AIDS AND HOMELESSNESS: PERSONAL ACCOUNTS

The following accounts were originally presented at federal and local hearings on the subject of AIDS and homelessness. All of the authors are members of Anger into Direct Action (AIDA) a self-empowerment direct action group based in New York City, whose members are homeless people with HIV.

To contact AIDA write: c/o Housing Works, Box 326, 111 East 14th St, New York, NY 10003. Many of the accounts, as well as other accounts by homeless people who have AIDS, have been published by the Coalition for the Homeless in a book entitled, Breaking the Silence. The book is available by writing the address above.

Ralph Hernandez

National Commission on AIDS
November 2, 1989

Good afternoon. My name is Ralph Hernandez. I am a Viet Nam vet. I am homeless, and I am living with AIDS. When I went to Nam, the government told me I was putting my life at risk for my country. I believed what they told me. And because I believed in my country, I became disabled and finally I got AIDS. Now that I am sick, my country doesn’t want to do anything for me.

Buenas tardes. Mi nombre es Raphael Hernandez. Soy un veterano de la era de Vietnam. Estoy sin hogar y viviendo con SIDA. Cuando fui a Vietnam, el gobierno me dijo que estaba arriesgando mi vida por mi patria. Y yo lo creí. Porque yo creí en mi patria, entonces me convirti en desabilitado y con SIDA. Ahora, que estoy enfermo, mi patria hace nada por mí.

Le servi a mi patria en tiempo de crisis. Ahora yo estoy en crisis. ¿Donde está mi patria?

I was honorably discharged from the United States Army in 1974 with a service connected disability. But I had another illness, too. In Nam, I had become addicted to drugs. Even with my handicaps I went to school, I got a job with the phone company, and I supported my wife and children. The whole time I was still using drugs.

When I went to Nam, the government told me I was putting my life at risk for my country. I believed what they told me. And because I believed in my country, I became disabled and finally I got AIDS. Now that I am sick, my country doesn’t want to do anything for me.

In 1987, I started getting sores on my skin and my physical appearance started deteriorating. I left my wife and started shooting up more and more. I felt too weak to go to work. Soon I lost my apartment and then my job. I tried to get into the VA hospital but they wouldn’t see me because I was homeless. They wouldn’t even let me into the detox program. They told me to just stop shooting.

The government is sick. Here I was dying. I had sores all over my body so deep that I could touch my bone. My clothes stuck to my skin, and no matter how many showers I took, I stunk because my skin was rotting; and they told me to just stop shooting.

I went to the Washington Heights Shelter. When I took my clothes off in the shower, the other homeless people kicked the shit out of me. Then they called the guards and the guards threw me out. I went to another shelter but I was afraid to stay there. So I started living in the tunnels under Grand Central Station. Even there I had to hide so no one would see the condition I was in.

Once I went to Bellevue, a New York City hospital. They asked me if I had Medicaid. When they found out I didn’t have Medicaid, they didn’t want to help me. The nurse said, “Oh, your sores don’t look that bad. I’ve seen worse.” My legs hurt so bad I couldn’t walk without the crutches I had stolen. But they didn’t even clean my sores. They just gave me antibiotics and put me out on...
the street to clean them myself. Now, how am I going to keep my sores clean when I am living in a subway ditch? You know they are going to stay dirty.

A month or so later, I went to Mount Sinai, another hospital. This time I realized I was being turned away because I was homeless. So I lied and told them I had lost my Medicaid card, and I gave them a false address. This time they gave me a bed. But after a week they said I had to leave because they traced through the system and found out I didn’t have Medicaid. They even had to get me clothes because the old ones had been stuck to my skin. So there I was, back in the subway system.

After the Coalition for the Homeless found me in Grand Central Station, the city did not want to help me because they said they didn’t have any evidence of my illness.

The VA had lost all my papers. I have been tested there for AIDS three times, but because I am homeless, they have lost my records each time. Because of a law suit, the city finally put me in a room in a hotel that is really a shooting gallery. That was all they wanted to do to help me.

One day last May, I went to a methadone clinic. When I said I didn’t have Medicaid, they wouldn’t accept me. So I went to another clinic, and I lied to them. Since they thought I had Medicaid, they looked at my tracks and once they had seen them, they gave me emergency medication right away.

For six months I have been in a methadone program and I try not to use drugs any more. But the VA is still not giving me any medical treatment.

People like me, who are fighting drugs and AIDS, need special help. One Friday I missed my program. I was too sick to stand up. My knees didn’t have strength enough. So I missed my weekend pickup. By Sunday I was detoxing. I called all over, but no emergency room would help me. I even called an 800 number drug hotline, but I couldn’t get anything. So I had to shoot up. Methadone is the strongest addiction in the world. To shoot up enough dope to not feel sick, you have to do one hundred and fifty dollars a day, at least. I kept on shooting all night until I lost all my personal belongings that took me months to gain. We drug users need a program for people with HIV that can help people on an emergency basis. Every time we fuck up we are putting ourselves and other people at risk, so we need extra help. We need emergency methadone pickup for when we are sick. But we also need programs to get us off methadone. The purpose should be to give emergency assistance and then to make you not drug dependent. Methadone deteriorates your body. AIDS makes you tired. Methadone makes you wasted so you can’t do anything. To fight AIDS you should be drug free. I want to be drug free, but there is nothing out there for me.

The welfare hotel is supposed to be emergency only. But the city has no one to help you find an apartment so they just leave you there. When you find an apartment on your own, you have to bring a signed lease to the case-worker and wait weeks for a check. Who is going to give a lease to a homeless person with AIDS who doesn’t have any money?

I finally found an apartment in the Bronx. But I had to lie to the lady and make up an illness. I told her my spine was injured. And I told her a check would only take three days. Then I called her, before it was approved and told her it was approved and the check would come the next week. The next week, someone from the Coalition lied for me and said the building where they cut the checks had asbestos. After three weeks I finally got my check. Only they forgot to put in for my furniture allowance. Two weeks later, last Friday, I got that. As of this week, I am no longer homeless. Not because anyone helped me, but because I beat the system, just like I beat the system with the hospital and the drug program — by lying.

Now I can move when I find a methadone program where I live. Until then, I have a room on Park Avenue and an apartment in the Bronx. The City is wasting its money on things that don’t help me, but it won’t give me the things I need.

I wish you knew how I feel when I go on the subway and see people move away from me. It’s a fucked up feeling.

I served my country in time of crisis. Now that I’m in crisis, where is my country?

I am not the only one who has experienced this. There are thousands of homeless men and women with AIDS struggling to survive. Not just in New York, but in every city and state. Like me, they have no place to turn to.

Estamos cansados de ser maltratados por otras personas sin hogar que creen que pueden defendarse del SIDA golpeandonos. Estamos cansados de ser expulsados de los refugios por el SIDA, y de esconder nuestra enfermedad para poder tener techo. Y estamos cansados de ser tratados como perros sarnosos cada vez que se enteran que tengo SIDA.


ACTUA AHORA!
COMBATE AHORA!
COMBATE SIDA AHORA!

We are tired of being beaten up by other homeless people, who think they can protect themselves from AIDS by hurting us. We are tired of not being allowed in your shelters, of having to hide our illness to get in to them, and we are tired of being treated like dogs when you find out we are sick. We are tired of living in the streets and dirty hotels.

We demand housing for people with AIDS now. We demand adequate services for homeless people with AIDS now. We demand medical care and treatment for homeless people with AIDS now. We demand the right to live our lives with dignity. And we are turning our Anger Into Direct Action.

ACT UP!
FIGHT BACK!
FIGHT AIDS!

Denise Walker

NYC Council Select Committee on Homelessness and Committee on Health

Hearings on Homelessness and AIDS

November 28, 1989

My name is Denise and I live temporarily in an SRO, so I am classified as homeless. I also have full-blown AIDS, as defined by the Center for Disease Control (CDC).

I found out that I had the HIV virus through a research program at Harlem Hospital on November 15, 1988. They were paying ten dollars an hour for people to be tested for the possibility of the virus. At the time, they were requesting that you either be an IV drug user or past user. I have tried it a couple of times in the past, so I qualified. The entire test takes about eight hours. It’s broken up into different parts, such as physical (blood, blood pressure, urine, heart, lungs), psychological, psychosexual and neurological. The worst of it is the taking of 3.3 ounces of blood. This research is done for each person every six months extending for five years. There is a psychiatrist to talk to if you are unable to cope with the results, but they do not provide you with a medical referral. Even though I have had pneumocystic pneumonia twice, I was only able to obtain primary care this October, and it’s at Harlem Hospital.

I had been ill twice before I took the test, and when I was hospitalized, both times, the doctors claimed they didn’t know what was wrong with me. I even suffered through liver biopsies with inconclusive results. The third time that year (1988) I was hospitalized it was at St. Luke’s, and they didn’t know what was wrong either. Finally, I went to Lamb’s Medical Group and the doctor requested my medical records from both hospitals and with my HIV diagnosis explained to me I had AIDS.

Approximately two weeks later, we lost our apartment where we were squatters for two years. The managers of the building knew we were there because we requested a lease and were told to wait for a court date. Finally, when we did get to court, we were thrown out of the place. We were willing to pay rent there but that was not to be. So we became members of that new, exclusive society, “the homeless.”

We stayed with my husband’s mother very shortly. Then one day we went to the Emergency Assistance Unit because my Public Assistance (PA) Social Worker tried to place us in separate shelters and they began placing us in different hotels every few days. Then my husband took ill in Queens and was hospitalized with pneumonia and bronchitis. In the meantime, I began trying to get into the Division of AIDS Services (DAS). That was a problem in itself.

My doctor had to fill out the form twice before I was accepted. Then my case with my husband was closed on regular PA and opened with DAS with a flaw and they dropped my husband off the budget. The reason given: “he’s not sick enough.” We had an M11Q filled out for him at Queen’s General. It was not accepted because it was not filled out the way DAS wanted it — he did not have the pneumonia that qualified him for their services. The bottom line is that he still is not in the AIDS Case Management Unit and has not been able to get his regular public assistance case reopened. So for the last five months we have used food money for one person to feed the two of us.

The Division of AIDS Services, commonly known as MAP, is an exercise in stress control (your own). Try waiting for a check which should be in the EPFT system (computer at check cashing place — no fee) for six hours or more in some cases, for a grant of $188 to cash it usually the next day, since you probably won’t get it before the check casing places close. If your check doesn’t come, don’t worry — they give you seven dollars, five dollars to eat, and two for carfare. This $188 is for a period of 15 days (try making it with two people for two weeks, eating, laundry, and personal items — I am a woman).

Now remember, your surroundings are important in stress control. While you wait for your check at DAS, you have to sit in an area approximately 12 feet by 25 feet with yellow walls, a very small window, two cots for laying down, two wheelchairs, three couches, a conference table, a few chairs and a 21” color television which a particular security guard takes over at 3:30 to watch his video music box, and has the nerve to threaten clients if we speak against it. The people! We are usually cranky, ill, depressing, and depressed at being there. There seems to be a vendetta out for the clients by not having food available around lunch time.

Does MAP already have a policy guideline or are they making them up as they go along? I vote for the latter. Take for instance when I first became eligible for the programs. They had me close out my case with regular Public Assistance which my husband and myself were on together. Then they reopened the case in their group only to tell me they were dropping my husband because he was not sick enough. Now, the second thing that they did to make me think someone was waiting for me to come along was when we had finally established a so-called “residence” in the SRO that I am currently living in — they dropped my name from the housing list. They gave me about 24 hours notice and I went mad. I had just furnished my kitchen (unlike most homeless people with AIDS, I got a complete kitchen) with all the conveniences (pots and pans, dishes, utensils, and other items such as food). And to think I had to pack everything from the kitchen and the bed/living room up and move.

We got an extension for a couple of days which extended to my payday (Friday). I thought, “Great, at least we wouldn’t go through what we had moving to the SRO.” That was a nightmare in itself. Then MAP has me and mine sit there until 6:30 pm and then says, “You won’t get a check today, come back Monday. But we will give you $21.00 for the weekend to eat.” Gee, thanks a lot. How am I supposed to move my belongings from 105th Street to 95th Street (my new SRO)? As for the new SRO, it had none of the features or comforts of the former place, with the exception of a TV. To this day, I won’t buy the line, “We are moving all our people out
immediately." I was the only one. Nice, right?

Next step is in what, on what, or how, am I supposed to move all my stuff, plus my husband's things, plus eat, and have money for incidentals and emergency, all in this one weekend. All this stress destroys me physically and my husband just got his strength back from a medical crisis. I asked the case worker whether there was some type of fund to enable me to move at their whim without any assistance and I was told "No" very emphatically, but I still had to move. I ended up losing most of my clothing, housewares, etc., with no replacement in sight. I also lost a full-length fur coat that was given to me by my inlaws.

The place where they placed us took some getting used to. The kitchen and bathroom were out in the hall, you couldn't put your pot on the stove and go in your room because someone would go in it. The people in the room next door were constantly fighting or playing their television at ear-splitting levels. The place was overrun with drugs. My husband and I separated for a few days and I went back to MAP to be rehoused and guess what? They placed me back in the SRO that was supposedly no longer being used and, ironically, in the same room. We lost our belongings downtown, and are starting all over again.

Does MAP/DAS have any real policies or are they doing as they want? The way they can move you around or deny a person doesn't seem fair. I am ill and the stress is that last thing I need them to inflict on me. There has to be a better and easier way for people like myself to receive some assistance with less aggravation. I was told they had filed for my SSI. I haven't heard anything yet. When I ask where to go, they give me all the misinformation possible. I think I will have to do it myself.

Phyllis Sharpe

My name is Phyllis Sharpe of Brooklyn, New York. I am a victim of years of drug abuse. I have six children and two grandchildren. I am single, Black, and have a very little means of finance. In February, 1989, I discovered I was HIV positive. At this time I was still a user. The Bureau Of Child Welfare was called by a family member and my youngest daughter was taken from me. This happened ten months ago. She is now two years old and is HIV positive also.

I was told to get in a drug treatment program, which I did. I have been drug free since November, 1988. It was believed that my drug problem was caused by the stress I was going through because I had no home and was forced to live with my parents. Even now I dare not let my family know I am living with AIDS or I would lose the only remaining security that I have.

A little more than six months ago I joined a women's support group to accept both my daughter's and my own illness. This group helped me put things in motion to get funds, medical care, and housing. I was told to apply for MAP, the Medical Assistance Program. At this time the apartments on MAP's list only had two bedrooms, and because of my family size I needed three bedrooms.

Without an apartment, the Bureau of Child Welfare wouldn't even think of returning my daughter. But MAP told me if I wanted one I would have to find it myself. Go to the real estate agent yourself, they said, and we'll pay the fee. This sounds easy enough, but what you must do is provide MAP with a signed lease. Then, if they determine that the rent is in the range that they will pay for your family size, the process can continue.

I was helped through the process by other members of AIDA and eventually found a landlord who was willing to give me a lease and wait two weeks for the first check. This was a great feeling — I was finally going to get my own place. Only then the check was late, a common experience with MAP. I had to face the possibility that I would lose this apartment. Just the thought of starting all over again was sickening. Most MAP clients have the same complaint about late checks. When you question your worker about it, you are told, "I'll call you when the check comes downstairs. I don't work upstairs." Meanwhile, you are left worrying about where to get food, clothing, and other things you need.

My question is — do patients with cancer go through this amount of mental abuse to get help? If not, why have I? Where can I go to feel and be treated like any other ill human being?

Due to changes I've been through, I have become more open about my illness and how I'm being treated when I try to get help. I've realized that the system that is supposed to work for me is actually against me. Sometime during my trials and tribulations I applied for disability. I'm not being considered. Supposedly I don't see a doctor often enough to qualify. So I've had to start going to a new clinic on a regular basis.

My question is — do patients with cancer go through this amount of mental abuse to get help? If not, why have I? Where can I go to feel and be treated like any other ill human being? I wonder if I am the ill person or if the sick people are those who create and work in the system that I need to survive.

When can I focus my attention on my own health and on my own well being, in peace with my family all together? There is no one to tell me what to expect as a woman living with AIDS, and I don't even know the right questions to ask. Yet I've had to be my own doctor, my own nurse, my own social worker, and sometimes I have to be an actor as well. The AIDS community has looked down on me for having a child with AIDS. Yes, I believe every woman should have the opportunity to be tested early enough in her pregnancy to make a decision about whether or not to have a baby. But that decision is hers to make.

Because of my illness I am treated like I'm no longer capable of being a mother. A big part of that is denying me the services I need to help me do that. All decisions concerning my daughter have been taken from
Because of my illness I am treated like I'm no longer capable of being a mother. A big part of that is denying me the services I need to help me do that. All decisions concerning my daughter have been taken from me.

At this point I'm told to prepare her to leave, to dress her and say goodbye. I'm crying, she's fighting to stay in my arms. This is something the worker says we both must understand. She'll get used to it. To top it off, every once in a while I'm asked do I still want her because the foster parent really has become attached to her. Now I live in fear of the smallest mistake or in waiting for the system to mess me over until they say I can never get her back. Where she is at is a secret to me. I often pray that soon I'll get her back and while she's away she doesn't forget me and how much I love and miss her.

I'd like to close with this fact. I've seen many slides, graphs and charts and heard a lot of statistics at this conference about what AIDS means. But this is what AIDS means to me. This is my daughter.

Wayne Phillips
My name is Wayne Phillips. I am a member of AIDA and am from New York City. I have come to talk to you today about dignity, common respect, care and compassion. You won't find any of these issues addressed in policy and service guidelines of the federal, state and local government agencies dealing with AIDS. Nor will you hear anyone else at this conference talk about the day to day humiliation experienced by those of us living with AIDS who are dependent on the social service system for our survival.

I first had occasion to call on this system in New York City in June, 1987. It's funny when you think about it. Here are people presenting themselves on the basis of need, not because they have a passion for standing in lines, filling out forms, and waiting for their number to be called. I'm angry that when I got out of the hospital recovering from pneumonia, weight loss, fevers, and fatigue, instead of getting the assistance I was entitled to, benefits were denied me for failure to comply with the public works program.

Sure enough, despite my second hospitalization, the Division of AIDS Services determined that I was not sick enough to be eligible for assistance. I was referred to a public shelter that sleeps 1,000 men in a single room and turns folks out at six in the morning so they don't become too lazy.

I was already living in the street, so what the hell: eating at soup kitchens, sleeping on the train, stopping by associates' houses to shower and shave, but hiding the fact that I had AIDS, holding on to that last piece of pride. It's very difficult to go to agencies that are supposed to help you when you are used to being independent. "I can handle it on my own," I said. And I continued to proceed on this pattern for about three and half months, until, tired beyond belief, I tried to commit suicide and wound back in the hospital.

This time I knew that I would need financial assistance, as well as food stamps, and SSI. But still I dreaded dealing with the system, not because of its reputation, but because of what I had already been through. Sure enough, despite my second hospitalization, the Division of AIDS Services determined that I was not sick enough to be eligible for assistance. I had a T-4 cell count of 200, continued weight loss, and chronic fatigue. I was referred to a public shelter that sleeps 1,000 men in a single room and turns folks out at six in the morning so they don't become too lazy.

Finally, I wound up at the Coalition for the Homeless in New York City. There I became an intervenor in a lawsuit against the City. Eventually I won a preliminary injunction ordering the City to provide me with services. Despite this order, which, by the way, the City is appealing, it took two months and an ACT UP sit-in at the Human Resources Commissioner's office before I was provided with a Single Occupancy Room.

What about those who are unable to speak up? What about those who don't have an attorney or a direct action group to advocate for them? Even with these people and organizations to back you up, things can be very trying.

The Division of AIDS Services first told me that I would have to go to their doctor to be examined even though I had all of the necessary documents to show that I was indeed qualified for their services. Then I had to wait for three months for a Medicaid card and a couple of more months to receive money for food and shelter. At the time it was very trying. I am still waiting for my first SSI check though my application was submitted almost a year ago.

I belong to the Village Nursing Home Day Treatment Program in New York City, the first day treatment program of its kind in the country. Yes, they have groups, and doctors and nurses, social workers, meals,
etc... But what they instill in the program the most is loving, care, and concern. In contrast, in many agencies, I am faced with people who are supposed to provide me with services with respect, but often I get non-caring, arrogant people who are just watching the clock. It is a disgrace.

Just because we are vulnerable and in need does not mean that the system should not also be responsive to our need for dignity. It's all right to dispense with love, but it's not all right to make us seem like we are outcasts.

The clock for us, my friends, is ticking. Anyone who has to deal with this system, confronts these problems. They might seem small to others, but to us they are overwhelming. Just because we are vulnerable and in need does not mean that the system should not also be responsive to our need for dignity. It's all right to dispense with love, but it's not all right to make us seem like we are outcasts.

If you are to make policies, if you are to set guidelines, then first you must come into the trenches. You must come to the welfare center and see the madness. You must call SSI and be put on hold. You must sit in our clinics, live in our housing, and deal with the red tape that we encounter every day. I doubt very much that this will happen. Still, let the people who make the decisions talk to us. Let them know that we still feel, still hope, still pray, not only for a cure, but to be treated like human beings, no matter the sexual orientation, race, or drug history. Let them know that if you keep telling someone that they are less than others, they will start to believe that. We with AIDS are not that, and we should not be made to feel like it either.

We will not go away, my friends. AIDS will affect every single person in the U.S. and abroad by the year 2,000 or sooner. So next time a person with AIDS comes to your agency for help, don't just shuffle the papers. Extend yourself in the context of your job because maybe sooner that you think, it might be someone you love, someone you care for, knocking on that same door for service that they so badly need.

In closing, I don't know much about how policies and guidelines and criteria are made up, but I do know about dehumanization, something that burns within you to break your soul, mind and spirit. Yet there are those of us who refuse to lay down and die. I am one of them, and I am very proud to be able to speak with you today for all of my friends whose torches have gone out and those whose torches continue to shine bright. For we are living proof that, despite adversity, not all our spirits could be broken, and that some of us have their strength not only to continue to live full lives, but to speak out as well.

Cindy


My name is Cindy, and I live in the Bronx. I was diagnosed as HIV positive in February, 1988. Since then, I have been through many troubles with the system — BCW (Bureau of Child Welfare), homelessness, becoming drug free and foster care. BCW removed my children and I was told to become drug free, which I’ve been now for one year. For this I’m thankful that two of my family members made this call for me. My case worker I had kept secret for one month the location as to where my baby was. Each time I asked, he’d go on with his questions. My brother, who was going to take her, once he found out she was HIV positive, also said no, but he wouldn’t tell me. When I did go before the judge and asked why I couldn’t see her, they told me what hospital she was in.

Being as my funds were very little, I would sneak on the train to see her. Carfare was given once through the social worker in the hospital, but after speaking to the worker at BCW, I was told they couldn’t give me the money any more. Doctors and nurses looked upon me like, where have you been all this time? One even went so far as to say, “You haven’t been here all this time, what made you show up?”

Last Christmas, me and my family bought presents for her and went to see her. When I got there, she was gone. The worker never notified me. Finally I got the name of the agency where she was placed and got a visit. Because of her name and her talking baby talk, she was placed in the home of Puerto Ricans. Now my little girl speaks English and Spanish. The foster mother and I have traded phone numbers because I only speak English. Some words she says I don’t understand and vice versa.

Sometime after going through these changes, this same worker was called by my father in anger and removed the other two children. He never bothered to call my counselor to verify my being drug-free. So now, I’m visiting one child in Brooklyn, the second in Queens, and the third in Staten Island. During this short removal of the last two children, my son was in a car with one of the counselors at the group home for boys and was in an accident. This is against the rules — the child wasn’t supposed to be in a car, and the counselor had been drinking. My son was told, “Don’t say anything, you’ll be all right.” Being he knew this wasn’t right and his head was hurting, he called home. I then notified BCW, and they acted one day later.

Anyway, when I went to court, the judge decided the children were illegally removed. They were returned to me. Finally, I couldn’t take living with my parents, all six children and two grandchildren in one and a half rooms. Me and the two youngest children moved into the Prince George Hotel: no stove, one room, drug infested, hookers, pimps, and the elevator not working. And two trips daily to take the children to school in Brooklyn. I became very ill and weak. Sometimes, my son would have to aid me up and down the train steps. Eating properly was impossible.
Due to may getting weaker, I was forced to return to my parents’, where my children and I really weren’t wanted. During this time, I still remained on my program to stay drug free. It was so hard, and I was so afraid that if my father got mad, he would call BCW again.

**Foster care has its ups and downs as well. Here I am drug free for a year now, and I have the apartment, which was part of the deal for her to be returned. But because I don’t have a bed for her I was forced to sign her into voluntary placement for another year.**

Finally, I started going to AIDA (Anger Into Direct Action), a support and activist group at the Coalition for the Homeless. With their help, I was referred to the Division of AIDS Services Medical Assistance Program. Again, with this system, it was late checks, and going without cash and food stamps for four months. I was afraid to answer the doorbell because if BCW checked the refrigerator and saw there was no food, they would remove the children. My case just got corrected at the beginning of this month. It was opened in August. Now I have a beautiful apartment in the Bronx. My baby is to be returned to me on December 1st.

Foster care has its ups and downs as well. Here I am drug free for a year now, and I have the apartment, which was part of the deal for her to be returned. But because I don’t have a bed for her I was forced to sign her into voluntary placement for another year. I couldn’t have overnight visits because of not having a bed. The worker for the agency talked over a plan to wean her back to me all the way into January 1990. On a planned day, I was to pick the baby up at 9:00 a.m. at the agency and have her back at 4:00 or 4:30 p.m. Now, from the Bronx to Brooklyn is one and a half hours. I have no stroller and I suffer from shortness of breath when walking myself.

**In other words, I’m not ill enough to receive disability and not well enough to hold a job. I feel like a ball being bounced around purposely to make me ill and die and be forgotten.**

Since then I was assigned a new worker from SSC who is basically on my side and feels this is too much for someone in my condition and the child. She says the return of my baby still stands for December 1st and that they are to issue monies for clothing, linen and a bed before the return of the child. The foster care agency says that they aren’t responsible for the issue of such monies. Meanwhile, the foster mother slipped and told how the foster care agency issued money for her for a VCR due to the fact that one of the other children she has is overactive. Now I ask you, which is more important, a VCR or a bed for a child that should be returned to its mother, a mother who has worked very hard at becoming drug free and getting a home for her children?

I sincerely hope that someone hears this testimony and puts a stop to these systems that don’t work for a person like me. They should make it work for the clients. Sometime back, I applied for SSI and disability. One week ago I was notified that if I can lift twenty pound tools, they feel I can work. It took them one year to make this decision. I never saw their doctors. In other words, I’m not ill enough to receive disability and not well enough to hold a job. I feel like a ball being bounced around purposely to make me ill and die and be forgotten.

**Tommy Cummings**

**NYC Council Select Committee on Homelessness and Committee on Health Hearings on Homelessness and AIDS November 28, 1989**

Ladies and gentlemen of the City Council, good morning. I have come here today to this hearing to testify not so much for myself as for those who cannot be here to speak for themselves. I want to dedicate my testimony to the following people in the hope that some good will come out of this. They are:

John Sutton and Michael Stevenson, dying.

Angel Miro, Sylvester Sterling and Ed Campbell, dead.

Kevin Gethers and Joel DiGuiseppe, recovering.

No matter what we say, we can never fully communicate how we feel since none of you have lived as we have. Yet we speak anyway because we know that only if we force you to hear us will we gain the housing, social services and respect that we need and to which we are entitled.

On November 14, 1989, I saw a program on television that mainly dealt with a person losing and dying with AIDS. I didn’t say winning and living with AIDS, because that is often something that does not happen in our sphere of reality.

The life of a person with AIDS (PWA) is a life of confusion, bureaucracy and anxiety. The battle to survive and exist from day to day is complicated by a system built on deception and ambiguity. Often a great deal of backlogged paperwork and red tape are involved when seeking decent housing as opposed to the hotels designated for PWAs. These hotels are for the most part unsafe and unclean, two aspects detrimental to the health of a PWA. There are many horror stories from people living in these hotels of being robbed and the buying and selling of drugs in the hallways.

Before becoming homeless, I was involved with intravenous drug abuse, getting high and sharing needles and works. The risk of being infected with hepatitis or AIDS did not exist for me. Like anyone else doing drugs,
the important thing for me was the high, the feeling of euphoria, or well being. The amount of money spent chasing the false dream — for that's all it was — was phenomenal. An example to illustrate what I am telling you is that at one time I spent two thousand dollars in three days chasing the magic-tragic dream. Concern for clean sets was only secondary to the high itself.

To be a homeless PWA in New York is no joke... PWAs who are homeless generally have no medical care, no shelter from the elements except a cardboard box. The shelters are full and more dangerous than the PWA hotels.

Slowly I began to lose my friends, and shortly thereafter I lost my apartment. It did not bother me too much to lose the apartment, the place I called home. Though I was homeless, this part did not dawn on me, nor did I allow it to enter my consciousness as long as I got my daily fix. Feeling that in some way my family was responsible for my drug addiction, I managed to live with my brother and his wife for a while, just a couple of months until I could find another room or apartment. Eventually I was asked to leave and went to live with my mother. At my mother's apartment I had it easy. In spite of that, I lost her confidence and trust. This time when I left I was totally homeless.

I want to state that my becoming homeless is not representative of all homeless people, especially homeless people with AIDS. My story is unique in and of itself, just as there are stories among you of success and failure, triumph and tragedy; unique because they are ours, yours and mine.

To be a homeless PWA in New York is no joke. Just look at our streets and our subway platforms, it's serious. PWAs who are homeless generally have no medical care, no shelter from the elements except a cardboard box. The shelters are full and more dangerous than the PWA hotels. Lastly, PWAs who are homeless, like all homeless persons, are without love.

The City of New York has set up shelters to house the homeless, which in my opinion is the equivalent of putting a bandaid on a shotgun wound. The shelters are large and extremely overcrowded, and there are anywhere from two hundred to seven hundred men on a floor with no privacy allowed the individual, a communal sleeping area, communal toilets and showers, and communal recreation. Whenever I had to use the toilet or showers there were at least ten other people there. Privacy cannot be found in a city shelter, nor can privacy and personal space be found in city funded flophouses or SROs. Many of the SROs are infested with bed bugs, roaches and rats. Drug use is rampant and is ignored by many of the security personnel. Some of the guards will even demand money for their silence about who is using or selling crack or dope. The strong will steal from the weak, those not able or too scared to fight back. It is very easy to get sick in a shelter or SRO because management dumps everyone into the same dorm; the young with the old, the healthy with the sickly, the thief with the honest man.

There is very little opportunity to get your life together in such an environment because one doesn’t live in a shelter or SRO. Rather one struggles to survive from day to day. I know. I’m one of the survivors of that shelter and SRO environment.

Eventually I left the shelters and flophouses for the streets of the city and its parks. The reason was for me a simple matter of life and death because in June of 1988 a revolver was aimed at my face and the trigger pulled by one of the flophouse gangsters, after which this person proceeded to pistol whip me, resulting in my being hospitalized for five days for an abscess on my left leg.

I was discharged from the hospital into the streets where I proceeded to spend the days going from soup kitchen to soup line and looking in the garbage to satisfy a hunger that was insatiable, a hunger that stayed with me, never truly satisfied. No matter how much food I was able to eat, I noticed that I kept losing weight and being constantly tired.

For me, living to my fullest potential can be summed up in the phrase “Life, Liberty, and the Pursuit of Happiness.” The reality that is my life is that Life is survival from day to day; that Liberty is being subjected to the indignities of humiliation and dehumanization; that Happiness is defined as a bed to sleep in or the next possible hot meal.

I had been diagnosed as HIV seropositive in February, 1988. To the best of my knowledge the AIDS virus has an incubation period of five to seven years. It devastated me to discover that I began getting sicker and weaker in less than a year while living on the streets. I realized I could no longer remain in the streets, living the way I had been.

Wednesday, November 14, 1989, I saw the program, MIDNIGHT CALLER. Tonight's episode dealt with a person living with AIDS and the problems endemic to a PWA. Problems ranging from acceptance of the illness through seeking social services from a society that is cold and unresponsive to the needs of PWAs, much less their wants and desires concerning their illness, to the acceptance of death and dying of a PWA. At first I felt good about what I had just seen because it was very realistic in its presentation. The more I thought about it, the angrier I became.

As a PWA myself, I know that there is a difference between reality and realistic. There is nothing realistic
about a PWA who is trying to live his or her life to the fullest. For me, living to my fullest potential can be summed up in the phrase “Life, Liberty, and the Pursuit of Happiness.” The reality that is my life is that Life is survival from day to day; that Liberty is being subjected to the indignities of humiliation and dehumanization; that Happiness is defined as a bed to sleep in or the next possible hot meal. There was a time not too long ago (six months past) when happiness was finding a dry cardboard box to use as a mattress and life was shelter from the elements. Too long have I wanted to write a journal of some important events in my life. I guess that for me the most important thing in my life is my spiritual and personal growth as a human being who has to live with AIDS.

My own experience with the Division of AIDS Services (DAS), the Medical Assistance Program (MAP) and the Human Resources Administration (HRA) is one unbelievable nightmare and horror story.

Once I became aware of how fast my health was deteriorating on the streets, my first priority was to seek housing through the Human Resources Administration. This proved an impossible task. When my case was accepted by HRA I found I was to receive a grant of $91.50 every two weeks beginning in May of this year. There is no way you can get a room even for $50 a week when all you get is less than a hundred dollars every two weeks. My Medicaid card has not been sent even though my public assistance case was opened months ago. This is a card I need for medical treatment I know I can’t pay for myself.

When I became aware that the Division of AIDS Services had been established by the City to help people with AIDS, I went to them for help. I was denied even an intake interview because, as they said, I was not “sick enough.” This despite an M11Q stating that I had pneumonia, swollen lymph nodes of the groin, massive weight loss, cellulitis and a T-4 cell count of 439. It appeared that the only solution was for me to remain in the streets until such time as I actually became sick enough to satisfy the arbitrary criteria of agencies set up to help people like me, people living in my situation, homeless and living with AIDS.

With the help of the Coalition for the Homeless, I was able to get an expedited fair hearing date. It was brought out that I was living in the streets and sleeping in subways for the last three months and that the illnesses on my M11Q were indicative of ARC. The decision of the judge was very ambiguous to say the least. Both DAS and I were losers. DAS was required to recommend housing but not provide housing itself.

The fair hearing decision was delivered after I had been accepted as a DAS client with an upgraded M11Q stating that I had ARC, cellulitis, pneumonia, etc. At DAS, my intake processing took a couple of hours at the end of which I had been placed in an SRO hotel on 26th Street and Park Avenue South. It is roach and rat infested and drugs and crack are sold as if the dealers had a license to sell.

Changes need to be made in the securing of decent housing. The large amount of paperwork and red tape needs to be reduced. Concerns for the homeless and PWAs need to be addressed and initiated quickly and effectively, then we can begin to solve the problem of housing for the PWAs and homeless in this city.

I remember five, six months ago I had a very bad case of athlete’s foot and cellulitis and I was forced to get medical attention. The transit police called an ambulance for me to take to the emergency room at Bellevue Hospital. When the ambulance arrived I told the medics what my complaint was, a swollen and painful left ankle, open sores and cuts on the heels and bottoms of both feet, that it was very painful for me to walk, that I couldn’t stand for more than two minutes without feeling pain. One of New York’s Finest, a cop, told the medics that I had been walking fine before their arrival at the subway station where I used to sleep. For a moment I doubted my own sanity, but when I looked at the officer who had made that statement, I realized that I was looking at someone who did not care two shits about me. This attitude of non-caring was also evident in the medical staff of the hospital. I was convinced, told, that I had an infection, antibiotics were prescribed and I was released.

During the time that my feet were hurting I was supposed to be in court for a hearing. The only way to get there on time was for me to ride the train to City Hall. I didn’t have the money to pay the fare so I approached a transit cop, explained the situation to him and asked him if he could let me through the gate. His answer was “Pay your fare.” I went to two other cops with the same request and was turned down both times after which I said “Fuck it, I don’t need this.”

You often ask why it is that we miss appointments that are important to us? Why we look so tired. The truth of the matter is that when we look tired and miss appointments it’s because we are too sick. We must deal not only with our sick bodies but we must also deal with an establishment that doesn’t give a damn about us.

On July 17th, 1989, my welfare case was closed because I had missed a Public Works Program though the appointment notice was never mailed to me. With the help of the Coalition for the Homeless I was able to get a letter addressed to my case worker requesting that she reopen my case. I know she got the letter because I delivered it myself. On my next benefit day, my case was still closed due to a severe lack of interest from my worker: She just didn’t give a damn.

There are many people out there in the streets who are homeless and living with AIDS. Because of the policies of particular government agencies, they are forced to remain in their present circumstances — without homes, food, or medical help, getting sicker and dying without hope.

I strongly recommend that HRA be renamed Human Repression Association, that DAS be renamed Death Assistance Services and that MAP be renamed Mental Apathy Program, since these are the things in which they are doing a great job.