

*Shifting Sands:  
The Changing Context of  
HIV/AIDS Social Services  
in Ontario*

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Social Services in Ontario*

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*Shifting Sands:  
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*Executive Summary*

*Introduction*

This report summarizes the findings of a project that examined how the changing welfare state in Ontario, and the changing HIV epidemic, affect social services for people living with HIV. Data for the study were drawn from in-depth interviews with a sample of 59 social service providers. Using a snowball sampling strategy, respondents were recruited in seven cities to reflect varying practice realities in different settings. Included in our sample were workers from a range of agencies that someone with HIV might be expected to use. Interviews lasted 60-90 minutes. They were tape-recorded and then transcribed verbatim. Transcripts were coded according to themes that emerged from the data.

*The Changing Policy Context*

The report identifies a number of changes that have taken place in recent years with regard to the state's role in the provision of social services, and it discusses how these changes are experienced by front-line social service practitioners. Respondents noted that there are currently fewer supports and benefits available to people living with HIV. Some HIV/AIDS specific programs have been curtailed, with the result that workers have fewer resources to offer their clients. Resources have not kept pace with increasing demands for assistance. The level of poverty among clients in many agencies has increased, and inadequate housing was identified by respondents as a particular concern. Many services have been restructured and new rules have been put into place, so workers are often unsure of what services are available and who might be eligible to receive them. Workers often need to devote more time to bureaucratic procedures, and they often have less flexibility and discretion than before. Respondents find themselves increasingly responsible for rationing services and for watching over clients to ensure that they do not 'abuse the system.' The climate that surrounds much of the work has changed for the worse; it often feels more punitive and intrusive than before. These changes mean that workers are often left trying to

support clients who are in *greater* need just at a point when they are able to offer *less* help than before.

### *The Changing Epidemic*

The number of people living with HIV is on the rise, and the populations affected by the epidemic are changing to include more youths, women, Aboriginal people, and injection drug users. People are living longer with the knowledge that they are HIV-positive. New anti-retroviral treatments help many people to live longer and healthier lives with HIV. These treatments, however, do not always work. Respondents expressed concern that they might start to see an increase in the amount sickness and death as a result of treatment failures and long-term toxicity of the new medications. As people live longer and healthier lives with HIV, the focus of much of the work of respondents changes from health-related concerns to social issues. HIV can be just one of many complex issues in the lives of clients, and it may not be the most compelling practice issue. Workers increasingly confront larger social problems, such as poverty, inadequate housing, or unavailable drug treatment services. They may have little training or experience in dealing with such issues. New treatments can create problems of their own, such as increased waiting lists, serious side effects or increased stress among clients as the result of their uncertainty about the future. Some workers now feel inexperienced and ill-prepared to deal with HIV-related sickness.

### *Negotiating the New Realities*

Front line workers are not passive in the face of such changes. Respondents described how they often bend agency rules to better meet the needs of clients. Their efforts to ‘work the system’ can raise ethical issues for respondents, who often feel individually responsible and vulnerable. Respondents described how new rules and procedures can help them manage the increasing stresses of their work, but such organizational changes may make it more difficult for some clients to access services. Advocacy can become more difficult, and many respondents spoke of the need to choose their battles carefully. Despite the many challenges they face, most respondents managed to find sources of satisfaction in their work.

### *Discussion and Implications*

Social service workers are expected to do more and more with less and less. The work of providing social services is characterized by considerable change and

instability. Not surprisingly given the context, respondents often appear to ‘hunker down.’ Most focus on trying to meet the immediate needs of individual clients; we heard relatively little talk in our interviews of creating organizational or social change. Many respondents spoke with a sense of fatigue and some sounded disillusioned about possibilities for change. The report shows that the changing policy context and, ironically, the advances in treatments, may be jeopardizing some of the innovative social service practices that were developed over the past twenty years of HIV/AIDS work. Social services for people living with HIV appear increasingly at risk of becoming like other underfunded and residual fields of social welfare. The report concludes with a series of recommendations for change.

### *Acknowledgements*

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## *1. Introduction*

Social services provided by community-based AIDS organizations, hospitals, social services, municipal governments, income maintenance programs, food banks, housing agencies, and the like represent important sources of support for many people living with HIV. Agencies like these provide such services as, financial assistance, disability pensions, supportive housing, individual and peer counselling, access to food banks, furniture exchange programs, or transportation to medical appointments. Many people require services for short periods of time, while others depend on them for many years.

Social services, like many public services in Ontario, have experienced drastic changes in recent years. Services have been reduced or cut as a result of changes in public policy. As well, advances in the treatment of HIV infection have had a profound impact on social service provision. Social services are essential to a large number of people living with HIV, but their provision has not received much systematic attention. As a result, many of the recent changes, and their effects on service delivery have not been detailed, and they are not well understood.

### *Research Goals*

This project aims to document and discuss how the changing welfare state in Ontario and the changing epidemic affect social services for people living with HIV. The principal goals of this project are to:

1. document how the context of HIV/AIDS social services has changed over the past number of years and to identify the practice challenges that result from the changing context of HIV/AIDS social services in Ontario.
2. examine how the introduction of new medical treatments affects social service delivery.
3. examine the ways that workers manage the challenges they face in practice and the strategies they employ to minimize the negative impact of these changes.
4. recommend changes in policy and practice to better address the social needs of people living with HIV/AIDS.

## ***2. Research Method***

To explore the changing nature of social services to Ontarians living with HIV, we conducted 59 semi-structured interviews with social service providers in a variety of fields of service. We spoke to respondents about their work, the challenges they face, and their concerns for the future.

### ***Who did we speak to?***

Data were drawn from a purposive sample of about 59 service providers. We recruited respondents from seven Ontario cities, as the realities of providing social services are shaped, in part, by the local context. Providing services in downtown Toronto is in many ways different than providing services in a smaller community, where there is often a different population of people needing assistance, a smaller network of social service agencies, few, if any specialized services. Issues of confidentiality and anonymity are often more acutely felt in smaller communities, and workers in such settings often have little experience working with HIV/AIDS. To reflect these realities, we sought to speak to workers in different areas of the province, choosing to interview respondents in:

- Hamilton
- Toronto
- Ottawa
- Kitchener-Waterloo
- North Bay
- Sudbury
- Thunder Bay

### ***How did we find respondents?***

The project began in each of these seven settings with key service providers, generally workers in the local AIDS service organization. We employed a ‘snowball’ sampling technique: initial respondents were asked to identify other service providers in the community whom we might interview. In this way, we were able to identify workers in local HIV services, as well as those in collateral services that are often accessed by people living with HIV/AIDS (PHAs). We thus captured the practice of ‘social service work’ in a comprehensive way, rather than restricting the study to those with particular degrees, professional backgrounds, or work experiences.

### *What kinds of services did we examine?*

The phrase ‘social services’ is used in this report to cover a broad array of financial, emotional, and social supports. To ensure that a wide range of services were included in the study, our sample included the kinds of agencies that someone with HIV might be expected to use:

- Community-based AIDS Service organizations
- Ontario Works
- Ontario Disability Support Program
- Hospital Social services
- Aboriginal Services
- Service to people with hemophilia
- Women’s services
- Ethno-specific community agencies
- Housing Services
- Correctional services
- Needle Exchange programs
- Drug Treatment programs

### *What were the interviews like?*

Our interviews were guided conversations between the respondents and researchers. An interview guide provided a general frame work for discussion, but interviews were flexible enough to pursue topics identified by respondents. The interview guide was developed with input from members of the project’s steering committee. As is typical of studies of this nature, the interview guide was revised and refocused in light of issues and concerns identified by respondents (Lofland & Lofland, 1986).

Interviews lasted 60-90 minutes, and were generally conducted in respondents’ offices. With respondents’ permission, we tape-recorded the discussion. Interview questions included:

- Who is your clientele?
- How is the demographic makeup of your clientele changing?
- What are the kinds of issues and problems your clients identify? How have these issues changed over time?
- Can you identify new issues that are emerging in your practice?
- Are there needs or issues that are particularly acute in this setting?

- With which collateral services do you work most often?
- What are the particular needs of different groups of your clients? How are they best addressed?
- What service gaps would you identify? Have the areas of gap/duplication changed?
- What would you like to see in terms of future service delivery? What stops that from happening?
- Are there agency rules and expectations that you need to work around to ensure that your clients receive services they need?
- Do you sometimes need to actively ‘work the system’ or bend rules to provide needed care?

### *How did we manage and analysis the data?*

Interviews were transcribed word-for-word. These transcripts represented the data for the study. Transcripts were managed using a software program called *Folio Views*. We coded the transcripts according to themes and theoretical categories that emerged from the data. A coding scheme developed as successive transcripts were interpreted. For example, looking for patterns in the worries of workers helped us identify the common concerns among workers.

### *3. The Changing Policy Context*

Significant changes have taken place in recent years with regard to the state's role in service provision. The federal government has reduced its contributions to the funding of health and social services throughout the 1990s. The reduction in the level of federal transfer payments has meant that the provinces have had to pay an increased share of social services. To cope with reductions in federal transfer payments and to realize its own ideological commitments to reduce the size and cost of its bureaucracy, the Conservative government in Ontario has cut support for a number of social services. Some of the services for which the provincial government was directly responsible have been 'devolved' to municipalities and regions. Ontario cut welfare rates by 21.6% in 1995 for everyone except seniors and people with disabilities, and the provision of income assistance was moved from the province to municipalities.

Policy changes such as these means that governments are currently less 'generous' than they once were. Services of all kinds are now withheld until the presenting problems of clients are acute. There is increased pressure for people to purchase services from private providers, rather than relying on government services. Those who need such care, however, are often unable to afford it, leaving them to rely on family and friends – or to do without the care they require.

This section of the report focuses on how broad policy changes such as these are experienced by front-line social service practitioners. The report does not directly examine how such changes directly affect people living with HIV, although the experience of workers clearly suggests many implications for recipients of services.

#### *Fewer supports & benefits*

The most obvious result of the various policy changes is that a number of supports and services for PHAs have been cut or reduced. Most respondents expressed grave concern about the level of benefits available through Ontario Works, the new name for 'welfare' in Ontario. Virtually all workers with whom we spoke stressed how difficult it is to live on the level of benefits offered by Ontario Works or the Ontario Disability Support Program (ODSP).

A predominant theme uncovered in our interviews is that securing an adequate income is fundamental, and that cuts to income support programs can have significant ramifications on all aspects of people's lives. Inadequate income has negative social, psychological, and health effects.

Not only are monthly social assistance rates reduced for many people, respondents identified other kinds of benefits that have been reduced. A caseworker in Ontario Works stressed that the cuts in her agency went beyond simply the well-known reduction in the amount of monthly payments available through Ontario Works. Supports of various kinds have also been reduced or eliminated:

*We used to issue money for bus travel. That's now not automatic. We used to issue first and last month's rent, as required. Moving costs used to be covered. Beds and bedding. It was all there. (Ontario Works caseworker).*

Beyond cuts to large public programs like Ontario Works, respondents identified a range of HIV/AIDS-specific supports that have been curtailed or completely eliminated, with the result that workers have fewer resources to offer their clients. Many agencies have had to reduce the amount of counselling they offer. Nutritional supplements, food, and food vouchers are now often more restricted. There is less financial assistance available to clients in need, and supportive housing has all but disappeared in many settings. A number of agencies have lost staff positions, with the result that there are increased waiting lists, a reduced level of service, and the elimination of certain services.

Such cuts to services means that there is less time to devote to the provision of ongoing and nonjudgmental support. As well, workers increasingly play a 'gate-keeping' role, determining who will be provided needed resources and who will be denied such support. As will be discussed below, these changes have an impact on respondents' relationships with clients, and on their satisfaction with own work.

### *Funding is not keeping pace with needs*

Even when agency funding has not been cut, respondents noted that their resources have not kept pace with increasing client needs. A number of agencies have not had their funding cut significantly or at all, but the number of clients to whom they provide services has increased markedly through the years. As well, clients often bring more complex problems, which often require more time and resources to address adequately.

Faced with increasing demands and fewer resources, workers now feel unable to provide an adequate level of assistance to anyone. A worker in an agency for families and children living with HIV summed up the current situation of many clients of her agency:

*Our client load has increased significantly and we 're still getting the same funding or less ... The pie is same size but the people that are eating the pie is growing. Every time it grows, people get a smaller chunk* (Worker in an ethno-specific agency)

Workers have fewer choices, and are often left to try to manage this tension with little support or direction from their agencies. Not surprisingly, respondents described much of their work as frustrating and unrewarding. Workers are feeling more reactive to changes in their environment and less able to engage in the preventive work that might successfully avoid the development of crisis situations.

*I think that we've become crisis workers as opposed to support coordinators. We are dealing with a lot of families in crisis, whether it be mom in crisis, dad in crisis, or the kid in crisis. I think we sort of run from fire to fire, whereas we didn't see that before.* (ASO worker)

### ***Level of poverty of clientele has increased***

The cumulative effect of these policy changes has been an increase in the level of poverty among people seeking services in agencies across the board. This is of particular concern because we know that HIV infection and disease progression are related to economic hardship (Ezzy et al, 1999; Gillies et al., 1996; Kass et al., 1994). Respondents noted that when compared to a few years ago, people living with HIV have fewer places to go to for assistance and most

agencies have fewer supports and services to offer those in need. Faced with cuts in other entitlements, many people living with HIV simply do not have the extra income they might require to take care of their health.

Although some community agencies try to provide short term relief to clients in desperate situations, they do not have the resources to provide meaningful assistance to individuals or families in need. Small agencies simply cannot make up for inadequate government benefits. Respondents note that they cannot pick up the slack from meagre state support:

*We provide emergency financial assistance to our families, but it's a very nominal amount. It's \$125.00 a year per family, which does not get you very far, whether you have one kid or six kids. It's just nothing. We are seeing the problems people are having on their government disability: they are having problems paying the rent and making the food bills once a month. It's really tough. [... We are seeing] a lot of debt accumulated and the stress of all that. A financial burden that brings a lot of stress to the home when you want to reduce your stress because you want to improve your health is just a really bad situation. (Community worker)*

Housing was identified as a problem in all settings. Aware of the importance of adequate, stable, and affordable housing in maintaining the health of people living with HIV, respondents expressed concern about the current situation in Ontario. Prices in the private market have increased, especially with the eradication of rent control. Governments in the 1990s withdrew much of the already meagre support for non-profit housing. Respondents recognized that housing concerns are tied to cutbacks in other areas, such as transportation and access to health care services:

*I know a housing worker who is very interested in trying to find some remedies for people living with HIV/AIDS and housing, and he said, "You know, even if people are prioritized to the top need through their special needs workers, they still have a five-year wait in downtown Toronto." But people need to be in downtown Toronto because they need access to the physicians. And the government is less and less able to pay for somebody to come in from Scarborough to their physician's appointment,*

*never mind whether the person can make it all the way down to the subway, climb up those bus steps. Oh, well, you need wheel-trans. Well, you have to come in to sign up for that. Hello? Like, how do you get in? (Hospice Worker)*

A worker in Toronto noted that her contacts in specialized housing resources are of less help than before. The service, that was once helpful in finding appropriate housing for her clients, is now of little help. The respondent explained: “We will get a letter from them saying don’t refer people to look for housing. There just isn’t any.” Again, as the possibilities for helping clients in immediate and concrete ways becomes more limited, the work of social service provision becomes more frustrating and stressful.

There has thus been a ‘thinning of entitlement’ for many benefits: even when supports and services are available, new eligibility restrictions have been introduced for many key services, and there are restrictions imposed on available benefits. Many of the remaining services and benefits have consequently been reduced. Workers complained that they have to complete their work in a limited number of sessions, or that there are lower limits on the financial aid they can offer. This means that even when they are able to provide help, they have less to offer.

### ***New rules generate uncertainty and instability***

Social services, like many public services in Ontario, have undergone considerable restructuring in recent years. In the name of cost-cutting and increasing efficiency, policies have been changed, agencies have been reorganized, and new eligibility rules have been put into place. One of the implications of such changes in so many fields of service is that workers are now confronted with learning new rules—‘the new realities.’ Respondents often reported being uncertain of what services are available and who is eligible to receive them. This was certainly true when workers spoke of services in other agencies, but workers were sometime even unsure of eligibility rules in their own agencies. An ODSP worker talked about the speed of change in her own agency: “Things are changing. They’re changing faster than we can actually learn.”

Evidence of this uncertainty is seen in the often contradictory messages that workers and clients receive from agencies like ODSP and Ontario Works. Workers from all kinds of agencies told similar stories. One respondent noted that she herself was once a recipient of ODSP. However, the rules are so unclear that she – as a worker and an ex-service user – often does not know the answer to questions and has difficulty finding information for her clients:

*I've gone to the different seminars and stuff and I have been on ODSP myself for a number of years so I also know what it's like to be on the receiving end of ODSP. I go to their seminars. I think it's just difficult because the system itself is overwhelming, ever-changing. They change rules as they go along. [...] So if I as a worker have been having difficulty negotiating the system, how can somebody who doesn't have my knowledge and skills negotiate the system? (Housing worker)*

Inadequate funding and the tensions it creates are seen by respondents as contributing to a high turnover rate among workers. This turnover was apparent in our sample: a number of our respondents were relatively new to HIV/AIDS work – despite the fact that we sought out experienced and knowledgeable workers. A hospice worker described a recent meeting in which the issue of staff turnover, which she linked to funding issues, was very apparent to her:

*I looked around the table, and I nodded to one or two people, but most people I didn't know. [...] What I was shocked about was that a lot of the people sitting at the table said, "Oh, I have no idea about what your agency does," ... What I see happening is, in the AIDS Service Organizations, funding is so poor that people are burning out so quickly, they are just quitting without any legacy. So you get these newcomers in, wet behind the ears, "honey, I could have burped you twelve years ago when I started in this, and you're telling me you don't know about us?" "It was appalling to me to see the loss of the legacy that is happening through all of these AIDS Service Organizations and I think that it goes right back to funding.*

### ***Increased Organizational Work***

Even if services and benefits are available, many respondents raised concerns that they are more difficult for client – and worker – to access. Respondents end

up spending much more of their time dealing with bureaucratic procedures and red-tape. One community worker described the situation for clients in the following terms:

*So much paperwork is required. It's just like you keep putting hurdles up and piling on more and more paperwork and responsibilities on people who have limited money to get around by bus, who have limited energy, who get ground down by the system and give up. (ASO Worker)*

Respondents reported that they spend more time dealing with forms or helping clients compile the paperwork needed to substantiate their applications. For example, housing workers noted that they have to engage in more work with community physicians to get them to produce the necessary documentation in support of a client's application, a process that can take considerable time and effort. Sometimes clients get caught in the absurdities of organizational rules. An ODSP worker described one such situation:

*Finding accommodation for clients in the community becomes a big problem because we can't pay shelter unless they have shelter. Of course a lot of them don't, and then it turns into a Catch-22. They have to show their money to get the shelter, but we won't pay shelter money because they didn't have any shelter. (ODSP Worker)*

Other aspects of the work feel increasingly bureaucratic, seemingly more focussed on organizational rather than client needs. An Ontario Works caseworker described the technological changes she has seen in her office:

*We all have computers now. You are staring at a computer more than you are staring at a client. You are spending more time in front of the computer than you are actually talking to a client. And you are more worried about helping them get off than addressing the problems or the issues that brought them here in the first place. (Ontario Works Caseworker)*

### ***Less worker discretion***

Workers reported having less flexibility in their practice than before, and they are less able to exercise their own professional judgements when faced with

individual clients. Previously, many workers were able to be sensitive and responsive to the special needs of people living with HIV. In recent years, however, this flexibility has been more restricted. A housing worker reported that she was once able to give greater priority to people living with HIV/AIDS who needed housing.

*I had discretion over my waiting list. It was a needs-based system. I looked at every application based on the person's income, their need for housing and certainly one of the needs would be medical, that's where I fit the group who were positive, in with the medical need. Now, the waiting list changed from a needs-based system to a chronological-based system. Modified chronological waiting, which is essentially chronological with a couple of exceptions. And the couple of exceptions are very, very limited. So now, to give anybody any priority on the list, I have to have a doctor's letter that says, not only that they're positive, but that essentially they're terminally ill, that they're in the stages that not getting housing will hasten their death. And we have to get a doctor to say that. (Housing worker)*

### ***Increased gate-keeping responsibilities***

The reality is that even if front-line workers do not agree with the shifts in policy, much of the responsibility for enacting these restrictive policy changes falls on front-line workers. Respondents find themselves increasingly responsible for rationing needed services and watching over clients to ensure that they do not 'abuse the system.' Their organizational responsibility to ration services can transform the nature of their relationships with clients. A case manager at a Community Care Access Centre (CCAC), which organizes and coordinates the provision of home care services, observed that many of her clients are now wary when she calls, fearing that she is simply trying to reduce their level of services. She tries to reassure them:

*[I tell them] "don't worry about my visit, I'm just coming to chat. I'm just coming to see how you are doing. I don't want you to have a heart attack the night before I come in or be so stressed out that you can't get up the next morning." But, this fear is more obvious than it ever was.*

An Ontario Works caseworker described how she has to ask questions about financial assets that seem particularly difficult and inappropriate to ask in the context of HIV. She noted, “One of the most god awful moments of taking the application is when I have to ask about assets. One of the assets is a prepaid funeral. I dread it every time.” Another caseworker for Ontario Works worried about what the introduction of drug testing would mean for her job and her relationship with clients. She worried that her work would become more intrusive than it already is, and furthermore that she would not have the required clinical skills and experience. Many respondents described the contradictory expectations under which they work: the weight of their responsibility has increasingly shifted to rationing and restricting resources and services rather than providing the nonjudgmental support they would like to offer. Workers in many community agencies, for example, have to distribute food, food vouchers, and emergency funds more carefully because they have fewer resources and more people in need of help.

### *Change in the climate of the work*

The reductions in benefits, the thinning of entitlements, the intrusive measures, and the need to ration services and supports all change the tone of service provision. Many respondents believe that the priority in their agency is reducing costs rather than helping clients in need. A caseworker for Ontario Works provided the following assessment of how recent legislation has changed the nature of her work:

*The new legislation, because it is so specific, is very punitive. This legislation makes it very difficult to focus on your clients. It is, “get them in, get them a job, get them off.” Or, “let’s reduce their money so they can get them off, then say, ‘look all the people we got off welfare’”. Well, you didn’t do it by doing anything positive. You just cut their cheques and made them ineligible, and now they have to live in poverty without a drug card, or without dental benefits.*

This change in climate was particularly noted by workers in OW and ODSP, who often feel acutely torn between their job requirements and their commitment to their clients, but such tensions were shared by workers in other

fields of service. An ASO worker with about ten years experience described the changes in tone that she sees:

*The system is just plain mean-spirited. There's no benevolence, there's no charitable quality, there's no heart in it. [...] I believe that if you're working with people and if you're working in difficult circumstances you need to have heart. Gosh, what if that was me? What if that was one of my family members? (ASO Worker)*

### ***Greater Needs, Fewer Supports***

Respondents described the frustrating irony of their positions. Clients seeking assistance often have needs greater than ever before, because there are fewer resources available in the community. The dilemma for workers is that these clients are in *greater need* just at a point when workers are able to offer *less help* than before. Not surprisingly in this context, many workers report feeling over-stretched, under-supported, and under-appreciated by their agencies and, often, their clients. But the news is not all bleak. Respondents spoke of positive changes in their work, largely related to advances in medical treatments. Changes on the medical front mean that many people with HIV are living healthier and longer lives. This creates an atmosphere of measured hopefulness – at the same time as it creates new practice challenges. In the next section, we will discuss how medical advances and changes in the HIV epidemic are reshaping the nature of social service work.

## *4. The Changing Epidemic*

The number of people living with HIV is on the rise, and the populations affected by the epidemic are changing. According to statistics from Health Canada's Surveillance Report to June 30, 2001, there were 17,812 reported diagnoses of AIDS in Canada, 7,004 of which were reported in Ontario (39.3%). The report indicates that of the 49,1555 HIV positive test results, 21,662 were from Ontario (44%). Health Canada estimates that 4,190 people in Canada were newly infected with HIV in 1999. The number of deaths attributable to AIDS has declined from a high of 1400 deaths per year in 1994 and 1995 to about 200 per year by 1999-2000. People continue to be diagnosed and are living longer with HIV, so the number of people seeking help from a limited number of overstretched services is increasing.

In recent years, we have witnessed an increase in the proportion of women, heterosexuals, and injection drug users, and a decrease in the proportion of positive test reports for men who have sex with men. Women accounted for 24% of reported HIV diagnoses in 2000. It should, however, be noted that Health Canada reported an increase in rates of new HIV infections among men who have sex with men, and the estimated number of annual HIV infections among such men increased from 1,240 to 1,610 (Health Canada, May 2001).

In the early 1990s, just under 90% of individuals diagnosed with AIDS were white, but by the late 1990s, Whites represented only about 75% of diagnoses. Aboriginal people, who comprise about 2.8% of the Canadian population, are the next largest group, representing 9.2% of AIDS diagnoses and 17.7% of HIV diagnoses. Blacks, who comprise about 2.0% of the population, represent about 8.3% of reported AIDS diagnoses. The epidemic continues to spread, people are living longer with HIV/AIDS, and the epidemic is increasingly diverse in terms of gender and ethnicity.

The epidemic is shifting in other ways. In the earlier years, people tended to be diagnosed at a late stage of infection, and typically did not live long after learning of their diagnosis. As a result, earlier services were designed on the assumption that users would become progressively ill. The focus of much of the work was helping clients cope with increasing disability. Now, in contrast,

people are generally tested earlier and often live longer with the knowledge that they are HIV-positive. As a result, services have also had to change.

The use of antiretroviral therapy (ART) for the treatment of HIV infection means that many PHAs are living longer and healthier lives. Many people experience their HIV infection less as a terminal illness than a chronic illness with which they live over many years. New antiretroviral treatments are extending and increasing the quality of many people's lives, but their benefits can come at significant cost. People often have trouble maintaining the strict regime required by many new treatments (Carpenter et al., 2000; Gallant & Block, 1998), and side effects of the medications can be debilitating. Given the problems many people experience in complying with strict treatment regimens, drug resistance, concerns about long-term toxicities, and treatment failures, one can anticipate the ongoing need to provide support to those for whom treatment is no longer, or has never been, effective. Those not responding to treatment may feel left behind and neglected in the face of public enthusiasm about new treatment prospects. As Brooks and Klosinski (1999) observe, "On the one hand, traditional programming must be maintained for clients whose health continues to deteriorate. On the other hand, clients with a sustained improvement in health will need assistance with planning for the professional, financial, and emotional challenges of living and working with a chronic, more manageable disability" (p. 213).

### ***Increased focus on social rather than health concerns***

The introduction of more effective treatments has changed the nature of social service provision in many respects. Sickness and death are not as central to much of the work as was once the case:

*Clients are living longer. We haven't seen ... I'll be honest that in a year, nobody has died from our client pool. So that's a good thing, that's a good thing. We are doing our Celebration of Life, where every year we have a list of names [of those who have died during the past year]. We have no names to call this year. We have had one name to call in two years. So that's great. That's progress. That's fabulous. (Hospital Worker)*

HIV is often not the primary concern of their clients. HIV infection is often just one of many complex issues in the lives of clients – and it may not be the most compelling practice issue.

*People suddenly have time to deal with issues that they didn't when it was they were sick and there was a short time between coming here and dying. So you get the mental health, get the sexual abuse, you get issues people had in their life [before their HIV infection]. (ASO worker)*

This is particularly true for certain groups of clients, such as those struggling with addictions or newcomers to Canada, who often have to deal with concerns relating to their immigration status, among other issues:

*They don't have any of the family support, they don't have friends that they have grown up with. They are very, very much alone and for those people there is no outside help. These women that are unable to work with small children, they seem to spend most of their lives just in their small apartments. They find it difficult to get outside, because they don't know the area and they have no money to go any place. You can't even go to the mall to have a coffee or anything like that because they may not even have the proper clothes to go to the mall. (Worker in child & family service agency)*

The range of issues that PHAs bring to service providers is much broader as a result of the effective treatments. As people live longer, and healthier lives with HIV, the focus of much respondents' work changes from health-related concerns to social issues. One worker described the changes she sees:

*There are different issues. It depends on the stage of the HIV. When the diagnosis is very recent, very new, that is the entire problem: how to deal with the HIV with their partner, and how to talk about that. They are very lonely, and they feel guilty all the time. The counselling helps them for that. When at 2 or 3 years, it's more [focussed on] social problems. You'll see now it's poverty. That is very, very hard, the poverty. Transportation, also. And legal problems. There's all these problems. Or immigration problems. (Community-based counselling service)*

As a result of such changes, many respondents described how they find themselves increasingly confronting larger and more chronic social problems over which they feel they have little influence. They may have little training and experience in dealing with issues such as housing, drug use or mental illness. An ASO worker stated, “Before it was about a disease that more likely was gonna kill you. Now it's about the social supports our society has or has cut back, how that affects people and how they can continue to live.”

Many clients seek assistance for more mundane problems of living. The observations of respondents in this study were consistent with other recent examinations of the experience of living with HIV. For example, Barry Adam, Eleanor Myticka-Tindale and Jeffrey Cohen (2001) stated in their recent study, *Living with Combination Therapies*, that “For most of the people we interviewed, living with HIV has become relatively normalized. [People living with HIV] take their medications and go on with their lives. They are no longer the pressing end-of-life and acute illness decisions to be made or searches for therapies to be embarked on that seropositive people faced in the earlier years” (p. 35). For many, going on with their lives means living in poverty, experiencing unemployment or underemployment, searching for affordable housing, dealing with depression, and living with the problems associated with drug and alcohol use.

### *New Clientele*

The clientele of many respondents has changed over time. Those clients who come with concerns directly related to their HIV receive relatively short-term service and then move on – often ‘leaving behind’ those clients with more serious and chronic personal and social difficulties. Combined with the aforementioned changes in public policy, workers often deal with clients who have long-standing problems and few resources on which to draw. Respondents discussed a number of concerns they had about particular groups of clients, such as recent immigrants and refugees, First Nations people, members of visible minority communities, women, gay men, and people who use injection drugs. While such concerns will be the topic of a separate analysis, they include such issues as client worries about their precarious legal status, their ability to access affordable health care, their access to rehabilitation services, and the availability of culturally relevant support.

To many respondents, clients once seemed to have more resources available to them. They recognized that their clients were often well informed and engaged in their own service delivery. However, while this is still true for many, most respondents described their clients as now more likely to present issues concerning drug use, mental health concerns, poverty, or inadequate housing.

*A lot of the clients [in earlier years] were gay men who were very often well supported by a network of people. Not necessarily their families but they had friends, they had career people involved in their life. They tended to be pretty on top of what was going on with the disease, what treatments were available, how to stand up to their doctor, how to push for more care. ... Now there's like this other category of people who found their way to our doorstep for whom disease progression is not the issue. It's getting the next meal and finding out how to access some treatment, any treatment; getting a doctor. And the challenges around keeping appointments or not keeping appointments; or street-involved, violence, poverty, just the whole list of things. A lot of transience, moving around. Things like a phone, you can't count on that. (ASO Worker)*

Of course, such clients are not really 'new': there have always been people living with HIV who experience difficulties like these, but changes in policy and in treatments for HIV have changed the balance of the clientele of many agencies. This shifting balance has meant that some workers, who may have come to AIDS work because of community ties and experience, no longer feel a strong affiliation with their clients. Indeed, several respondents reported feeling quite ill-equipped to meet the needs of their new clients. The new clientele were often different from their workers in terms of social class, race or experience with drugs or alcohol, which created feelings of distrust for both client and worker. Respondents thought that some clients were often less welcome in the agency, and that staff members were wary of their presence:

*Depending how someone looks or how they present themselves, people tend to, I think, be a little more alarmed—and this is my perception here. It's like, 'You don't fit in', or 'You're talking really loud', you know; 'Who's attending to this person?', so there seems to be a little concern about are we aware of what people are doing in the building. Whereas before it just*

*seemed like the door was opening and closing a lot and it didn't really matter. (ASO Worker)*

### ***The Complications of Treatment***

Ironically, the health benefits resulting from new treatments can create complications of their own. Housing workers describe how their clients no longer turn over like before, increasing their waiting list. Health improvements in health can have serious psycho-social ramifications for some individuals. These can include depression, social isolation, and underemployment:

*Years ago [clients] were expected to die relatively soon and everyone else expected them to die. They spent a lot of time coming to terms with that, in fact they spent a lot of time in here coming to terms with that. Sort of reevaluating their goals, making short term goals, still trying to live a life that was meaningful but they knew it was going to be really short. So more people adjusted to that idea. They lived their lives accordingly. Then all of a sudden they were faced with the possibility of actually living to be old people, and that was really frightening for a lot of people. When you think about it, it is pretty obvious why. A lot of their friends are dead, they have no savings, they have no computer skills, the workforce has changed dramatically since they left. It changes dramatically for the people in the workforce year by year, never mind, imagine leaving for five to ten years, three to four years, and try to integrate back in. (ASO worker)*

The side effects of treatments create additional social and psychological stresses. Treatment regimens can serve as a constant reminder of clients' health status. Many clients worry that their medications may not be effective over the long-term, and they may struggle with fatigue or other side effects from their drugs. Changes in physical appearance cause by lipodystrophy can be as emotionally difficult and socially stigmatizing as the kaposi sarcoma (KS) lesions that were characteristic of the earlier years of the epidemic.

The new treatments do not work for everyone. A number of respondents pointed out that they need to continue to work with those who may feel abandoned and forgotten in all the enthusiasm surrounding medical advances.

*The focus has been on getting people back to work, getting people back into the mainstream. People who don't fit into that category feel quite left behind. For instance, trying to find a bereavement group these days is very difficult, but there are still people who are dying. (ASO worker)*

Improved treatments also took away some of the excitement and interest in the work for some respondents. What once felt like a dramatic crisis of life-and-death has, to a large extent, been replaced by the frustrating slog of dealing with poverty and inadequate resources. This shift in the nature of the work created a sense of confusion and crisis for some workers.

*We had a cause: it was helping people learning to live with dying and helping people to wrap up things and get ready for death. I remember, I hate to use the word excitement, but there was a cause. Then protease inhibitors came. I was on maternity leave. I came back and it was like, "Whoa, what happened here?" (ASO worker)*

This same respondent recalled hearing a speaker who used the imagery of a dining table to illustrate the upset caused by the new treatments:

*What it felt like for him was that the protease inhibitor moment was like the table was all set. We knew where everything was. The candlesticks were here, and all the cutlery was here. Then somebody came along and just lifted the tablecloth and everything went flying. Now, we're running around trying to catch things to figure out what we're supposed to be doing here because people are living longer.*

### ***Worker Inexperience with sickness***

In the early years of the epidemic, most traditional social service agencies did not provide many services to people living with HIV. Over the years, however, agencies became more responsive to the social needs created by the epidemic. And, as the stigma surrounding the epidemic has somewhat diminished, people living with HIV are more willing to seek out services from agencies that do not specialize in HIV/AIDS. The result of these shifts is that many workers who

provide services to people living with HIV may not have much experience dealing with HIV. Several respondents, particularly those in smaller locales, stressed that they had only ever worked with one or two clients who had HIV. A number of these workers felt, in hindsight, that their few HIV-positive clients probably did not receive the best of care because they were not well-acquainted with clients' needs or available resources.

Even those workers who are employed in HIV-specialized services often said that they did not have much experience dealing with serious illness or issues of death and dying, whereas in the earlier years of the epidemic, much of the work focussed on those at later stages of infection. Then, workers organized care teams, counselled partners and family members over issues of grief and bereavement, helped people come to terms with increasing disability and sickness, and supported individuals and families through the dying process. Since the late 1990s, however, with the advent of ART, the majority of respondents' clients have been relatively healthy.

Further compounding this change has been the relatively rapid turnover of front line staff in most agencies. Most workers do not stay in the same position for many years. This means that most respondents – people who were invited to be interviewed because they provide key HIV/AIDS services – did not work in the field prior to the introduction of ART. A generational divide was apparent in our sample of respondents. Some worked prior to 1996, when sickness and death were more central concerns to much of the work. Other respondents have come to their current positions since that time. Several said that they have not known of any clients at all who have died as a result of their HIV infection. A couple of workers in addiction services said that they are as likely to know of clients who died of other causes than HIV infection.

Like many of the people living with HIV, a number of respondents spoke about how the new treatments leave them feeling uncertain about the future. The relatively recent success of these treatments, coupled with worker turnover, may mean that there will not be a large pool of experienced workers on which to draw if and when people start becoming more symptomatic. Some respondents expect their work soon to become more focussed on sickness and death as a result of increasing treatment failures: “We’re definitely going to return to

palliative but will it be in twenty years or five is the question.” They anticipate that the return to a increased focus on supporting people who are sick or dying will be emotionally difficult. For newer workers, it will be an unfamiliar experience. This inexperience among front-line service providers worries respondents who anticipate an increase in the numbers of people who are not be able to tolerate the new regimens. Those who worked in the field prior to ART may feel unprepared to return to work that is more focussed on issues of sickness and death. The lack of experience among workers in other positions may also affect those providing front-line services in that colleagues may not fully understand the demands of working with clients who are serious ill and dying.

## *5. Negotiating the New Realities*

The shifting context of service provision presents new challenges to workers' skills in that they must become adept at 'working the system' in the best interests of clients. Front line workers are typically not passive in the face of such changes. They often develop innovative ways to mitigate against the negative impacts of restrictive policies and agency practices (Lipsky, 1980). At other times, workers cope with the demands of their jobs by enforcing rules and regulations; they play by the rules rather than bending them. This section of the report examines the ways that workers manage the challenges they face in practice.

### *Bending Rules*

Many respondents noted that they do what they can to work around the constraints of their jobs. Some spoke of 'fudging' rules in support of their clients, which often meant closing their eyes to issues or interpreting rules as broadly and generously as possible. Others try to use the bureaucratic rules of their agency to benefit clients:

*I am making this decision that you are ineligible, but you can appeal and then while you are appealing, we might in turn give you assistance. We do whatever we can do because we may be wrong. You might win, so guess what, we are going to do the interim assistance and then they're getting their needs met. They're going to be able to maintain their housing and their food and provide for their families. (Ontario Works Caseworker)*

Similarly, another worker indicated that she coaches clients on how to best fill in paperwork to increase the chances that the request for services will be approved.

*One person who I was really concerned about, I went in to coach them without telling them to lie. In this case, you can't lie because that would be wrong and you don't want to do that, but you need to answer in a pretty specific way. (ASO worker)*

Respondents from various types of agencies talked about how they try to provide concrete resources to clients even if doing so breaks agency rules. ASO

workers sometimes provide emergency financial assistance, knowing that the receipts the client provides them are not legitimate. A public health worker would occasionally ‘lose’ or ‘miscount’ boxes of syringes to be able to provide free needles to clients who inject drugs. Another needle exchange worker provides more syringes than she is supposed to:

*It's when clients come in, requesting for syringes. And where, let's say, we can give ten. And I know that the person is using coke, and there's a couple of buddies – the potential for sharing is there. So, I will give more than what our limit is.*

While respondents noted that they have less discretion over their work than they once did, discretion is still an integral part of front line social service delivery. Agencies’ efforts to limit professional discretion are invariably restricted, leaving workers with the opportunity to make judgements and interpretations of agency and government rules and policies (see Lipsky, 1980).

*[Our turn-over rate is ] very, very low. Typically someone who's HIV positive needs a one bedroom unit, although I have over-housed a few in two bedroom units just because I can't stand it anymore. (Housing worker)*

The ethics of such situations sometimes feels clear. On other occasions, it feels more murky. One respondent reflected on the morality of such situations, when the choice is between doing what is clearly in the best interest of an individual client and breaking agency policy:

*Am I cheating my employer or am I cheating my client? Those money situations are very difficult. I had a client that has numerous health problems and she couldn't even wash her hair. I got her money to have her hair washed and done to make her more employable. Well, it was true – it could make her more employable. But when is she ever gonna work? (Ontario Works caseworker)*

Worker discretion is one way around inflexible bureaucratic rules, but it opens up the possibility of unfairness. Few respondents bend rules for all clients, but most seemed prepared to be ‘flexible’ for at least some clients. Rather than

being entitled to receive certain kinds of support, clients are sometimes required to depend on the kindness and willingness of individual workers. Deciding who is 'worthy' of such special consideration raises a host of questions with regard to the provision of fair and equitable treatment for clients.

### *Limits to 'Fudging'*

In most instances, workers are both individually responsible and vulnerable as a result of their efforts to 'work the system.' Many are careful to make sure that no one else knows of their rule bending and 'fudging.' Sometimes, they have the tacit or explicit support of supervisors, who feel they can trust the worker to make responsible and reasonable decisions.

*My supervisor is pretty good. She will try usually to do what she can. She follows the rules, follows the legislation, but if an extraordinary situation presents itself then she will try to work around it as well. She will problem solve with me and with the other workers to see what we can do about that certain situation. (Ontario Works Caseworker)*

Other times this support is much more conditional. There is an understanding that workers may bend rules, but if found out, they will not receive support from the supervisor or manager.

*My organization is supportive of me. What we look for is to just have it not be public, just keep it quiet and I'm not criticized for it, unless it were to become a problem and then I would be criticized for it. (Housing worker)*

Some workers simply plan to plead ignorance if they are ever caught breaking rules:

*I have manipulated the system in the sense that I have access to food vouchers, even though I'm not a Parent-Child team and they are very comfortable with the idea that I'm doing that. If I'm challenged and they ask me about it, I'll say, "Oh, I didn't know I was supposed to keep track..." I do keep track but I don't do any major documentation. (Public Health worker)*

Some workers are able to take advantage of organizational change and disruption. Workers in community groups, for example, can negotiate fairly freely because of the relative informality of their agencies. This is particularly true in those organizations that have a history of instability and upheaval:

*One of the good things about the complete disorganization this agency in general has been – it's really been a difficult thing, but it's also been a good thing – a complete lack of policy. A complete lack of any structure around job descriptions, what to do under different circumstances. In some ways, that's given me incredible freedom to do what I think is best for clients.*  
(ASO worker)

Most respondents will not directly lie for clients, but they may be prepared to omit details of client situations or ‘stretch’ the truth if that might be of benefit. One needle exchange worker described her approach in these terms: “I wouldn't say break rules. Bending. There are degrees of bending, I would say. But break? No.” One of the greatest limits to respondents’ ability to work the system is the risk that their activities become the subject of public scrutiny. This can place both the worker and the agency at risk.

Most respondents seemed to draw a line between breaking agency policy and consciously breaking the law. For instance, one worker described a situation where she and a parole officer tried to find ways to getting more money to a client:

*I was working with the Parole officer there, and we tried to figure out what to do. “What if I charge you rent” he said. I said “If you charge him rent, it will go up by the rental amount but then he has to pay it because you can't get into a fraudulent situation where you are charging him rent to get him on, because if his case is reviewed and we want to see rent receipts, you can't provide them, and you don't want to go there. He agreed. (Ontario Works caseworker)*

### ***Creating Barriers***

Respondents can also play by the rules to manage the stresses associated with their work, such as that cause by increased number of clients. Respondents in

a number of agencies described how their particular agency has created new organizational barriers to help them manage increased demands for their services. A few agencies use their phone mail system as a barrier between workers and clients who might request services. A hospital worker described how her old system of keeping track of clients no longer works:

*I keep track of phone messages in my diary and I don't have room. I'm so afraid I'm going to forget details because people count on you. There's no space to write anything anymore because there are just so many phone calls.*  
(Hospital social worker)

Some agencies try not to advertise all of their services, fearing that they will be overwhelmed with requests. Others have limited the hours of operation to cope with reduced numbers of staff members. Agencies that once prided themselves on being open and accessible are increasingly demanding that clients set formal appointments to see their workers. As well, respondents recognized that the move to increased formalization of services comes at a time when many of their clients will have difficulty negotiating bureaucratic rules and regulations.

*We've just started a "no-show" policy [...]. We're starting to talk to people about it, just to let people that after the first no-show we'll bring out the form and ask you to sign that you will call and let us know that you can't make it. At least call. You can cancel as many times as you want but hopefully to encourage some behaviour change in that you get your butt to a phone, please and call us so that we might be able to slide somebody else in. We've kind of gone the "Catholic-guilt" route.* (Drug Treatment Worker)

### ***Managing Safety Concerns***

Beyond increased numbers, several respondents talked about how some of the new clients they are seeing, particularly drug users, sometimes feel threatening to them and to other service users.

*The IDUs come with quite a different background and much harder to deal with than the gay—they were mostly gay men. They were very easy; you had*

*no problems dealing with them. They didn't have the baggage—they had some baggage, but not the street baggage like the folks who are coming in now. ... They're much tougher to deal with. They're manipulative, they lie in your face and some of them are quite tough; they can be in your face, and she couldn't take it. (Housing worker)*

Reflecting a fairly extreme example of such a concern a clinic worker described what the change in her clientele has felt like for her personally:

*We've got gang members ... it gets scary sometimes. Whoa, and me, I live in my nice white picket fence world. When we get involved in that element, that scares me. I get frightened by that stuff. Not to the point that I can't work, but it's like, 'wow, Hells Angels, eh?' We're talking interesting connections. (HIV clinic worker)*

To respond to an increased need for security, some agencies have erected glass partitions between workers and clients. Clients may have to be 'buzzed' into the offices. While staff concerns about security are important, the findings suggest the need for flexible outreach services to better meet the needs of people who cannot adhere to agency regulations.

### ***Controlling Client Behaviour***

In a number of agencies, new rules have been developed to regulate client behaviour: cursing is not allowed, drugs are not allowed, weapons are not allowed, and lending other people money is not allowed. Some respondents felt that increased rules such as these are helpful to both workers and clients alike:

*One of the few things that I think we can offer people is consistency. I think that's a huge benefit for some people. They know what they can expect, they know everybody is being treated the same and everybody is treated fairly. There aren't any special favours going, people that we like more. So in some ways, we try to be very consistent. (Drop-in centre worker)*

Rules are not seen simply as controlling. They can sometimes be framed as helpful and therapeutic to clients themselves. Other times, rules regulating client conduct are justified in terms of meeting the needs of other clients.

*It can be complicated but I think for the context of being in the drop-in and sharing and talking with people and keeping, I just consider it boundaries around what you can do and what you can't do, I think that does help a great many people and the volunteers are available for people to talk to and I think that means a lot for some people and it's quite helpful. (Drop-in centre worker)*

Strategies such as these reflect significantly different organizational cultures and models of service than some of the previous client-driven models. The move to more staff-driven approaches has both costs and benefits. Such approaches attract workers with different kinds of priorities, values and work experiences.

### ***Justifying bureaucracy***

In the earlier years of the epidemic, community workers focussed much of their efforts on advocating on behalf of clients to unresponsive bureaucracies. In contrast, some of our respondents now engage in discussions to help clients understand the realities of social service work by explaining why it might be hard to contact their workers, why calls might not get returned, etc. In doing so, they are hoping to reduce clients' level of frustration, and to help them understand the realities of the provision of services. However, they may ultimately be defending an unresponsive and uncaring system:

*We try to establish relationships with the individuals within those systems and we try to understand it and do a lot of education with our clients that the social worker who can't help them is not necessarily deliberately not answering their calls, but to understand their workload issues. So we have to learn those ourselves. (Community Organization)*

The individualized practice of 'working with' unresponsive service delivery systems rather than collectively 'working against' them can serve to depoliticize the experience of receiving services.

### *Advocacy*

Advocacy has always been a core element of social service work with regard to HIV/AIDS. Because of the seeming reluctance of governments and traditional health and social service agencies to respond to the needs created by HIV, workers, who often came out of the community movement, were driven by a strong personal commitment and passion. There was a clear sense of what had to change. But this energy and direction now often feels harder to identify and hold onto. People are not dying as they once were. Treatments are relatively accessible. More health and social service professionals are providing appropriate services and care. More importantly, the general belief seems to be that the availability of new medical treatments means that people feel that the crisis has passed. This belief can severely limit workers' ability to advocate for clients and assist them in accessing services, particularly in times of crisis.

*Why is there so much quiet? There's a general acceptance that science has provided a way to live with HIV. You can go on drugs and maintain yourself the same way as a diabetic. Nothing could be further from the truth. The quality and even the quantity of your life after you've begun a protocol is dramatically different from what you were before, but that's not the general public perception, it's not even the perception of some people who acquire HIV/AIDS. (ASO worker)*

Workers described how they are more selective about when to advocate for clients. They are faced with so many situations where they could take on an advocacy role that they need to carefully 'pick their battles.' A worker on a hospital HIV team described how she has to be careful not to alienate her teammates by being seen to 'cry wolf' too often.

A community worker talked about needing to protect her image with other agencies as someone who only advocates when she absolutely has to:

*We try to be extremely careful not to pretend someone needs a bus pass if they don't need a bus pass in our medical opinion. If there's a legitimate need to advocate strongly for that, but to tell our clients honestly that, no, we won't say they need extra food when we don't have documented reason. Although for everybody's health, having enough food would be better, but*

*we try to be very careful about that sort of thing so that our reputation will be one of honesty. If we say someone desperately needs housing this weekend, we mean they desperately need housing, not just that they're unhappy where they are, or they've been evicted but they're healthy and they could solve the problem.* (Hospital worker)

Advocacy work is complicated by the fact that much of social service work has changed from providing support to judging the legitimacy of client requests. A respondent who works in an ASO noted that she is prepared to help pay a client's rent when the client has inadequate income, but she is not prepared to help when she believes the problem is the client's 'bad spending habits.' She said, "I'm not helping if the problem is one of spending, not income."

Rapid changes brought about by restructuring and cutbacks in the social service systems mean that workers of all types feel as if they are playing 'catch up'. Respondents do not have the time or opportunity to stay in contact with other service providers, many of whose agencies are undergoing significant changes. Turnover in staff undermines workers' ability to advocate because new workers often lack the specialized knowledge and insider contacts to 'work the system' effectively. Many respondents feel fairly isolated in their positions and disconnected from a political movement that aims to make services more responsive. Effective advocacy is hard to do without insider connections and good support.

Issue advocacy, as opposed to case advocacy, requires long term vision, and often, collaboration with others. Because of increased demands for help, most respondents focussed on immediate client needs. This leaves little time and energy for other tasks that are often seen as equally important: prevention, advocacy, developing ties to collateral agencies, and coalition building.

### ***Finding Support***

Coworkers and supervisors are often a key source of support and connection for workers, but these relationships can become complicated as a result of organizational upheaval and change. In some services, such as those in hospitals, organizational restructuring has changed collegial relationships in that social work departments have generally been disbanded in favour of program

management models. And, as well, in some community groups, organizational tensions make it difficult to form supportive ties with other workers.

A key source of support for many workers are committees and extra-organizational networks to which they belong. As it becomes more difficult to find time for committee work, developing and maintaining these external ties can become more of a challenge to workers. A hospital worker noted, “We used to have our counsellor support groups. We'd meet there. But we don't meet anymore.”

### ***Worker Satisfaction***

Our data show that, in many ways, the work of providing social services is becoming more demanding. Respondents feel overstretched and unsupported, conditions that make it hard to consider the work as a long term career. Worker dissatisfaction can lead to burn-out, and high worker turn-over, which in turn, exacerbates many of the challenges identified by respondents.

Despite these difficulties, most respondents appear to find sources of satisfaction in their work. Often they spoke of the rewards of working with their clients. Helping people in times of crisis, making connections to variety of people, learning/thinking about new things are all important sources of worker satisfaction. The ability to help clients work around agency or legislative rules is often an important source of satisfaction for workers, who like using their skills and expertise for the direct benefit of clients in need. Most respondents described their HIV-related work as very rewarding. Some left less fulfilling work to move into HIV/AIDS organizations, even if the pay is less and the working conditions somewhat more demanding:

*It's like I found out what my purpose in life is. I used to be in a totally different type of work in terms of nine to five, working in a bookkeeping kind of position and I was never happy, then I found out that I would start volunteering in this type of work in the mid eighties. I started to get more involved and then this organization formed and everything just kind of clicked for me. I said “Now I'm finding my purpose!” (ASO Worker)*

Appreciative comments from clients, and being seen to make a difference in people's lives, can make up for the many work-related frustrations:

*We have lots of clients who are very thankful that we're here and it just makes the job better and knowing that you're doing something that is important to someone, even if it's just one person out of those forty-seven people that came back and said, 'That really helped me in a time of need.' It's worth it. (ASO worker)*

## *6. Discussion & Implications*

The nature of social services for people living with HIV/AIDS has changed in significant ways over the past few years. The policy context of services has become more restrictive, leaving workers and their clients with fewer resources and services. Services that are currently available are often more limited than before and they can be more difficult to access. People living with HIV who have fewer personal resources to draw on in times of need are forced to rely on a less generous welfare state and well-intentioned, but overstretched community agencies. Social service workers are essentially expected to do more and more with less and less.

Features of the HIV epidemic have also changed significantly over the past few years. The introduction of more effective treatments means that many people are living longer, healthier lives despite their HIV infection. Many people with HIV have adequate resources, and so, do not require social services. But the new treatments raise problems and concerns of their own, not the least of which is the uncertainty about whether people will be able to tolerate their medications over the long term and whether the drugs will continue to be effective in staving off illness.

Although workers still need to focus on HIV, it is less central than it once was. Many client needs have little or nothing to do with HIV itself. Much of the work of providing HIV/AIDS social services now focuses on chronic social problems like poverty, poor housing, and addictions. While they were always factors for the clientele of those needing social services, changes such as these have shifted the balance in the caseloads of many workers: individuals who cannot afford nutritious food, who lack adequate housing, or who struggle with addictions now make up a large proportion of the caseload of many agencies. This situation further taxes existing resources and the ability of workers to provide effective support. Workers have developed a number of strategies to deal with the increased demands and stresses of their jobs. HIV/AIDS service provision, in these ways, has become relatively unexceptional. In many ways, it is becoming simply one more health condition that can impoverish or marginalise people.

Despite the fact that we are now twenty years into the work, the data we have collected on social service delivery reveals that much of the work is characterized by considerable change and instability. Where one might have expected workers to develop their careers in AIDS work (and certainly some have), many of our respondents felt inexperienced and uncertain as to how to provide needed services. Social service work often appears as characterized by newness and uncertainty as it did years ago. Today there is a broader range of complex needs that workers need to address, increased numbers of clients, and a social environment that no longer sees HIV/AIDS as a crisis. Workers need to be abreast of developments in a number of areas: housing, income support, home care, health care, and the provision of emotional support. To complicate this daunting task further, social service systems have changed quickly. Respondents are often unfamiliar with the rules and eligibility requirements of collateral agencies and, sometimes, even of their own.

Given the experiences described in this report, it will not be surprising to hear that workers often appear to ‘hunker down.’ We heard relatively little talk in our interviews of creating change. Rather, we heard talk of the everyday struggles of workers trying to respond to individual clients and their immediate needs. Many respondents spoke with a sense of fatigue. Others sounded disillusioned about possibilities for change. Also, many workers are more careful about taking risks in their agencies, or in alienating professionals in collateral services on whom they sometimes rely for assistance. They choose their battles carefully.

For all of the devastation caused by HIV over the past twenty years, the epidemic in North America held out hope for some positive changes in how social service could be delivered. New and innovative services have been developed, often by people who were directly affected by HIV. Models of service provision were developed based on the principles of community involvement and the empowerment of clients, where workers and agencies would be more clearly accountable to their constituent communities. Workers developed approaches to social service delivery that aimed to address broad social and political issues, as well as the needs of individual clients.

The changing policy context and, ironically, the advances in treatments described in this report are putting at risk some of these gains. The findings

from this study suggest that despite all of the hard work and dedication of workers, social services for people living with HIV are becoming like other underfunded and residual fields of social welfare. There appears to be an increased social distance between many workers and their clients, despite the years of analysis suggesting the need to minimize divisions between those who provide services and those who receive them; workers are less intimately familiar with clients' lives and the concerns of clients than they once were. This makes it hard for workers to relate to their clients, and it can generate feelings of fear and distrust for worker and client alike.

### ***Practical Implications***

The findings from this study suggest a number of changes that would be helpful to front line workers.

- A centralized source of information would be useful to many workers. A common concern of respondents is that it is difficult to stay abreast of changes in entitlements. Workers need up-to-date information on services and benefits, such as Ontario Works and the Ontario Disability Support Program. This might be an appropriate project for a provincial organization, such as the Ontario AIDS Network.
- An information sheet that summarizes agency services would be useful to many workers and clients. Clients are often unaware of the benefits and services to which they are entitled.
- Agencies could create opportunities and provide support for workers to become involved in community task forces or other kinds of inter-agency committee work. Respondents reported that committee work is often the most useful way to meet colleagues in other agencies, to identify common concerns and issues, and to recognize the structural forces that shape client realities.
- Agencies need to be more active in their support of front line workers, who often feel overwhelmed by the daily demands of their jobs. Supervision needs to go beyond the discussion of administrative and

bureaucratic concerns to better support workers and to promote their professional development.

- It might be useful to examine possible ways of separating gate-keeping functions from the responsibilities of front line service provision. Respondents indicated that their work is increasingly gate-keeping; rather than supporting clients. This places them in a role that is often inconsistent with that of a nonjudgmental helper.
- Coalition work with workers and agencies outside of HIV/AIDS would probably prove useful to workers as they attempt to address broad social issues that shape the epidemic. Broad concerns such as poverty and inadequate housing were identified as common worries by respondents in all fields of service.
- Workers need to resist feelings of resignation when it comes to broader social issues of poverty, housing, or transportation. These long-standing social problems need to be as much of the focus of advocacy and political organizing as HIV-specific concerns, such as access to treatments.
- Peer-consultation sessions through networks such as the OAN or CAS might be useful. Workers often spoke about how little opportunity they have to reflect on the broader context of their work, to meet with other workers to share their experiences and insights, or to talk about the future of their work.
- Opportunities for mentoring and training would be useful to workers trying to keep up with developments in the field. Many respondents are fairly new and inexperienced with regard to HIV/AIDS.
- New rules and regulations may be necessary to help workers and agencies manage the many demands they face. Agencies need to consider ways of reaching out to clients who can be expected to experience difficulties relating to increasing bureaucracy.

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