

# TURNING HIV-POSITIVE CLIENTS INTO “RESPONSIBLE CITIZENS”

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Submitted to the Graduate Faculty of  
Arts and Sciences in partial fulfillment  
of the requirements for the degree of  
Masters of Arts in Sociology

University of Pittsburgh

2003

UNIVERSITY OF PITTSBURGH

FACULTY OF ARTS AND SCIENCES (change whole name if not in FAS)

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In this thesis, I examine an ASO in Pittsburgh, Pennsylvania, in order to explore how case managers interpret the complex needs that HIV-positive clients present while trying to encourage them to become responsible citizens. The data are drawn from participant observation, structured interviews with case managers, and a content analysis of case managers’ notes in clients’ files. I find that clients do not regularly ask for services related to health maintenance, case managers negotiate surveillance and empowerment strategies in four ways, and external factors complicate case managers’ ability to carry out their jobs in a climate of surveillance and empowerment. I conclude that responsible citizenship, in the sense of describing how case managers encourage clients to become more self-sufficient, is present in the language that case managers use to depict their approach to case management with clients.

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## 1. Introduction

Johnny has been a client with a Pittsburgh-based AIDS service organization (ASO) for five years, who returned to the organization after being reclassified as an inactive client. The ASO specifically serves the HIV-positive community by coordinating a variety of services such as housing, food, transportation, and medication adherence. He is a heterosexual African American man who is HIV-symptomatic, which means that he displays signs of HIV infection such as weight loss and does not have a CD4 count of less than 200.<sup>1</sup> He has experienced problems with homelessness and drug addiction, the latter of which he is still trying to combat. Despite his lack of sustained contact with the ASO, his health and appetite have remained stable according to the case manager's occasional reports. Yet Johnny's situation is complicated by his engagement in "risky" behavior, according to the case manager's notes, which may put his health management at risk. The case manager writes in the progress notes in Johnny's files after a meeting with him,

He was very pleasant and in good spirits. He told me that a woman is staying with him temporarily and does not know his HIV status. We talked briefly about safe sex and he said that he uses condoms and was not interested in more information. He's hoping the woman would be leaving soon because she's bringing drugs into the house and these are tempting for [Johnny] although he feels he could quit if he wanted to, which he feels he's ready to do. He inquired about rehab.

Underneath Johnny's sunny disposition lies an inability to recognize that he may be jeopardizing his health; he may also not want to change the current situation by asking the woman to move

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<sup>1</sup> The Centers for Disease Control (CDC) use the CD4 cell count as a way to distinguish between people who are HIV-asymptomatic (Category 1), HIV-symptomatic (Category 2), and AIDS-diagnosed (Category 3), but AIDS-related illnesses are also used to classify where people fall in this system. "Category 1 includes counts of 500 or more cells per microliter; Category 2 includes counts from 200-499; and Category 3 includes counts below 200 cells. . . The use of both the CD4 cell count and clinical categories provides a shorthand for where the patient stands in the course of the HIV/AIDS continuum" (McGovern and Smith 2001: 35-6).

out because he derives pleasure and benefits from her presence. The case manager does not mention that asking the woman to leave is an option, which resonates with a case management model that tries to empower clients to make decisions for themselves. Has the case manager done Johnny a disservice by not pointing out the potential negative consequences of slipping back into drug abuse, which include missing crucial medical appointments and doses of medication? Johnny does not seem to “be aware of [his] embodied experience” as a person living with HIV/AIDS (PLWHA), which refers to his understanding of his relationship with his body and how he uses it, and how drug use can interfere with his medications, thus potentially putting his health at risk.

As director of the housing program and supervisor of several case managers, Allen witnesses firsthand the complexities that may hinder clients’ progress in realizing their goals. He emphasizes the importance of initiative and interest in improving their situation on the part of clients in order for case management to work, or else the issue of self-determination is irrelevant. Once clients can “put their homelessness behind them and focus on other issues,” then they can move on to other issues. He mentions, “It’s difficult to work on anything if you’re hungry, homeless, and tired.” Thus, with these basic needs met, clients have to display an interest in solving their problems so that they do not keep falling into the same pattern of homelessness. In fact, Allen spends some time talking about everyday concerns for some clients in the housing program that others may take for granted. These include “finding shelter, taking care of their hygiene, and finding a way to go to the doctor or therapist.” He contends that clients may not be able to concentrate on the big picture of achieving independence when they struggle with more mundane issues that present themselves as obstacles everyday. In Johnny’s case, this may entail having a case manager step back from him and allow him to decide to ask for help, or if his

situation visibly deteriorates, then a case manager may intervene directly. Although clients may express similar needs, their individual case histories, current situations, and personalities all inflect how case managers help clients devise a practical plan that will increase their self-sufficiency. Once case managers and clients work to get these under control, from the perspective of case managers, then clients are able to develop and sustain an interest in taking better care of themselves, or at least caring for themselves in a manner consistent with what the agency identifies as “responsible,” which entails clients demonstrating an ongoing commitment to resolving their immediate concerns. And it is the goal of most human services organizations to enable clients to achieve self-sufficiency so that they are not so reliant on the agency for their everyday needs. Allen acknowledges that clients, especially those who are homeless, live in crisis from day to day, which necessitates a closer working relationship between case manager and client than between a client with a job and residence.

In this thesis, I examine an ASO in Pittsburgh, Pennsylvania, in order to explore how case managers interpret the complex needs that HIV-positive clients present while trying to encourage them to become responsible citizens. The data are drawn from participant observation, structured interviews with case managers, and a content analysis of case managers’ notes in clients’ files. I find that clients do not regularly ask for services related to health maintenance, case managers negotiate surveillance and empowerment strategies in four ways, and external factors complicate case managers’ ability to carry out their jobs in a climate of surveillance and empowerment. I conclude that responsible citizenship, in the sense of describing how case managers encourage clients to become more self-sufficient, is present in the language that case managers use to depict their approach to case management with clients.



## **2. Theories of Empowerment Vs. Theories of Surveillance: The Emergence of Responsible Citizenship**

Theories of citizenship have received attention recently due to a renewed interest in civil society organizations at a time when the national state is privatizing and decentralizing certain social services. Most citizenship theorists have largely discounted T. H. Marshall's (1965) ideas that the welfare state would minimize class difference and boost individuals' support of the system by granting social, political, and social rights to all individuals in a society (Saunders 1993: 61). There has been a recent turn in scholarship that embraces citizenship as a metaphor for practices of living whereby individuals take responsibility for their health, actions, and behavior so that they do not become drains on their family, the state, and social service agencies, hence preserving the Western ideals of independence and individualism. Yet in order for individuals to live as "responsible citizens," social institutions must introduce them to the acceptable range of behaviors, and individuals must internalize them.

### **2.1. Citizenship as Metaphor**

A recent study that posits citizenship as a metaphor for action and living is Michael P. Brown's (1997) ethnography of local, institutional responses to HIV/AIDS in Vancouver. He builds on Chantal Mouffe's notion that radical citizenship "must be agonistic; in other words, it must strive for effect and material change in people's lives" and antagonistic by combating oppressive hegemonic practices that occlude participation in political action (Mouffe in Brown 1997: 11-12). Brown situates these enactments of citizenship in the actions of AIDS activists, volunteers for advocacy groups, and PLWHAs. Situated in civil society, these actions occurred in response to the state or in order to elicit responses from the state. Talking about radical citizenship in terms of agonism and antagonism then requires one to think of it in terms of

enactment in response to social actors and forces that *one must know* or be able to identify. I became interested in applying the notion of citizenship as metaphor to an organizational setting, namely an ASO, which seeks to improve the lives of people living with HIV/AIDS (PLWHAs) by equipping them with the knowledge and information to live responsibly and independently. To understand how case managers in an ASO encourage their clients to become responsible citizens, it becomes necessary to look at the tension between theories of surveillance and empowerment. I am interested in exploring how case managers deploy notions of action and responsibility when working with clients as they encourage clients to become more aware of the disease's effect on their lives and to identify their needs directly. In other words, I am interested in how case managers seize the notion of radical citizenship, as Brown uses it, and promote client action and responsibility.

## **2.2. Surveillance**

Though it is important to distinguish between paradigms of citizenship, it is also necessary to understand the ways in which citizenship is enacted and constructed in micropolitical contexts where individuals are held to implicit standards of conduct and self-presentation (Howson 1998; Richardson 2001; Turner 1993). The question is: how is citizenship enacted and under what circumstances? Michel Foucault's (1977) theories of surveillance and the cultivation of self-surveillance as a mechanism of turning people into docile subject-citizens of the state offer insight into the modern-day human services organization that aims to "correct" behavior that keeps clients from conforming to ideals of autonomous "good citizens" who do not drain the state's or a community's resources. Foucault's (1977) influential work explains some of the processes by which the state disciplines and molds individuals into citizens able to take care of themselves vis-à-vis different social institutions.

Foucault's archeological perspective allows him to examine different social institutions holistically. In particular, he is concerned with how institutions in the eighteenth and nineteenth centuries, such as the military, prisons, and schools, strictly regimented the days of their charges such that soldiers, prisoners, and students were able to internalize discipline. Through this process of internalization, overtly oppressive regimes shift to more democratic systems premised on a social contract in which citizens were responsible for monitoring their own conduct and accountable for their own actions. In this model of citizenship, self-surveillance and discipline function as key mechanisms in regulating and ordering society, and bureaucratic institutions, such as religious organizations and schools, are integral to the task of socializing individuals into acceptable behavior. Institutions in civil society such as religious organizations thus become extensions of the state by doing its bidding in the process of turning people into responsible citizens.

A number of social science studies have built on Foucault's (1977) pivotal work on institutions that discipline clients into submission and turn them into citizens who are capable of supervising themselves, thus becoming responsible citizens (Barron 1995; O'Neill 1986; Pavlich 1996). Some studies (Higgs 1998; White and Hunt 2000) focus on the "care of the self," as citizens become aware that they are responsible for their bodies, actions, and conduct and take the appropriate steps to ensure that they act as responsible citizens. These studies argue that in institutional settings, emphasis is placed on individual conduct and responsibility, this ignores that for individuals to achieve the status of responsible citizen, they are necessarily drawn back under the control of bureaucratic institutions and measured against an ideal type of responsible citizenship. In this latter scenario, the institution's control over individuals flows through surveillance mechanisms to construct a framework of acceptable, expected behaviors of those

under the care and control of the institution. For example, a military boarding school disciplines the charges who do not comply with a regimented schedule of exercise, classes, and military training to ensure that all of the students conform to the school's standards of performance and behavior.

### **2.3. Empowerment**

Yet how do these social institutions succeed in convincing individuals that it is in their best interest to conform to expectations of living and behaving "responsibly"? One answer is by demonstrating the benefits, such as praise and access to necessities such as bus tickets, which individuals can receive if they internalize and practice these norms. Thus, the language of empowerment, the discourse that champions an individual's ability to live independently and make informed decisions about how to live within the rules of the state and institution, is one means by which agents of social institutions can enforce codes of responsible citizenship and maintain their surveillance of their charges.

I find Pierre Bourdieu's (1984) theory of the habitus to be an interesting parallel to Foucault's (1977) description of surveillance and discipline. Individuals' acquisition of "habitus" is akin to "getting their bearings" in society or in a social institution and figuring out what is expected of them socially. Put simply, habitus "functions as a sort of social orientation, a 'sense of one's place'" such that a social agent who has been constantly resocialized and refamiliarized into a particular social situation is able to anticipate of what will occur in a particular transaction, to negotiate within a set of social meanings and values, and to respond to social agents without upsetting the balance of the habitus (Bourdieu 1984: 466-7). Important in this formulation is the notion that the individual is *actively* involved in the task of social reproduction, and agents of the social institution reaffirm this by deploying the language of empowerment to encourage

individuals to keep engaging in responsible behavior. Thus, citizens conform to the expectations of a given habitus, and by following the rules through self-discipline, they are accorded the status of “responsible citizen.” This “fluency” stipulates that agents both reproduce the social relations and practices in a given habitus and themselves are “adjusted” or “corrected” by these practices in ways that hint that “habitus-making” is ongoing (p. 467). What is important in Foucault (1978a) and Bourdieu’s (1984) formulations is the detailed process by which individuals are socialized into the expectations of different social circumstances and how they respond to them. These descriptions provide an analytic model within which I situate my understanding of how case managers function as institutional actors who guide the progress of clients’ to empowered, responsible citizens.

### **3. Research Questions**

Integral to the model of responsible citizenship is monitoring one’s adherence to prescribed social norms. Jeffrey Weeks (1986) astutely notes that sexuality and sexual practices are intimately bound up in the responsibilities of moral individuals to society. Foucault (1978) himself outlines the influence of institutional oversight in the rehabilitation and resocialization of unacceptable social and sexual behavior, exemplified in the treatment of homosexuality and masturbation in the eighteenth, nineteenth, and twentieth centuries. The adherence to a moral code governing sexuality depends entirely on the success of individuals’ acceptance of institutional rules and regulations. Cindy Patton (1996) suggests that citizenship in the time of AIDS is very much about docility and adherence to social and state expectations in light of safe-sex campaigns that police sexual behavior. For Patton (1996), safe-sex education and the strategies case managers and other social workers use to get clients to divulge information about their sexual behavior are ways of “bringing bodies into positions of duty and obligation” and making them responsive to and responsible for their actions (p. 9). Michael Warner (1999)

proposes that in the effort to promote safe sex, supporters attempt to “clean up” sex, although, he argues, sex “cannot be divorced from things that we really dislike about sex: irrationality, impulse, shamefulness, disgust” (p. 211). Over the last two decades, ASOs, which are nonprofit institutions that provide services to people living with HIV/AIDS that have sprung up in the United States and in other countries hit hard by new HIV cases, may fill the role of turning marginalized individuals who contracted HIV through “unsafe” sexual practices into model citizens and keeping them from becoming the radical citizen or “pervert” that David Bell (1995) holds up as a challenge to responsible citizenship.

The contrast between theories of empowerment and surveillance motivates my interest in examining their functions in the setting of an ASO and what contradictions arise from their simultaneous operation. The public tends to code PLWHAs as morally ambiguous and dangerous because they supposedly engaged in risky behaviors, such as intravenous drug use or unprotected sex, and contracted the disease. Hence, their lack of responsibility and self-surveillance puts their health and the health of others at risk, giving rise to the stigma associated with the disease. The onus of atoning for past “mistakes” and behaviors then may take the form of PLWHAs managing their disease and trying to live a more healthful lifestyle.

My thesis explores how case managers work with their clients to enable them to become more responsible and self-sufficient by presenting themes that emerged during structured interviews with case managers and content analysis of clients’ files regarding their health status and requests. The research question driving my inquiry is: how do case managers interpret the complex needs that HIV-positive clients present while trying to encourage them to become responsible and self-sufficient? In a sense, the language of empowerment is paradoxical in a setting such as an ASO that is premised on surveillance and compliance. If empowerment means

that the empowerment of clients occurs within a bureaucratic framework, then clients are constantly under the surveillance of case managers and do not exist independent from this setting. In theory, empowered clients will be able to take care of their needs on their own and will stop using the services provided by ASOs in the future. However, social service providers and healthcare professionals construct people living with HIV/AIDS (PLWHAs) as having needs because the disease eventually results in debilitation and death, making them dependent on others for ongoing care, whether it is health care or service coordination.

Another way to conceptualize this dilemma is to consider Gail Weiss' (1999) idea that it is the responsibility of those with means, in this situation, case managers, to "attend morally to the needs of bodies who are unable to articulate those needs for themselves" (p.162). This statement does not mean that PLWHAs are not capable of taking care of themselves, but rather it means if they do need and ask for help, then case managers have a moral responsibility to help their clients. How then do case managers, as agents of the institutional setting of the ASO, interpret their roles in helping clients to become responsible citizens?

## **4. Research Methods**

### **4.1. Participant Observation**

The research is based on participant observation in which I engaged while an intern with a Pittsburgh ASO from July to December of 2002 totaling 200 hours, a content analysis of 30 files in the Client Services division's files<sup>2</sup>, and seven structured interviews with case managers

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<sup>2</sup> I randomly selected every tenth file from the files contained in the Client Services files, which total approximately 300. The Client Services division serves clients who do not have case managers or have special housing needs. I was unable to obtain an accurate count of how many files are housed in Client Services because the database is not updated regularly enough to provide this information, and case managers and interns often retrieve files, making it difficult to locate each file. In addition, some clients' files are filed incorrectly in Client Services, or the files remain

at the ASO. In the early 1980s, gay rights activists and advocates for people living with HIV/AIDS (PLWHAs) organized around issues related to HIV/AIDS (Epstein 1996; Gamson 1991), which included stigmatization, legal discrimination, participation in the development of clinical trials for drugs, and the media's portrayal of PLWHAs as victims or immoral citizens. They established AIDS service organizations (ASOs) that attend to the specific needs of PLWHAs. ASOs "act as mediators between individuals and the state" in the procurement of necessary social services for clients (Altman 1994: 55). Depending on clients' health and socioeconomic status, they might need housing, financial assistance, help obtaining health care, counseling and social support, food and vitamin supplements, help adhering to a treatment regime, and legal services. ASOs typically follow a social work model in which case managers are assigned a number of clients with whom they meet regularly. It is not unusual for case managers to have clients who share special needs, such as drug and alcohol addiction and mental health issues; in these cases, case managers are able to address their needs specifically because they have expertise and experience with these matters after dealing with similar clients. Sometimes clients do not have family, friends, or other means of social support, prompting them to turn to case managers for advice and personal contact. Clients may have multiple needs; others opt to use ASOs only for one or two services, such as legal advice or transportation.

In July of 2002, I obtained an internship at the ASO in the Client Services division so that I could familiarize myself with the daily routine of working with clients and the paperwork case managers fill out in order to document their contact with clients. As an intern from July until December 2002, I had the opportunity to work one-on-one with clients and to help them meet their basic needs. For instance, I assisted clients select groceries in the food pantry, distributed

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in the filing cabinets until the division engages in its routine reclassification of clients who have not maintained contact with the agency or who have died.



condoms and lubricant, gave them bus tickets, helped them fill out applications for financial assistance, and occasionally advocated for clients with overdue utility bills by calling the utility company and explaining the client's situation as a representative of the ASO. I also had to document my interaction with clients, which allowed me to become familiar with the procedures involved in meeting with clients, identifying their needs, and resolving their concerns. I regularly made entries in the "progress notes" section of clients' files that documented my interaction with clients; in these entries, I included information about the clients' requests, their demeanor, and what problems they faced. Making these entries allowed me to understand the logic underlying the necessity to document interaction with clients so that another case manager or intern could pick up the file and work with a client without having to track down the last person who worked with her/him and obtain a verbal update about the client's progress.

I became interested in the conundrum posed by defining clients as "always, already" needy. On the one hand, PLWHAs would not seek services from the agency if they did not need them. Yet this does not take into account how case managers interpret clients' motivations for fulfilling their needs. While it is true that in order to qualify for services, clients must offer verification of their HIV-positive diagnosis, this is merely a way to meet the funding specifications of governmental and philanthropic agencies that finance nonprofit organizations working with PLWHAs. The ASO itself does not require clients to be indigent in order to receive services; implementing income restrictions would be one way for the ASO to segment further the population it is intended to serve.

There remains, however, a conception among case managers that clients have needs that case managers are supposed to fill, and in a sense, case managers "need" clients to keep presenting needs so that their jobs are secure. As long as there are clients, case managers have

jobs. Pondering the implications of how clients and case managers in the context of the ASO sparked my interest in the question of the language of empowerment and how case managers act as facilitators and “cheerleaders” in their endeavor to help clients achieve more self-sufficiency. Thus, I view this problem as one of negotiation: how do case managers help clients to become more self-sufficient and empowered so that they no longer rely on the ASO’s services, while keeping in mind that clients are HIV-positive and have specific needs related to the illness, their treatment regimes, and the medications’ side effects?

#### **4.2. Case Managers’ Entries in Clients’ Files**

In the spring of 2002, the ASO initiated a program in which clients would no longer have a case manager if a group of case managers determined that they were independent enough and only contacted the agency when they needed certain services. Case managers in charge of the program then presented clients with the option of entering this program or remaining assigned to a permanent case manager who coordinated their services. Clients who elected to enter the program were still eligible to receive the same services, such as receiving bus tickets and using food pantry, and they could speak to a case manager at any time if they needed. Because the vast majority of clients (80%) now belong to this voluntary program, it made sense for me to consider these case files. The agency itself is working toward implementing institutional markers that will aid in determining which clients are truly in need of intensive case management (ICM) and those who can manage themselves. Nonetheless, the goal of case management remains that case managers help clients to figure out how they are to manage the disease so as to release them from concentrated bureaucratic scrutiny. Once I obtained permission from the University of Pittsburgh’s Institutional Review Board (IRB) to conduct the study, I selected every tenth case file for a total of 30 files, or 10% of the files housed in Client Services, from these non-case

manager assigned client files to examine what case managers reported related to the client's health and general well-being.

Since case managers regularly make entries in clients' files that document their contact with them, reading and taking notes allowed me to understand what case managers deal with on a daily basis. These entries may recount clients' requests for services, the difficulty case managers have in contacting them, the specific problems faced by clients, and the concern and speculation of case managers about how well or poorly clients are doing, which explains why they are named "progress notes." I read the case managers' "progress notes" in clients' files and took notes on entries related to clients' identification of needs and requests, their health and mental health conditions, and social problems that may affect their health, such as incarceration or homelessness. In addition, at one time, all clients "in the system" were assigned to a case manager who maintained regular contact with them such that I found a substantial number of health-related entries in these files. I removed all identifiers from my notes and only recorded entries related to health, health-related services, and personal, social, and environmental issues that provide a context in which the case manager understands the client's situation.

There may be fewer recent health-related entries due to the lack of sustained contact with one case manager, but there is documentation provided by interns or another ASO staff member who had contact with the client. Although some entries seem rather formulaic, as in the case of perfunctory calls that case managers place to clients in order to keep regular contact with them, many entries narrate the face-to-face encounters that occur at the ASO or at the client's home and capture the complex social environment in which clients' lives play out. Though one must be HIV-positive to be a client of this ASO, case managers are not solely concerned about the progress of clients' health. In general, their entries reflect a tendency to enable clients to live

their lives as independently and comfortably as possible under difficult health, financial, and living conditions. Thus, clients' health encompasses a wider range of behaviors, practices, and images than those commonly associated with the "guilty" HIV-positive individual who is seen by the general public as having contracted the disease by engaging in illicit sex or intravenous drug use. Case managers do not reduce clients to the moment of seroconversion in these entries, although they may certainly continue to counsel clients on safer-sex practices by supplying them with condoms and informal tutorial sessions, but rather they construct clients as "beings-in-process," whereby there is always the possibility that clients' behaviors will change, for better or worse in some cases, as they manage the disease.

I coded my notes using NUD\*IST qualitative software as a way to familiarize myself with range of services clients request and the subjects that case managers cover in their description of their interactions with clients. Major themes that emerged from my analysis include health, surveillance, clients' level of interest, expertise, and obligation.<sup>3</sup> I used these themes to orient the interview questions that I devised because I wanted to ensure that I was asking questions that reflected the practices and attitudes of case managers that I observed in my reading of clients' files.

### **4.3. Interviews**

I interviewed seven "case managers"<sup>4</sup> in their offices at the ASO using structured interviews and tape-recorded their responses.<sup>5</sup> The interviews lasted 30 to 60 minutes. Interviewing case managers about their attitudes toward and clients' response to case management seemed logical because it would allow me to ascertain to what degree assumptions

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<sup>3</sup> The coding categories are located in Appendix A.

<sup>4</sup> I use the term "case managers" loosely to encompass staff who have regular contact with clients regarding the attainment of the goals outlined in the Service and Coordination Plans (SCPs), which are also referred to as "treatment plans."

<sup>5</sup> The interview questions are located in Appendix B.

about clients' neediness and their capacity to take on more responsibility in the pursuit of independence remained intact. At the time I conducted interviews with ASO personnel, the agency's budget was drastically cut back due to the loss of some government funding and the failure to meet its fundraising projections. As a result, the agency terminated several case managers, HIV prevention and outreach specialists, and other staff who provided technical support. These dismissals reduced the number of individuals currently employed by the agency who were qualified to answer questions about their philosophies regarding case management and client self-sufficiency.

#### **4.4. Methods of Data Analysis**

I used my notes from my observations while I worked as an intern at the ASO, the content analysis of the notes I took after examining clients' files, and case managers' responses from the interviews to construct a "complete picture" of how clients are socialized into behaviors and practices of responsible citizenship at the ASO. My observations from my internship familiarized me with routine procedures involving paperwork and how the ASO works with clients so that I am able to describe how case managers perform my job. My examination of clients' notes yielded the following emergent themes that formed the basis of my interview questions: health, surveillance, rhetoric of responsible citizenship, obligation, and expertise. Finally, case managers' responses to interview questions are evidence of how they interpret their roles in helping clients to become responsible, self-sufficient citizens.

#### **5. Description of Clients and Case Managers**

The vast majority of the clients whose files I examined for the content analysis are living in poverty and struggling with their finances. Their primary motivation for accessing the ASO's services is to obtain short-term financial assistance. They are also likely to utilize the food pantry

and to request bus tickets for their medical appointments on a monthly basis. A handful of clients also currently participate in or have participated in one of the ASO's housing programs. Other clients ask for assistance in obtaining their disability, social security, and welfare benefits. But many clients simply want to maintain contact with a case manager who is familiar with their circumstances and is someone with whom they can talk if the need arises. The following narrative that I wrote after coding the information I obtained from clients' files reflects the range of issues that clients may face when seeking services from the ASO:

Selena is a heterosexual African American woman in her 40s who is raising a young son on her own and has to contend with living in what she feels is a dangerous neighborhood. Diagnosed as HIV-positive in 1997, Selena first reacted to this information with some trepidation because she was not fully aware of what the diagnosis would mean for her future. The services she has requested over the last few years include bus tickets, food pantry, vitamins, furniture and clothing referrals, and financial assistance with a security deposit at a new apartment. Her status as a new client coincided with the physical abuse she suffered at the hands of her partner. In addition, her unsafe surroundings made her fear for her personal safety.

She continually missed medical appointments once she became a client at the agency, and she only offers, "There is no reason [that she does not attend appointments] except when the day comes, she does not want to go." In order to encourage Selena to attend these appointments, the case manager suggested, "If she is not ready to work on the goals that she and I agreed to, maybe she should try to volunteer case manager." With the threat of her relationship with her case manager being severed, Selena immediately responded that she "would be more compliant and would like to remain" with her case manager in the intensive case management program. In this case, the case manager's extension of a threat is an effort to force a client who can offer no substantive reason why she does not attend medical appointments to be more compliant. While this tactic might seem heavy-handed, it is within the case manager's discretion to remind clients of the importance of fulfilling the goals they outline with case managers during treatment plan appointments. Moreover, if clients do not maintain active relationships with their physicians, their physicians will not be able to provide accurate information about the client's health status to the agency, which is a necessary condition for clients to be considered as "active" within the system. However, the threat of withdrawing services from the client is an attempt on the part of the case manager to establish the connection between localized behaviors, such as missing medical appointments, and the failure to meet the expectations of the agency and the case manager so that the client understands that there are tangible consequences to her actions.

After this particular episode, Selena began to attend her medical appointments regularly and report back to her case manager that her appetite has improved. She also began to draw emotional strength from her religious convictions, stating to her case

manager that she is ““trying to do things right.”” She also has expressed renewed interested in extending her social support system so that she is able to lean on other people, such as a buddy, for emotional support. She also obtained a new job as a private duty nurse over the course of her time as a client with the agency. As of one year ago, Selena reported that she still did not need to take HIV medications because her viral load and CD4 count were promising.

Tables 1, 2, 3, and 4 all display demographic data, including information about sexuality, gender, race, and HIV diagnosis, about the 30 clients whose files I selected to code. The clients range in age from early twenties to mid-sixties, showing that the ASO is able to serve clients regardless of the generation gap, although it has yet to devise a program targeting those who are aging and are retired. It is important to note that the agency does not serve minors under the age of eighteen, but case managers go out of their way to serve the special needs of clients with children who are also HIV-positive. In one instance, a case manager reported in her client’s file that her client’s refusal to take her HIV-positive son’s medical condition more seriously would threaten his health, and she speculated in her notes about what steps she and case managers at another agency working with the son could take to intervene should the situation deteriorate.

The majority of the clients in my sample identified as heterosexual, but the large number of clients who identify as gay is significant because it indicates that the ASO is serving Pittsburgh’s gay population, a group it continues to recognize is at risk for new HIV infections. In addition, more clients identify as men, but two clients in this sample identify as transgendered women, meaning that they are biologically male but identify as women. In interviews, case managers acknowledged that clients seeking services are increasingly female, due in part to the rise in new HIV infection rates among women, but among women of color in particular. 70% of the clients in the sample identify as African American, which is higher than the ASO’s own statistic of approximately 55%. It is difficult to verify clients’ demographic data due to the

ASO’s failure to keep updated written and computer records. Finally, there appears to be a fairly even distribution of HIV diagnosis across the HIV-asymptomatic, HIV-symptomatic, and AIDS-diagnosed continuum. This is significant because it signals that the ASO does not serve one particular group more than others. However, the lack of end-of-life services that one case manager lamented in an interview suggests that the ASO may need to reexamine its targeted consumers.

Table 1: Clients’ Identification of Sexual Orientation

	Heterosexual	Gay	Total
Number of clients identifying as	17	13	30
Percentage of clients identifying as	57%	43%	100%

Table 2: Clients’ Identification of Gender

	Male	Female	Total
Number of clients identifying as	17	13	30
Percentage of clients identifying as	57%	43%	100%



Table 3: Clients' Identification of Race

	African American	White	Hispanic	Total
Number of clients identifying as	21	8	1	30
Percentage of clients identifying as	70%	27%	3%	100%

Table 4: Clients' Identification of HIV/AIDS Diagnosis

	HIV-Asymptomatic	HIV-Symptomatic	AIDS-Diagnosed	Total
Number of clients identifying as	8	11	11	30
Percentage of clients identifying as	26%	37%	37%	100%

The seven case managers I interviewed have a range of educational and professional experiences. Tables 5, 6, and 7 offer demographic data about the case managers I interviewed. Of the seven case managers, six are women, and one is a man who runs the housing program and occasionally serves as a case manager. Three of the seven are African American, which

demonstrates the ASO's recruitment of qualified social workers of color in order to reach underserved minority communities, and the remaining four are white. The two case managers who are African American women report that they purposefully use their gender and racial identification in developing rapport with clients so that they feel more comfortable divulging information to someone who seems more approachable and sensitive to their particular situation of poverty and disease. The case managers also range in age from mid-twenties to mid-fifties, and some case managers report that their age plays a role in their ability to form meaningful connections with clients. In the case of the younger case managers, clients perceive them as being tolerant and eager to help them, while clients may regard the older case managers as having more expertise and knowledge in navigating the complex welfare benefits system and in being familiar with the progression of AIDS.

Of the seven, five have undergraduate degrees in Social Work and have obtained or are in the process of seeking a graduate degree in Social Work; the other two case managers have undergraduate degrees in liberal arts. The case managers vary in the amount of experience they have in the clinical social work setting. Two have accumulated more than twenty years of experience working in social work, two have more than ten years, and the remaining three have less than five years of experience in the field. Although between them, these case managers have a great deal of varied clinical experience, no one has worked at the agency for more than three years, a finding in keeping with some case managers' complaints about the ASO's high turnover rate. The disruption of care worries several case managers because clients find themselves having to repeat their stories again and again to new case managers.

Table 5: Case Managers' Identification of Gender

	Male	Female	Total
Number of case managers identifying as	1	6	7

Table 6: Case Managers' Identification of Race

	African American	White	Total
Number of case managers identifying as	3	4	7

Table 7: Case Managers' Age

	20s	30s	40s	50s	Total
Number of case managers aged	2	0	3	2	7

**6. The Service and Coordination Plan (SCP) and Goal Formation as Surveillance**

Most of the case managers I interviewed suggest that the degree to which clients comply with the Service and Coordination Plan (SCP), informally known by case managers as the “treatment plan,” pivots on how interested they are in their goals and whether they initially raised them during the period of goal identification. All of the case managers agree that clients typically determine the type and range of services they want and need. However, there is a battery of questionnaires and diagnostic tools that case managers can use to help them assess clients. One

case manager, in particular, cites these tools as especially helpful in clarifying contradictory or misleading information provided by clients. Such information can include dates of diagnoses, medications they are currently taking, and their symptoms.

Often, clients who have just learned of their HIV-positive diagnosis may not be able to supply accurate information about their condition because the disease is still new to them; as a result, they are not very knowledgeable about the disease yet. In order to obscure the fact that they have not been going to their physicians regularly and to keep case managers from inquiring about their health, some clients who know enough about their diagnosis and the progression of the disease will provide inaccurate information about their CD4 count and viral load. In this instance, clients are trying to buck case managers' direct surveillance of their medical adherence because they do not want to risk the case manager chastising them for being "irresponsible." Yet having access to this information allows case managers to ask for more information if clients do not volunteer much or if case managers suspect that clients may be intentionally withholding important information about their condition, especially if in the past the client has had bouts with AIDS-related illnesses, such as shingles.

During a client's initial meeting with the assigned case manager and every three months thereafter, both individuals complete a Service and Coordination Plan (SCP), informally known as a "treatment plan." Much like the healthcare field's treatment plan, which specifies the medications, dosages, and times of dosages along with lifestyle recommendations for patients, the SCP outlines the client's needs and targets specific ways in which they will be met. Clients may state that they want to "maintain their health," and then the case manager has to determine how to interpret this goal, usually by asking a series of questions related to the information the clients provided at the time of their intake. Maintaining one's health may involve making and

attending all healthcare appointments, taking medications correctly, enrolling in a drug and alcohol detoxification program, improving one's nutrition, and exercising with regularity. On the SCP, the case manager may prioritize these approaches to health maintenance, beginning with taking medication correctly.

My interviews with case managers all revealed a concern with identifying clear, attainable goals for clients so that they do not feel overwhelmed by the number of steps they must take in order to achieve them. Case managers often prefer to establish these smaller steps as larger goals so that when clients master them, they derive a sense of accomplishment from them. In this manner, case managers play a very important role in the interpretation of clients' goals. If they dismiss a client's regular attendance of therapy appointments and focus on the client's poor nutrition, the client may feel dejected and ultimately disinterested in the attainment of independence. All of the case managers I interviewed agreed that celebrating a client's accomplishments while keeping in mind the next step instills in clients a sense of hope and eventually responsibility for their actions, in the event that prior to their interaction with case managers, they had not perceived it within their power to complete certain goals. In other words, when setting goals with clients, it is essential that they remain *manageable*, which is a catchphrase to which I will return later when considering case managers' understandings of how clients cope with the disease. By being manageable, case managers are still able to monitor clients' progress and acclimation to taking more responsibilities, thus keeping clients' in the system of surveillance from which the ASO claims to want to free clients.

## **7. Analysis of Surveillance and Empowerment**

Although case managers agree that client empowerment is the ultimate goal of case management, the means by which clients attain empowerment is through case managers' surveillance and evaluation of their progress. Where one finds empowerment in the ASO, one

also finds surveillance. Surveillance and empowerment are twins in the Foucauldian sense that where power circulates, resistance also resides, suggesting a tension between them that neither case managers nor clients resolve. But surveillance and empowerment are also competing discourses and practices. When clients fail to follow through on case managers' recommendations, case managers may admonish them, which is a sign of surveillance. Conversely, if clients report that they have attended all of their scheduled medical appointments for the month, case managers may celebrate their accomplishment and herald it as a sign of their responsibility, which is an example of empowerment. The tension between surveillance and empowerment is most visible, however, in case managers' formulation of client plans and how case managers and clients negotiate their power-sharing relationship. The power-sharing often takes the form of "taking turns" in that case managers may initiate goal formation, for instance, with some clients, but in other cases, clients may initiate this process. The extent to which either case managers or clients take the lead in the relationship depends on the individual case manager's approach, the determination and promotion of clients' self-sufficiency, the case manager's interpretation of clients' needs, and the rapport that case managers develop with clients. The micropolitical context of the client-case manager relationship exposes the tension and oscillation between surveillance and empowerment and demonstrates the subtle ways in which case managers balance discourses of surveillance and empowerment. Below, I discuss two scenarios in which the experience of surveillance and empowerment can be seen: the client plan and the monitoring of health.

### **7.1. The Client Plan**

My field observations and interviews with case managers revealed four ways in which case managers enacted surveillance and empowerment through formulating a case management

plan with clients. First, in the team approach, case managers view their relationship with clients as one of teamwork, as both parties collaborate on the identification of clients' needs and formulation of a treatment plan. Second, by emphasizing self-sufficiency, case managers shift the burden of responsibility completely to clients so that they develop a clear sense of what they are capable of doing, thus intensifying their empowerment, but the shifting of responsibility also allows case managers to keep tabs on clients' progress as they give clients more referrals to pursue. Third, in the intervention approach, responding directly and immediately to clients' needs links surveillance and empowerment in case managers' strategies only provisionally, as case managers focus intently on meeting clients' needs at that moment. Case managers may not stress goals of empowerment and self-sufficiency in this approach because clients are juggling so many needs that the premature enforcement of a treatment plan may have unforeseen consequences; thus, case managers' actions take the form of intervention, which is a form of direct surveillance. Fourth, establishing rapport with clients allows case managers to meet clients "where they are," to foster trust with clients who may be suspicious of invasive organizations, and to disguise their intentions as they shift responsibility to clients by using the rhetoric that it "is in clients' best interest" to take certain actions themselves.

### **7.1.1. The Team Approach**

Marilyn has worked with PLWHAs in the clinical social work setting for more than ten years. She no longer works solely as a case manager; instead, she helps other case managers at the ASO to optimize their abilities. From the outside, it appears that case managers are directive in their approach with clients, but Marilyn states that this particular flow of power is reversed. In fact, the direction of power flows may be more subtle and subject to flux. For instance, a client

identifies that maintaining optimal health is her only goal, but after reading over her answers on the medical history and medications questionnaires, the case manager realizes that the client has a history of not going to medical appointments and decides to bring this up as another goal for the client. The client may be receptive to this idea because it complements her goal of maintaining optimal health. Although case management in principle may be client-directed, in practice, the process may resemble a collaboration, or in some cases, mediation. By ceding power in the relationship to clients, case managers begin to cultivate a sense of responsibility in them or demonstrate a viable path they can take on the road to independence. Becoming a responsible citizen in this case takes time and practice, and as clients enact specific behaviors on a regular basis, they become accustomed to the routine of responsibility.

Anna and Marilyn have similar philosophies about case management, especially regarding clients' role in the identification of goals and how case managers facilitate the shaping of these goals into a workable plan. Anna just completed her Masters degree in Social Work in the spring. She has been a case manager with the agency for eight months. She selected HIV as a specialty within social work because she knew that she would be able to learn much about poverty and mental health issues, which affect "part of the fabric of our society." In fact, she believes that "all social ills have a huge impact on HIV." Only working with clients who have mental health issues, Anna believes, pigeonholes social workers, whereas her present position permits her to work with these "larger social ills" such as poverty. Anna's style of case management situates clients in their social environment and takes into account obstacles that may prevent them from taking on certain responsibilities.

Anna distinguishes between intensive case management (ICM) and mid-level case management (MCM) according to the severity of the client's situation and how much contact



he/she needs on a regular basis. Generally, clients in ICM “live from one crisis to the next,” and this requires case managers to adopt a diverse approach to resolving clients’ problems, according to Anna. This diversity can encompass relationship building, advocacy, life and people skills training, and the facilitation of putting these skills into effect. Clients in MCM tend to function very well, may not want case managers “in their lives,” and may only call case managers with specific needs. Occasionally, case managers may find clients in MCM to be resistant in that when they approach them with suggestions, clients instead prefer to obtain their services and leave. Anna tries to engage these clients because “sometimes people just need an opening to talk things through.” Thus, for Anna, although clients may want to walk out the agency’s door as soon as they get what they need, she intervenes occasionally in the event clients are facing issues they have not addressed yet. She views it as part of her job to encourage clients to confront their difficulties early so that they do not spiral out of control, which is what often happens with clients with multiple needs, such as financial and housing assistance.

Interestingly, Anna disputes the discipline’s jargon related to goal-setting with clients. For her, the goal of “maintaining optimal health could be so many things” such as removing oneself from a dangerous situation that it truly depends on the client’s situation. Anna differs in her approach to case management from Marilyn in that she rejects the notion that one can generalize from one client to another the appropriate course of action, although she agrees that clients ultimately determine what goals to set with their case manager.

### **7.1.2. Emphasis on Self-Sufficiency**

Juanita has worked for the agency for one year as the entitlement benefits specialist in the housing program. She is not technically a case manager because she does not help clients

identify and formulate their specific goals, such as adhering to their medications, but she plays an important, concrete role in helping clients achieve different levels of independence, as they take on more personal responsibility in following up on leads she gives them. Put simply, Juanita specifically works on goal achievement, although she does admit that it is up to clients to maintain contact with her. Since she works in the housing program, she maintains contact with 30 to 50 clients who are or were at one time homeless. Originally, her position was conceived as a job placement specialist who would help HIV-positive clients find suitable work, but she discovered that once she began working with clients, many were not immediately employable because they did not have the necessary skills or resumes to take with them to job interviews. Instead, her job description changed such that she helped homeless clients obtain their entitlement benefits, such as Social Security, disability, and medical assistance. When clients reach a certain level of independence whereby they can manage these benefits on their own, Juanita aids them in securing employment or enrolling in a job-training program. Each client with whom she works has a mailbox at the agency into which she deposits information about available jobs, and clients can visit the agency to check their mailboxes or call Juanita to inquire about the positions.

In contrast with Anna, Juanita describes her direct approach with clients as “in your face,” as it is premised on a self-sufficiency model that differs from the harm-reduction model that other case managers use with clients. According to Juanita, the harm-reduction model involves a case manager slowly trying to “wean a client out of certain habits.” For instance, “instead of having three beers in one day, the client may cut back to one and then to half a can,” whereas in the self-sufficiency model, the case manager presents the client with two options: the client can continue to engage in self-destructive behavior or renounce it altogether. Although the

approach may sound like “tough love,” Juanita finds that it works for her with the type of clients she sees.

Juanita primarily works with clients for whom HIV/AIDS may be a secondary or tertiary issue due to mental-health and/or drug and alcohol addiction issues. On top of these concerns, they need housing to escape the trap of homelessness. Since most of her clients are African American, they regard her approach as in keeping with her self-presentation as the “typical, domineering African American matriarchal woman.” Juanita then uses her gender, race, and age to her advantage to portray a specific persona of surveillance that many African American clients are accustomed to being around. Certainly, some clients may not like her approach at first, but after five months of working with them, they may realize that “babysitting” does not yield anything substantial. Juanita comments that other case managers interpreted her approach as harsh, but she acknowledges that when she meets with clients, she sees a side that case managers often do not. She says, “I get to see the best in clients,” and the self-sufficiency model is successful, in her estimation, because the incentive to improve one’s circumstances “is within the client.” Thus, clients have to want to commit to the goals they outline with case managers, who may only see clients as needy when they make requests of them.

### **7.1.3. The Intervention Approach**

Susan has more than 20 years of experience working as a clinician in the mental health field. She has been a case manager with the agency since January of 2003 working with homeless clients. Her caseload hovers around 20, eight of whom live in a transitional housing facility intended to help them “get back on their feet.” Describing herself as not subscribing to traditional approaches to case management, Susan, instead, responds to what the clients need:

making doctor's appointments, managing crises, obtaining entitlement benefits, addressing drug and alcohol issues, escorting clients to different appointments, and finding resources typically not available to clients, such as legal assistance with their immigration status.

Since her clients are often immersed in what outsiders interpret as a turbulent lifestyle, Susan has to be able to adapt to a variety of situations. Working with clients with multiple needs necessitates that she "has to be prepared for anything." She cites a recent case with a client who was murdered by his roommate that required her to devote four entire days to helping his family make funeral arrangements and retrieve his personal effects; she was unable to help any other clients while she spent time with his family. Responding in such a manner to clients' emergencies may interrupt Susan's time and relationship with her other clients, but in the moment of crisis, she is a comfort to clients.

Susan also finds paperwork, such as the treatment plans, which she is required to fill out for accountability purposes to document how she spends her time with clients, to be stifling and a "waste of time." Since clients needs constantly change, SCPs become out of date very quickly, and she argues that it makes no sense to revise them constantly. In fact, case managers can only really write "very general, bogus things" on them to cover the entire range of activities in which the clients and case managers may engage. With a client whose long-term goal is to obtain employment, getting him to work on his personal hygiene involves very specific steps, such as bathing and wearing clean clothes, before he can attain his larger goal. Documenting their discussions on the SCPs would be exhausting and exasperating, Susan says, but she does make it a point to update her progress notes regularly so that anyone can retrace her steps with a client and get a sense of what they have worked on together. Susan's clients may be special in that she devotes so much time to helping clients develop a sense of personal responsibility. For instance,

by concentrating intently on a client's personal hygiene, she is encouraging him to spend the time and energy on conforming to potential employers' expectations. Performing the routine of taking care of his hygiene on a daily basis is a sign of taking on personal responsibility, and with the boost in self-confidence that accompanies his improved hygiene, the client hopefully will be ready to tackle other concerns.

Despite a client's desire to achieve self-sufficiency, Susan believes her clients' abilities to determine their own needs rests on their health. Based on her observations, clients who have been HIV-positive for fifteen years or more are unable to tolerate the high toxicity of their medications, or their bodies are rejecting them altogether, which partially explains the increase in AIDS symptoms. Conversely, clients whose doctors recently put them on medications are doing well, and still other are doing well because they register no discernible viral load. Susan ultimately believes the connection between health and self-sufficiency hinges on "how badly they've [clients] beaten up their bodies."

Like Susan, Andrea finds that adjustment to the client's needs is a demanding element of her job as a case manager, but a necessary one. Andrea recently switched fields from medical photography to social work. Although she has only been at the agency since November of last year, she has become the senior case manager in the housing program, due in part to the high rate of turnover in case managers recently. In spite of the job's large workload, she has discerned for herself some of the important principles of case management, one of which is "meeting the client where [he/she] is." Andrea comments, "Every job since has been easy." She finds her case management responsibilities to be a "good fit," though at the moment she only has seventeen clients and knows she take on a few more. She also finds more gratification in her present position because she is working with higher-functioning clients because she can work with

clients “on establishing more meaningful goals than sustaining eye contact when talking with the case manager.” Most of all, she takes pleasure in developing a “continuing relationship with clients even if they are challenging,” which she describes as individuals who may be belligerent or make excessive demands of case managers. In addition to the continuity of care and the rapport she establishes with clients, she likes learning on the job because clients’ needs vary all the time. The learning process entails “knowing when you can step away and when to jump in.”

Since Andrea has only been at the agency for less than a year, she still is negotiating her role with clients. She cites a familiar feeling she has when a more senior case manager shows her other steps she should take with clients. She states she asks, “We were supposed to do that? Sometimes we put concrete goals on clients, and we [case managers] are too lax in how we interpret our role.” Though it is her intention to involve clients in the active process of setting goals, she acknowledges the influence that case managers can exert in the pursuit of certain goals that may be more pressing, especially regarding achieving housing stability.

Allen affirms Susan’s concerns about attending to clients’ basic needs before undertaking a program in which clients slowly take on more responsibilities. He has more than twenty years of experience working in the mental-health and addiction clinical setting as a case manager, supervisor, and liaison between healthcare providers and insurance companies. He oversees a staff of four case managers, the employment and benefits specialist, and the transitional housing facility in addition to acting as a liaison between the housing program and the client services division and between the agency and the Housing and Urban Development (HUD) agency. During the course of the interview, Allen demonstrated his commitment to a style of case management in which clients are encouraged to comply with the recommendations of specialists and to identify their needs to case managers.

#### **7.1.4. The Establishment of Rapport**

Sylvia has been with the agency as an intake specialist for one year, and she was promoted to case manager three months ago. She now has a caseload of eleven clients, which she will soon have to turn over to the new case manager because the agency again is promoting her to an outreach specialist. The new job will entail Sylvia making contact with at-risk African American women and men who have sex with men, which are just two of the groups with climbing HIV infection rates. As an intake specialist, Sylvia addresses the immediate needs of new clients who have just entered the agency's case management system. These needs include obtaining bus tickets, food, and referrals to physicians and housing services.

As the first person clients meet at the agency, Sylvia emphasizes the need to make clients feel comfortable talking about very private issues related to their diagnosis, especially if they were recently diagnosed. She is conscious of relating to clients on "their level," which means that she may emphasize the common bond of being a "person of color, young, a woman" in order to encourage clients to open up about their needs. Like Juanita, Sylvia uses her social location as an African American woman in her twenties to her advantage as a way to make clients feel more at ease with divulging intimate information. She takes pride in her ability to elicit comments about clients' personal lives, such as their relationship difficulties, because to Sylvia, this is a sign of the client's trust in her. Even though clients eventually are assigned a case manager depending on the intensity and type of their needs, many return to Sylvia to talk to her about their lives because their initial contact with her was so positive. She states she works with her own clients in a similar fashion.

In addition, it is imperative that Sylvia probe clients' needs thoroughly in order to provide them with the resources they identify themselves to her or those she believes they need. This probing consists of Sylvia finding out if clients have health insurance, a primary care physician they see regularly, medications they take correctly, and the ability to pay for the medications. Clients who have recently been diagnosed with HIV may not immediately start on a regime of medications, but those who are seeking services from the agency after a long absence or because they are becoming ill may need to be placed on medications as soon as possible. Therefore, as a gatekeeper for the agency, Sylvia plays a very important role in establishing first contact with clients. The completion of the required paperwork also constitutes an important part of her duties because the client's assigned case manager then has a starting point from which to proceed. Thus, Sylvia has to be very meticulous in her documentation of a client's history and needs so that clients do not have to keep retelling their stories repeatedly to each new person they encounter in the agency. Once she has ascertained a client's needs, she then prioritizes them based on urgency.

In Sylvia's experience, clients usually identify their needs to the case manager as soon as they set foot in the door of the agency. In the rare cases that clients are reticent about discussing their needs or unsure about them, she "finds out what they need by any means necessary. If they see you helping them, such as by talking about different issues they face as a woman or as a person of color, then they will begin to talk to you." Sylvia's pattern of establishing rapport with clients seems to be based on affirming social identities premised on race and gender that influence how clients respond to her queries and relate to being HIV-positive.



## 7.2. Monitoring Health

Serving a population that healthcare professionals define according to their health condition requires that case managers address clients' health and particular needs related to their health, which will worsen eventually. Therefore, the monitoring of clients' health is another context in which case managers negotiate the complex dynamics of surveillance and empowerment. The assumption underlying the client-case manager relationship is that clients seek case management when they are desperate, when they can no longer help themselves, and once the case manager intervenes, the clients' situation will undoubtedly improve. The assumption remains flawed because it conceptualizes clients as only accruing more independence and life skills, when in reality, clients face challenges that may prevent them from following through on all of their goals. Some case managers interpret this relationship as case manager-initiated, on the one hand, as when case managers inquire about clients' behavior related to health and safe sex and encourage them to practice safe sex. Case managers may intervene and inquire about clients' behavior in the interest of dissuading them from engaging in risky behavior such as drug use and unsafe sex. Usually, case managers are more interested in meeting clients' immediate psychosocial needs, treating HIV prevention as secondary. In fact, several case managers I interviewed expressed dissatisfaction with the fact that reinfection is not a regular topic at staff meetings and training sessions; when reading clients' files, I did not encounter mention of reinfection education.

On the other hand, some case managers interpret the relationship as client-initiated in the sense that clients request certain services or identify specific needs. The duty of maintaining contact then devolves on clients. Thus, ASOs continue the work of surveillance by employing case managers who expect clients to maintain regular contact and withhold services if clients do not comply with this stipulation. In one sense, though, enforcing the rule of regular contact is one

means by which the ASO can decrease case managers' workloads by changing a client's status to inactive and allowing clients on the waiting list for a case manager much-needed access to intensive case management services. Conversely, case managers can use this rule to oblige clients to maintain regular contact, and they can use other bureaucratic rules such as having a statement from the client's physician about his/her HIV diagnosis that is less than one year old as a way to ensure that clients make and attend medical appointments.

As a document of surveillance, the treatment plan allows case managers to enforce regular contact because the ASO requires clients to formulate a new plan every three months. Therefore, clients must meet with their case managers, if they have one, and outline reasonable goals. Marilyn states that at the very least in the treatment plan, clients identify maintaining optimal health as a primary goal. Even though clients may have other pressing needs, such as staying clean and sober or securing short-term or long-term housing, they usually rank their health as a principal concern. However, the majority of the case managers I interviewed acknowledge that clients may not identify all or even some of the most pressing needs in their lives because they may not be interested in pursuing them at the moment or because other concerns take precedence. Marilyn also suggests that at any point in case management, clients can and do alter their goals in their treatment plan, which points to more flexibility in the case management model than I had originally hypothesized. Rather than viewing the treatment plan as an immutable document from which clients may not deviate, Marilyn understands it as establishing a series of guideposts that will help clients get a grasp on their problems as they are able to locate concrete ways in which to solve them.

In order to understand how case managers interpret clients' compliance with or adherence to the treatment plans they create together, it is important to have a complete picture of the range

of issues clients may face regarding their health. Additional social factors such as recurring homelessness and poverty can aggravate and interfere with clients' abilities to achieve the goals they help to set for themselves. Clients are required to report their diagnoses and any changes in their diagnoses so that case managers are aware of any sudden changes in their medical condition due to the disease's progression. Sometimes clients are unexpectedly hospitalized due to the onset of an opportunistic infection, for instance, or become medically unable to work; if case managers are apprised of clients' conditions, they are better able to help clients file for disability or to arrange for occasional home hospice care. On the intake forms that clients complete once they initially become clients of the ASO, they are required to specify their CD4 and T-cell counts, viral load, diagnosis as HIV-asymptomatic, HIV-symptomatic, or AIDS-diagnosed, any HIV or non-HIV medications they are taking, and any HIV-related or non-HIV-related symptoms they might be experiencing such as fatigue, weight loss, and thrush.

Diagnoses do not resurface often in case managers' comments. Once the diagnosis is registered, it seems unnecessary to mention it repeatedly because it becomes an integral part of defining a client by the particular symptoms s/he experiences. For instance, case managers are able to inquire specifically about client's recent bouts with shingles or anal warts if they know that this is part of the client's health profile. Yet the advent of life-lengthening drugs for PLWHAs has altered contemporary notions of what it means to live with HIV/AIDS today. But there are still unmistakable signs of AIDS. Julien Murphy (1995) bluntly remarks how AIDS transforms bodies: "AIDS marks the body in obvious ways: the purple KS lesions on the neck, face, arms, chest; the signs of weakness, skin discoloration, and weight loss. Such symptoms make the HIV-infected body identifiable for others" (p. 69). This striking comment indicates how the body can be ravaged and changed by AIDS and raises interesting issues about how case

managers interpret these changes in clients' bodies. Emaciation, physical weakness, and the use of a wheelchair are all indicators that clients are having physical difficulties, but lack of attention to personal hygiene and appearance may also arouse case managers' concern.

Yet with the advent of AIDS "cocktails" and other drugs, PLWHAs are living longer, healthier lives, contributing to a common perception of AIDS as a "chronic, manageable, and less sensational illness" (Ward 2000: 247). Although Jane Ward (2000) conducted her research in a residential facility for PLWHAs that was a place in which clients, residential managers, and case managers shared intimate knowledge of the clients' situations, her linkages between the ASO and effective drug combinations shed light on the importance of the construction of AIDS in case managers' assessments. In addition, the impact of AIDS on the body has significant effects for PLWHAs. H. Tate and R. George (2001) examine how weight loss influences the body image of HIV-positive gay men. Elizabeth Chapman's (2000) longitudinal study investigates the body image of PLWHAs and those who were HIV-negative. She reports that the PLWHAs had negative images of their bodies and did not want to be touched due to a sense of contamination. Additionally, it problematizes the much-discussed issue of stigma vis-à-vis the physical appearance of PLWHAs, despite whether or not they display "signs of illness" (Chapman 2000: 841).

Diagnoses and symptoms form part of the official knowledge that case managers deploy regularly in their interactions with clients so that not only can they more effectively manage their time together. They can also refer to clients as individuals and reinforce the case manager-client bond that facilitates communication and enables case managers to help clients achieve their goals of eventual self-sufficiency. But the diagnosis serves a regulatory function by establishing a

baseline for how case managers deal with clients; at the same time, the diagnosis and particular symptoms turn the client into an identifiable individual with specific needs.

For Foucault (1977), “the power of normalization” flows through the diagnosis and reportage of symptoms and “imposes homogeneity; but it individualizes by making it possible to measure gaps, to determine levels, to fix specialties and to render the differences useful by fitting them one to another. It is easy to understand how the power of the norm functions within a system of formal equality, since within a homogeneity that is the rule, the norm introduces, as a useful imperative and as a result of measurement, all the shading of individual differences” (p. 184). This common vision then relies heavily on thorough documentation and case managers’ familiarity with clients’ situations. As case managers become more intimate with clients’ specific problems, they may begin to omit superfluous detail such that the entries seem more perfunctory. For example, Rodney, a client who has been with the agency for more than three years, was hospitalized when he completed the intake process. In the months following his release, his case manager called to check up on him, and she writes several times, “Health is stable,” as a sign that he has not experienced any other complications and that he has not requested services related to his health. Even though the entries may seem pared down to the untrained reader, to the case manager, these entries relate only the important information that is useful for handling the clients’ future needs. Case managers do retain informal knowledge about how to interact with clients and which subjects are off-limits. This information does not appear in their comments, but comes up in discussions with other case managers. The entries are intended to serve as verification of the case manager’s handling of a client’s case and to familiarize other case managers with the client if they work with him/her in the future. Below I discuss three

mechanisms, expertise, compliance, and obligation, which serve as examples of factors that mitigate case managers' monitoring of clients' health.

### **7.2.1. Expertise**

Evaluating a client's expertise as a function of monitoring her/his health is a particularly vexatious issue because it supposes that case managers have the training and expertise themselves about the disease and treatment to make this evaluation. But who really is the final authority on what is healthy in light of the fact that case managers rely on clients to divulge information about their health and wellness? Before I began my content analysis of these case files, I hypothesized that case managers would be reliant on clients' understanding of and education about HIV/AIDS, making it easier to coordinate services and to enable clients to remain independent and responsible for their health and behavior. I initially thought both case managers at ASOs and clients rely on intimate firsthand knowledge of the disease and also the exasperation they share in trying to decide on a specialized course of action for clients. Although I did not uncover many references to clients' explicit knowledge about the disease in the sense that case managers might be informally testing what clients knew about the disease, prevention, and transmission, case managers may still assume that clients know enough about the disease such that they do not have to review information with them all the time. Or they may assume that clients obtain this information from their physician, which supposes that clients regularly make and attend medical appointments.

The interviews with case managers confirmed that they believe that clients are the best assessors of their situations because they inhabit the bodies ravaged by HIV/AIDS. Case managers do rely on clients to divulge information about their health and condition so that they

can make recommendation about the best course of action. Thus, this exchange of knowledge occurs between two sources of expertise: clients who know their bodies and needs and case managers who supposedly know the disease's progression and ways to meet clients' needs. For instance, Anna finds that clients ultimately know what they want and need from case management, although these goals may change over time. In a sense, she believes that clients are experts on their own condition and do know enough about what they need to request services that are a "good fit." Nevertheless, her statement contradicts my finding that in the progress notes that case managers compose, clients do not regularly request information related to HIV/AIDS or demonstrate knowledge about the disease that they have acquired. However, case managers may not report this information in the clients' files because they view it as tangential information, concentrating solely on the clients' clearly stated requests.

For Anna, clients are experts in their own right when it comes to goal formulation. Due to the mutability of clients' goals, Anna discerns between short- and long-term goals. The key to achieving both is planning, which is an "underrated skill" in her estimation. The temporal parameters of these goals shift according to the skill because a client may want to remain "clean and sober for the next three weeks" rather focusing on the long-term goal of staying clean for the rest of her life because accomplishing this goal can be important to rebuilding the client's self-esteem. Hope is fundamental to this process, Anna states, because it is harder to work with clients who are uninterested in improving their situations. Therefore, clients whom she is able to help become more responsible display both hope and expertise in their condition; hope is the emotion that allows clients to actualize their expertise. Sometimes clients may not come in with any concrete goals; in these cases, Anna uses the technique of "leading" to build a framework for

understanding the client's concerns and then proceeding to the identification of attainable, realistic goals.

When clients change their goals or no longer seem interested in working on them, Anna attempts to ascertain the cause for clients' disinterest in them as a means to determine what has changed in their lives and outlook because it may be a sign of a larger problem. Clients also determine the amount and nature of contact they have with case managers. Anna does not believe that the amount of contact a client has with a case manager is a predictor of their success in achieving independence. She states, "Some people work very well on the own," but others have mental health issues that may complicate the client-case manager relationship because clients come to rely too much on their case manager's approval.

My findings do not demonstrate that clients regularly ask for services related to health maintenance. This is consistent with the case managers' statements about the self-directed nature of case management in that clients determine the agenda and ask for services they need. Therefore, I cannot make any substantive conclusions about their expertise about HIV or general health knowledge. The model of responsible citizenship I have observed then may not be so concentrated around clients' expertise, but is instead concerned with the actions that clients take in terms of feeling obligated and interested in maintaining their physical and psychosocial health. David Silverman's (1996) work on HIV counseling in Great Britain identifies the dilemma that many pre-test and post-test counselors face when they try to rely solely on educating clients about the transmission hazards concerning HIV/AIDS and the importance of compliance with treatment regimes once diagnosed HIV-positive. Education itself does not result in spontaneous responsible behavior from clients; clients have to digest the information, organize it, and then consciously choose to act on it. Thus, the focus should be on the encouragement and advice that



case managers give to clients regarding the actualization of their intent. I find that encouragement and empowerment take the form of case managers transferring responsibilities to clients through the act of making them feel obligated to take steps toward becoming more independent.

### **7.2.2. Compliance and Obligation**

In some cases, “doing well” is an appropriate description for how clients are managing the disease, their symptoms if they have any, their medications, their lifestyle, their financial status, and any social pressures such as stigmatization and lack of social support. In fact, “doing well” may also function as a synonym for independence. At the same time, this also marks a client’s compliance with her/his treatment plan and indicates that s/he has taken responsibility for her/his health. Most scholars agree that independence is one of the hallmarks of citizenship, and those who cannot meet this criterion are second-class citizens who are stigmatized for their inability to take care of themselves (Young 1997). This exclusion is characteristic of universalistic conceptions of citizenship that some scholars reject (Marks 2001; Young 1990). Nevertheless, these scholars note that citizens are still accountable to their local communities, depending on their ties to that community, in this case to case managers and the ASO.

One way in which citizens are accountable is through their care for their bodies and health, and PLWHAs may be held to higher standards of self-care than the public at large so that their health does not deteriorate as a result of their neglect to take medications correctly and to attend doctor’s appointments on a regular basis. A number of scholars have addressed the connection between health and citizenship (Ellis 2000a, 2000b; Howson 1998; Rose 2000). In particular, Adkins (2001) comments that health-conscious citizens are ideal, responsible citizens

because their good health will ensure that they are not a drain on community resources, unlike the PLWHAs who frequent the ASO. In fact, the preservation of health and body maintenance ameliorates citizenship, as evidenced by activists who try to encourage health-conscious behaviors (Ellis 2000a), such as breast-cancer awareness (Klawiter 1999) and regular health screenings (Howson 1998; Jallinoja 2001). Thus, the “imperative of health . . . becomes a signifier of a wider – civic, governmental – obligation of citizenship of a responsible community” (Rose 2000: 101).

Yet many PLWHAs are struggling with the psychological toll that their HIV status has had on them, which is compounded by the public’s expectations that they must take better care of themselves. For some, the stigma of being HIV-positive can trigger anxiety and depressive symptoms. Some PLWHAs actually internalize the negative rhetoric accompanying stereotypes of HIV-positive individuals, believing that they “have a disorganised lifestyle and are irresponsible, unreliable and undeserving” (Clarke 2001: 53). Many clients also experience financial hardship related to being on welfare or on disability that complicates their ability to maintain their health. Case managers then fulfill an additional role as coordinator of services and help clients try to resolve these issues by assisting them with financial aid applications or by advocating on their behalf with utility companies when an overdue bill is concerned. In addition, conflict with family members and domestic partners may impede a client’s ability or interest in caring for him/herself. Living in an unsafe neighborhood can also reveal feelings of insecurity linked to clients’ diagnosis as HIV-positive and the fear that this diagnosis may put them at risk for physical violence in a crime-ridden area.

Obligation and responsible citizenship are certainly categories that are difficult to disentangle from one another. Certainly, the focus here is on the process of self-surveillance, and

case managers expects clients who may be juggling different issues still to develop the ability to monitor themselves. Self-surveillance entails the realization on the part of individuals that they are “active participants and knowledgeable subjects” even though they remain objects of scrutiny for case managers, for example (Howson 1998: 224). The language of responsible citizenship also takes the form of “compliance” or “adherence” to treatment regimes that doctors prescribe for clients. Alexandra Howson (1998) explores the connection between obligation and responsible citizenship in her qualitative study of British women who submitted to regular cervical cancer screenings and the social pressure they internalized, which made them comply with medical recommendations about attending regular screenings. Howson (1998) is not content to define obligation simply as compliance; for her, it is a “complex expression of self-governance” that emanates from “an active, embodied engagement” with the task at hand (p. 234). Case managers appropriate this term to refer not only to clients’ correct taking of medication, but also to their following through on goals they set with case managers.

For Allen, helping clients to comply with the treatment plan they have established is a primary objective for case managers. He repeatedly used the language of compliance throughout the interview in the sense that case managers seemed to function as enforcers of compliance. Although, for Allen, the ultimate goal for case management should be to “assist the client in achieving a higher level of independence,” the case manager should clearly take the lead in guiding clients down the path to responsible citizenship. Therefore, case managers have to support clients’ full disclosure of their needs, and if they identify none, then they must be proactive in eliciting information from client that they can use when creating a treatment plan. Allen hopes that case managers are able to assist clients in raising their level of personal responsibility, for instance, to begin to manage their monthly finances and to pay the nominal

housing program fee, and to help clients to maximize resources at their disposal and to be sensitive to relationships with their landlords, family members, and neighbors.

Compliance is too totalizing a concept for Anna because it connotes a set of directives disseminated from the top down and to which case managers are supposed to hold clients. Adherence is a better term because it is premised on a partnership between the case manager and client who share in the formulation of a treatment plan. The client-centered model allows these partners to identify what goal is important for the client, and that may be medication adherence. Anna likens this partnership to a contractual relationship. If clients do not hold up their end of the relationship, there may be negative consequences. Ultimately, if clients do not meet the goals they identified in their treatment plan, they face very little “backlash.” As a way to reassure clients that it is all right for them to change their goals, Anna emphasizes that her professional feelings in no way depend on whether they fulfill their treatment goals. Her clarification dilutes the surveillance she employs because she temporarily steps out of her role as a case manager into that of a neutral party who does not judge clients’ actions.

In fact, there are few negative sanctions for clients if they do not follow the agency’s expectations that they maintain contact every six months, come to the food pantry when it is open, not behave in an abusive manner when working with their case manager, and make and keep appointment with case managers instead of showing up and demanding to see a case manager. Clients may be asked to follow the “rules,” but there are no negative sanctions for clients who do not achieve the goals they set for themselves. Since clients determine their own goals, they only disappoint themselves if they do not meet them. What is clear from Anna’s standpoint is that clients have to *want* to make progress and to be self-sufficient. Independence

comes from the client's interest in the outcome, and case managers have to ask themselves: "Does the client want to get better, or do I want him/her to get better?"

But what about clients who are not ready to take on certain responsibilities because they lack a support system or other forms of stability? Susan acknowledges that most of her homeless clients are not ready to take on additional responsibilities because that presupposes stability. Achieving stable housing is often a precursor to the formulation of goals such as taking medications on time and attending medical appointments. If clients worry about where they will sleep that night, long-term goals seem illusory and not nearly as important as the urgency of locating shelter. Thus, mitigating circumstances may influence a case manager's decision to delay shepherding clients to a position in which they take on more responsibilities. After all, if clients feel deluged by too many responsibilities, such as paying bills and locating work, they may "relapse" and return to behaviors that case managers identify as contributing to their recurring homelessness.

Unlike Anna and Marilyn who tend to let clients identify their goals, albeit with some prompting, Juanita challenges clients when they do not comply with their treatment plans or fail to follow up on her recommendations and referrals. Departing from a case-management model in which clients and case manager share the responsibility of formulating goals, Juanita challenges her clients to be accountable to themselves, thus shifting the burden of becoming responsible on the clients. Her "challenge" takes the form of direct surveillance, but Juanita states that she sees clients at their best when she employs this method. In fact, many clients respond quite favorably to direct surveillance because they interpret the contact as coming from "someone who is in their corner." Certainly, all of the case managers I interviewed emotionally invest in their clients and want to see them become more independent, but surveillance is the mechanism by which they

encourage clients to embrace empowerment. Juanita states that clients who are empowered begin to relax with case managers: “Everyone likes to talk about [him/herself]” and celebrate past achievements, and her job, especially when helping clients assemble a résumé for the first time, affords her the opportunity to see clients as achievers, instead of as a class of people who lack something.

Juanita also believes that clients have an *obligation to themselves* to find tasks and opportunities that keep them busy. Embracing this obligation then is a form of empowerment as clients realize that they have the ability to do something meaningful, even if the task is not paid work. Even though Juanita cannot guarantee all clients a job, she does believe that everyone is employable and can keep busy volunteering or acquiring new life skills so that they can feel better about themselves. Juanita’s attitude, however, matches that of Susan and Andrea, who suggest that “treating clients with dignity and respect” remains fundamental to their approach to case management. By treating clients in such a manner, case managers nurture a relationship of reciprocity in which they encourage clients to mirror the responsible behavior they demonstrate in the presence of clients.

The nature of Juanita’s relationship with her clients is based on how frequently the clients want to contact her. If they check in with her regularly or work with her in person on their resumes, they can benefit from sustained contact and develop a greater sense of self-worth and self-reliance because they see themselves being productive and working toward a concrete goal. Yet even though she “sees everyone,” they see her when they desire. Juanita notes that when she asks clients to describe their skills and she points out that a single mother with three children is an excellent manager, clients begin to derive a stronger sense of self and what they can do since she draws their attention to skills they take for granted. Having someone such as Juanita tell

clients that they have *abilities* can heighten their self-awareness and increase their desire to achieve a greater level of self-sufficiency. Thus, Juanita's approach to working with clients in this situation could be described as one of building momentum; once clients attain smaller goals, their desire to achieve larger ones accumulates over time and carries them into success.

Sylvia uses a similar "tough love" tactic to enable clients to become more self-sufficient, which takes the form of shifting responsibilities from her to clients. She states that she wants clients to take the initiative to call physicians, government agencies, and other agencies from which clients seek services; "they have to want it," even though clients have to be aware what their limitations are. Most often, clients are able to call a physician, for instance, on their own, but occasionally, Sylvia will make the call with the clients present in order to demonstrate how they can interact with a person on the phone. In this example, she clearly shows clients how to carry out the task so that they will be able to replicate it with success; they prove to themselves that they are capable of taking on this responsibility.

Sylvia still encounters frustrated clients who ask her, "Can't you call for me?," and she inevitably responds, "No, it's better for you to call because it's your story to tell, and I can't explain what you've done and your history." In this way, Sylvia shifts the burden of communicating with physicians and other professionals and following up on the leads she gives them to clients so that they become accustomed to taking responsibility for their needs. It is a version of requiring clients "to own up" to their own experiences and using "their own voices" to tell their stories, since they are better equipped than case managers to explain exactly what they need. She calls it "tough love," but she acknowledges that she has other clients, and interceding on behalf of every client does not permit her to address the needs of her other clients adequately, a concern she shares with clients who make this type of demand.

In the case of the ASO, case managers might reasonably expect clients to assert themselves and act in a manner consistent with the recognition that they are accountable for their conduct, which is characteristic of the rhetoric of empowerment that accompanies case management. As such, case managers play an instrumental role in helping clients become responsible citizens who actualize their social entitlements and make choices that help them maintain an active interest in their health. Therefore, encouraging clients to be more active in decision making may be one aspect of a case manager's job; exploring options and explaining the consequences of a client's actions also fit into this framework.

### **7.3. Complications of Surveillance and Empowerment**

For the most part, case managers seem able to negotiate the web of surveillance and empowerment such that they succeed in help their clients identify their needs, meeting some of their clients' needs, and formulate a plan enabling the client to become more responsible and independent. Yet in the course of my interviews with case managers, several mentioned scenarios and existing structural problems that impede their abilities to do their jobs. On the one hand, the nature of case management poses a problem for case managers because they have to rely on clients' acclimation to the ASO's expectations and to the treatment plan by modifying their behaviors, a problem that further complicates the connection between surveillance and empowerment. On the other hand, larger structural issues render it impossible in some cases for case managers to perform their duties because they do not have access to the necessary resources, such as bus tickets or funds, or because the ASO prescribes a certain manner for discussing sensitive subjects regarding the disease's progress and dying. I discuss these below as the problem of judging clients and structural gaps with which the ASO is currently grappling.



### **7.3.1. Judging Clients**

Issues of surveillance and empowerment become entangled as case managers have to rely on clients' self-surveillance. Case managers and clients may meet in person sporadically, and clients may not fully disclose all of their behaviors during a phone conversation. Thus, case managers are not able to supervise clients' conduct outside the ASO and must depend on clients' internalization of their treatment plan through self-surveillance. In addition, case managers increasingly their obligations to clients and clients' obligations to them. Is it in the client's best interest for case managers to perform basic tasks for her/him regularly? This may relieve clients of the need to develop a sense their personal responsibilities. Yet what do clients owe case managers? Do they owe case managers full disclosure of their behaviors? These questions surface again and again for case managers.

For Anna, it is extremely important that case managers remain objective in their assessment of clients' needs. Objectivity is necessary because it is not the case manager's place to superimpose her values onto the client or to assess the situation based on only one set of criteria. She cites the possibility that clients may "look to connect to someone and may not have tangible needs." In this situation, there is not a predetermined or prescribed manner in which case managers should proceed with the client. Therefore, in addition to objectivity, case managers must be flexible enough to deal with the "poor choices" that clients may make.

Similarly, Juanita stresses to clients that she does not judge them personally for the decisions they make regarding their goals and their plan of attack. Additionally, she treats clients equally. She states, "I don't care about your health even if you're not feeling well" because even if clients are ill, they can read newspaper advertisements for jobs and complete job training exercises at home. Even if clients have a debilitating condition such as neuropathy in their lower

extremities, clients' "hands are free" to work on other tasks. Another factor bolstering Juanita's "equal treatment" of her clients is that for the majority of her clients who all experience difficulty maintaining stable housing and employment, their HIV status is a secondary issue. Many are newly diagnosed and have lost their housing after a catastrophic event such as termination of employment; mental-health or addiction issues are usually the primary reasons why clients are homeless anyway, according to Juanita. However, Juanita is clear to state that objectivity does not prevent her from empathizing with clients. She states, "This client needs my help," no matter what other issues he/she might be facing, and acknowledging this enables her to do her job.

Susan takes a more conditional approach to case management that she labels "looking at a day in a client's life." Although she relies on the clients' history, their self-identified needs, and other people's views, she prefers to examine every client with "fresh eyes." For instance, Susan says, "If you only see a client as a drug addict, it may prevent you from seeing a client's other needs." She acknowledges it is important to remember that clients may have drug-addiction issues, but only going on preconceived ideas about what clients need does not allow a case manager to be flexible enough to respond to a client's changing needs. In addition, relying only on preconceived notions does not recognize that clients are capable of changing and determining their own needs or that a client's health condition can change quickly due to neuropathy, weight loss, and dementia. Even though Susan may revise her assessment of client's needs, this revision may not stray too far from her original recommendations. Her assessment still pivots on the fact that some clients are always in crisis and how they look or behave on a particular day. She goes so far as to say that she does not know what she will be doing on a given week, and she amends her weekly many times over the week to reflect the changes in her calendar.

As Andrea familiarizes herself with the intricacies of her job, she is learning when to get directly involved in clients' lives and what necessitates her intervention. She related a vignette in which she intervened directly in a client's situation because she feared that he was in physical danger. He had obtained an apartment through the permanent housing program, but because he had an active drug addiction, maintaining his independence and meeting his obligations, such as paying his utility bills and program fees, became unmanageable. Andrea transferred him, or demoted him as it were, to the transitional housing program so that the resident advisors and other tenants in the building could check in on the client to ensure that he was all right. But one day, after several failed attempts to reach him on the phone or through the resident advisors, she went to his apartment and found him unconscious on the floor. Without her direct intervention, the client might have died from a drug overdose.

Striking a balance between intervention and withdrawal concerns Andrea because it requires her to be familiar enough with clients' needs and behavior and to know when to disengage, even though she is aware clients may engage in dangerous practices such as intravenous (IV) drug use. She admits that she has become adept at discerning "liars" who are used to "manipulating" case managers and the system so that no one discovers what they are hiding, whether it is drug use or financial difficulties. By reading a client's body language and being attuned to what they request on a particular day, Andrea is able to ascertain how that fits in with her/his pattern of behavior. At this point, she can deploy her skills associated with harm reduction, but she acknowledges the limits of this approach. With clients' housing needs, the problem becomes more complex. Andrea states, "With subsidized housing, we're providing a lot of things to the client. If he has an active drug habit, then we're subsidizing the habit." Discussions about how to address the conflict of enabling clients to engage in behaviors coded as

risky by case managers when the agency's intention is to equip clients with the skills they need to be self-sufficient currently go on in the housing program and the agency in general. It is an important question because it underscores the agency's identity crisis and how it wants to be perceived by the community and clients. Yet the situations in which case managers have to intervene so directly in clients' lives may be small in number. For Andrea, then, the goal as a case manager is to be approachable with clients, even as they confront problems together. She describes that the degree to which she is successful in being accessible depends on the level of involvement she has with clients. Her greatest worry is that she will inadvertently "close the door" on clients, causing them to withdraw and not identify their problems to her. She admits that she does better with some clients than with others.

### **7.3.2. Structural Gaps**

Structural problems currently afflict the ASO, and case managers view these as constraining their abilities to help clients become more self-sufficient and to monitor their progress. These problems result in gaps in service. They also exacerbate tension between surveillance and empowerment in the sense that case managers may be unable to offer incomplete in one area, leaving the other unattended, which may result in the failure to meet clients' needs or in the failure to uphold the ASO's objectives, both of which underscore case managers' duties. Therefore, the frustration that case managers feel is related to their inability to perform their jobs that complements the agency's vision. In a sense, the ASO's current situation may lead to its eventual undoing with respect to the irresolvable conflict between surveillance and empowerment.

According to Sylvia, the agency is facing a budget crisis due to the curtailment of the number of bus tickets clients can obtain and to the fact that Section Eight is no longer taking new housing applications. Case managers are now unable to make crucial referrals for which clients ask, frustrating clients and case managers alike. Now, when clients present important transportation needs, case managers will have to inform clients that they can no longer have as many bus tickets, even though many clients visit several doctors each week. In some cases, clients' bus passes will not be renewed, further exacerbating existing hardship.

In addition to not being able to meet the basic needs of clients, Juanita believes that the agency is not addressing the clients' social and moral needs. She has an advanced degree in theology and is active in a Christian ministry, and she is aware of the implications of discussing clients' fears of death and dying. In the setting of the AIDS service organization, however, engaging in a conversation about the religious interpretations of death is frowned upon because practitioners envision it as encroaching on a client's personal beliefs and forcing ideas on clients with which they may disagree. Nevertheless, Juanita insists that as long as the agency shies away from speaking with clients about these issues when clients themselves initiate the conversation, it is not "treating the whole person," despite the agency's mission statement to address any and all needs a client might have. Since Juanita is active with different community and religious organizations outside the agency's setting, many of her clients know about her credentials and regard her as an authority on the matter of Christian perspectives on death. She contends, "When people are faced with their mortality and faced with moral issues, at some point, they ask, 'Did I do right?' As an agency, we've put this aside." She would like to see the agency allow clients to explore their own conceptions of mortality in addition to the established convention of encouraging clients' to make peace with the eventuality that they will succumb to AIDS.

Juanita also links the agency's lack of attention to issues of death and dying to its disregard for minority groups that are disproportionately impacted by HIV-positive diagnoses. Although the agency has recently begun to target the African American community with the recent hiring of African American HIV prevention specialists, Juanita acknowledges, "We're way behind." She attributes this neglect in part to the lack of representation of minorities in the agency's administration. Marilyn and Anna also concur with Juanita's statements about the agency's inability to reach out to at-risk populations apart from white gay men, but they are not as critical as Juanita is of the agency's reluctance to involve minorities in the determination of what services the agency offers and to recruit minorities to work with hard-to-reach groups such as IV drug users and the homeless.

For Andrea, the agency neglects end-stage AIDS and does not ask the crucial question, "What can we do to keep [these clients] functioning as well as possible?" In addition, the agency has not tackled the growing misconception that they can live with AIDS indefinitely due to the life-lengthening drugs to which they have access. Andrea also expresses frustration with the limitations the agency places on case managers' abilities to meet clients' needs with mounting paperwork, time-wasting staff meetings, and increasing caseloads. The "bouncing around" of clients also distresses Andrea because clients experience no "continuity of care" as long as the agency transfers the client from case manager to case manager in the search for the perfect fit for the client's multiple needs. Meanwhile, the client becomes frustrated with having to explain his/her needs repeatedly, while never having any of them met. She would like to see the agency become more "user-friendly."

## 8. Conclusion

Howson (1998) proposes an alternative interpretation of responsible citizenship in which individuals see themselves as embedded in a social milieu such they practice an “ethic of care . . . not only in relation to self-care, but also in relation to their watchfulness over other” individuals in similar situations (p. 235). By striving to empower clients to manage their own health and achieve a level of self-sufficiency by attending medical appointments regularly and taking medications faithfully, case managers try to instill in clients this “ethic of care.” This ethic sutures together the individual health experiences of clients with the social context in which they live their lives. Not only do case managers monitor clients’ progress regularly, but they also act as cheerleaders in a sense, who may sit on the sidelines occasionally as clients figure out for themselves how to manage their care, but who nonetheless play an active role in encouraging clients to make decisions that will benefit themselves.

Although my methodology afforded me the opportunity to develop a multidimensional sense of how empowerment and surveillance work in this ASO, I have been unable to outline the specific enactments of responsible citizenship. Researchers should shadow case managers who work consistently with a handful of clients. In this manner, researchers would arrive at a more complete understanding of how empowerment unfolds. In addition, this approach would enable researchers to identify concretely how clients respond to case managers’ effort. Certainly, this study lacks the voices of clients who are the subjects of all of this institutional scrutiny. I did not include interviews with clients in my original methodology due to the ethical considerations attached to studying a group reduced to their health diagnosis, but I was also aware that it would have been difficult to account for the inconsistency of care that clients receive in the ASO due to

the high turnover rate among case managers. It seems that researchers should explore the phenomenon of turnover and its effect on clients of social service agencies in a separate study.

One problem with the sampling of case managers at only one ASO is that it is beyond the scope of this thesis to generalize my findings to other ASOs. In addition, due to the high turnover of case managers in the last two years, it is nearly impossible to discern a workplace culture into which case managers are socialized. In fact, several case managers have very different experiences in the social work setting, ranging from working with the elderly in a long-term care facility to working with clients battling drug and alcohol addiction in a rehabilitation center. Although these experiences may bear directly on HIV-positive clients, the diversity of them makes it difficult to identify common patterns in how case managers work with clients. Moreover, some case managers are disgruntled with how the agency restricts their ability to help clients. For instance, several case managers admitted openly that this ASO was “antiquated” in comparison to other ASOs in terms of its approach to case management and community intervention and the lack of diverse programs. Nevertheless, I selected this particular ASO because it is continually hailed as the most visible ASO in the Pittsburgh metropolitan area. It has been in existence for more than a decade, and it is the only place in the Commonwealth of Pennsylvania where people can be tested for HIV under the conditions of anonymity and confidentiality. In other words, a person can walk in off the street and present a fake name to be tested, but s/he has to return to collect the results. This is still an important service offered in a politically conservative urban area.

Further studies examining ASOs’ organizational ethos and workplace culture are necessary as they continue to proliferate in parts of the world hit the hardest by HIV/AIDS. If social service providers embrace these organizations uncritically as an answer to relieving the



immediate needs of PLWHAs, what happens if the same problems, such as the disruption of care, take root? Will these countries have the infrastructure and funding to address these problems in a holistic manner? According to the case managers I interviewed, it is unlikely that the ASO will bounce back from its budget cuts and recent layoffs. What vitality it once had seems to have disappeared with the case managers who dedicated themselves to improving their clients' lives.

## APPENDIX A

### **Coding Categories for Content Analysis of Case Managers' Progress Notes in Clients' Files**

#### *Health*

Health-diagnosis: (The health diagnosis is the medical diagnosis of the client as HIV-asymptomatic, HIV-symptomatic, or AIDS-diagnosed.)

Health-Tcell: (Health-T-cell is the client's most recent T-cell count self-reported by the client.)

Health-CD4: (Health-CD4 is the client's most recent CD4 count self-reported by the client.)

Health-viral load (Health-viral load is the client's most recent viral load self-reported by the client.)

Health-OI: recent opportunistic infections (Health-OI refers to any opportunistic infections that the client has recently experienced.)

Health-HIV medications: (Health-HIV medications refers to the kind of HIV medications the client is taking.)

Health-non-HIV medications: (Health-non-HIV medications refers to the non-HIV-related medications the client is taking, such as for mental health or cardiological concerns.)

Health-medication adherence: (Health-medication adherence refers to whether the client is taking his/her medications in the correct dosage and at the proper times.)

Health-doctor relationship: (Health-doctor relationship refers to the quality of the relationship that a client has with his/her HIV doctor or mental health specialist.)

Health-appointments: (Health-appointments refers to whether clients are keeping regular HIV, medical, psychological, and D/A appointments.)

Health-hospitalization: (Health-hospitalization refers to whether a client has been recently hospitalized with a condition related or not related to HIV-positive status.)

Health-mental: (Health-mental refers to whether the client is experiencing mental health issues.)

Health-mental type: (Health-mental type refers to the type of mental health issue that the client is experiencing; it may include depression, anxiety, and/or schizophrenia.)

Health-mental treatment: (Health-mental treatment refers to whether the client is undergoing treatment for reported mental health issues.)

Health-cxsuicide: (Health-cxsuicide thought refers to a client's admission to thinking about suicide.)

Health-cmsuicide: (Health-cmsuicide refers to a case manager's query about client's suicidal thoughts or tendencies.)

Health-addiction: (Health-addiction refers to drug and alcohol addictions that may impact progression of HIV disease.)

Health-environmental: (Health-environmental refers to situations in which the client's environment is affecting, usually negatively, their physical and mental health. Situations might include homelessness, poverty/restricted income, domestic violence, crime, living in a dangerous neighborhoods, problems with family.)

Poverty, violence, homelessness, crime, dangerous neighborhood, family/domestic partnership

Health-social support: (Health-social support refers to the presence and type of social support that clients report.)

Health-insurance: (Health-insurance refers to the client's problems with or lack of health insurance.)

### *Surveillance*

Surveillance-services (Surveillance-services refers to the type of services provided by the ASO that the client uses. These services include food pantry, bus tickets, housing referrals, provision of housing, legal referrals, e funds, support group/counseling referral, clothing referral, GE vouchers, assistance with medications, referral for Cadex watch, bus tickets, cab vouchers.)

### *Responsible Citizenship*

Coding categories for rhetoric of responsible citizenship include: independence, self-sufficiency, "client is looking well," "client reports no needs/problems at this time," and ability to care for self and family.

Independence: (Independence refers to the client's ability to rely on her/himself and not to depend solely on the case manager for the provision of services.)

Self-sufficiency: (Self-sufficiency refers to the client's ability to be resourceful and to satisfy needs on her/his own.)

Wellness: (Wellness refers to the client's overall wellness in terms of a generic response to the query, "How are you doing?")

No needs: (No needs refers to the fact that the client does not report any needs to case manager in response to the question, "Is there anything (else) you need?")

Caring for others: (Caring for self and others refers to the client's ability to be responsive to her/his own needs and those of her/his family.)

### *Expertise*

Coding categories for expertise: how much client knows about HIV/AIDS, medications, and health according to case managers; client knows to ask for services related to health, such as needing a watch that alerts owner that it is time to take medication.

Expertise-HIV knowledge: (Expertise-HIV knowledge refers to what clients know about HIV/AIDS, medications, and the progression of the disease.)

Expertise-little HIV knowledge: (Expertise-little HIV knowledge refers to clients' limited knowledge about HIV.)

Expertise-HIV prevention: (Expertise-HIV prevention refers to client's degree of understanding about how to prevent transmission of the disease such as through practicing safer sex by using condoms or by using clean needles if injecting drugs intravenously.)

Expertise-health: (Expertise-health refers to clients' ability to ask for health-related services, not just specific to HIV.)

### *Obligation*

Coding categories for obligation: case managers' perceptions of clients' understanding that they have to "take better care" of themselves; clients' avoidance of "risky" behaviors such as IV drug use and unsafe sex.

Obligation-self-care: (Obligation-self-care refers to clients' understanding that they must take care of themselves.)

Obligation-avoiding risky behavior: (Obligation-avoiding risky behavior refers to clients' understanding that they must avoid risky situations that can lead them to unsafe situations that can jeopardize their health and put them at risk for transmitting the disease to others.)

## **APPENDIX B**

### **Interview Questions**

1. Please briefly describe your educational background.
2. How long have you worked at PATF?
3. How would you describe your job as a case manager to a layperson? In what does it consist?
4. What are your goals for your clients as a case manager? Could you briefly explain the rationale behind the client's treatment plan?
5. What role does a client's health play in your working with him/her? What goes into your assessment?
6. How do clients respond to case management?
7. How important is it that a client comply with the treatment plan? In your estimation what does it mean for the client's health?
8. What do you do if a client is not complying with the treatment plan? Can you tell if a client is not complying?
9. For you, is there a connection between a client's compliance with the treatment plan and his/her ability to be self-sufficient and responsible?
10. Based on your experience, how manageable is HIV/AIDS for clients?

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