Kitten Does Disability

Why do public services become public humiliation?

June 1, 1995 By Kiki Mason

I have been watching the struggle of a good friend who recently went on disability. For purposes of protection from a vengeful bureaucracy, we shall hereafter refer to him by his nickname, Kitten. Now Kitten has always been a hardworking homosexual, from solid New England stock, and grew up in the same kind of town that Anne Wells came from in Valley of the Dolls, where a fierce work ethic was pounded into everyone from birth.

After arriving in New York City in the late 1970s to pursue a music career, Kitten found himself working as a retail queen, which he was very good at. But after his lover died and he was diagnosed, Kitten couldn't take all of that standing around. He tried a desk job in the garment center but the pressure cost him 200 T-cells. "I found that all I was doing was going to work and sleeping," he told me. "It didn't seem like much of a life."

Last fall, Kitten made the difficult decision to go on disability. While he remained his usual cavalier and optimistic self, we had lots of unspoken fears. I was afraid because I've seen many people go on disability and give up on life. I also feared what would happen to my beloved Kitten in the cogs of DAS, SSD and all of those other acronyms we love to hate.

The puritan work ethic part of me believes that we should all work until we drop and frankly, part of me wanted to say, "Bitch, I'm sicker than you and I drag my tired ass into work!" But I didn't. My judgment rested on the fact that Kitten has never had a major opportunistic infection. His T-cell count is low and he gets things like fatigue and diarrhea, but to someone who has worked through ravaging KS and chemotherapy, he sounded, well, a little whiny.

I had to remind myself that we all have different levels of strength and tolerance to pain. Mine, thank God, is high. I am also in the luxurious position of doing something that I truly love. Let's face it, most people aren't doing something that fulfills them.

So I abandoned my judgment and listened to Kitten's horror stories about New York City's Division of AIDS Services (DAS). Kitten waited for hours in a not-very-clean room filled with people who were apparently high and mothers with screaming children. When he finally got a caseworker, she was extremely apologetic, promising him that he would not have to come back for repeat visits. "I'm so sorry that you had to be subjected to these people," she said.

“I almost felt as if she was apologizing to me because I was middle class,” he said. “I told her that I didn’t mind sitting in a room full of drug users but I did mind sitting there for hours. She offered me subway tokens and told me that I would get my first welfare check in a couple of weeks,” which would pay for his rent. Every two weeks he would receive $160 plus $115 in food stamps a month. In the meantime, he applied for SSD, the federal government’s official disability program, which we’re all supposed to be able to get if we need it.

Kitten schlepped to another waiting room, this time on 42nd Street, to be examined by an SSD doctor. Again, he waited for hours, finally freaking out when it was 7:30 in the evening and it appeared that he might have to come back the next day and repeat the whole process. After a perfunctory examination, he was told that an eligibility decision would be made for sure “within a few weeks.”

It took four months for Kitten’s application to be turned down. “My doctor says that they’re turning down almost everyone on the first try,” he said. “It’s not enough to have low T-cells and fatigue. It’s not even enough to have had PCP [Pneumocystis carinii pneumonia] or KS. They’re making it really hard for people to collect.” So Kitten’s doctor has written a much stronger letter and Kitten is now going through the appeals process, which will again take months.

Initially, I was quite worried about my Kitten. How could anyone live on his income in New York City? During the first few weeks he seemed to be sinking into depression, sleeping endlessly and not feeling well. Finally, I sat down and slapped him around. “Look,” I said, practically shaking his shoulders, “if you sit around with no purpose in life, there won’t be any reason to live. Find something -- volunteer for an AIDS service group, burn something down, just find your reason for being on the planet.” Finally Kitten called me up. “I’m starting a new group,” he announced, “Queers for Allah. It’ll be a gay Muslim fundamentalist terror organization. Do you think they’ll accept us?”

Kitten is still waiting to hear on his appeal at SSD and vows to fight on for his benefits. In the meantime, he has returned to his first love, music, and has actually produced a demo album. He is motivated and happy, out in the world.

Kitten’s struggle has forced me to think about my own life. Even when the stress and messiness of it make me wonder why I’m still working, even on days when I’m in pain and would rather be in bed, my work provides purpose. If I did have to go on disability, however, I know I would still pursue my raison d’괚e. It’s not the disease, pussycat, it’s what you do with it.

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