developers. So clearly creating the resources will have a big impact on getting the housing providers to be willing to do the work.

In terms of when we were talking about the lack of long-term funding and the problems that that creates, I just wanted to highlight a couple of other issues. Aside from the fact that on the service side it makes it very difficult to plan a project when you have no ongoing service money, we are also now starting to have a hard time that even on the bricks and mortar side in terms of the subsidy for ongoing sort of operational costs of buildings, we also have a problem now.

HUD's tendency these days and the tendency for funding sources that used to be 15 year programs are now to cut them to five year programs, and in cutting it to five year programs, it makes it almost impossible for us to get mortgages, for example, from a bank. No bank wants to give you a mortgage when you only have five years worth of commitments on the operational side. They want to see at least 15 to 20 year commitment before they're willing to give you a 30 year mortgage. So it's frankly the problem that we're experiencing in terms of the lack of long-term funding is happening really on the service side as well as the bricks and mortar side.

MR. KURLAND: I think, and I'm happy to once again mention the Multicultural AIDS Coalition, which is a coalition of a lot of service providers, many of whom were not in the sense AIDS providers in the beginning. They provided other kinds of services, and they identified them. I think that's part of a solution, too, and also part of the frustration of not having ongoing funding streams. Many of the people that are doing the work, that have been in the trenches, that would be willing to step up and develop housing that would provide continuum of services that are already in and of the community are marginal at best.

I mean these are community based organizations. They're often partially voluntary, and they do extraordinary work, but they're always on the margin financially and one cannot ask them to develop new programs with the promise of one year funding. And as wonderful as the Ryan White CARE Act is -- and it is wonderful, and Senator Kennedy is a champion on this -- each year we have to worry about whether the pool of cities is expanded and the money stays the same or neither happens.

And we would argue that we would like the pool to be expanded and the money to be expanded commensurately. But you can't ask these small community based organizations which range from neighborhood health centers to church organizations to organizations that are anti-poverty organizations and social service, that are not hospitals with deep pockets or they're not for profit organizations of any type, to enter into new ventures with no promise of funding. And yet we have this wonderful avenue to do the work if we could ever get the funding promised in a reasonable way.

MS. LIEBERMAN: In Seattle, we have a whole host of nonprofit housing providers, everything from churches who have, as Commissioner Kurland has said, have taken up the mission of providing low income and subsidized housing to a number of nonprofit housing providers. One of the things that we don't see a lot of that exists, as Mr. Goldman asked me earlier, is we have a number of licensures that exist for elderly where our state Medicaid offices are paying the cost of supporting people in that housing, and that does not exist for people with AIDS because we're needing to develop very innovative types of housing.

There is not these neat compartments where someone needs independent housing and then someone needs skilled nursing facility. We need to have housing that has an ongoing reimbursement stream that can support flexible services so that people are not moving every six months. Oh, you need 24 hour nursing care; you need to move to this facility. Oh, you're back in the community; you need to move there. And I'm convinced because some states have been somewhat responsive to this, the state of California, the state of Washington, the state of New York in its own peculiar way, have tried to look at interesting kinds of licensure that will provide the support for services.

And I think we need to have some federal policies that require all states to do that, to develop some reimburseable facilities that you don't set up huge criteria that people can't afford to build something, but that you develop some kind of flexible licensure much like they did in the state of Florida with this adult congregate living facility. They set up this very flexible licensure and then the state didn't allocate any money to reimburse for it. So they have all these wonderful licensed facilities but no one to pay for the care, and I am a big proponent of really looking to create that on a state by state level that can be responsive to that state's specific needs.

CHAIRMAN OSBORN: Dr. Rogers, I'll give you the last word before we break.

DR. ROGERS: Well, this has been very elegant and very helpful. I'm perseverating a bit on my first question, and I want to build a bit on what Mr. Johnson said. I wonder, Commissioner Kurland, if you and Mr. Greenwald could get together, and it is so clear that humane, common-sense kinds of housing programs would save us so much damn much money in terms of not only money but human misery in terms of how we now deal with the problem, could you put together kind of a cost sheet for us? I think you could, and I don't mind if you cheat a little bit and use some of your anecdotal stuff, which is five hospitalizations until he had housing, none afterwards. And transport it for a thousand AIDS patients in thinking about the sort of thing the commission might pound home in Washington.

Those things that would save dollars are sometimes more effective than simple appeals to humanity, and I think you could really put us together a very powerful, simple set of figures that say here's what you could do, and you would vastly improve human lives in the process.

MR. KURLAND: Be happy to.

DR. ROGERS: We're very grateful to all of you for elegant testimony. Thank you.

MR. GREENWALD: Thank you.

MS. LIEBERMAN: Thank you.

CHAIRMAN OSBORN: The University of Michigan appreciates the unpaid announcement.

(Laughter.)

MS. LIEBERMAN: You're welcome, Dr. Osborn. Thank you, all. We're going to take a break a little bit early so that we don't press ourselves too much in the next segment.

I think we'll try and reconvene five of 11, if we could.

(Whereupon, a short break was taken.)

CHAIRMAN OSBORN: We have some fairly tough time constraints starting at 11:45 for some of the commissioners so I want to be sure we have full opportunity to talk with the group that has agreed to come and talk with us. And so if I could get everybody to be seated, it would be very helpful. I have to confess this room has enough of an echo effect so that conversations in the back do carry forward and make it a little distracting. So I'm pressing you a bit for that reason, unsuccessfully, but I am trying.

(Laughter.)

CHAIRMAN OSBORN: I'm pleased to turn over the discussion dynamics to Michael Cronin, who is Director of the Office of AIDS Services at the Justice Resource Institute, chairs the Boston AIDS Consortium, is a member of ACT-UP Boston, and is a person living with AIDS, and we are very pleased that you have been willing to join us to enhance our understanding of things. Thank you. And let me turn things over to you.

MR. CRONIN: Okay. Thank you very much. I'd also like to mention that I'm a member of the board of the AIDS

Housing Corporation here which is one of those organizations that attempts to bring the housing world and the service world together. Before introducing the rest of the panel, I would like to spend a few moments giving you the perspective of a human service provider who's been attempting to provide housing for people with AIDS, different supported housing scenarios.

In fact, within three weeks, we hope to open our River Street Community which will provide supported housing for 13 people with AIDS and the concomitant neurological disturbance. You've already heard, I think, very eloquently, this morning the fact that housing for people with AIDS is a very complicated issue. Housing needs range everywhere from individual apartments to highly supported living situations, and I think we all agree on the premise that the people should be able to remain in their homes and that the services that they need as the disease progresses along its roller-coaster course, that the services that they need should be able to be brought into the home so that they can remain living in their homes.

This is not only cost effective, of course, being, as you've heard, far less expensive than either acute hospitalizations or other institutional settings, but it enables the individuals to retain a sense of dignity and to live as autonomously as possible which is extremely important in the course of this epidemic. In trying to actualize this premise, we often talk about how the housing world and the services world need to come together, and yet the two major players in housing and services on the federal level, HUD and HHS, their Medicaid Division, all but refuse to acknowledge the presence of this plague that we're living in, and they take a head in the sand, business as usual like approach, matter of factly stating that rules are rules, and that they have no intention of making exceptions.

I feel they are a full ten years behind the times here. On a local level, that leaves us needing to piece together very tenuously financing for housing and housing subsidy packages, relying on a very odd collection of federal, state, and local programs that sometimes work and sometimes don't work. I know of three supported housing programs that failed before they even started because the housing money fell through. One of them was housing for women with AIDS and children. The service money was already approved, and the housing money fell through at the final moment so we weren't able to get that up.

Even the housing that we are able to produce often takes upward of about two years to get going. Now I understand that in housing circles two years isn't a whole long time. For people with AIDS, however, that is a long time. I hope you realize that between now and the end of next year or a two year span, twice the number of people will die of AIDS as have already died in the entire course of the epidemic, or twice as many people will die in the next two years while we're waiting, you know, for some of this housing to come on line. Many of the people who die will be homeless when they die.

This underscores the point that what we need immediately is more mobile rental subsidy certificates, more Section 8 mobile certificates, so that we will have the flexibility to provide the housing that people need right now. We'll have the flexibility to let them live independently if that's what they're able to do, or we'll have the flexibility to actually pool the certificates together and provide supported housing services. From the service end, here on a local level we're faced with the task of piecing together money for services from Ryan White CARE Act, funding from local health and hospitals, funding from the Department of Public Health on a statewide level. What we need to do is to move into a situation where instead of having to rely on soft money that may or may not be appropriated every year, we need to move to a situation where these services become entitlements through the Medicaid program so that we don't have to worry about whether the service dollars will be there when we finally get the housing dollars.

A word about our panel here this morning. You're about to hear some very compelling testimony from the people with AIDS who have been lucky enough to actually find housing, and I'd ask you to keep one thing in mind as you listen to their testimony. These are not ordinary people. Just look around you at the cameras, at the audience. The courage that it takes to come forward in a very public way and to tell your story about living with AIDS and the problems that surround that is really nothing short of phenomenal. These are strong, courageous, well-informed, outspoken, empowered individuals, and their stories represent what we have come to consider success in housing.

But listen to their testimony very, very carefully, and as you listen to these strong, empowered individuals tell their stories of housing, ask yourselves if you would want to live in the situations that they're living in right now, and remember these are our successes. And then think of the tens of thousands of other individuals who are homeless living with AIDS who aren't so empowered, who aren't so strong, who don't have this incredible strength that these individuals have, and then I think you might begin to get a little flavor of what it's actually like to be homeless and living with AIDS. Our first speaker is Michael Cox.

MR. COX: My name is Michael Cox. I live in Cambridge, Massachusetts, and I have full-blown AIDS although I don't look like it. It was a very difficult decision for me to make today to decide whether to come and testify or not. But I hope that my experience will enable policy to be developed so that others can have a quality of life that I believe all human beings deserve. My ability to provide for myself ended with my inability to work. Repeated stays in the hospital caused me to be unreliable, and this virus that I have just made me too weak to be able to work.

Without income, I became homeless. I literally had no money, none. If it wasn't for friends, I don't know really what I would have done. But hopping from place to place was not healthy for me. It was a burden on my friends, and it took away my self-respect as I did not have the ability to take care of my basic needs. I get my medical care from the Cambridge Hospital. Through them I was put in touch with an organization called Cambridge Cares About AIDS. It's a service organization designed to help people with HIV infection and AIDS. They helped me apply for Social Security, and while my claim was being processed, they provided for me a room at the YMCA in Cambridge.

This past January, I received my first Social Security check for $691, and I'm now able to pay my own $300 rent. I am grateful for Cambridge Cares and the Y for providing me a room, but I wish you could know what it's like to be reduced to a room in the Y with no cooking facilities and a common bathroom shared by an entire floor. I need and I believe I deserve a better place to live, but I don't have any choice. I applied for housing assistance and was approved. I got a letter stating that my name would come to the top of the list in about nine months. Without being morbid, I don't know if I'll be here in nine months, and I might be too sick to care by then.

Through no fault of my own, my world has been reduced to a six by eight foot room. Commissioners, I'm considered a success story, and again I want to say that I am grateful to have a roof over my head, but I have an education, I have the ability to ask people for help, and this was the best I could do. I realize that by the time your policy recommendations are acted upon, it will be too late to have an effect on me. But I hope by breaking my anonymity my story will spark some improvement to help the quality of other's lives who are in my same situation. Thank you for listening to me today.

CHAIRMAN OSBORN: Thank you very much.

MR. CRONIN: Next we'll hear from Jean Desir.

MR. DESIR: I'm Jean Desir. Ladies and gentlemen, my pleasure is not only to meet face to face the superstar Magic who has become an AIDS educator but to testify to talk about the needs we have in the black community, especially in the Haitian community. For myself, I'm HIV positive. I have been working in the Haitian community since four years making education in the high school and the churches. I used to work as a case manager/counselor at voc ed making hospital visit and home visit with Haitians living with AIDS. During my four years, I have seen so much needs than I am able to offer detail of the needs of the Haitians living with AIDS in the community.

Let us focus on the housing problem. This problem is one of the biggest we have, and to understand that, we have to know how are living the immigrants in the country. Sometimes three or four people living in a bedroom. Sometimes two or three families living together in the apartment. Suppose one of them becomes sick with HIV positive, he cannot back where he was because there are babies, young people, young children, and adult, and by the time he stay in the hospital and the social worker in the hospital is always after you, after the case manager to say he has to leave the hospital. He has to leave. It's time to discharge this patient. At this time, we don't have any place to send him, and that's a big deal for us.

By the time the case manager fill out form for housing, but we have to wait for until nine months to get the certificate, and by the time we have to do something, then we don't have funding in the Haitian community to help this patient. It's very uncomfortable for us. And sometimes when we cannot find a place, they send him to the shelter, but culturally Haitians cannot tolerate shelter, and this word sounds bad for him, no privacy. If you are sick, they ask you to wake up and go out in the morning. It's very difficult for us, and sometimes it is the issue.

But the significance of the housing problem is very important. We are dealing most of the times with undocumented people, illegal alien. They are not qualified for the welfare so they are not qualified for the housing. So they are homeless. That's a big problem for the Haitian organization. We cannot handle these cases because we cannot handle this case. That's why I am here talking for me and for them. Something has to be done. Something has to be done now. The group of the persons living with AIDS is going up. If we don't do something now, tomorrow will be too late for us. We need more housing facilities. We need emergency funding to resolve this problem. We need funding to build or buy some facilities, some complexes. Then we can face the reality of the people living with AIDS in the community.

Before I stop, before I finish, I would like to remind all of you we are going, even we are sick or not, even though we are HIV positive or not, that's a natural law. We have to go. But don't forget where we are sitting today. That's where our sons, teenagers, and the elementary school, in the high school, will be sitting tomorrow. Therefore, in the high school now we are starting to find some HIV cases for who can understand only one word is enough. Thank you.

CHAIRMAN OSBORN: Thank you very much.

MR. CRONIN: Thank you, Jean. Just a reminder before our final panelist. Many of you will be visiting programs this afternoon. This is also another opportunity that you'll have when we're through of asking questions and really augmenting your own understanding of what housing search is actually like for people who have AIDS.

Finally, we're joined today by Connie Amaral, who is here to my left, and her daughter Corrine. Thank you.

MS. AMARAL: I hope to be one of the positive roles to show you what happens when someone gets their needs met. I'm one of the fortunate ones because someone, a counselor in a halfway house, chose to move out of her apartment and spoke to the landlord and I moved in. And I was very lucky. Before that four years ago, the only home I had was because of my drug addiction maybe I'd walk the streets for days and nights and find a home in an abandoned building while my daughter went from house to house, and I thought I was bad. I thought that I didn't deserve to live.

But my daughter did not deserve a mother to die of AIDS in the street. And she gave me the courage to get sober, and in spite of it all, with two diseases, I have a life. I have my daughter back. I have a grateful heart, but I find it so hard to look the other way. Why am I so lucky when others aren't, when others can't speak like I can, and get their needs met? Because that landlord gave me, let me move into that apartment, I had to let him know, I was too scared to tell him that I had HIV, but I was able to tell him that I was in recovery, and he took a big chance by letting a mother that was a recovering addict to move into his apartment.

And instead every time he has an empty apartment, he asks me if I know another woman in recovery because he believes that he wants to rent to people that need it, and I let him know. Like I couldn't get my little girl back until I had a home, and he made it possible for me. But that was just by chance. And because of that I was able to get an education and get a job in spite of two diseases. Because I have housing I can focus on my number disease which is my addiction because that will kill me a lot faster than AIDS. I'm allowed to work the hours I can work because in order to stay sober I have to go get my medicine and I have to go to meetings, I have to have counseling. It's a fulltime job.

Today I can work, and I can work in a detox and help others and hope, and hope that they will get the same dignity and quality of life I have today. Although I still wish, I wish that some day that my name would go on the waiting list for housing, and I may go home to my family. I'm on the North Shore and my family lives on the South Shore, and I fear when I become ill, will I be able to ask my neighbors to cook dinner for my daughter? Will I have a choice of where I get my health care? Will I have a choice of living in a safe community?

You know housing can be a stress reducer. And I have seen how much, how stress can affect my health. I become symptomatic when I'm under stress on worrying about the drug dealers two houses down, the murders, the murder after murder happening only four houses down. You know but I have hope. My daughter believes in people, and I believe people do care, and I believe housing should be number one priority for AIDS services. Thank you.

CHAIRMAN OSBORN: Thank you on behalf of all of us. The courage shines from the table, and I really very much appreciate your all sharing with us the power of your experience and your hope for others, too. It's really very special. Would you be willing to have the commissioners interact? Anybody want to? Harlon.

MR. DALTON: Mr. Desir, you mentioned at one point that sometimes it takes nine months to get a certificate. Were you talking about a Section 8 certificate, rental assistance certificate? Is that -- and I guess I was curious with the first speaker, Mr. Cox, would you be eligible for rent subsidies. You mentioned that you now since January get $680.

MR. COX: 691.

MR. DALTON: $91, I guess in Social Security disability, and your rent is virtually half that. Are there programs available for you to get rental assistance or are you on one of these waiting lists that we just heard about?

MR. COX: I'm on the same waiting list. I don't know. There may be other programs I'm not aware of. I just do what I was told to do, and I went and applied for housing so that I could get something to help me stay healthy, make me feel viable, and the waiting list was nine months for me, and that's all I know.

MR. DALTON: Right. And then I wanted to ask Ms. Amaral, is it? I can't read your last name. Yes. One thing you didn't mention was how you're paying for that apartment. I agree it sounded like just a total stroke of luck that your counselor moved out, and it's probably an unusual landlord who knowing of your being in recovery would rent to you, but still somehow you're paying for that, and I guess I was curious how.

MS. AMARAL: I work at a detox. The apartment I have is a moderate rehab. If I move out -- at one time I almost, my daughter and I almost ended up in a shelter because we were in such fear that we weren't going to live the night. But thank God for AIDS Action who have guided me and said don't leave that apartment because if I left it, I wouldn't have it when I came back. It's not mobile. I don't have the choice of moving home to my family.

MR. DALTON: And when you say "mobile," and Mr. Cronin also used that phrase, what do you mean by that?

MR. CRONIN: We mean certificates that are usable, that the tenant can actually take with them and use in a variety of Section 8 approved housing. So the actual certificate travels with the individual as opposed to a project based Section 8, which, you know, the actual unit is actually subsidized.

MR. DALTON: Right. So if Ms. Amaral had a mobile Section 8 certificate, she could go back to the South Shore and be closer to her family and support services; is that the idea?

CHAIRMAN OSBORN: Harlon, Larry was going to toss in a bit here, too.

MR. KESSLER: I think one of the advantages, Harlon, is that right now because of the recession and a surplus of housing that's available, landlords are more open to taking a certificate, but if the certificates are not mobile, then we are in the situation where someone may be in, like in Connie's case, two doors away from a crack house, four doors away from repeated murders. Obviously, a home is better than not having a home, but being in that stressful situation creates another layer of stress.

If we could take that certificate and then negotiate with other landlords who I think would be actually happy to rent empty apartments and get them off their hands, then we'd all be better off. This is a new phenomenon because prior to the recession the vacancy rate was about one percent in

Boston, and it's now up to six or seven percent, I believe, in the greater Boston area.

MR. DALTON: And what determines whether a certificate is mobile or not and what determines how many Section 8 certificates there are in a given community?

MR. KESSLER: I'm not sure I can answer that. Perhaps can you answer that question, Michael? I'm not sure of the exact determinant unless -- Cindy, can you answer?

MS. COLBERT: There are two types of programs that -- and my name is Cindy Colbert. I work for AIDS Action. There are two types of programs that HUD runs, the Section 8, where it's project based certificates where the unit is subsidized. The other is a mobile program where the recipient or applicant gets a certificate that they can then use to go locate an apartment. The AIDS Action Committee was able to secure 20 certificates such as those through a state administered program. Robert Greenwald spoke, and the Feds turned us down. So we created the program with the state.

It took, again, a couple of years, but if we could access these certificates now, people could use them to locate appropriate housing. I interviewed someone last week who was fortunate after about two years on a waiting list to get one of those mobile certificates. What he did was he took that certificate and rented an apartment in a building above a pharmacy, above a restaurant, two blocks from his health center. He feels as though he will now be able to live with minimum stress and be able to live for a long time independently. That's why that program is so important.

MR. CRONIN: The other issue is that it's a lot quicker. If you have a mobile certificate, you can find housing now. If you're awaiting for some of these mod rehab units to actually come on line, you may be dead by the time the housing is actually built.

MR. GOLDMAN: I have two questions. Ms. Amaral, you said that the ability of your having housing enabled you to be reunited with your daughter. Where was your daughter prior to that?

MS. AMARAL: With my family in the South Shore. And if the counselor didn't give me her apartment, I don't know how long it would have taken because I had to work and with that money I had to try to save two months rent. And I was spending money traveling every weekend to visit my daughter.

MR. GOLDMAN: Well, conceivably, if your family weren't available, and I don't know, maybe your family was, that your daughter might have been or perhaps was at least in a family setting in a kind of foster care.

MS. AMARAL: She was very fortunate. I was fortunate.

MR. GOLDMAN: And you were fortunate in that respect, but clearly the example that you give is one in which the other alternative would have been for the government to provide some kind of shelter care housing, would have to been to provide your daughter foster care, all at a rather great cost and expense in addition to the deterioration of your own health care, and instead simply by providing some modicum of being able to obtain a modicum of housing, a lot of those problems were able to resolved.

A question, I guess, for Mr. Cronin and others, in your advocacy of mobile kinds of units, you certainly are not suggesting that facility-based Section 8 housing be eliminated because those apartment buildings, if the Section 8 housing that has gone along with them, if that were eliminated those housing units would probably go bankrupt and you'd be eliminating thousands and hundreds of units of housing for people who, in fact, it is appropriate, and I don't think you're suggesting that?

MR. CRONIN: No. I mean we need it all. You know we need more project-based units. I'm involved at the moment in developing some of those with various developers like in the city. But in addition to those we need more mobile certificates, and we need them now. There are folks out there like in the streets. There are estimates that a third of the people living in shelters in the city are HIV positive. They're going to get sicker, and as they get sicker in order to keep them out of acute hospital beds, which are far more expensive, we need to house them now, get the preventive health care services that they need now so they can live longer and live healthier.

MR. GOLDMAN: But I gather what you're suggesting is in light of the current economic situation and the absence of the kind of housing unit shortfall that exists that there is a greater need now for mobile types of rent subsidies than there is, at least in the Boston area, for facility-based and new construction of housing units; is that what you're suggesting?

MR. CRONIN: Yes. Yes.

CHAIRMAN OSBORN: Harlon.

MR. DALTON: I have one question for Michael Cox and one for Jean Desir. Michael, I understand the Y would not be your first choice as a place to live, and I guess I wanted to ask you what kind of housing arrangement would you want at this point in your life? You indicated that you have an AIDS diagnosis. You're right. You look terrific. But obviously your health is compromised. Would your preference be a group home? Would your preference be a supported setting? Would your preference be an individual apartment?

MR. COX: What I would like is to have like I always had in my life a nice apartment, maybe a little studio apartment, have my own kitchen, my own bathroom. I could watch my own TV. I could be a real person living his life the best he can. At some point obviously my health will deteriorate so much that I may need to need to a hospice situation, somewhere where I can get continuous care. But I personally don't want to move into an HIV hotel.

I mean I don't want to have to walk down the sidewalk, oh, he lives there. I mean what a stigma. It's too bad it's a stigma, but I want to be, I want to have dignity. I want to have my life back, and all I wanted was some help because with $691 you can't do a whole heck of a lot, and I don't know. I couldn't, if I saved all the money -- I couldn't pay my rent and save money. It would take me too long to come up with the first and last month's rent and plus I couldn't do it. I think that's all.

MR. DALTON: Yes, thank you. And Jean, you mentioned the problem of undocumented aliens. You said many Haitians are undocumented and therefore don't qualify for various kinds of entitlement programs. What in the world happens to them in terms of being able to, when they're HIV positive? I mean what options are available for them?

MR. DESIR: When we are illegal, we are not qualified for some help given by the government. Then if you don't have any income, you are not qualified either for housing. Anyway you have to pay even less money, lot of money. That's why I say it is a big problem for Haitian community to handle this case, and what I would like to see personally even though we are not qualified to receive the housing, but if we could not create a program and this program will be handled by the Haitian community, and we can find some facilities here for people like this.

MR. DALTON: But what happens to them now though? You say you're not able to help them, so they do wind up in shelters or that is what happens to undocumented Haitians who don't qualify for government funding?

CHAIRMAN OSBORN: Larry.

MR. KESSLER: Fortunately, Harlon, in this city we do have a compassionate health and hospital system that accepts all-comers regardless of whether they're residents of the United States or not. Likewise, the shelters, some of the housing that we do have on line, and some of the proposed housing will also take people whether they're documented or undocumented. This is a commitment that we've made citywide. That's unusual in some senses. I know that other states and cities are under the gun to penalize illegal immigrants, but we have taken a strong stance in this city not only, at least to this stage that we will do the best we can, and not penalize.

Yet we do -- I think it's important to acknowledge, too, that this puts an additional stress on those immigrants to often lie about their status, to say they may be from Puerto Rico when they're from Santo Domingo, whatever. But that is not the criteria we've been forced into at this stage. Obviously, we're worried about that because of immigration rules, the immigration policy, and federal and state guidelines. But we're on thin ice, but there's a commitment to try to keep this program humane and compassionate, and you'll meet some of those people on your tours this afternoon.

CHAIRMAN OSBORN: As I mentioned at the beginning, we do have a fairly tight schedule starting in a couple of minutes so I want to give Commissioner Diaz a chance to interact and Dr. Rogers, and then I think we probably need to move along.

MS. DIAZ: Yes, I wanted to thank Mrs. Amaral and her daughter for the very important testimony you gave here today, and also for her courage in coming with you and what you have expressed as her desire to encourage you in the process of recovery. And I just wanted to ask you with the women that you work with and particularly the caseload that you have and in detox facility, do you find that your experience is able to inspire hope? Or perhaps go the other way, for the women and the clients that you have they seem themselves not able to get the kind of housing opportunity that you did, and perhaps they see themselves as sometimes disconnected from their family or not having the support of their daughters or sons? And I'm wondering if you have some very important words for them that you would like to have us remember?

MS. AMARAL: I don't know about any important -- it's not to give up, you know, and to other mothers living with this disease, I offer them hope that you can get your needs met, you know. I just try to be a role model and to be a power of example that this is what can happen. We can have a life. We can have dignity. We can have quality in our lives, and we can be mothers and working single parents. We can do it. It can be done.

MS. DIAZ: Thank you.

DR. ROGERS: We're grateful to all of you for putting a face on a dreadful problem. Mr. Cronin, could you put some figures around it, too? You've had three impressive people who have housing of one sort of another. How many clients do you have that you're seeking housing for? How many have you been successful with? How many are still having a very tough time getting any housing at all?

MR. CRONIN: I think in the service provider community, we consider housing the paramount need in AIDS at the moment. We're able to hook the people up with medical care, with case management for other services. But the thing you need to remember is that AIDS is a disease of poverty. If you aren't poor when you start out with this, you are by the time you're finished in 99 percent of the cases.

What we do often because of the lack of resources is we help match people up with other roommates. Our 13 beds for PWAs with neurological involvement are filled even without any advertising, without any -- I mean people hear of a resource, and instantly the program is filled. You know in addition to the folks that are living, and a third of the folks living in the shelters, there are so many people in the gay community that I know about who live with neighbors, who live with their friends, who live with their lovers, oftentimes the other person in the household is also sick.

So you have a situation where a lover who may not be as ill as another person is actually caring for that individual. There are situations that I know of where four or five individuals are sharing an apartment because that's the only way they can afford it because they're on the waiting list for housing certificates that never seem to come. You know there are so many different scenarios that it's really hard to put an exact number on this. Then there are so many people who are at risk of homelessness by spending far more than 50 percent of their income on housing.

And it's really only a matter of time before they need to choose between eating and having a roof over their heads, between certain medications and having a roof over their heads.

CHAIRMAN OSBORN: I'm going to give Earvin the last word.

MR. JOHNSON: Michael, what is it going to take for Mr. Cox? Connie has an apartment. What are you paying?

MS. AMARAL: What I am paying?

MR. JOHNSON: Yes, rent.

MS. AMARAL: 114 a month rent and all utilities. I have to pay for my utilities.

MR. JOHNSON: So what is it going to take, money-wise what is it going to take him to be able to have an apartment which he wants, Mr. Cronin? I mean --

MR. CRONIN: If he were to finally to get on to the list, I think the current rate is 30 percent of your subsidy, of your income. So in his case it would be 200 something dollars that he would have to pay. But that's once you're in the subsidized like housing situation. The other point is that Mr. Cox is somewhat luckier than others. He had a good paying job for a whole long time, and his Social Security payment is higher than what an average individual would get on SSI which is only something like $400 a month.

MR. COX: For my age. They were shocked. I get a lot. They think it's a lot.

MR. JOHNSON: Okay. And then last question. Where are you living, Mr. Desir; is that how to pronounce it?

MR. DESIR: I'm living in Dorchester.

MR. JOHNSON: Okay. Apartment?

MR. DESIR: Apartment, yes.

MR. JOHNSON: Through the government or?

MR. DESIR: Government.

MR. JOHNSON: Through government. So are you paying money though?

MR. DESIR: Yes.

MR. JOHNSON: Are you paying 30 percent also?

MR. DESIR: 30 percent, yes.

MR. JOHNSON: And yours is what a month?

MR. DESIR: Actually I pay 30 percent is $82.

MR. JOHNSON: Okay. Thank you.

CHAIRMAN OSBORN: Well, once again thank you all for sharing your powerful messages with us. These are much more powerful than anything we can read so we're especially appreciative of the courage that you've taken to do that. We are going to adjourn now. After lunch, the commissioners are to gather at the back near the easels in order to collect for the smaller groupings that will be visiting some of the housing sites this afternoon. The next general session of the commission will be tomorrow morning at 8:45 back in this room. Thank you all for being with us.

(Whereupon, at 11:45 a.m., the hearing was adjourned, to reconvene at 8:55 a.m., Tuesday, March 3, 1992.)