Chapter 5

The Allure of Community

The Ethical Journey of People Living with HIV Disease in Philadelphia

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“Community” has become an indispensable concept in the government of postindustrial cities in the United States, and those who take on the task of participating in and representing communities have become key players in U.S. urban governance and politics.1 Perhaps surprisingly, the communities formed in response to the AIDS crisis have taken on particular importance in popular and academic discussion of the power of community in contemporary urban contexts.2 Indeed, the “AIDS community” exemplifies what Nicolas Rose, following Paul Rabinow (1996), calls “biosocial community” (Rose 2007, 136–38). In contrast to political communities organized around race, gender, class, sexuality, ethnicity, or other markers of social difference and inequality that are typically associated with identity politics or struggles for national citizenship, biosocial communities are organized around a biomedical classification, such as HIV infection, Parkinson’s disease, ADHD, cancer, or depression (see also Petreyna 2013). For Rose, AIDS activists, by contesting the power of medical expertise, by viewing their diagnosis as an opportunity for empowerment and as a pathway for self-fulfillment, and by demanding more participatory models of research, social service provision, treatment, and prevention, are biosocial pioneers. Their communities are important examples of the forms of political belonging and sociality that emerge as biomedicine increases its influence over social and political life.

In this chapter, I explore what biosocial community is and does from the perspective of low-income and homeless African Americans who became part of the AIDS community in the city of Philadelphia in the period between 1985 and 2015. Broadly speaking, I am interested in the ways that different people involved in AIDS care, activism, advocacy, and politics imagine “the
AIDS community” as a site of illness, biomedicine, care, support, responsibility, welfare, and survival. More specifically, I am concerned with the challenges and opportunities created for the city’s most vulnerable and precarious HIV/AIDS sufferers by the forms of community belonging that became enshrined in the city of Philadelphia’s response to the epidemic. Importantly, I do not treat “community” as the natural and inevitable scale at which health and social service interventions are enacted. Rather, I treat it as a contested site of politics and government that poses unique challenges for low-income African American urban residents.

I focus on three related issues. First, I tell the story of the rise of Philadelphia’s AIDS community, emphasizing the formalization of the city’s response to the epidemic and the ways that racial politics shaped the pattern of inclusion and exclusion in this biosocial community. Second, I highlight the depoliticizing effects of organizational participation for low-income African Americans and show how they were exploited and marginalized as clients, volunteers, and workers. Third, I describe the ethical journeys of several low-income black Philadelphians. By ethical journey, I mean the actions they took in the aftermath of an HIV diagnosis to enact virtue, goodness, and responsibility in their own lives. Here I highlight the importance of AIDS organizations in enabling the pursuit of ethical life for people who are popularly and politically represented as deviant, dangerous, and disposable. Ultimately, I argue that it is this capacity—to provide the material and symbolic basis for vulnerable people to act as right, good, and responsible in a context in which they are popularly and politically considered otherwise—that explains the allure of the AIDS community for the most vulnerable and precarious. Indeed, this capacity makes the AIDS community an appealing, durable, welcome place in the lives of many low-income African American Philadelphians. Importantly, many HIV-positive people come to see their own ethical actions in the context of the AIDS crisis as essential to their personal well-being and health. I end the chapter with a caution against critical accounts of “community” that underestimate its political potentialities, the beneficial role that it plays in the lives of the sick, the poor, and the vulnerable, and its contributions to their well-being and health. In this chapter, I draw upon ethnographic and historical evidence gathered through long-term fieldwork I conducted in Philadelphia from 2000 to 2017.

IMAGINING THE AIDS COMMUNITY

As in other major cities across the United States, AIDS activism in Philadelphia was first organized around voluntary service and grassroots
action, and the earliest AIDS community to form was an extension of the local gay community. As elsewhere, members of the gay community who were politicized in the gay liberation struggles of decades’ past became the earliest AIDS activists. In the name of the “gay community,” they formed activist groups and voluntary organizations in the commercial zones and gentrifying neighborhoods in Philadelphia’s downtown and they mobilized collectively to demand public resources and funding to care for HIV-infected individuals and to prevent the disease from spreading.5

Activists embraced the community-based health model as the primary means to expand and formalize the local response to HIV. As the number of AIDS cases increased, voluntary groups found it difficult to meet the needs of the growing number of seriously ill people who needed support. Only a community-based system, they argued, could provide alternative access points to social services and healthcare to protect people with HIV from the stigma of homophobia and AIDS-related discrimination that was pervasive in the health-care and welfare systems of Philadelphia. In response to activist pressure, in 1988, a group of public health, philanthropic, and political leaders issued a groundbreaking report that recognized and legitimated the work of voluntary community-based organizations as essential to the fight against HIV. The report explained:

It is hard to imagine what the AIDS epidemic would be like in Philadelphia today without the existence of community-based organizations (CBOs) which have grown up in response to the AIDS epidemic. From the early years of the epidemic until the winter of 1988, CBOs provided virtually all human services for persons with AIDS in the Philadelphia area. In addition, because the City of Philadelphia took so long to commit resources to community education, CBOs provided virtually all AIDS education to both the general community and to high-risk populations. The importance of these organizations goes beyond their providing essential services to persons with AIDS. CBOs have also been the conscience of our community. They have consistently advocated higher levels of funding from both the city and the state; they have pointed out the virtual ignoring of the epidemic by important sectors of the private community; they have prodded the media to pay more attention to the epidemic; they have worked to raise the consciousness of elected officials and other concerned individuals. These organizations have done all this on shoestring budgets, relying primarily on volunteers. It is testimony to the great reservoir of compassion and empathy in our community that hundreds of volunteers from all age groups, communities, and walks of life continue to devote unpaid, unsung hours to fight against AIDS. The community-based organizations have been the main mobilizers, organizers, and beneficiaries of this volunteer energy. (Philadelphia Commission on AIDS 1988, 23)
For many activists who had been at the forefront of the city’s early AIDS mobilization effort, the report gave credibility to activities they had been doing without recognition or support for years. Yet the report also reveals the political erasures that emerge in the making of a biosocial community. Although its authors celebrate volunteerism and community care, they were evasive about who the volunteers actually were. This is a glaring lapse since it was gay men and their allies who did most of the volunteering at local AIDS organizations. Ultimately, the report downplays the role of the gay community in the fight against AIDS. This is what Cindy Patton famously referred to as the de-gaying of AIDS (Patton 1990).

The city eventually expanded its funding to community-based AIDS organizations, and state and federal agencies also organized care, prevention, and funding priorities at the community level. Volunteers welcomed the influx of public funding and resources, though they were also forced to contend with new reporting requirements, fiscal oversight, and the imposition of nonprofit management techniques as a condition for receipt of public funding. Accordingly, the AIDS organizations that were once egalitarian ventures in community care adopted more rigid divisions of labor, formal hierarchies, and professional organizational structures. Scholars observing these dynamics elsewhere described one effect of these developments as the clientization of people with HIV because their roles in these organizations became increasingly passive as clients receiving care from professional service providers (cf., Brown 1997; Maskovsky 2013, 2018).

As the AIDS community professionalized, the politics of race became steadily more important. The location of middle-class white gay men and their allies at the visible forefront of the early AIDS mobilization effort placed them in a pivotal position when city, state, and eventually federal agencies finally began directing funds to establish HIV prevention and care programs in the late 1980s and early 1990s. They formed and controlled three of the first five local AIDS service organizations, and these had the earliest access to funding and government support. Their leadership lobbied successfully to form a consortium through which they dominated system-wide HIV services planning. Control of the planning process in turn enabled them to appropriate further to themselves the authority to define and prioritize certain kinds of social and health services. For example, early planning prioritized case management services over outreach, recovery services, or housing. At the same time, recognition of the disproportionate impact of the AIDS crisis on communities of color also encouraged middle-class African American, Latinx, and Asian American activists to form agencies designed to serve the members of their communities. These organizations vied for power and influence in the AIDS community, at times challenging the dominance of white-led organizations that sought to overcome resistance to their leadership by
transforming themselves into multicultural organizations. Eventually activists were successful in securing some funding for organizations led by people of color. But the earliest AIDS organizations flourished while those founded to serve other groups received less support, nor was their influence as great in planning and priority-setting.

The clientization of HIV-positive people themselves as members of the “AIDS community” also created unique challenges for low-income HIV-positive people, especially those who were African Americans and from other communities of color. As mentioned above, the leaders of AIDS organizations were recognized as AIDS service “providers” with expertise in HIV care, prevention, planning, and priority-setting. In contrast, people with HIV, an increasingly large number of whom were black, gay, and poor, were forced to adopt the identities of “clients” or “consumers” of HIV services. As in other cities, Philadelphia’s HIV planning council, which controls priority-setting for services and programs that receive public funding, has a committee comprised of HIV-positive people. Its purpose is to enhance the role of consumers of HIV services in planning council activities. Consumers of HIV services are also given important roles in AIDS service organizations by way of seats on boards of directors and other means. But most HIV-positive people, especially those who are homeless or living in poverty, tend to see these roles as tokenistic and marginalizing, about which I will say more below (Maskovsky 2013, 2018).

### Dilemmas of Difference and Inequality Inside the AIDS Community

“Hello, my name is Robert and I have been living, I say living, with HIV for more than 20 years.” Robert Church was addressing a group of formerly incarcerated people in one of the hundreds of talks he gives as a peer educator for a local AIDS organization. He went on to describe the journey he took from being an incarcerated drug addict to a worker for a project that offers educational training for people with HIV who have been recently released from prison or jail. Robert is a compelling speaker. The audience clapped loudly at many times during his talk, especially when they heard that he is a long-term survivor who has been living with HIV for more than 20 years. Before Robert died, in 2012, I heard him tell his personal story dozens of times. It always starts with the same opening line, followed by his life story: he grew up in Baltimore, came to Philadelphia, got clean, and then became involved in AIDS service and activism. His goal, he told me, was to inspire hope for people with HIV and to encourage them to become involved in AIDS activism. He explained his goals in the talks he gave this way:
I let people see that even though they could live and die and never encounter this activism piece, the idea that things could change, here we are saying that on this issue, concerning HIV, we can change it. We don’t have to sit back and take it. . . . But for right now, we are targeting some bad isms, be they people, patriotisms, people, ideas, or buildings, or concepts. We’re coming up against them, and we need help, and we’re asking your support. And the majority of the time we get that. I have . . . I did something the other day. It was so good that I really haven’t . . . I think . . . I was in a presentation. I did a presentation in Baltimore. And you could hear a pin drop in a room full of recovering addicts. People had their mouths open. And I almost cried as I told them that I was from Baltimore, how I left that city, how I arrived in Philadelphia, and what I’ve been doing one day at a time for the past seven years. It was unreal. It was just unreal.

Robert is careful, he explained, never to tell people what he thinks that they should do. He only tells people what he did for himself and that they are free to take inspiration from his story or not. And it is precisely by telling them a deeply personal story, a testimony about this own life, his own suffering, his mistakes, and then his triumph as a recovering addict and AIDS activist, that he seeks to inspire others.

From the early days of the epidemic, HIV-positive people like Robert Church have been invited to speak about their intimate experiences as disease suffers in workshops, classrooms, conference sessions, and recovery meetings. In addition to their roles as clients or consumers of HIV services, this is one of the most important ways that they participate in AIDS organizations. Early AIDS activists and volunteers, taking their cue from the women’s health and civil rights movements, organized speaker’s bureaus and other ways for HIV-positive people to share their experience with others who were at risk of contracting HIV. In his book, *The Republic of Therapy*, Vinh-Kim Nguyen (2010) describes the importance of the performance and circulation of testimonials to the organization of the AIDS community in Cote d’Ivoire. Following Foucault (1988, 1985), Nguyen refers to testimonials as “confessional technologies” that are designed to mobilize the “truth” about the self to incite appropriate behaviors in others (see also Nguyen 2013). A similar dynamic has played out in the AIDS community of Philadelphia. As AIDS organizations formalized, so too did their speaker’s bureaus, which were transformed into formal peer education programs. Peer educators are dispatched to doctor’s offices, health clinics, schools, hospitals, recovery groups, and substance abuse treatment programs, where the peer educator shares their own experiences as an HIV-positive person with others, sometimes in one-on-one sessions, and sometimes in groups. Peer education has become an essential part of HIV-related care and prevention, and it is frequently organized to target “high-risk” or “hard-to-reach” populations such as women, gay men of color, drug users, and youth.
To fully grasp the peer educator experience, it is important to understand the employment structures and hierarchies that are typically in place in most AIDS organizations where peer educators work. Peer education is a precarious work. In most cases, peer educators are consumers of HIV services who volunteer where they receive care. Some eventually become part-time employees while they continue to receive services. As peer educators, they frequently earn minimum wage or slightly more, and they are required as part of their job to travel cheaply across the city (mostly by using public transportation) to meet “high-risk” people in community settings. Most peer education programs employ low-income people, few of whom receive health benefits, vacation pay, childcare, merit or cost-of-living raises, or have any job security (other than the good will of their supervisors). There is also little opportunity for advancement or support for the development of professional skills in program planning, administration, or advocacy. In the organizations where I did fieldwork, many peer educators burned out after doing the job for a few months. Program supervisors often assumed that peer educators receive public assistance or disability insurance payments and that the money they earn is “supplemental” income. While peer educators are often appreciative of the additional income, their structural position in relation to other staff can have a very negative effect on their morale and work ethic. In many AIDS organizations, peer educators quickly learn that they are the “last hired, first fired” and that other people with higher educational levels or professional skills, but not necessarily more commitment to combating HIV, make more money and have more job security than they do. Further, many HIV education and prevention programs (inadvertently and sometimes unavoidably) place peer educators in direct competition with each other for a limited number of outreach hours. The criteria for who gets to “go out” to different assignments may be subjective or unstated, and available hours are often not distributed fairly.

The affective and emotional labor that peer educators are required to exert in the course of their peer-to-peer interactions is also frequently devalued (cf. Rodriguez 2011). Peer educators receive minimal training, and program supervisors frequently believe that peer educators will be automatically empathetic and skilled at expressing that empathy in a way that is useful to clients, simply because they are living with HIV and are socially or culturally similar to the peers whom they encounter. In extreme examples, they are hired to serve as “bad examples” for presumably HIV negative people. They are instructed to endlessly repeat their “story” to warn others “not to become like them.” With little or no training on counseling or communication skills, and little support for the stress of their jobs, peer educators face enormous job pressures.
In the AIDS community, peer educators are in many respects typical precarious workers. They find work in racialized, low-wage labor markets that have been found to be hyper-exploitative and discriminatory. Further, it is impossible to ignore the coercive aspects of the testimonial component of peer education. With no choice but to commodify their own stories about suffering and redemption they are constrained by the very affective and emotional scripts that their testimonials are designed to induce. This creates significant challenges, when, for example, a peer educator has a health setback or lapses in their recovery. Often, in situations like these, many peer educators feel that they have no choice but to quit their jobs—because they have failed to live as the role models that they are employed to be. This is precisely what happened to Robert Church, who walked away from the AIDS community in the mid-2000s after he relapsed. Yet it would be a mistake to conclude from this discussion of HIV-positive people’s testimonials that AIDS service organizations are totally inhospitable places for the low-income African Americans and other vulnerable people. Indeed, despite the challenges they face in establishing a foothold in the AIDS community for themselves, they nonetheless do so frequently and in ways that contribute meaningfully to their well-being. It is to these dynamics that I now turn.

THE ETHICAL JOURNEYS OF PEOPLE LIVING WITH HIV

The AIDS community may be a site of contentious politics, and the idea of being a client or contingent worker in an AIDS service organization may appear to be a position of relative powerlessness. But these unequal relations of power are also infused by a different kind of power: the power of ethical life (Foucault 1988). Indeed, interactions in the AIDS community teach newly diagnosed HIV-positive people how to be “proper” clients or consumers—how to respect the professional status and expertise of frontline providers and how to act appropriate to gain access to lifesaving medications, services, and support. But these interactions also instruct people on the art of living with an HIV diagnosis. This includes teaching people about how the virus is transmitted, how it is treated, about support, social, and health services that are available, and about public health insurance and other subsidies for people living with HIV. Low-income African Americans who I have interviewed describe the process of learning about HIV as lifesaving, as giving them a sense of personal power over a potential deadly threat. This entails living a healthy life by taking medications on time, learning all that one can about HIV, and getting medical care regularly. Importantly, it also entails learning how to avoid infecting others and, for many, gaining a foothold in the AIDS community as a client, volunteer, or worker. The journey often
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involves moving from a sense of bewilderment, despair, and hopelessness to embracing life and joining the fight to save the lives of others. It is possible to argue that this journey is one in which race and class politics collude to offer the most vulnerable and precarious people a false promise in the face of poverty, drug use, and a life-threatening disease. But my informants insist that their journey is one comprised not just of confessional testimonials about their true selves. It is also an opportunity to take ethical action: to exercise judgment about how best to take better care of themselves and others.

In How It Works: Recovering Citizens in Post-Welfare Philadelphia, Robert Fairbanks describes the mundane activities through which recovering addicts in Philadelphia are “responsibilized” into virtuous, self-governing subjects in recovery house settings (Fairbanks 2009). For Fairbanks, again following Foucault (1988), it is precisely through their daily routines—filling out forms, following intake procedures, having their cases managed, and volunteering—that they learn to regulate and judge themselves in accordance with a new moral code, in Fairbanks’ case, of recovery (Fairbanks 2009, 146–47). For low-income and homeless African Americans in Philadelphia, AIDS service organizations perform a similar role to recovery houses. They are often the first places people go when they learn they are HIV-positive, and they provide lifesaving services including medical care, case management, support groups, housing, and job training. These organizations are sites of essential institutional interactions through which an afflicted person learns that HIV is not a death sentence. Participation in the AIDS community affords them the opportunity to learn the tools and knowledge they need to take positive actions in a city that has frequently vilified them or treated them as disposable or undeserving. The ethical journey of the HIV-positive person typically has four parts: (1) diagnosis; (2) choosing life, not death; (3) becoming a proper client; and (4) working for others as a volunteer or peer educator.

Diagnosis

The start of an HIV-positive person’s ethical journey begins with an HIV diagnosis. Many of the city’s most vulnerable and precarious residents find out that they are HIV-positive when they are hospitalized for drug-related illnesses, during a stay at an inpatient drug treatment, recovery, or detox program, or through an HIV test obtained from a neighborhood clinic. Often these individuals have problems related to poverty, drug addiction, or homelessness. For individuals living in poverty, an HIV diagnosis may not be the most urgent health-related concern. Yet an HIV diagnosis is always also a blow. I have heard stories of many different reactions to the news of an HIV diagnosis, from denial to an overwhelming feeling of hopelessness to suicidal thoughts. This situation is made considerably worse for people who
have little to no knowledge of HIV, which is frequently the case for many of Philadelphia’s most vulnerable and precarious residents. Donna Jones, an HIV-positive woman who grew up in New York City learned she was HIV-positive in 1990 while receiving treatment in a Philadelphia rehab facility for drugs and alcohol. She recalled:

It was rough at first, real rough. . . . Just coming to grips with the virus, and not having any knowledge of it really. You get HIV, AIDS, and you die. And not really knowing which way I was going to really go. It was scary.

Even those, in contrast to Donna Jones, who found out that they were HIV-positive after the clinical effectiveness of anti-HIV medications had become public knowledge still often told me that they knew almost nothing about the disease. Many feared the worst. Many people told me that the challenges they experienced coming to grips with their HIV status were exacerbated by poor quality medical care and by being treated in an undignified and inhumane way by health-care workers. For example, Charles Russell was hospitalized at the VA after a heroin overdose. He learned he was HIV-positive when an orderly passing by his bed read it to him from his medical chart.

Choosing Life, Not Death

Yet, like Donna Jones, many also experienced their diagnoses as a “wake up call” or as a message that it is time to “get my life together,” as Jones went on to explain in our interview. She remembered her first encounter with a peer educator as a very powerful moment for her. She describes the impact that the peer educator’s testimonial had on her:

I remember Chris, the peer educator. And I remember his smile, and him saying how grateful he was. How grateful? And they’re recovering. They can’t drink, they can’t drug. And they got something that’s going to kill them. You know? And they’re standing there talking about they’re grateful. But it was just a strength that I saw in him. And I said what the hell. I’ll go ahead and get tested because we had a testing facility on site. And I got tested. Of course, it came back HIV-positive.

Learning to cope with one’s diagnosis, to live with HIV and not to die from it, is also an important moment on the HIV-positive person’s ethical journey. In a 1996 interview, Jacqui Monae told me about one of the first interactions she had with a peer educator at a local AIDS organization:

I said real fast, “I have HIV.” And I kept talking. She said, “Wait a minute. Back up. What did you say?” I said, “I have HIV.” And she said, “Why did you
say it so fast like that?” And I started telling her I just found out about it. . . . Then she said, “Did you grow a tail?” I said, “What do you mean, did I grow a tail?” Because I thought she was trying to be smart. And she said, “What’s the difference between you now and three weeks ago when you found out?” And I thought about it. And I smiled. And said, “Nothing. I’m still the same.” And I smiled for the first time in three weeks.

“Living in the moment,” “Not letting the disease take over,” “There is no day like today”—these are mantras that newly diagnosed HIV-positive people learn to say to themselves to reorient away from being overwhelmed by the threat of death and the burdens of treatment, and toward the constant, daily pursuit of life that living with HIV frequently entails. For most diagnosed people this tends to involve a complicated set of reorientations dealing with family, romantic partners, alcohol and drug use, housing, and work. It often requires “stepping into the AIDS world,” as one HIV-positive person once put it to me.

**Becoming a Proper Client**

In addition to embracing living life, the ethical journey also often involves establishing a long-term relationship with a case manager, whose purpose is to work with the HIV-positive person to gain access to medical, social, legal, and emergency services and to navigate the social service and medical systems. As I mentioned above, case management has been a core AIDS community service since the beginning of the epidemic. At first, case managers saw themselves primarily as advocates for the sick people who needed access to services that were only available in a hostile, homophobic, racist, and AIDS-phobic system. Volunteers learned anecdotally about the availability of social and health services by befriending bureaucrats and frontline service providers in the city’s nonprofit, public health, and social welfare institutions. By the late 1980s, because of the efficacy of this work, the advocacy role of the case manager was integrated into a clinical model involving professionally trained frontline social workers and other service providers offering psychosocial support, regularly scheduled appointments, and clinical and medical oversight. By the early 1990s, as medical treatment for HIV improved, case management took a biomedical turn, with surveillance activities such tracking CD4 cell counts, viral load, and, when necessary, prophylaxis for HIV-related opportunistic infections overseen by the case manager. The medical orientation of case management became even more pronounced after the advent of anti-HIV drugs in the late 1990s. Adherence to treatment became a primary concern (Maskovsky 2005). By the early 2010s, case management was integrated into HIV prevention programs for “hard-to-reach” populations,
especially gay men of color, who have been targeted for PReP (HIV Pre-exposure Prophylaxis drugs) with tailored social marketing campaigns. The shift from voluntary advocacy to biomedical surveillance and psychosocial support mirrored broader changes in the spectrum of services offered by AIDS organizations, as leadership and staff adjusted their programs in line with treatment advances and the invention of new prevention models.

Case managers, for their part, tend to view their jobs as stressful and challenging. One of their main tasks, as they see it, is to get HIV-positive people to follow the rules and fill out paperwork so that they can gain access to the services and healthcare to which they are entitled. But this is never easy. Although some clients comply willingly, others are more difficult to handle. Case managers complain about high caseloads and poor treatment by clients and supervisors. They express frustration when clients are unresponsive, when clients cancel appointments, or when they do not show up or do not fill out paperwork properly, despite the best efforts of the case manager to help them to do so. But the biggest complaint by far is that case managers are unfairly blamed for systemic issues such as the chronic lack of housing units or available drug and alcohol detox beds. “Case managers are not houses,” said the leader of a large AIDS organization in Philadelphia during an HIV planning council meeting in the 1990s. She made the comment in defense of case managers, who embraced the slogan and frequently repeated it when clients blamed them for the lack of available services.

From the point of view of many low-income African Americans, case managers are not always effective advocates, and being a client can sometimes be a frustrating and humiliating experience. Donna Jones sees case management as superfluous to her efforts to “work the system” to get the services to which she is entitled. She explained,

Well, you know, when I got my housing—I went and got my own housing—I had a . . . I thought I had a case manager. She didn’t even know I was on her roll for three years. By the time she realized I was on her caseload, I had gotten an apartment, moved like two times. I did everything that I needed to do for me, and that’s only because I was able to beat the system and my addiction. And I can read. And so, if there’s any free money for gas, electric, whatever, I’m on it.

Some low-income African Americans even came to see case management as an impediment to access to life-supporting services. Frank Johnson saw case management as a needless layer of administrative bureaucracy, in contrast with what he views as direct services such as food, medical care, and housing. He told me:

As far as liaisons and case managers, fuck all that bullshit. You know, a lot of administrative stuff, like the overhead. “I need an extra computer so I can put an
extra mark on my calendar.” Fuck all that bullshit. I’m talking about food and the necessities of life. Food, good health care—that’s a direct service—hospice care, medical, stuff like that, clothing, and most of all housing. That’s most important.

In the complaints expressed by Jones and Johnson, as well as in the comments by the case manager discussed above, we can see two strands of governance that frequently play out in the case manager-client interaction. The first is the classic dynamic between street-level bureaucrats and clients (Lispy 2010 [1980]; Kingfisher 1996; Weigt, Acker, and Morgen 2009). In this dynamic, those on the front line of policy implementation have limited ability to shape the ways that policies are set or services are funded but they nonetheless exercise considerable discretion in the day-to-day implementation of service provisioning. This often creates resentments on both sides of the table, as case managers who feel disrespected by the organizations for which they work sometimes displace their anger on the clients whom they serve. Clients, for their part, are also frustrated when the caseworker is unable to meet the long and complex list of needs that the clients bring to the table. Yet whatever the tensions between them, case managers and their clients are bound in a relationship requiring reciprocity and respect, and the well-being of many HIV-positive people depends on navigating this relationship successfully.

The third stage of ethical action involves negotiation over autonomy and dependency in the context of care. For low-income African Americans, as for others, it is important to parse out the extent to which it is necessary and beneficial to do things for oneself and when it is necessary to rely on the help of others. Indeed, asserting one’s own expertise, as Jones does above, is more highly valued than is the expertise of a case manager. Learning to mark a line between autonomy and dependency and between agency and passivity is crucial to the well-being of each HIV-positive person. Case managers and their clients tend to agree on this. For their part, case managers routinely describe their jobs as helping clients do for themselves rather than doing things for them. In practice, negotiating these mutually reinforcing relations of power is tricky business for clients and case managers alike. However, it is the negotiation over autonomy and agency itself that ultimately links clients and case managers inextricably to each other and to a sense of belonging in the AIDS community.

Working for Others

A final stage of the ethical journey I am describing is moving beyond the client role to become a volunteer or a worker in an AIDS organization. Escaping the passivity and dependency associated with the client role is an essential
part of transitioning to a more robust form of virtuous citizenship within the AIDS community. Since the inception of the AIDS movement, clients have moved into staff, board, and leadership positions in AIDS organizations and this is as true for low-income and homeless HIV-positive people as it is for their more affluent counterparts. Yet the pathways to advancement and the opportunities to wield authority are far fewer for the less affluent. They can volunteer as buddies for sick clients or serve as client representatives on organizational boards or on HIV planning commission committees. Occasionally a low-income client is hired into a low-level frontline service position, such as case management assistant, housing counselor, or peer educator (discussed above). Furthermore, they do not always experience the same benefits of volunteer work as do their more affluent counterparts. For example, Jones and Monae volunteered to serve as patient representatives on a clinical trials oversight committee run by a federally funded local AIDS organization in the late 1990s. As part of their volunteer work, they gave input into the design of clinical trials and of ancillary programs aimed at supporting people in those trials. They were deeply involved in designing a new treatment education program for low-income people of color. The federal government eventually funded this program. But when it came time to hire staff to run it, Jones and Monae were passed over. Jones explains her disappointment and frustration at not being offered a paid position:

Jacqui and I were clinical trials representatives. And there was a proposal that was written that we had no knowledge of. . . . They didn’t ask Jacqui and myself. They came to Derek, who had far less experience than we did and said, Do you want the job training 30 to 40 African Americans? My thing and Jacqui’s thing was, how can you ask him if he wants the job to train 30 or 40 African-American people about HIV and AIDS if we’re the ones going to Washington? What are we supposed to do, come back and feed him the information? And then he gets paid a salary, and we get paid $6.50 an hour as a volunteer site worker? That’s a little backwards, I feel.

In the AIDS community, as in other nonprofit and health-care sectors, volunteers hold an exalted, honorific position. By being a volunteer, clients can remake themselves into the unpaid stewards of the organizations they represent and the people they serve, and they can do good and act responsibly on their behalf. In some ways, volunteerism is a special form of giving that generates for the giver a type of virtue that is unalienable because it is a gift outside of the larger circuit of paid work and compensation. But when volunteers give of themselves, they frequently expect reciprocity in return, in the form of paid positions, perks, or other benefits for which they deem themselves worthy. This is the same kind of reciprocity that aspiring professionals and private school students cultivate by volunteering as unpaid interns in order
to advance their careers. Low-income African Americans come into AIDS organizations with professional disadvantages that are not easy for them to overcome, and they are vulnerable to forms of exploitation and precarity that affect low-wage workers across the nonprofit sector.

Yet the AIDS community still offers them opportunities for ethical living. In the introduction to the book *Ordinary Ethics*, Michael Lambek asks anthropologists and scholars from other disciplines to consider ways that our informants exercise judgment in the context of constraints imposed through speech and action (Lambek 2010). For low-income African American, the AIDS community is a racialized and classed space where their speech and actions are severely constrained. But in parsing out the differences between autonomy and dependency, agency and powerlessness, and life and death, and by choosing to save themselves and to help others via volunteerism and paid work, they discover and help to create a space where they can exercise judgment in ways that are frequently denied to them in other social and political spheres. The AIDS community is thus an important site where low-income African American can act ethically just like others who work, volunteer, and receive services there. In a city where low-income African Americans, especially those with HIV, are often treated as disposable and incapable of taking a moral stance or practicing ethical action, the importance of being able to exercise this kind of power should not be underestimated, nor should the sense of personal well-being that it gives to those who exercise it.

**CONCLUSION**

My approach to the study of community and well-being in this case has been to explore the dilemmas that ensue when competing ideas about life, disease management, prevention, care, bureaucracy, and justice are brought together under the sign of a community, the “AIDS community.”

The AIDS community, as with other biosocial communities, reflects many of the current governing priorities. In an age when neither mid-twentieth-century grand schemes about social engineering or nineteenth-century liberal notions of *lazier faire* capitalism and rugged individualism are politically triumphant, governing through communities makes a great deal of sense. Yet as Miranda Joseph has argued, “It is crucial not to know, in advance, where the practice of community might offer effective resistance and where it might be an unredeemable site of cooptation, hegemony, and oppressive reiteration of norms” (Joseph 2000, xxv; see also Creed 2006).

I have provided ample evidence that claiming membership in the AIDS community of Philadelphia has been a tricky business for low-income African Americans. It frequently entails subjecting themselves to forms of
conduct as clients, volunteers, and workers that are difficult to achieve or sustain and that make them vulnerable and precarious. But it is important as well to emphasize that the allure of community is not merely an expression of false consciousness by people who are hapless dupes of a system of false empowerment. Indeed, by choosing to live with, not die of, a life-threatening disease, and by choosing to embark on an ethical journey as an HIV-positive person, low-income African Americans find powerful reasons to participate in the AIDS community. The opportunity for living an ethical life, for exercising judgment in the effort to help themselves and others, contrasts positively with the kinds of opportunities that are available in other institutional locations from schools to public-sector programs and in residential life.

The AIDS community has been romanticized by some scholars as a site of unity from which it was possible to create a systematic, flexible response to HIV in all of its social and biomedical complexity (Altman 2013; Rose 2007). Similarly, it has also been described usefully as an interstitial space where urban citizenship emerges among those who have been left to die or treated as outcasts because of their disease status (Brown 1997). But it has also been critiqued as a depoliticizing space that threatens to occlude its own historical links to gay liberation or as a fundamentally hierarchical racialized, classed, sexist, and de-gayed space devoted to exclusionary practices in the name of unity in the face of HIV (see Patton 1990; Chambré 2006; Stockdill 2003). These perspectives are all valid, which may be an unhelpful way to characterize the community’s definitive nature and politics. But the fact that the AIDS community can be all of these things at once is important to recognize, since it helps us to account for its persistent allure, even for the most vulnerable and precarious of urbanites, and even as it never fully escapes, as with all communities, its exclusionary underpinnings, among other limits and limitations.

NOTES

1. Acknowledgments: I thank AIDS activists and service providers in Philadelphia for their helpful insights. J. D. Davids and Ennes Littrell were especially helpful. This chapter also benefited from comments by Janet Page-Reeves, whose editorial suggestions strengthened it in many ways. All mistakes or remaining points of confusion are my own.

2. Early accounts of the AIDS community include those by Brown 1997; Crimp and Rolston 1988; Patton 1985 and 1990; Shilts 1987. For more recent accounts that discuss racial hierarchies and class asymmetries in the AIDS community, see Stockdill (2003) and Chambré (2006).

3. I draw here on Redfield (2013), Fairbanks (2009), and Nguyen (2010) for this part of the chapter. On the place of the ethical in modern society, see, of course,
Foucault (1985); on ordinary ethics, see Lambek (2010); for an overview of anthropological research on ethics, see Mattingly and Throop (2018).

4. Research by the author was supported by the PhD Program in Anthropology at the Graduate Center and by the Department of Urban Studies, Queens College, City University of New York, and from grants by the Wenner Gren Foundation for Anthropological Research and the National Science Foundation. This research received approval from the Temple University Human Research Protection Program and from the Queens College, CUNY, Office of Regulatory Compliance. All participants provided signed informed consent.

5. For an early account of gay and lesbian activism in Philadelphia before the AIDS era, see Marc Stein’s brilliant and expertly researched book City of Sisterly and Brotherly Loves (Stein 1994).

6. In Philadelphia, as elsewhere, the community-based model of AIDS care and prevention that the City government first recognized and funded was rooted in the public-private partnership model of health-care provisioning, which it had pioneered decades earlier in its community mental health program that deinstitutionalized the mentally ill (Parsons 2018). In Philadelphia, recipients of HIV service were called “consumers,” not clients. This reflects the dominant private sector ideologies around healthcare of the late twentieth and early twenty-first centuries. On the implications of consumerism for recipients of publicly funded HIV services, see Maskovsky (2000).

7. All names of informants have been changed to protect their confidentiality.

8. In making reference to ethical journeys, I am drawing on Peter Redfield’s (2013) account of the ethical journeys taken by doctors associated with Doctor’s Without Borders in the context of humanitarian intervention. I am drawing on this, and on Fairbanks (2009) and Foucault (1985), to direct attention to the fact that it is not just the professional or frontline staff whose ethical journeys need to be accounted for; recipients of care, aid, publicly funded services or charity also face unique ethical dilemmas as they interact with providers in arenas of social welfare and health-care provisioning.

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