Getting "Hooked Up" An organizational study of the problems people with HIV/AIDS have accessing social services

A Research Proposal

prepared for

National Welfare Grants Health and Welfare Canada

Co-principal Investigators

George W. Smith
Senior Research Officer
The Ontario Institute for Studies in Education

Eric Mitchell, Co-ordinator
The Community AIDS Treatment Information Exchange

Douglas Weatherbee
The Community AIDS Treatment Information Exchange

December 1, 1990

PROJECT DESCRIPTION

1.0 Statement of Objectives

People who are HIV+ or who have AIDS experience distinctive problems because of their infection: The impairment of their health is long-term; if AIDS has developed, it is a terminal disease; they may be well for long periods of time, or suffer from long periods of low energy, interspersed with episodes of more or less serious illness. In spite of a changing public opinion, they are likely to be stigmatized. There are still irrational fears of contagion. If a man is identified as HIV+ or as having AIDS, he is likely to also be identified as homosexual and hence experience the widespread homophobia typical of our society. People with HIV/AIDS may find friends and relatives unable or unwilling to sustain support, either material or emotional. They may be unable to sustain employment at their former level or at all; coworkers may be unwilling to associate with them. They can experience emotional trauma as a result of any combination of these factors.

People who are HIV+ or who have AIDS have radically to revise their lives and expectations. They are forced to live differently. How people reorganize their everyday lives under conditions of HIV/AIDS, consequently, can be viewed (as "Wages for Housework" theorists have viewed it) as work. For example, they may well have to change their lives if they are to maximize their chances of not progressing to frank AIDS by seeking sources of health care, information, and support. If they have AIDS, illness commits them to ongoing participation in the health care system on a chronic basis. This is particularly so during periods of severe illness. In addition, those close to them who choose to become involved in their support are also absorbed into this work regime, contributing resources of time and effort. What we are interested in, in the first instance, is the organization and reorganization of this kind of personal work regime necessitated by HIV/AIDS. We call this the "life work" of people because it is critical to their efforts to extend their lives. It is the organization of this "life work" and its necessary linkages to the health care system that distinguishes people with HIV/AIDS from the majority of recipients of social services.

For the most part, the main business of AIDS is addressed from the standpoint of the health care and social services systems—e.g., the problems they confront in providing care, public health information and education, and in providing welfare supports, and so forth. This study takes a different approach. It begins from the standpoint of those who are HIV+ or have AIDS; it examines the social services system from this standpoint. This procedure is not concerned, however, with the subjective feelings or perspectives of these people. Nor is it intended to indict or to criticize social service agencies or the "attitudes" of their workers. Rather, it is focused on how the interface between the two gets organized as a matter of the everyday encounters between individuals who are HIV+ or who have AIDS and social service workers. For this reason, we have conceptualized the issues for people with HIV/AIDS in terms of the everyday on-going organization and reorganization of their "life work." We want to insist that people with HIV/AIDS put time, thought, and energy into their daily living and that this "life work" must, of necessity, be organized in relation to the social services system they depend on.

On the one hand are the distinctive configuration of everyday problems and working solutions these people put together, and on the other, the institutionalized practices of agencies organized by legislation, administrative regulations and practices, professional

philosophies, etc. Our questions are these: How is this relation actually organized? In particular we want to examine the legislation, regulations, policy directives, and standard paperwork practices, that organize the interface between people with HIV/AIDS and social agencies from the institutional side. What characteristic problems emerge? How are such problems generated by the interplay between the HIV/AIDS configuration of life problems and the institutional structure within which social service agency employees work? How do the conditions of the everyday work of living with HIV/AIDS, the organization of that work, and its relation to social service agencies, vary with the different social locations (e.g., class, gender, ID-use, ethnicity, race, etc.) of these people? And, lastly, what effect does the stage of someone's illness have on this organizational matrix?

In preparation for this project, we interviewed advocates for people with HIV/AIDS who described this interface as a process of "hooking up" individuals to the services to which they are entitled. It is this "hooking up" of the everyday "life work" of HIV+/AIDS people with the institutional structure of social service agencies that is the focus of our study.

2.0 Background Information

2.1 Establishing the Problematic

Our problematic arises out of the everyday experiences of people with HIV infection as they encounter the organization of social service agencies. Within the HIV community stories constantly circulate about the problems people have getting the social services to which they are entitled. Here are some examples:

- ** there were the problems a mother encountered last summer trying to secure home care for her son who was in the terminal stages of AIDS. She wanted to take care of him at home rather than leave him in the hospital. He was a single person in his late thirties who had lived on his own for many years. When she took him from the hospital to her home, her income rather than his became the basis for determining the services to which he was entitled. Because hers was a middle-class family that was entitled to very limited social services, his home care became a burden on the family's financial resources, even though these arrangements saved the government the cost of hospital care.
- ** An 18-year-old woman with HIV infection is attempting to return to high school in January of 1991. She had been living on-and-off with her mother in northern Toronto; the high school she is able to attend is in central Toronto. She intended to move into an apartment near her new school at the beginning of November. Her living arrangements with her mother have been precarious because of her HIV infection. She also wants to establish herself in her own home before school begins. She expected that Student Welfare would cover her living costs for November and December. However, she found out at the beginning of November that she would not be eligible for Student Welfare until she actually begins school. This news came as a complete surprise to her. She then applied for General Welfare but was told it would take at least 1 1/2 months before she would receive any money. She approached a community-based group in Toronto for assistance, but it too was unable to help. She is now trying to raise enough money to live on her own for two months until her schooling and Student Welfare begins.

These two stories illustrate the disjunctures between the way people with HIV/AIDS, and their supporters, organize their "life work" and the institutionalized responses of social service agencies. These organizational disjunctures can take many forms. What we are particularly interested in is how the "life work" of people with HIV/AIDS is impacted by both the stigma and stage of their illness in relation to the operations of social service agencies.

Another, quite different example, comes from the group interview we conducted with benefits counselors working with people with HIV/AIDS.

In my experience there's a difference between the people who for what ever reasons in their lives were previously hooked into social services, they've been on welfare, they know the ropes, they know what they can expect. . . . So people who've been users of those services ahead of time. . . . Once they've been diagnosed for HIV, it's easier for them. They've adjusted to poverty, it's not a good thing but they can live on it, they know what that cheques means. . . . It's the family or the individual, whether gay or not, who suddenly realize that this cheque is what they've got to make do with. This is it. There is no more out there. So we [counselors] can say "You need to adjust to living within this amount." But, Family Benefits is a joke! What's much harder is their friendship network may not realize that living in poverty is a real problem. . . . You know, they can go ask for a winter coat. Well, you know what it's like to go sit down there at the [Welfare] office and have to wait there and ask for something. The shock of this, what this is a class crisis. . . .

Here the organizational disjuncture between a person's everyday life and the institutionalize work processes of social service agencies can be seen as one of class. This kind of problem has also been described by Kaetz (1989). What is ordinarily not visible to middle-class people applying for welfare is the work the welfare system does in helping manage the labour market (Hick, forthcoming). If at nothing else than an intuitive level, this condition is understood by the poor because it is integral to the official treatment meted out to make sure they are not merely poor but are the "deserving poor" before providing financial relief. People living in poverty, consequently, often know how to organize their lives more easily to fit the constraints imposed by dependence on social services. For middle-class people with HIV/AIDS, who have never been unemployed and who now can no longer be employed, the work welfare agencies do managing the labour market creates organizational problems for them in their efforts to get general welfare or family benefits. The work social agencies do to ferret out "free-loaders" is the bane to people with HIV/AIDS. They are, in this respect, a feature of the social organization of class in our society.

The organizational disjuncture, presupposed by the metaphor of "hooking up." is the focus of counselors in community-based organizations who see their work as helping to bridge this gap. They do this primarily by being advocates for people with HIV/AIDS.

Well I know when I have a woman who comes in, an immigrant woman or a woman who speaks Portuguese, English as a second language, and [she has] AIDS. It really is about. . . empower is such a nifty word these days. . . but it's how to very carefully go through, "You have a right to ask for these things," "Can I partner with you." Being an advocate for somebody. That tends to be our role in these kinds of community based agencies.

From our preliminary inquiries, it appears that the organizational disjuncture that we have identified as existing between the everyday, common-sense organization of people's lives

and the institutionalized work processes of social service agencies is what needs to be understood if the barriers affecting the delivery of social services to persons living with HIV/AIDS are to be identified and modified.

2.2 Review of the literature

2.2.1 The study of the relation between people with HIV/AIDS and social services agencies

Literature that addresses social services with regards to people with HIV infection is scant. Some articles have as a focus the attitudes and perceptions of social service practitioners and society as a whole as they relate to social services for HIV+ people (Andy Fraser, 1987; Dhopper et al., 1987-88). There is also literature which concentrates on the education and training of social service practitioners as it relates to people with HIV infection (Michéle Bourgon and Gilbert Renaud, 1989; Canadian Association of Schools of Social Work, 1988), and on the community response to AIDS in Canada (Nils Clausson, 1989; William Ryan, 1989). There are researchers who have made use of a needs assessment methodology to ascertain the perceived needs of social workers and HIV+ service users (Elizabeth Clark et al., 1989; Fred Mathews et al., forthcoming) and others who have measured the attitudes, knowledge and behaviours of uninfected Canadian youth (Allan King, et al. 1988; Joyce Radford, 1989).

In a review of the available literature, which is included in Appendix A, we have found that study of the social organization of the social services from the standpoint of people with HIV whose "life work" includes accessing these services, has not taken place. The accounts of HIV+ people on their daily work of accessing social services remains absent from the literature with one exception (Deborah Kaetz, 1989); however, this article remains only an introduction to this subject. The kind of organizational study we propose, of social services as they relate to the organization of the "work life" of people with HIV and AIDS, has thus far not been undertaken.

There are, however, some studies of social service agencies and of the delivery of social services that have both a substantitive and methodological connection to the research proposed here. The 1979 study by Bodnar and Reimer on "The Organization of Social Services and its Implications for the Mental Health of Immigrant Women" is a good example. This study investigated the accessibility and relevance of social services to immigrant women experiencing "mental health" problems. The work was taken up from the standpoint of immigrant women. Two other studies by Ng (1981) and Cassin and Griffith (1981) have a close methodological relation to this work. Two studies of social work by de Montigny (1987), and Hick (forthcoming) are particularly useful ethnographies of social service agencies that are methodologically similar to the research design put forward in this proposal.

2.2.2 The study of textually-mediated social organization

The study of the organizational significance of texts and documents originates in Max Weber's early, twentieth century studies of bureaucratic forms of authority (Weber, 1978). He gives considerable emphasis to the importance of files and records, an example that was followed by years where this aspect of administrative and managerial practice was neglected. The production of forms, instructions, factual data, etc. is a specialized, technical matter. The organization of systems of corporate "memory" in files was already highly sophisticated before the generalization of the computer and the advent of computer-based systems of data management. Studies of the formal organizational significance of texts and documents are relatively sparse and recent. These include: Zimmerman's (1969) pioneering study of facts as

practical accomplishment, showing the facticity of welfare claims as a routine organizational product; Atkinson's (1974) extensive study of the social construction of suicide, in which he elucidates coroners' methods of transposing lay accounts of a death into the forms required for official records; a study by Silverman and Jones (1976) of the language practices involved in promotions procedures in a corporation; two excellent Canadian studies of bureaucratic 'ideologies-in-practice' by Handelman and Leyton (1978) on legal and professional definitions of child abuse (Handelman) and on the local operation of the Workmen's Compensation Board (Leyton); Burton and Carlen's (1979) study of the language of a parliamentary commission; Chua's (1979) valuable contributions to an analysis of textually-mediated discourse as a component of democratic process; Green's highly innovative study of the textual organization of the British Poor Law Commissions of 1834 and 1909 (1983); and Campbell's (1984) analysis of documentary practices of accountability in the context of hospital nursing.

3.0 Design of the Study

The design of this study takes the form of an institutional ethnography (Smith, 1987). This is a method of research which investigates, ethnographically, a "section" of the social world from the standpoint of the organization of the work of those who in various ways are involved in its production. This kind of ethnography takes as its problematic the complex of relations in which this local world is embedded. In this sense, the ethnographic enterprise is not confined to what can be directly observed, or to what informants have directly observed. Rather, it seeks to reveal the extended bureaucratic, professional, legislative, economic, as well as other social relations involved in the production of local events and activities.

Various methodologies are used in institutional ethnographies, including: in-depth interviews, archival research, and textual analysis. The choice of methodology depends on the social organizational properties of the phenomena under investigation. In this study, the methodologies to be used are in-depth interviewing and the analysis of documents. The focus of research is the forms of social organization coordinating relations between the "life work" of people with HIV infection and social service agencies. Three main sites have been identified: the social locations of individuals with HIV infection, the location of community-based people who act as advocates for them vis-à-vis social agencies, and the location of social service agencies, themselves.

3.1 Starting from the standpoint of HIV infected individuals

The design of this study starts from the standpoint of HIV infected individuals. What this means is that conceptually the study is designed to take up the problems people with HIV infection face in accessing social services. It is their experiences that define this starting point and not the legislative, bureaucratic, or professional requirements governing the workings of social service agencies. In this respect, the study is neither one of the attitudes of social service workers (Dhooper et al., 1987/88) (e.g., homophobia, AIDSphobia), for example, nor a needs assessment survey of HIV infected people (Mathews et al., forthcoming). Rather it is a study of social organization—first, in terms of the "life work" of people with HIV infection; and secondly, in terms of the social organization of the delivery of social services. In this context, the problem HIV+ individuals face in accessing social services is taken up in terms of the ways in which the managerial organization and everyday practices of social agencies connect or fail to connect with their lives.

3.2 The reflexive basis of our understanding of the give-and-take world of social services

The research is to be carried out in a reflexive fashion from inside the social organization of not only our own world as researchers, but by extension, the social worlds we intend to investigate. The point of doing interviews and of perusing the relevant documents is to extend the everyday, common-sense understandings we have of our own world to understanding other people's lives--in this case to the "life-work" of people living with HIV/AIDS and to the everyday work processes of social service agencies. Three additional strategies are relevant to this reflexive orientation:

- 1. Informants are to be treated as knowledgeable about the social organization of the local settings in which they conduct their affairs. Informants are taken to be competent practitioners within the context of their everyday world. The point of interviews is to have them share these competencies, thereby extending them to the interviewer.
- 2. The social world under investigation is not taken to be truncated at the boundary of local settings, but to be treated as extending in a contiguous fashion beyond the purview of the everyday. These extended courses of action are taken up as social relations organized as a series of moments that are dependent upon one another and articulated to one another not functionally, but reflexively, as temporal sequences in which the foregoing intends the subsequent and in which the subsequent "realizes" or accomplishes the social character of the preceding.
- 3. Texts and documents are investigated as active constituents of social relations. We want, in this respect, to see how they operate as extra-local determinants coordinating and concerting the organization of local settings.

3.2.1 Interviews

The interview procedure will be open-ended. Tape recordings will be made for transcription. Tape recording and transcribing interviews is essential to be able to develop detailed and systematic interpretations of the data. Making interpretations as part of "in situ" note taking, makes it more difficult later on to explicate the social organization of the relations of which informants descriptions are embedded. These procedures, consequently, provide for a more rigourous approach to data collection and analysis. The interviews, themselves, will address the organizational knowledge of those who are active participants in relevant settings. Interviewing will involve two main strategies:

- 1. Investigating with respondents their own working knowledge of the organizational processes they are part of. Interviewing a series of respondents positioned differently in the "hooking up" process enables us to assemble a picture of relevant organizational sequences as actual courses of action. In particular we will be concerned with informants' normally explicated and practical knowledge of "how things work;"
- 2. Previous work in the area of textually-mediated social organization has led us to see organizational documents as significant constituents of organizational processes. Interviews will also try to uncover what respondents can tell us about how documents enter practically into the routine ordering of their work.

The recruitment of informants will be organized through community-based AIDS organizations and social service agencies. To begin with we intend to set up focus groups of clients from community-based organizations. On the basis of these group meetings, we would then do in-depth interviews with a number of selected individuals. We will attempt to include individuals from different backgrounds and circumstances. However, we will not attempt to develop a randomized sample. The general and generalizable features of the analysis are taken to lie in the abstract, general character of the "hooking up" phenomena under investigation. For example, provincial legislation and government regulations controlling the operations of social agencies organize them "in general," in much the same way the social relations of gender organize the lives of women in general. Descriptions of these abstract, generalized characteristics of the society, consequently, have the same general properties as the phenomena they describe.

3.2.2 The study of social agencies and community-based organizations as textually-mediated social organizations

An important feature of our society is the ability of documentary forms of organization to shape and determine events in local setting. A good example is they way legislation, passed in one location, comes to impact people's lives in other locations across time. This iterative, recursive capacity resides in its documentary, or textually-mediated character. This is the reason why, in addition to interviews, techniques of textual analysis are an important aspect of institutional ethnographies.

An ordinary property of textually-mediated social organization is its exploitation of the capacity of texts to crystallize and preserve a definite form of words detached from particular local contexts. Texts speak in the absence of speakers; meaning is detached from local contexts of interpretation; the "same" meaning can occur simultaneously in a multiplicity of socially and temporally separated settings. This social character of texts is essential to their uses in organizing administrative, managerial and professional forms of organization.

The organized character of institutions and agencies depends heavily on the various uses of texts to coordinate, order, provide continuity, monitor, and organize relations between different segments, phases and levels of organizational courses of action. Organizational texts order and coordinate activities which are dispersed spatially and temporally in a variety of organizational settings. In the context of this study, this theoretical framework directs investigation and analytic strategies towards the textually-mediated processes which are used to articulate the needs of people with HIV/AIDS to social service agencies. Our interest is in providing an account of organization and how it works and not in evaluation as this is ordinarily understood.

The theoretical approach which the research will, in part, make use of, consequently, is one which emphasizes the significance of texts and documents in professional organizations. This is not news to practitioners. Nonetheless it is only recently that researchers have begun to take seriously the project of investigating *just how* texts and documents enter into these organizational processes. The work of Dorothy Smith (Smith 1974b, 1975, 1979, 1981, 1983, and 1984; Smith 1983) has provided both a conceptual framework and analytic strategies for investigating textually-mediated social organizations. We view this textually-mediated character of the "hooking up" phenomenon we intend to investigate as having special relevance to the study of how relations between institutions and people's everyday lives are structured.

3.3 Case studies

The first six months of the proposed research will be devoted to interviewing HIV+ clients of social service agencies with a view to discovering how these individuals, with different backgrounds and located in different situations, go about organizing their "life work" and how this ties into their access to social services as part of coping with HIV/AIDS. With the passing of social welfare legislation, it might appear that social services are simply there to be had. However, anecdotal accounts provided us in our preliminary investigations indicate that this is not the case. This discovery, in turn, directed our attention to what people have to do to get the social services they need. In studying and documenting these activities, we would not want to examine them as just a set of personal experiences, but instead take them up as work processes that make sense within the context of how these people's lives are put together. We would want to be able to provide a description of how HIV+ people go about getting access to social services so as to study the interaction between the organization of their everyday lives (and the lives of their friends and families), and the institutionalized work order of social service agencies. For example, what organizational assumptions does this institutionalized work order make about the lives of people with HIV infection? Do they assume, for example, that clients are experienced at getting on welfare etc.

We expect that in a six month period that we would be able to do approximately 60 interviews. Because they involve individuals who do not work in institutional settings, these interviews will take a considerable amount of time both to organize and to do as we try to fit into the "life work" of informants with HIV/AIDS. Not only will these interviews involve holding focus groups at the outset, there will be individuals who would be missed by these activities that will need to be included (e.g., individuals from minority groups--native, black, Asian, etc.-, which in this case, would also include IVD-user, hemophiliac and heterosexual groups). This will also be an intensive period of research as we learn from our informants just how things work for them, given how they organize their "life work." Informants will be selected from a variety of backgrounds in order to study the various ways the standard practices of social service agencies, as these are shaped by legislation etc., come to interface with the everyday lives of people with HIV/AIDS.

3.4 The textually-mediated work of community-based AIDS organizations and social service agencies

We want to be able to study the work organization of these groups. Again, our interviews will begin, if at all possible, with focus groups that will be used to establish for our informants the relevancies of our research, and to select individuals for later in-depth interviews. The hub of our investigations will be the everyday work done by social service workers in processing various applications made by people living with HIV/AIDS. An important part of these investigations, as has already been pointed out, will be the examination of documents as coordinating and concerting the work of these agencies. The range of documents to be encompassed is quite wide, from legislation to office forms. The work of community-based AIDS organizations will be examined in relation to group mandates and the mandate created by specific grant applications.

We intend this part of the research to take four months and involve approximately twenty interviews. The organization of Unemployment Insurance, General Welfare Assistance, Family Benefits Allowance, housing agencies like City Homes, co-opts, City Shelters, along with Homecare, Homemaking and transportation services etc. as these are related to the needs of people with HIV/AIDS will be studied. Interviews will also be conducted with workers at the major community-based AIDS organizations. From specific interviews with community-based

and social service workers documents will be identified and collected in relation to the work of both groups and agencies.

3.5 Time line

This project will be managed using Time Line project management software. Status review reports will be produced monthly. The project grant period is divided into 4 periods: 6 months for completing the case studies, and a period of 2 months each for studying advocacy groups, social service agencies, and for report writing (see Appendix B).

4.0 Analysis

The central analytic for this research project is the notion of "social relations." Within the context of this research, this notion operates as an investigational technique for locating and describing the social form of people's activities over time. It provides a method of looking at how individuals organize themselves vis-à-vis one another. The notion of "social relations" in this sense, does not stand for a thing to be looked for in carrying out research; rather it is what is used to do the looking. It operates as a methodological injunction that requires the researcher to examine empirically how people's activities are reflexively/recursively knitted together into particular forms of social organization.

People's lives do not exist in a social vacuum. When individuals apply for welfare, for example, they are entered into an institutional course of action over which they have limited control. This course of action organizes them not only in relation to their friends (in terms of money for socializing) and to their landlord (in terms of their ability to pay rent) etc., but also to social workers (in terms of determining their eligibility), and indeed to the government of the Province and of Canada (in terms of providing the necessary cash allowance) -- to name just a few organizational features of this form of social action. It is in identifying and describing how this institutional course of action works to shape and determine people's lives that the notion of social relations guides the analytic work of the researchers. Another example of the social organization produced by individuals with HIV/AIDS that comes to organize their lives is the organization of what we have called "life work." This is a self-generated course of action that individuals organize for themselves as a result of testing positive for HIV antibody. Analyzed as social relations, it is possible to see how, as a practical, everyday matter, this activity organizes people with HIV/AIDS vis-à-vis others engaged in providing emotional support, medical services, social services, and so forth. Moreover, it is also possible to see how external social courses of action such as the relations of gender or of homophobia can have a negative impact on the organization of these people's "life work." In examining how people's lives are put together, the notion of social relations is used to carry out just such an analysis by being used to help determine where to look, and how to see the coordination and concerting of social organization.

An important discovery of this method of work is the active role documents play in coordinating and organizing people's lives and hence their activities. This discovery provides for the researcher's ability to investigate and describe networks of co-ordered activities going forward simultaneously across a number of distinct sites of social action. The concept of "social relations" also operates, in this sense, to enter the social world into the text of the research report by helping researchers formulate their descriptions of it.

The notion of "social relations" is employed in a practical manner to talk about and to investigate the actual practices of individuals, articulated to one another, as constituting work

processes where different moments in a course of action are dependent on one another and are articulated to one another not functionally, but reflexively. These are courses of action that, while coordinated and concerted over time in the activities of people, are neither initiated nor completed by a single individual.

Secondly, the notion of "social relations" is involved in discovering the recursive properties of spatial-temporal forms of social organization. Texts as active constituents of social relations can iterate the particular configuration of their organization in different places and at different times, thereby conceptually coordinating and temporally concerting a general form of social action. Recursion, consequently, is also discoverable in how particular, textually-organized local experiences of people have the same social configuration as the experiences of others, organized extra-locally through the same text, at other times and places. The cursivity of a generalized course of action, consequently, makes it possible to go from particular events in local settings to a set of general, textually-mediated social relations because they have the same social form.

5.0 Results and Their Dissemination

The results of this research will take two forms. First, there will be a detailed description of the social organization of the work of social agencies and community groups and they way these organizations are articulated to the organization of the "life work" of people with HIV/AIDS. Secondly, this description will provide the basis for recommendations reorganizing the work of social agencies in order to provide a better organizational fit with the lives of people with HIV infection. Given that the report will feature a description of the current organizational disjuncture between social agencies and the lives of people with HIV/AIDS, it will also provide managers of social agencies and policy makers an opportunity to take initiatives on their own to make recommendations for change. They will not, in this sense, be limited to the recommendations of the report if they can see a better way to improve the situation.

The main deliverable produced by this research will come in the form of a report to Health and Welfare Canada. With permission of the Department, journal articles will also be prepared for journals such as The Social Worker that are ordinarily read and used by social service agency managers and workers. The results of our study will also be disseminated to community-based AIDS organizations and to social services policy makers at the 1992 Delegate Assembly of the Canadian Association of Social Workers. And lastly, results will be made available to the academic community through the presentation of papers at the Learned Societies meetings and the publication of results in suitable Canadian academic journals.

6.0 Ethical Review

An ethical review will be completed for this project by an ethics review committee at OISE before it begins. This review will be conducted in accordance with standards set by the Social Sciences and Humanities Research Council of Canada. It is important to emphasize, however, that this is not a study of individuals. Informants are not the subject of an investigation. What is being studied are forms of social organization that operate independently of any particular person. See Appendix C for copy of the consent form.

Appendix A: References

- Anderson, Gary R. "Children and AIDS: Implications for Child Welfare" Child Welfare 63(1)
 January 1984:62-72.
- Atkinson, J.M. (1978) <u>Discovering Suicide: Studies in the Social Organization of Sudden Death</u>
 London: The Macmillan Press.
- Black, David (1985) The Plague Years: A Chronicle of AIDS, the Epidemic of Our Times, New York: Simon and Schuster.
- Bodnar, A. and M. Reimer (1979) "The Organization of Social Services and Its Implications for the Mental Health of Immigrant Women" Report prepared for the Secretary of State in conjection with the Working Women Community Centre in Toronto, Ontario.
- Boland, Marty G., et al. "Children with HIV infection: Collaborative Responsibilities of the Child Welfare Communities" <u>Social Work</u> 33(6).
- Bourgon, M. and Gilbert Renaud "AIDS and Social Work: a Fruitful Juncture for Thought" The Social Worker/le Travailleur social 57(1) Spring/printemps 1989:48-52
- Burton, F. and Carlen, P. (1979) Official Discourse: On Discourse Analysis, Government Publications, Ideology and the State London: Routledge and Kegan Paul.
- Campbell, M. (1984) Information Systems and Management of Hospital Nursing: A Study in the Social Organization of Knowledge. PhD thesis, Department of Education, University of Toronto.
- Canadian Association of Schools of Social Work (1988) <u>AIDS and social Work Training in</u> Canada Report Ottawa: Federal Centre for AIDS
- Cassin, M.A. and A. I. Griffith (1981) "Class and Ethnicity: Producing the Difference that Counts" Canadian Ethnic Studies/Etudes Ethniques au Canada 13(1):109-129.
- Cecchi, Robert Lee "Health Care Advocacy for AIDS Patients" Quality Review Bulletin 12(8) August 1986:297-303.
- Central Toronto Youth Services AIDS Project (for Ontario Ministry of Community and Social Services) (1989) HIV Infection and AIDS: A Policy Development Framework for Children and Youth Social Service Agencies Toronto, Ontario: CTYS.
- Child Welfare League of America Serving HIV-Infected Children, Youth, and Their Families: A

 Guide for Residential Group Care Providers (1990) Washington D.C.:Child Welfare

 League of America Inc.
- Christ, Grace H., et al. "Psychosocial issues in AIDS <u>Psychiatric Annals</u> 16(3) March 1986:173-
- Chua, B. (1979a) Describing a National Crisis Human Studies 2:47-62.
- Chua, B. (1979b) Democracy as Textual Accomplishment Sociological Quarterly 20:541-49.
- Clark, Elisabeth et al. "An Assessment of the Psychosocial Needs of the HIV Antibody Positive Population using the Montreal Health and Social Service Network" Abstracts: V International Conference on AIDS: The Scientific and Social Challenge, June 4-9, Montreal, Quebec, Canada. Ottawa: International Development Research Centre.
- Clausson, Nils I. "AIDS: The Community-based Response" Canadian Journal of Public Health 80 (Supplement 1) May/juin 1989: 18-20.
- de Montigny, G.A.J. (1989) Accomplishing Professional Reality: An ethnography of social workers' practice. Ph.D. Thesis, Department of Education, University of Toronto.
- Dhooper, S.S., David D. Royse, and Thanh V. Tran. "Social Work Practitioners' Attitudes Towards AIDS Victims" <u>The Journal of Applied Social Sciences</u> 121, Fall/Winter 1987/88:108-123.
- Direction Générale de la Santé France "Compte rendu et évaluation d'une expérience de formation des travailleurs sociaux sur la SIDA" Abstracts: Ve Conférence internationale

- sur le SIDA: Le défi scientifique et social, 4-9 juin 1989, Montréal, Québec. Ottawa: Le Centre de recherches pour le développement international.
- Doherty, John P. "AIDS: One Psychosocial Response" Quality Review Bulletin 12(8) August 1986: 295-297.
- Doyle, R. and Visano, L. "A Summary of Actions: Access to Health and Social Services for Members of Diverse Cultural and Racial Groups" Toronto: social Planning Council of Metropolitan Toronto.
- Fietz, Margaret "Children with AIDS in Need of Care and Protection" <u>The Social Worker/Le</u> Travailleur social 57(1) Spring 1989.
- Fraser, Andy _"Dealing with AIDS in the Community ... Avoiding the Plague Mentality" Family Service Canada/Services à la famille-Canada, 6(4) December 1987:1-3.
- Furstenberg, Anne-Linda and Miriam Meltzer Olson "Social Work and AIDS" <u>Social Work in Health Care</u> 9(4) Summer 1984:45-62.
- Goulden, Peter Todd, et al. "AIDS and Community Supportive Services: Understanding and Management of Psychological Needs" <u>Medical Journal of Australia</u> 141(9) October 1984:582-586.
- Green Bryan (1983) <u>Knowing the Poor: A Study in Textual Reality Construction</u> London: Routledge and Kegan Paul.
- Handelman, D and Leyton, E. (1978) <u>Bureaucracy and World View: Studies in the Logic of Official Interpretation</u> Institute of Social and Economic Research, Memorial University of Newfoundand.
- Hick, S.F. (forthcoming) An Ethnography of an Ontario Welfare Office: The reproduction of labour market relations. Ph.D. thesis, University of Toronto.
- Isaacs, Gordon "Crises Psychotherapy with Persons Experiencing the AIDS Related Complex" Crisis Intervention 14(4) 1985:115-121.
- Kaetz, D. "Living with HIV" The Social Worker/le Travailleur social 57(1) Spring/printemps 1989:65-68.
- Kelly, Jeffrey A. (1989) <u>The AIDS Crisis: Psychological and Social Intervention</u>, New York: Plenum Press.
- King, Alan J.C. et al. (1988) <u>Canada Youth and AIDS Study</u>, Kingston, Ontario: Queen's University (Social Program Evaluation Group).
- Lane, Steven R. and Richard N. Levine "Caring for Homeless People with HIV Disease" Focus: A Guide to AIDS Research and Counselling 5(5) April 1990:1-2.
- Lee, Jacalyn et al. (1988) Counseling and Education for the Prevention of AIDS: A Training

 Course for Health and Social Service Workers. New York: City University of New York

 (Center for Community Action to Prevent AIDS).
- Lewis, Laurie "Housing People with HIV Dementia: No specialized Programs, but Communities are Coping" AIDS Patient Care June 1988:35-37.
- Lopez, Diego J. and George Getzel "Helping Gay Aids patients in Crisis" Social Casework: The Journal of Contemporary Social Work, 65(9) September 1984: 387-394.
- Mathews, F. Joyce Radford and Douglas Weatherbee (forthcoming) "HIV+ Youth: A needs assessment study" Toronto: Central Toronto Youth Services. 1991.
- National Lawyers Guild AIDS Network "Housing and the AIDS Epidemic" <u>The Exchange</u> 12 April 1990:1-8.

- New York State Department of Social Services "Toward AIDS Awareness in Housing" <u>AIDS Update</u> 2(3) Spring 1989: 1,3.
- New York State Department of Social Services "Living at Home: The Preferred Option" <u>AIDS</u> Update 2(3) Spring 1989:8-9.
- New York State Department of Social Services "DSS Exploring AIDS Housing Alternatives for Homelesss Adults" AIDS Update 2(3) Spring 1989:11-12, 19.
- Ng, R. (1981) "Constituting Ethic Phenomenon: An Account from the Perspective of Immigrant Women" <u>Canadian Ethnic Studies/Etudes Ethniques au Canada</u> 13(1):97-108
- O'Neil, B. and Joesphine Naidoo "Social Services to Homosexuals in Ontario: Major Issues and Annotated Bibliography" (Available from B. O'Neil, Faculty of Social Work, Wilfrid Laurier University, 75 University Ave. W., Waterloo, Ont, N2L 3C5.
- O'Neil, B. and Josephine Naidoo "Social Services to Lesbian and Gay Men in Ontario: Unrecognized Needs" <u>The Social Worker/Le Travailleur social</u> 58(3) Fall/Automme 1990: 101-104
- Price, Monroe Edwin (nd) <u>Shattered Mirrors: Our Search of Identity and Community in the AIDS Era</u>, Cambridge Mass.: Harvard University.
- Ryan, W. J., "AIDS: The Community Response" <u>The Social Worker/Le Travailleur social</u> 57(1) Spring/Printemps 1989:53-56
- Radford, Joyce et al. (1989) <u>Street Youth and AIDS</u> Kingston, Ontario: Queen's University (Social Program Evaluation Group).
- Schinazi, Raymond F. and Andre J. Nahmias (eds.) (1988) <u>AIDS in Children Adolescents and</u> Heterosexual Adults, New York: Elsesvier Science Publishing Co.,Inc.
- Silverman, D. and Jones, J. (1976) <u>Organization Work: The Language of Grading and the</u> Grading of Language London: Collier Macmillan.
- Snowden, Donna and David F. Cassidy (eds.) (1989) AIDS: A Handbook for Professionals, Carswell: New Book.
- Smith, D.E. (1974a) The Ideological Practice of Sociology Catalyst No. 5, pp. 39-54.
- Smith, D.E. (1974b) The Social Construction of Documentary Reality <u>Sociological Inquiry</u> 44:257-68.
- Smith, D.E. (1975) The Statistics of Mental Illness: What they will not tell us and why, in Smith, D.E. and David, S. (eds.) Women Look at Psychiatry Vancouver: Press Gang
- Smith, D.E. (1979) A Sociology for Women, in Sherman, J. and Beck, E.T. <u>The Prism of Sex</u> Madison: University of Wisconsin Press
- Smith, D.E. (1981) The Active Text: A Textual Analysis of the Relations of Public Textual Discourse. Paper presented at the World Congress of Sociology, Mexico.
- Smith, D.E. (1983) No One Commits Suicide: Textual Analysis of Ideological Practices <u>Human Studies</u> 6:309-359.
- Smith, D.E. (1984) Textually-mediated social organization <u>International Social Science Journal</u> 36(1):59-75.
- Smith, D.E. (1987) <u>The Everyday world as Problematic: A Feminist Sociology</u> Toronto: University of Toronto Press.
- Smith, D.E. (1990) <u>Conceptual practices of power: A feminist sociology of knowledge</u> Toronto: University of Toronto Press.
- Tresse, Gary G. "Psychosocial Issues Related to the Diagnosis of AIDS" in <u>Lesbian and Gay</u>
 <u>Issues: A Resource Manual for Social Workers</u>, Hilda Hidalgo et al. (eds) Silver Spring,
 MD: National Association of Social Workers, 1985.

Weber, M. (1978) <u>Economy and Society</u> Guenther Roth and Claus Wittich (eds.) E. Fishoff et al. trans. New York: Bedminster Press. Reissued at Berkeley: University of California Press.

Zimmerman, D.H. (1974) Fact as a Practical Accomplishment in Roy Turner (ed.) <u>Ethnomethodology</u> Harmondswork, Mddx.: Penguin Books.