

A New Kind of AIDS: Adapting to the Success of Protease Inhibitors in an AIDS Care Organization

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Using a case study analysis of Heath House, a Santa Barbara residential care facility for People Living With HIV/AIDS, this paper examines the effects of protease inhibitors on the life of an AIDS care organization. The case of Heath House reveals that when care providers are committed to static conceptualizations of an epidemic and its "victims," and have defined the value of their work in relationship to these conceptualizations, new technologies threaten organizational identity and stability. While prior research on goal displacement has emphasized the process by which an organization's members lose sight of their original goals to achieve greater efficiency or legitimacy, this study offers an example of the process by which members adhere to original goals and ideologies, even when change becomes necessary for organizational survival. This article examines tensions between residents and staff at Heath House that occurred when the very institutional culture that allowed it to thrive became anachronistic as AIDS changed. I explore problems of internal dissent and external problems of legitimacy.

KEY WORDS: AIDS organizations; goal displacement; caregiving; protease inhibitors.

In 1996, the advent of the protease inhibitor, a medication that inhibits HIV's capacity to replicate, revolutionized the experience of living with AIDS for people with access to medical insurance. Successful combinations of protease inhibitors and antiretroviral medications, popularly referred to as "cocktails," have resulted in phenomenal improvements in the health of People With AIDS (PWAs), as well as new understandings of AIDS as a chronic, manageable, and ultimately less sensational illness. As protease inhibitors change the nature of the PWA population, AIDS organizations and caregivers must adapt to the changing needs and desires of their clients. For caregivers accustomed to providing care for the dying, these

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changes can be difficult as healthier clients begin to assert their independence and autonomy. Changes in the perceived “neediness” of clients also have implications for community support, as organizations may fear that local donors and volunteers will be less inclined to give to clients who do not appear physically dependent.

According to “natural systems” theory, organizations are rational structures designed to achieve specific goals, even as their goals are constrained by the non-rational characteristics of individuals and the external environment (Selznick, 1949). Thus, in the interest of survival, organizations must adapt to these influences by becoming “institutionalized,” a process in which the self-defense of the organization and the maintenance of self-defense mechanisms become ends in themselves and the organization becomes “infused with value beyond the technical requirements at hand” (1957, p. 17). At the ideological level, institutionalization relies upon goal displacement, the processes by which the *values* of participants become displaced by the bureaucratic goals of efficiency or access to resources. Michels’ (1949) classic analysis of the German Social Democratic party is perhaps the clearest demonstration of how political goals are sacrificed in the name of organizational preservation, as he exposed the ways in which party leaders publicly maintained the revolutionary agenda of the party while becoming increasingly conservative and invested in bureaucratic power behind the scenes. Similarly, Clark’s (1956) study of an adult education program, Messinger’s (1955) study of a senior citizens’ economic advocacy group, and Zald and Denton’s (1963) study of the early YMCA emphasize the ways in which original humanitarian and political programs were eliminated in favor of less controversial, recreational programs that were more likely to ensure organizational legitimacy and survival. Thus, a common theme emerged from these early goal-displacement studies—organizations “sold out [their] goals in order to survive and grow” (Perrow, 1979, p. 182).

More recent organizational research supports these conclusions. Simmonds’ study of a feminist health clinic (1996) examines contradictions between the feminist ideals of collective decision-making and client sensitivity held by front-line staff and the bureaucratic, top-down structure imposed by administrators in the name of efficiency and professionalism. Staff complaints of being overworked and underappreciated reflected tensions between staff and administration that had resulted in a weakening of organizational morale and a sense among workers that the clinic was “a ship sinking under the weight of hypocrisy” (1996, p. 154). Emphasizing the external constraints faced by state-funded rape crisis centers, Matthews’ (1995) study highlights the ways in which data collection and formalization required by granting agencies also compromise the goals and methods of feminist service providers. And Liebow’s (1993) study of a women’s homeless shelter focuses not only on the amount of staff time spent filing paperwork, enforcing rules, and conducting interviews, but on the ambiguity of purpose produced by tensions between the goal of moral rehabilitation and the more value-neutral goal of providing shelter.

Similarly, AIDS service organizations (ASOs) are not immune to the internal and external pressures of institutionalization. In his study of the Gay Men's Health Crisis (GMHC), the largest ASO in the United States, Kayal (1993, p. 166) acknowledges the potential for GMHC to "become an end in itself," but concludes that this did not happen as a result of the uniquely empowered and unified nature of the gay volunteer community:

The agency began as the embodiment of gay community and that . . . is what motivates volunteers and defines the nature of the role that they perform—primarily healing homophobia. Undoubtedly, this goal and connection stand in opposition to both bureaucratization and the complete routinization of the volunteer role as experienced by the volunteers as representatives of the community. (p. 171)

Despite the changing population of GMHC's clients (no longer all gay men by the time of Kayal's study), Kayal argues that the unified expression of gay pride and the humanitarian struggle against homophobia remained antithetical to bureaucratization. This analysis suggests not only that some grassroots organizations are immune to goal displacement, but also that gay communities in particular may be more "responsive and sensitive" than other volunteer communities that might succumb to formalization (p. 170).

In response to Kayal's claim, I would argue that the extent to which AIDS organizations and volunteers are sensitive and flexible relies upon the image and reality of gay men being *sick*, in contrast with gay and lesbian resource centers, for example, that receive less money and attention for gay men (and lesbians) who are well. In their study of a Toronto AIDS Hospice, Chiotti and Joseph (1995, pp. 135–137) argue that AIDS organizations are symbolic spaces that embody the gay community's empowerment to take care of their sick, but are also unthreatening spaces that are used to bring AIDS, and gayness, to the attention of the straight public, especially the liberal elite. The promotion of a "right to live" agenda over a gay liberation agenda allows for greater support from the mainstream public, and indeed ASOs were developed (by gay men and lesbians) to provide services that improved basic quality of life for *dying* gay men. Prior to 1996, AIDS was presumed fatal (Callen, 1990; Ross, 1988), a presumption that had significant implications for the public image of PWAs as dependent, hopeless, and confined to the private sphere. To the extent that ASO funding, volunteer labor, and other forms of community support were provided in response to this image, it follows that any threat to it, including medical progress, would create a period of organizational identity confusion and require internal adjustment. Adjustment may take the form of changes in staff training and client service procedures, as well as larger changes in organizational identity (i.e., goal displacement). For example, following the advent of the Salk vaccine that ended the national polio epidemic, thousands of volunteers and paid organizers in the March of Dimes turned their attention to birth defects in general, demonstrating that organizational survival had gained as much, if not more, importance than the fight against polio (Sills, 1957).

This article, on the other hand, focuses on an organization that did *not* adapt its goals and internal mechanisms in response to environmental changes, even as these mechanisms became inappropriate and ineffective as means for providing client services. Whereas organizational research tends to emphasize the process by which members lose sight of their original goals and change organizational procedures to achieve greater efficiency, this study offers an example of the process by which members strictly adhere to original goals and refuse to change organizational procedures even when change becomes necessary for the organization's survival. While both processes reflect the nonrational characteristics of organizations produced by the personal and political commitments of individuals, the sorts of tensions they produce between management, staff, and/or clients are different. In other words, the source of "misbehavior," "betrayal," or "selling-out" shifts depending upon which actors (i.e., the staff, management, or clients) are invested in preserving original goals and which are posing challenges to these goals.

The data presented here is taken from a case study of Heath House, a residential care facility for PWAs in Santa Barbara, California. Similar to Kayal's description of GMHC, the culture of Heath House was centered around a staff ethos of sensitivity and flexibility, characteristics believed to be essential to caring for the dying as well as important to the house's reputation in the community. However, by 1996, residents taking new and successful AIDS medications were no longer dying, and as the staff maintained long-established care strategies and a traditional conceptualization of their work, tensions arose between the paternalism inherent in the house philosophy and the new autonomy of residents. The very institutional culture that allowed Heath House to thrive when residents were dying became anachronistic as AIDS changed.

BACKGROUND: THE HEATH HOUSE MODEL OF AIDS CARE

The Heath House Family

In 1996, the city of Santa Barbara, California, with a population of 85,600 persons, had two residential facilities for PWAs, Heath House and Sarah House. Opened in 1991, Heath House was designed as a residence for the dying, a comfortable alternative to the sterility of a hospital room. Heath House was not a hospice, as was frequently assumed. Hospices, originally established as an alternative to the medicalization of death and the concomitant disempowerment of terminally ill patients, find their ideological roots in a commitment to palliative care (symptom management and pain relief) and in an opposition to "aggressive" treatments (Levy, 1994). In contrast, many residential care facilities such as Heath House have invested in the philosophy that PWAs are more effectively empowered when they are allowed to choose among aggressive treatment, symptom management, or a combination of both. Whereas popular medications such as AZT and the new

combination “cocktails” were frequently taken by residents at Heath House, the use of such medications is prohibited for residents living in hospice facilities. Also, unlike traditional AIDS hospices, residents at Heath House paid approximately \$600 per month in rent, a fee that, if not for the inclusion of meals and the 24-hour presence of a staff person with basic nursing experience, is above the average cost for a single room in Santa Barbara.

As a method of understanding the intimate nature of their relationships with residents, staff traditionally adopted a family model of care in which they conceptualized the house as a family “home,” themselves as “mothers,” and the residents as “the boys.” The staff’s commitment to the family model was based upon the premise that providing a comfortable environment for people who were dying meant creating a space that resembled a family home in both its appearance and function. Because Heath House was a two-story Victorian-style home originally built as a private residence, there were no medical facilities in the house, nor was there anything about the house (with the exception of a pay phone in the hallway) that suggested institutional living. In fact, the only area that was designated “staff space” was the manager’s small office in a converted closet. The rest of the house was resident territory, complete with carpet, lace curtains, and a pet dog. The staff, predominantly female, were also explicitly advised that maintaining a family environment required that they be nurturing and attentive, qualities that Nancy, the house manager, associates with motherhood.

Nancy advocates a “maternal” relationship between the staff and residents because she believes it is “what works best” as a care strategy. In this sense, family-making at Heath House was not a process by which nonbiological intimates chose one another for long-term, reciprocal relationships (Weston, 1991; Stack, 1974); instead, similar to the maternal work done by women child care providers (Nelson, 1990; Wrigley, 1995), Heath House staff used the ideology of family, signified by the presence of a loving and authoritative mother figure, both as an explicit strategy for providing intimate care to people who are not intimates and as a justification for particular caregiving practices (that were eventually contested). At a 1993 board meeting of Congregate Care, the administrative umbrella agency that funded and operated both residential AIDS care facilities in Santa Barbara, the house manager reported to fellow board members about the smooth operation of Heath House. The subtext of her report was a poignant description of a large, well-mothered family:

We now know that we can prepare, without blinking, two dozen meals a day, while accommodating food idiosyncrasies and special nutritional demands. Everyone now can add oil to the van, and has been taught the location of the hidden lever to open the gas tank. The unequivocally best place for the Christmas tree has been officially established, as well as a decision that we would rather decorate it ourselves even if it takes three days. The carport is a great place for a barbecue, no matter what the weather. And clearly, the front porch is one of the best vantage points in Santa Barbara to see any parade. The coffee pot is almost always full, the washer is almost always emptied, and there are homemade cookies on plates

everywhere several times a week. And the residents—well, they are the people this place is really all about. We love them all—individually, and as a group. We have chosen to throw our lives together.

Not only was the ideology of family important to the daily operations of Heath House, but its very success as an organization was measured by the extent to which the house functioned as a family home. If Heath House did not maintain its special character as a site of maternal care for the sick, it would be indistinguishable from the impersonal facilities to which it was intended as an alternative.

Heath House and the Community

As is the case for many communities in which the wealthy congregate, Santa Barbara boasts a long tradition of community service, nonprofit organizing, and lavish \$200-per-plate charity fund raisers for local causes. AIDS has become one of the most fashionable of the causes to which Santa Barbarans generously give their financial support. Because the public embodiment of AIDS was concentrated in only three buildings—Heath House, Sarah House, and the local AIDS Service Organization—Heath House, the first and better known of the two residential facilities for PWAs, was extremely high profile in Santa Barbara. Each of the seven residents has had his/her picture on the cover of the local newspaper, has been interviewed on the local news, has been recruited for public speaking engagements, or has been showered with free goods and services from local businesses and volunteers. Unlike thousands of lonely and invisible PWAs around the country, Heath House residents mingled with local celebrities, talked politics with the mayor, and had an abundance of baked goods and flowers regularly at their disposal.

The histories and identities of the staff also contributed to the “special” character of the house. Nancy identifies as an AIDS activist and explains that she became the Heath House manager following the death of her husband (who was a resident) and as a result of her established membership in the house “family.” The other staff, in addition to having basic nursing skills, receive special AIDS-related training and are told upon hire that homophobia will not be tolerated, that their work will be emotionally exhausting, and that they must be prepared to deal with the visually excruciating dying process and the concomitant burnout that many staff experience. These expectations, explained during interviews for new staff, as well as Nancy’s self-proclaimed “eye” for who will fit in at Heath House, are intended to ensure that only brave, loving, and committed people end up working at the house.

The Cocktails

With the introduction of over one hundred combinations of new AIDS drugs have come astounding testimonies from PWAs experiencing the “Lazarus effect.”

In 1996, T-cell counts were rising and viral loads were plummeting as PWAs who were recently planning for death suddenly found themselves planning for life. The media were eager to report on the ramifications of the phenomenon by questioning what happens when AIDS becomes a “chronic, manageable disease” instead of a terminal one. With stories such as “The End of AIDS?” (Leland, 1996), “When Plagues End” (Sullivan, 1996), “The Twilight of AIDS?” (Rotello, 1996), and “O Brave New Protease World: AIDS Undergoes a Sea Change” (Griffin, 1996), the word from diverse sources was that the meanings associated with AIDS (i.e., AIDS = death, AIDS = disability, AIDS = social isolation) had undergone revolutionary changes. Yet despite the primarily hopeful message of these reports, each also notes that protease inhibitors do not work for everyone, are not readily available to PWAs without health insurance, and slow the course of the disease rather than cure it. This means that the long-term effectiveness of protease inhibitors, and therefore the future of AIDS, remains uncertain.

At Heath House, although not all of the “healthy” residents were taking protease inhibitors, some had begun to rethink their plans and opportunities in light of the visible effects of these drugs on their friends and acquaintances. Perhaps the most significant effect of protease inhibitors on Heath House was evidenced by its shortened waiting list. Because there were fewer end-stage PWAs with an urgent need for care and housing, Heath House was becoming home to a new population of relatively healthy and active people living with HIV.

METHODS

Initial access to Heath House was aided by my past volunteer status at a local AIDS service organization and a referral from staff at the second residential AIDS care facility in Santa Barbara (where I had frequently visited a sick friend). The details of my research agenda were explained in my proposal to Congregate Care and passed on and agreed to by Heath House residents and staff before the project began. Residents and staff agreed that their names would be disguised on any report I wrote, while the name of the house itself could be identified. In order to both facilitate my research and express my gratitude for their willingness to participate in this project, I became an official volunteer, cooking and cleaning while I talked to residents and staff about the Heath House “family.” I had two regular evening shifts per week, in addition to casual visits that became more frequent as I befriended some of the residents.

When research for this project began in January of 1996, six gay-identified white males and one straight-identified white female were living at Heath House. I collected data from January through July 1996, the six months during which I served as both a volunteer and a researcher at Heath House. During this time, formal, structured interviews (tape-recorded and transcribed) were conducted with Nancy, the house manager, and Shane, my primary resident informant. After these

interviews, and as I became more aware of the staff's concerns about information control, I discovered that informal interviews were more practical and informative because they allowed residents to be more spontaneous and less self-conscious. Multiple informal interviews (conversations within the context of my participant observation) were conducted with all of the residents, with the exception of William, who was particularly ill throughout the course of the project. I recorded the details of these conversations in my field notes either privately while at Heath House, so as not to distract the residents and staff, or immediately upon returning home.

Being a participant observer and a volunteer at Heath House necessitated developing intimate relationships with the residents, an experience that was both part of a natural progression in the research and a strategy for gaining greater access to the very private life of the house. I became emotionally invested in the lives of the residents, and like other ethnographers doing AIDS-related research (Kotarba, 1990; Gagnon, 1992), I considered the extent to which it was important, or possible, to create and maintain a professional boundary between myself and my research participants. This boundary work takes center stage for Pearson and Bourgois (1995), whose work suggests that when one's participants are HIV-positive heroin addicts on the streets of San Francisco, emotional distance from the unpredictable and emotionally charged details of participants' lives is not a useful or realistic goal. My approach, like theirs, was to become immersed in the lives of my primary informants while simultaneously being explicit with them about the progress of my work. As I came to know the residents well, it became apparent that personality and life style differences made some more accessible and vocal than others. Some were curious about what I hoped to learn by observing their daily lives, while others, according to the house manager, "just need[ed] someone to listen." Irrespective of their motivations, four of the seven residents became primary informants, spending considerable time away from the house (most often in bars or restaurants) sharing their thoughts about its atmosphere and operation, as well as their strategies for coping with illness and group living. Although I ended active data collection in July of 1996, I remained connected to the house and kept abreast of its news (through resident informants) until its closure in July of 1997.

I used a "grounded theory" approach to analyze the data collected during participant observation at Heath House, allowing theory to surface and be transformed throughout the research process (Glasner and Strauss, 1967). I began the project interested in the general subject of family-making and other strategies for giving and receiving terminal care. Beyond that, however, I let relevant data emerge from the narratives and behaviors of the residents and staff, as well as from textual sources to which I was directed, such as rental agreements and newspaper articles. Yet as a result of the time frame in which I happened to study Heath House (the year in which protease inhibitors were made available), as well as of my methodological approach (allowing residents' theories about their lives to centrally inform my own), even the general subject of the study shifted many times. Given that only

one of the seven residents at Heath House was “dying,” it became evident that the story of Heath House was less about how terminal care is provided and more about how staff and residents negotiate the expectation of terminal care provision when it is no longer needed. As I observed the staff and residents spend more time arguing with one another about house rules than providing or receiving physical care, I shifted my theoretical focus to this struggle between residents’ autonomy and the paternalism built into the traditional caregiving model of Heath House.

FINDINGS

Old methods of house administration and caregiving that were once appropriate for residents confined to their beds have new and complicated meanings when applied to a house that is primarily occupied by healthy HIV-positive adults. At the time of my study, some Heath House residents were patronizing local bars, vacationing in Hawaii, starting relationships, and, in one case, getting engaged to be married. It was this pattern of resident activity that put the identity crisis of the house in the foreground, making explicit that previously effective strategies for resident care were no longer suitably meeting the needs of healthier residents. This identity crisis was manifested as a series of conflicts between residents and staff over the family model, and specifically the tradition of maternal love/authority embodied by the house manager and unquestioned by previous residents. Improvements in the residents’ health also produced tensions between active resident life styles and Heath House’s legitimacy as a favored nonprofit organization.

Resistance to the Family Model: Rules, Subversion of the Rules, and Sanctions

When residents move into Heath House, they are given an admissions agreement that includes a list of house rules. Some of these rules are meant to be solutions to, or clarifications of, the problems that arise in group living arrangements, while others are “basic safety rules” dictated by the licensing agency.

Heath House Rules¹

1. No alcohol or drugs are allowed in the house or on house property.
2. Smoking is prohibited inside the house.
3. All medications, including over-the-counter medicines such as aspirin and laxatives, are kept in a locked drawer in the house office. Only staff are allowed keys to this drawer.
4. Residents take medications at regularly scheduled times.
5. With permission, residents may take less than the prescribed amount of a particular medication, but not more.

¹This is an incomplete and paraphrased list.

6. Residents must inform staff before leaving the house.
7. Residents must obtain permission from house management before going on vacation or spending the night elsewhere.
8. Residents must obtain permission before having overnight guests.
9. When not in their rooms, residents are requested to leave their bedroom doors open so as to “encourage a family environment.”

Heath House residents were divided into two camps when it came to adhering to the house rules. Healthier residents resented these rules, while those who either needed or wanted to stay at the house expressed appreciation for behavioral guidelines. Healthy residents argued that while it is sensible for staff to be constantly informed of the whereabouts of those residents who required frequent medical attention, there was little reason for other residents to report to staff each time they went shopping or out to dinner. Similarly, whereas it seems logical for staff to monitor drug interactions for residents in the latter stages of illness (when dementia may be a factor), healthier residents felt frustrated and humiliated by rules prohibiting their keeping cough syrup or aspirin in their rooms, and requiring their asking a staff person to retrieve such minor medicines from a locked drawer. As a trained pharmacy technician, Shane found this and other routines especially humiliating:

Shane: God, you read these rules, you know, Heath House and Sarah House philosophy, blah, blah, blah. It sounds, oh, it sounds great and loving and totally focused towards the residents. That’s how it should be but it sure doesn’t feel that way.

JW: Why doesn’t it feel that way?

Shane: Because it feels like they, it feels like what they’re doing is they want control. They want too much control . . . They don’t just let you live. They’re invasive into every aspect of your life, you know. I mean . . . when I leave the house, I’m supposed to tell them where I’m going.

JW: Every time you leave the house?

Shane: Yeah, as a common courtesy, but you know, I don’t a lot of the time. And I don’t get chewed out for that ’cause they kinda know me. And maybe someone more like William, say William was gonna leave the house, they’d wanna know where he’s going. With me, they kinda, unless I’m gonna spend the night out anywhere, I could be gone the whole day and not really be chewed out too much by it.

According to Nancy, the house manager, the primary reason that Heath House needed to have rules was because “a lot of people who don’t know each other living together is a very difficult situation. And a lot of people [move in] without basic consideration skills, and sometimes you really *do* have to dictate these things.” Despite this rationale, healthier residents believed many of the rules were inappropriately applied to healthy adults, and were therefore able to rationalize

breaking them. This created a dynamic in which the more healthy/active residents (Shane, Kevin, Patrick, and Mike) lived with the concern that they would “get in trouble” or “get chewed out.”

Because the house rules were conceptualized by the staff within a logic of how families operate (i.e., residents are like children who need to be given behavioral guidelines), residents’ resistance to these rules was also a resistance to the imposition of the family model. In the past, intimate kinship roles at Heath House appeared to supplement, and in many cases replace, biological family support. At the time of my research, although some of the residents at Heath House had little or no contact with their biological families, this was often due more to geographical distance than poor health or social stigma. Yet Nancy still imagined herself a surrogate mother: “You know, in watching different styles of people who have worked here, I always think it works the best. Because truly, where is everybody’s mother who lives here?” It was a tradition for the Heath House manager (who, with one temporary exception, has always been female) to be referred to as the “house mother” or “house mom.” Conversely, the house manager and other staff members could be heard referring to the residents as “the boys” (there is only one female resident), despite the fact that the youngest resident was twenty-four years old, while Nancy, herself, was in her mid-thirties.

Age is not the operative characteristic that distinguished the residents from the staff; it was, rather, the relationship between “the provider” and “the dependent” that was cast as a biological relationship and that distinguished between the roles of mother and son. The insignificance of age is illustrated by a conversation that occurred between William, a sixty-eight-year-old resident, and Denise, a nineteen-year-old staff person.² Denise was attempting to reassure William that the discomfort of being moved around on the bed while she changed his dirty sheets would soon be over. “That hurts,” William was crying. “I’m sorry. I know it hurts, William. I don’t want to hurt you, but we have to take off the dirty sheets. I’m sorry. I’m *so* sorry.” Denise’s voice wavered as if she were about to cry. Any words of comfort that Denise gave in this intimate moment, no matter how infantilizing they may be in another context, were likely to be appreciated by William, or were, perhaps, due to his intense pain, of no consequence at all. It is this caregiver-dependent relationship to which the staff had been accustomed since the house opened in 1991. They changed sheets and diapers, cradled residents in their arms, and offered words of compassion. By the end of my study, William was the only resident at Heath House who required such intensive care, and there appeared to be fewer and fewer PWAs like him in Santa Barbara.

Despite the ways in which family-making provided needed stability and support for physically and emotionally dependent residents, the frustrations of healthy

²When the staff are not able to sit with William in his bedroom, they listen for any sounds of pain or discomfort using a Fisher-Price baby monitor. One afternoon I happened to be sitting in the living room next to the monitor while Denise was changing William’s bedding. The volume on the monitor was high enough that I heard their conversation without intending to do so.

residents suggest that when PWAs conceive of themselves as healthy and independent, these same strategies are no longer effective. For this growing group of asymptomatic residents, adopting an alternate family is not of primary importance, and is acceptable only when it does not interfere with often very different goals. Shane, an asymptomatic twenty-four-year-old resident, explained his reservations about Nancy's preferred care strategy:

I just feel that as long as she knows her place—I know that sounds awful—but she's just the resident manager. She's *not* my mom . . . I feel like she's almost a probation officer or someone, someone you gotta report to, and everything's gotta be cool with.

Another matter that disrupted family-making at Heath House was the lack of dinner attendance by the healthier residents, purportedly due to conflicts with the six o'clock dinner hour. The absence of Kevin, Shane, Mike, and Patrick at the table had been a significant source of frustration for "loyal" dinner attendees such as Philip and the staff. Philip, a newly healthy resident in his forties who often spoke about his "near-death experience," had been the most vocal resident on this front, regularly showing up at the half-vacant dinner table and characterizing the absence of these residents as "rudeness and insensitivity." When confronted by Philip at the weekly house meeting, the younger or healthier residents (who tended to either eat out at restaurants or make meals for themselves later in the evening) responded by stating that they had a right to eat when and where they desired as long as they followed house rules requiring prior notification.

The debate over dinner attendance speaks not simply to the issues most visibly at stake. By complaining about the absence of the younger residents, Philip made explicit a debate about the extent to which the residents are obliged to participate in making Heath House into a family home. For years, residents who were too sick to leave the house understood it to be the place where they would eat their meals, spend their holidays, and find companionship. Younger and healthier residents, however, expressed the importance of being active and spending time away from the house "because they could." These residents believed that their health might last indefinitely, making their resistance to being treated as sick people even more pronounced. Alternatively, their resistance was based on an awareness that their health might be fleeting and that they should enjoy it while they could.

Healthy residents also expressed their displeasure with the way that house rules affected their private lives. When Shane and Kevin requested approval from Nancy for a three-week vacation to Miami, she responded that Shane, but not Kevin, could go. Kevin was told that his request was denied because he was already going on a vacation during the month in question. Nancy argued that Heath House "can't have residents gone for weeks at a time when other people are on a waiting list to live in the house." Shane and Kevin did not accept this logic because, like most renters, they are accustomed to a system in which if one pays rent, one's presence is of no significance to the manager or owner. These debates intensified on June 1, when Heath House instituted a new three-night absence policy. The new policy stated that residents must receive advance approval for absences longer than three nights per

month. Patrick, who had been spending several nights per week with his partner, and Kevin, who had previously been reprimanded for spending too much time away from the house, both decided to move out within a week of implementation. In the past, both Patrick and Kevin had asked Nancy for permission to have overnight guests as an alternative to spending nights away from the house. Patrick claims that Nancy responded by stating that “this house isn’t a place to bring your tricks.” Yet it is not surprising that these requests would be denied, as the staff at Heath House were grappling with the contradiction between their sense of what a home for PWAs should look like and the reality of what the residents wanted the house to be. House founders and current staff had not expected residents in an AIDS care facility to bring home sexual partners, nor had they imagined that residents would be healthy enough to do so.

Although the ultimate sanction for breaking Heath House rules was eviction (with minor punishments being, for example, refusal of a vacation leave), staff made use of more subtle disciplinary mechanisms to regulate resident behavior on a daily basis. Of these mechanisms, the residents appeared most preoccupied with “being charted.” Charting, or recording the daily happenings of the house, was part of each staff person’s regular duties. The chart itself was a spiral-bound notebook that was “off-limits” to the residents and served as a record for Nancy and the other staff of what had transpired during a given shift. The residents believed that staff were charting not simply administrative notes, but also personal information about their social lives, a belief that persisted in part because residents were not informed about the contents of the chart unless disciplinary action was pursued. For example, when Patrick, Kevin, and Mike were gathered in the living room talking about their frustrations with Shane (who was upstairs), the staff person on duty overheard this conversation and charted it. The residents involved were later reprimanded for “gossiping.”

When I asked Nancy about charting, she wanted to dispel what she perceived to be resident rumors about its function and stated that only physical symptoms and other health-related issues were written in the chart:

Charting is a state rule and it’s something we’ve always done anyway. It’s a way for one shift to communicate with another. It’s not . . . it’s truly not about behavior. I’ve tried to explain that to them (the residents) before. Because everybody gets really paranoid when you sit down and write, and they think they’re being written up, and this and that. No, it’s, you know, what a state of health was in that day. And sometimes it just says “fine.” It’s not behavior, and I told them that before, unless it’s truly really erratic or really unusual, which of course we would write it . . . It’s things like how much somebody ate if they ate meals, you know. It’s . . . [laughs] . . . they’re so paranoid.

Still concerned with the residents’ beliefs that their social lives were being “monitored,” I asked Nancy whether the staff ever recorded conversations that occurred among residents:

Nancy: Never. But it could be . . . “Shane seemed very depressed.” But people are very scared. You know, we don’t use a lot of subjective things. It’s mostly

objective: “This is what I saw,” not “this is what I felt was going on.” You know, subjective doesn’t really do anybody any good. It’s a point of paranoia, though. JW: So is the belief that their interactions are being charted in the residents’ imaginations?

Nancy: Mostly it is, yeah. If there is a fight between residents it would be charted. I mean some things really are real problems. And when I come in the next day, it helps me to be able to read that that happened. ’Cause everybody acts different around the manager.

As Nancy and I discussed charting further, it became clearer why the residents might be suspicious about what was being charted. Nancy stated that only health-related matters were charted, yet she also said that resident arguments were documented in the chart. Residents were not “paranoid,” therefore, as much as they were alert to being watched by the staff. Careful monitoring and observation were part of the routine functioning of Heath House because staff were instructed that they needed to “watch” and “listen for” residents who were very ill. When applied to healthy adults, however, these practices elicited feelings of anxiety. Residents learned to monitor their own behavior while in the presence of staff, knowing that particular behaviors could result in being charted. Like Foucault’s prisoners in the panopticon (1975), the Heath House disciplinary apparatus was so effective because the residents learned to self-regulate, assuming that a staff person might always be watching or listening. After years of unquestioned charting, this practice had become a problem not only as residents became healthy enough to notice it, but as staff found themselves with fewer medical conditions to write about and more “interpersonal” material upon which to focus.

Crisis of Legitimacy: Relations with the Environment

Heath House’s reputation as one of the most deserving and “special” local nonprofit organizations in Santa Barbara, as well as its financial dependence upon this reputation, made the management of resident behavior particularly important to Congregate Care. The culture of the house enforced the notion that there was a Heath House image to be preserved, an image that was largely dependent upon visions of needy and sick PWAs. Residents who appeared no more physically dependent than potential donors matched neither the traditional intentions nor the need to protect the Heath House image. Therefore, when Mike and Shane were dramatically evicted during the summer of 1996 for drunkenness and urinating on the front lawn, the staff explained to me that the eviction resulted not only from the need to follow house rules and act in the best interest of the other residents, but also from the need to protect the Heath House image. After six months of my field work, more than half of the original residents had left Heath House to live elsewhere, a surprising outcome given the house’s function as a place for the dying. Health

brought with it the luxury of other living options and increased the opportunity for rule breaking and rebellion within the constraints of semi-institutional living.

In the midst of these changes at Heath House, local newspapers broke the story of resident neglect at Christopher House, another residential AIDS care facility approximately forty-five minutes south of Santa Barbara (Saillant, *Ventura County Star*, May 18, 1996). By calling into question the image of noble and well-intentioned staff members working to improve the lives of PWAs, the story had significant implications for Heath House and local AIDS care in general. The media coverage the incident received created an atmosphere in which both residents and staff knew that the quality of Heath House services could be a matter of public concern. Although I never witnessed the types of neglect reported at Christopher House, Philip and I had a telling conversation shortly after the story broke in May. As he had many times before, he shared his frustration with the quality of meals at the house, yet this time added that if there wasn't an improvement, he was going to contact the *Santa Barbara News Press* and "break the story" about resident neglect. Other residents had also begun to develop a sense that "injustices" were being committed at the house and decided to share their feelings with outsiders. One evening while Patrick, Shane, Mike, and I were at a local bar, they began grumbling about the unfairness of the three-night absence policy in front of Sam, a fairly well-known AIDS activist and educator in Santa Barbara. After being told the details of the policy, Sam became angry. "What?! That's ridiculous! Just because you have AIDS and you live at Heath House, you have to stay home and not have a life? I'm going to talk to [the director] about this . . . and if nothing gets done, I'm going to report this to the Stonewall Committee (a local LGBT political committee)."

After the Christopher House story had gone public, I noticed an increase in the control of information at Heath House. Staff concerns about my presence as a field worker, the discussion of personnel matters, and resident "confidentiality issues" increased at the same time that healthy residents began considering alternate living arrangements and speaking openly about their dissatisfaction with the house. Suddenly, Heath House was in danger of having the very people who had traditionally been grateful for the services of the staff go public with their complaints about disciplinary mechanisms and quality of life.

Approximately one year after my fieldwork had ended, a local newspaper reported that the board of directors had reluctantly decided to close Heath House on July 1, "a difficult but unavoidable decision spurred by changing AIDS trends." The article stated that "the advent of powerful new drugs, known as protease inhibitors, allows those with AIDS to live longer; locally, that translates to fewer residents—and thus rental income—at Heath and Sarah Houses" (*The Independent*, June 1997). Although the Board of Directors stated publicly that the decision to close the house was "difficult but unavoidable" in part due to "fewer residents," what was not publicly discussed was the high number of residents who were either

evicted or moved out due to dissatisfaction with the house rules. In other words, while linking the decrease in residents to protease inhibitors is not inaccurate, this account overlooked the tensions produced between residents and staff and the relationship of these tensions to resident health and staff paternalism.

ANALYSIS AND CONCLUSIONS

Unlike grassroots organizations in which volunteers and front-line workers struggle to maintain the “vision” of the organization in the face of top-down administrators who “sell out” their original goals, the management and staff at Heath House did not lose sight of their original commitment to fight AIDS by providing care to people who were stigmatized and had few other living options. Instead, AIDS itself changed, transforming along with it the dynamics of stigma and opportunity, if only temporarily. To the extent that Heath House rules and procedures became more important than respectful care and responsiveness to residents’ needs, the story of Heath House demonstrates the familiar trajectory of organizational goal displacement. Yet it is perhaps more sociologically significant to note that these rules (and the ideology of family that supported them) had always existed, were once of no consequence to residents, and yet became a source of considerable tension that took management and staff quite by surprise. This change in the effectiveness of Heath House procedures was not a result of a change in the procedures themselves or of a change in the organizational ideologies themselves. Rather, it was a result of a change in exogenous forces that highlighted a previously hidden, or previously less problematic, aspect of organizational ideology and identity. At Heath House, this process occurred as the dual nature of the maternal care model—mother is both unconditionally loving (despite stigma associated with AIDS) and a well-intentioned disciplinarian who sets rules for “appropriate” and “safe” behavior—became evident when residents began to challenge house rules. While both of these aspects of “mother” were present from Heath House’s beginning, the former and more benign aspect was foregrounded during the years in which Heath House residents were sick, and the latter took center stage as they became well. In other words, the ideology of a Heath House family, composed of a mother and her sons, was not just a means for providing intimate motherly care to non-intimates, it was also a model intended to ensure a smoothly functioning organization in which rules were dictated and followed.

Yet still the question remains—why couldn’t Heath House staff adapt in order to prevent or ameliorate the tensions produced by resident health? The organizational literature I have reviewed here suggests three different considerations that drive organizations to adapt to external demands or internal pressures. First, members may become personally invested in increased bureaucracy as a result of the power, efficiency, and/or legitimacy that bureaucratic structure brings. Second, members’ duties may become increasingly administrative, despite

recognized drawbacks, in order to manage the extensive paperwork that must be done in order to receive funds from granting agencies that allow for more or better services. Third, members may choose to focus on an entirely new program, service, or issue because organizational survival is being threatened. While the first and second considerations are not relevant to the Heath House trajectory, certainly Congregate Care could have ensured the long-term survival of Heath House by changing the kind of care provided there. For example, a few larger urban cities have established living environments for PWAs that provide each resident with privacy (individual units in an apartment complex, cottages connected to a central house, etc.), while simultaneously providing for emotional and practical needs such as medication management and health care referrals. Because the long-term effectiveness of protease inhibitors is uncertain, Heath House staff could have resolved many of the tensions with residents by letting go of the family model in favor of a “boarding house” model that still recognized the need for minimal PWA care.

Despite these options, Heath House staff remained invested in a terminal care model because they had committed themselves to AIDS at a time when it was, and because it was, synonymous with death. As part of the AIDS activist community and as the widow of a PWA, Nancy’s motivation for working at Heath House was to care for bodies that wore the “spectacle of AIDS”³ (Watney, 1994), work that few others had the courage to do given the looming presence of death (at the house) and fears about transmission by “casual” contact. Staff came to Heath House to change diapers, perform spoon-feedings, and attend to wasting bodies because to provide such care for dying gay men was not just professional, it was political and even spiritual. It was what brought Heath House staff respect and admiration in the AIDS community, and, more broadly, the Santa Barbara nonprofit community. Staff were conceptualized as “special” people and the house’s reputation relied on the notion that it and its staff were “blessed.” Staff training and job descriptions also reinforced the expectation of a special Heath House family, including paid group therapy for staff and collective grieving rituals. All of these practices and their ideological foundations not only produced a resilient Heath House culture, but were part of the Heath House “project” from the time of its opening in 1991.

Thus, the autonomy demanded by residents and the ordinariness of their lives once they became well completely transformed not just the logistical aspects of the staff’s work, but its very meaning. On one hand, this process put the ideological character of family into relief by revealing that, unlike in “real” families, Heath House “children” weren’t allowed to grow up.⁴ On the other hand, because Heath House staff conceptualized themselves as family, this metaphor holds some explanatory power by highlighting that, as in “real” families, children rarely grow up without conflict over rules and autonomy, and when they do, a parent’s work

³I.e., lesions, wasting, hair loss, etc.

⁴Thank you to William Arney for clarifying this point.

is (presumably) over. Given the importance of family ideologies to the staff, one would in fact expect such conflicts, and perhaps ultimately the closing of the house. These organizational tensions are the less predictable social outcomes of the proclaimed "end of AIDS," tensions that developed in response to a new kind of AIDS that challenged the "specialness" of Heath House and the noble character of the work that was done there.

The story of Heath House provides an example of the complicated role that management ideologies and individual motivations, both personal and political, play in helping to determine an organization's ability to adapt its goals and internal mechanisms in response to environmental changes. While Heath House may not have been a more ideological organization than larger organizations such as the March of Dimes, it relied heavily on ideology in lieu of the bureaucratic structure and reliable funding characteristic of larger organizations. Thus, small, ideologically-based organizations may find it especially difficult to adapt to environmental changes if they have fewer material resources to struggle to maintain, and therefore rely on ideology to recruit and motivate staff and volunteers. While a powerful ideology may make it possible for an organization with few resources to survive in the face of challenging circumstances (such as an AIDS epidemic), the very same ideology may make it difficult for the organization to adapt to changes in these circumstances.

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