

DISTRICT



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December 19, 1986

Daniel Stone, Deputy Commissioner
City of Philadelphia
Department of Human Services
Broad and Arch Streets
Philadelphia, PA 19107

Dear Mr. Stone:

Gary Lyles died today. He was 20 years old.

I know you didn't know him, but Gary was a "resident" of the housing program for homeless and indigent people with AIDS run by your Department through a contract with Philadelphia Community Health Alternatives.

Gary came to that program because he had no place to live. He came because he had lost the last job he could find and was forced to live on public assistance. He came because he had been promised a place where he could live out his last days with dignity and with caring people around him.

But he died without receiving any of that.

He didn't receive it because, like Myron Hansberry before him, he didn't fit the standard that PCHA requires its people with AIDS to fit. While he wasn't disreputable and dirty like they say Myron Hansberry was, he just didn't belong, he didn't play the game or fit the mold the same way the others did.

So instead of caring he got abuse and neglect. Instead of comfort he got harassment and cruelty. Instead of dignity he was forced to submit to ignorant and humiliating demands that sought to rob him of what little independence and pride he was able to hold on to.

And as a result, a publicly-funded program that was supposed to provide him housing and comfort drove him out, so that he spent most of his time as a 'House resident outside the House, staying with friends so he could get the care he needed and at least a little peace of mind.

Gary died a frail and physically helpless person. But one of the goals he strived to continue living for was to re-build

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his strength and regain the powerful physical presence he once had. He frequently told his friends, especially in his last days, that he wished for the strength to be able to go down to PCHA and give them a message: that what they and their program and their insensitive staff had tried to do to him had failed.

They tried to rob him of his dignity and his happiness, Mr. Stone, and all the while his only crime was that he was dying. They did that not because they're evil people, but because the people running this program simply don't know how to make it work. And Gary was another victim of their ignorance.

Gary didn't get the chance to go down to PCHA and tell them his mind. And though I know I'll get trashed and abused for it, I'm going to tell you for him. Because Gary was my friend. And the people you entrusted with his life did what they could to erode his dignity and rob him of what little contentment he could have had in his final days. That just isn't fair. And though I'm sure your bureaucratic needs don't make room for such things, the human cost of the Department's short-sighted trust in PCHA must be known.

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I was the guy who drove Gary to the "AIDS House" the first day it opened. He had just gotten out of Episcopal Hospital and was excited and happy, looking forward to a friendly, comfortable home for the first time in a long time. He was full of plans to take advantage of the comfort and supportive environment we promised him, so he could re-build his strength and live each of his remaining days fully.

It was a short visit, though, because while the other two residents had beds or cots to sleep on, Gary's room was empty--no bed, no bureau, no nothing. So for the first few days of his "residence" in the House, Gary had to stay elsewhere so he'd have a warm place to sleep. (PCHA has never been able to justify why after six months lead time and a \$30,000 advance from your Department, they weren't even able to find beds for their residents to sleep on.)

There were other reasons why it was difficult for Gary to stay at the House those first few days. As soon as he walked in the door, he was publicly condemned by one of the other residents because this other resident had found out that Gary was paying a lower rent than he was (because Gary's income was lower); it turned out that the House director, Terrence Young, had already

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informed the other residents of Gary's financial circumstances, the course of his disease, and the family situation which had led him to need a place to stay. Gary was angry and uncomfortable that so much of his personal business had been discussed with people he didn't even know, especially when this other resident continued to do what he could, armed with Mr. Young's reports from Gary's file, in making him feel unwelcome and "second class" because he was paying a cheaper rent.

Gary needed a place to live, so he kept his hurt inside, waiting for the day he'd be strong enough to stand up and defend himself. But he shared his hurt with his friends.

Gary also had a more practical problem. As a result of his disease, like many people with AIDS, he had a lot of difficulty simply walking. When Gary arrived at the House, he discovered that Mr. Young had assigned him to a third floor bedroom, which meant Gary had to walk up two long flights of stairs to get to his room. Meanwhile, Mr. Young kept the first floor bedroom for his own office, refusing requests that it be held open for residents when the walk up the stairs proved too much for them.

Gary, needing a place to live, kept his hurt inside, waiting for the day he'd be strong enough to stand up and defend himself. And he reconciled himself to the pain Mr. Young's decision required of him.

Eventually, PCHA was able to find a bed for Gary, though to this day they've never come up with the rest of the furniture he was promised. And they somehow were never quite able to make the House work for his other needs either, at least in the ways they so proudly proclaimed in the newspapers they were established to do.

When Gary needed confidentiality, Mr. Young would have House meetings at which no one's privacy was respected, and personal secrets became community property.

When Gary needed the feeling of "home," he had to contend with drinking bouts and drunken fighting among the other residents and their friends, in a House where there was no supervision or staff in residence.

When he needed to sleep, he had to climb a painful path to his third floor room while Mr. Young's first floor office stood empty and largely unused.

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When he needed to be with his friends, PCHA told him he wasn't allowed to be with his closest friends, because Mr. Young didn't like them--and even asked him to sign a paper prohibiting them from visiting at his home. Gary wasn't sure what would happen to him if he refused to sign that paper, so he asked his friends to visit him elsewhere rather than risk PCHA's ire.

And when he needed just a little bit of nursing care--just the minimal kind PCHA admits it's supposed to provide--he couldn't get it. Even if PCHA had been able to overcome the systemic incompetence that has destroyed so many of its services, and had been able to arrange for home care for Gary, it would have come too late. Because by that time Gary's experience as a House resident had been so poisoned by their insensitivity that to have to tolerate the insane atmosphere PCHA had created in the House was, to Gary, too much a price to pay for the minimal nursing service they might have been able to provide.

And Gary needed a place to live, so he kept his hurt inside, waiting for the day he'd be strong enough to stand up and defend himself. So he sought his nursing care from his friends.

The consistent PCHA message to Gary Lyles during his time in their care was that they didn't have time. They didn't have time to get him a bed to sleep on, they didn't have time to find him a bureau to put his clothes in, they didn't have time to hook up some home care, they didn't have time to pay attention to him as an individual human being, they didn't even have time to say a kind word to him when he went to the hospital to die.

If Gary had had more time, however, and if he had been able to build up his strength, there are things he would have liked to tell you about the program you so lightly entrusted with his last days.

He'd tell you about the time PCHA sent someone to interview him in his hospital bed to figure out if he was sick enough to be moved out of the house, so that the lover of one of the other residents could come up from Virginia to move into Gary's room.

He'd tell you about the time PCHA staff and volunteers tried to destroy his relationship with his "buddy" and his friends, because of personal jealousies between PCHA volunteers.

He'd tell you about how Mr. Young unofficially made one of the House residents into the "straw boss," giving him the power to harass and intimidate the other residents unless they followed

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special rules and regulations not written in the manual given to them when they signed their leases.

He'd tell you about the time PCHA unilaterally interfered, without his permission or that of his family, in his application for social security benefits, so delaying the process that benefits he should have received months ago still hadn't arrived at the time of his death.

He'd tell you about the time his "buddy" was condemned by other House residents because he was spending too much time with Gary, and because he offered him a sane place to live when the internal fighting and craziness of the House threatened Gary's mental and physical health.

He'd tell you about the time one of the residents was found physically ill and incapacitated on the floor with no one to assist him, since PCHA priorities are to spend money on new furniture and rental on empty houses, rather than a house staff that would assure a response when emergencies arise.

He'd tell you about the time PCHA spread the news that he had died and that the other resident's lover would now be able to legally move in--almost a day before his death actually occurred.

And if he had been alive to witness it, he'd let you know that even after his death, PCHA played bureaucratic games with processing his mother's request for burial assistance, so that even the dignity of his funeral was almost robbed from him.

Gary Lyles would tell you how little the PCHA housing program helped him, a typical victim of AIDS--and how his needs were progressively ignored the farther his disease took him from the fantasy of "independent living" PCHA--and DHS--alone believe in.

During most of the period when Gary was officially a "resident" of the House, he lived with friends, because the House was not a safe place for him. Physically he was forced to suffer to merely get to his room; emotionally, he was drained and harassed by the incompetence and insensitivity of the House managers.

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Gary and I once had a conversation about safe sex and its role in preventing the spread of AIDS. "Safe sex?," he said. "It's a little too late for me, isn't it?. Somebody should have told me a long time ago."

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That's "somebody" is PCHA, because that's the public responsibility they've claimed for themselves. And while the record clearly shows that it is young black men like Gary Lyles--the group with the highest risk of contracting AIDS--that PCHA always manages to forget, it is especially sad that even when he was admitted to their own housing program, they continued to ignore him--and with the same tragic results.

When we met after the Hansberry incident, you and Mr. Phillips informed me that changes were being made which would insure that the housing program was based on the real needs of homeless and indigent people with AIDS--not PCHA's fantasy image of what homeless and indigent people with AIDS should be.

I don't see much evidence of change, but if you say it's happening I'll believe you.

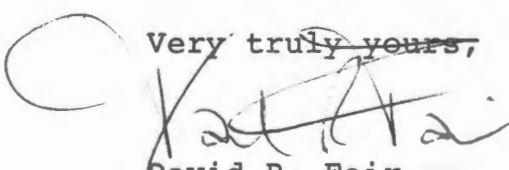
What I do know is that it didn't happen in time for Gary Lyles. And if the Department would simply recognize its mistake in entrusting this program to PCHA, it won't happen to the Gary Lyleses--or the Myron Hansberrys--still to come.

I don't know why the Department has applied such low standards to this program, but with thousands of new AIDS cases expected over the next few years, I suggest that serious attention be given to raising those standards.

Because the City of Philadelphia held out a promise to Gary Lyles, that it would help him live his last days with dignity.

But somehow it didn't pay enough attention to fulfill that promise, and now, just like it was with its safe sex information, PCHA is again too late for Gary Lyles.

And you, Mr. Stone, have a responsibility to do something about that.


~~Very truly yours,~~

David R. Fair
Secretary-Treasurer

cc: Commissioner Pernesley
Commissioner Clifford
Deputy Commissioners Williams, Burks, Phillips
Mayor Goode