The involvement of people living with HIV/AIDS in community-based organizations: contributions and constraints

C. M. ROY[1] & R. CAIN[2]

[1]*AIDS Committee of Toronto* & [2]*School of Social Work, McMaster University, Hamilton, Ontario, Canada*

Abstract   *An important feature of the social and organizational response to the HIV epidemic has been that many people living with HIV/AIDS have demanded to have a say in the development of policies and the delivery of services. Surprisingly little attention has been paid in the literature to this involvement. This paper is based on a participatory action research project that involved 70 people with HIV/AIDS in 15 focus group discussions. Findings from the study show the complexities of translating organizational commitments to involve people with HIV/AIDS into practice. This paper outlines the organizational contributions of people with HIV, and examines the difficulties and obstacles to their meaningful involvement. The paper concludes with a discussion of the challenges of user empowerment and with recommendations for policy and practice.*

Introduction

An important feature of the social and organizational response to the HIV epidemic has been the growth of a self-identified community of people living with HIV and AIDS that has demanded to have a say in the development of policies and the delivery of services. From the early years of the epidemic, people living with HIV and AIDS (herein called PWA) have mobilized to challenge inadequate responses to their needs. In the early to mid-1980s, members of urban gay communities who were directly affected, and often infected, by HIV developed community-based education and support services. Drawing on their experience in gay political organizing, PWA in the USA formed the National Association of People with AIDS in 1983 to identify their common issues and assert that people living with AIDS have 'the right and the responsibility to determine their own experience with AIDS'. (Callen & Turner, 1989, p. 20). This association produced the 'Denver Principles' that stressed the involvement of PWA in their own care and in the broader social response to the epidemic. Rooted in similar principles of self-empowerment, statements such as the 'Montréal Manifesto', released at the International AIDS Conference in 1989, advocated for an international code of rights to promote the 'active involvement of affected communities of people with HIV disease in decision-making that may affect them' (AIDS ACTION NOW!/ACT-UP New York, 1989).

Address for correspondence: Dr Charles Roy, AIDS Committee of Toronto, 399 Church Street, Suite 400, Toronto, Ontario M5B 2J6, Canada. E-mail: croy@astoronto.org

These broad principles and commitments have served as a basis for mobilizing PWA around local issues and concerns. Service users within local organizations were often dissatisfied with the services they received and the scant attention paid to issues directly affecting them, such as gaining access to new treatments. They often saw community-based AIDS organizations as slow to respond to changing needs. Users often saw their local groups as increasingly bureaucratic, and they criticized workers for not making the immediate and practical needs of PWA enough of a priority. PWA in many communities organized themselves to gain more power and influence in their local community AIDS service organizations. In many North American settings, PWA formed their own community organizations as a result of their dissatisfaction with their local AIDS service organization, and in some cities, organizations were established by and for specific communities of PWA. In Toronto, for instance, specialized groups now exist for HIV-positive gay men, women, youths, straight men and those infected through blood products. These organizations, which typically provide practical services to assist individuals in their day-to-day lives, often require majority control by people living with HIV/AIDS. The voices of PWA have also become institutionalized into decision-making structures in the broader AIDS movement. In Canada, for example, the national coalition of community-based AIDS organizations, the Canadian AIDS Society (CAS), formally recognizes a caucus of people living with HIV/AIDS and requires strong PWA representation on its board of directors. CAS also requires as a condition of membership that local organizations provide 'significant and appropriate representation' of people living with HIV on their board of directors and in other facets of their organization. In 1997, CAS accepted a Declaration of Rights for People living with HIV/AIDS that claims the right of people living with HIV/AIDS to 'full involvement in any decision-making process affecting our lives' (CAS, 1997). Similarly, the United Kingdom Declaration of Rights of People with HIV and AIDS (1991) states, 'We believe that people with HIV and AIDS should be fully involved in a working partnership with medical, health and social care workers and researchers to develop policies and practices which meet their medical, health and social care needs.'

Principles of PWA involvement and empowerment have become reflected, to varying degrees, in official policy statements. The latest AIDS strategy of the Canadian Government, for example, states, 'People living with HIV/AIDS will have a central role in providing expertise and leadership […]' (Health Canada, 1998a, p. 3). Internationally, 42 states signed the Declaration of the Paris Summit in 1994. Stressing the desire for 'a spirit of true partnership', the statement identifies the need to:

> Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all—national, regional, and global—levels, this initiative will, in particular, stimulate the creation of supportive political, legal, and social environments (International Council of AIDS Service Organizations, 1996, p. 5).

While governments may vary in the degree to which they have enacted such principles, the PWA movement has clearly contributed to the recognition of a new role for people directly affected by a health threat. The involvement of PWA is seen to have benefits on several levels: involvement can be experienced as personally empowering, it can help create more effective and appropriate services, it can help to create social and political change leading to a more compassionate social environment, and it can help mobilize people with similar experiences and concerns into a potent political force.

User involvement in service delivery and policy development

Recognition of the personal, social and political benefits that derive from client involvement pre-dates the HIV epidemic. So, too, does the recognition of the tensions and difficulties of ensuring meaningful participation. Arnstein observed back in 1969 that, 'the idea of citizen participation is a little like eating spinach: no one is against it in principle because it is good for you' (p. 216), but she described how different levels of participation can variously contribute to, or undermine, efforts to bring about a genuine redistribution of power and social change. More recently, authors in several fields of service have offered critical analyses of the tensions associated with consumer involvement in service delivery and policy development (e.g. Aronson, 1993; Church, 1996; Croft & Beresford, 1989, 1992; Forbes & Sashidharan, 1997). The mental health literature has addressed questions concerning consumer involvement, although this has typically been done from a provider-led perspective that provides little opportunity for challenging established power imbalances (see Church, 1996; Forbes & Sashidharan, 1997). Because of their roots in the oppositional politics of the gay and lesbian liberation movement, those working in AIDS services have probably been more attentive to issues of power, professional privilege and social change than has typically been the case in other fields.

The AIDS movement in North America has probably made more progress in involving 'clients' in policy development and service delivery than other fields of health and social services, yet surprisingly little attention has been paid to these developments in the academic and professional literature. Kayal's book, *Bearing witness*, examines volunteerism in the Gay Men's Health Crisis (GMHC) in New York, but he largely speaks of GMHC volunteers as caregivers to people living with AIDS, rather than as people who may be infected themselves (Kayal, 1993). A few authors have discussed the move to involve people living with HIV in service delivery and policy development (e.g. Altman, 1993), but little attention has been focused on the details of efforts to promote their meaningful involvement (but see Ariss & Dowsett, 1997; Stoller, 1998). Halleran *et al.* (1996) discuss the training needs of HIV-positive participants in AIDS services and describe a training programme to provide them with skills and self-confidence, knowledge of services, personal contacts and an appreciation that organizations can be flexible and welcoming structures, all of which help in the recruitment and retention of HIV-positive volunteers.

Involvement in community-based organizations can take a variety of forms: service users who provide periodic advice on services, volunteers who provide direct services or sit on agency committees, volunteers for special fund-raising events, representatives on boards of directors, representatives on regional policy and funding committees, or paid employees. Some of these roles allow for more influence over decisions and services than others. Professionals may retain control over decisions, and committees on which community representatives sit may not be given much decision-making authority (Hardina & Malott, 1996). Licking envelopes during a fund-raising campaign may help service users to become less isolated and to feel that they are making a contribution, and it may be helpful to the organization; such activity, in itself, will do little to provide greater influence over the services and policies that affect them. Providing opportunities for greater responsibility and influence in local organizations and more broadly is a central challenge to workers in community-based services. As will be seen below, translating ideological and policy commitments regarding the meaningful involvement of people living with HIV/AIDS into practice can be complicated and fraught with tension. In the following analysis, we examine some of the benefits derived from involving PWA in community-based AIDS organizations, and identify obstacles to their involvement. We conclude with some thoughts on the principle and practice of involving service users in AIDS organizations.

Methods

The following paper draws on data from Charles Roy's doctoral dissertation (Roy, 1995). This study was based on the principles of participatory action research. Whyte (1991) describes participatory action research in these terms:

> Some of the people in the organization or community under study participate actively with the professional researcher throughout the research process from the original design to the final presentation of results and discussion of their action implications (p. 20).

Whyte's position presupposes a clear distinction between the researcher and the researched. This project went beyond the expectation outlined by Whyte in that the principal investigator (Roy) is himself living with HIV and worked with a group of six other Canadian AIDS Society board members, all of whom were HIV-positive, to plan and monitor the entire research design and implementation. Unlike the 'professional expert model' described by Whyte (p. 8), this study was developed and conducted by and for people living with HIV/AIDS who had a strong commitment to linking the research to social change. The findings from this study formed the basis for policy change in the Canadian AIDS Society, and in a number of AIDS service organizations in Canada.

The study comprised two phases. First, a comprehensive survey was completed by 65 of the 70 (93%) member organizations of the Canadian AIDS Society. Two-thirds of the surveys were completed by board chairs or executive directors, most of whom are believed to be HIV-negative. The questionnaires provided descriptive information on the degree to which people living with HIV/AIDS are involved in local AIDS service organizations. Respondents were also invited in open-ended questions to provide their views of the role that PWA can and should play in local service delivery. The following discussion draws on the qualitative responses to these questions; it does not make use of the survey data. The second phase of the study was based on focus groups with people living with HIV. Fifteen focus groups were organized in seven cities of various sizes across Canada. These groups consisted of PWA who were involved in local AIDS organizations as clients, volunteers, board members or staff. In total, 70 PWA participated in the focus groups. The study reached a cross-section of PWA throughout Canada. The groups were diverse in terms of regional representation, age, gender, sexual orientation, cultural background, health status and in the nature of their involvement in an ASO. Participants ranged in age from 19 to 60 years. Men represented 83% of focus group participants; 69% of the participants identified as gay. Almost a third of the respondents said that they had an AIDS-defining illness. Sixteen of the 70 participants indicated that they came from a distinct cultural background.

The research had four basic objectives: to describe the current level of participation of PWA within the community-based AIDS movement in Canada; to determine the nature of their involvement; to identify successful strategies used to promote greater and more meaningful involvement of PWA; and, finally, to identify barriers PWA were experiencing and to develop strategies on how to bring down these barriers. Focus group discussions were tape-recorded and transcribed verbatim. Using an inductive grounded method, the transcripts were analyzed by searching for patterns and emerging themes about their involvement in community-based AIDS work (Lofland & Lofland, 1984; Taylor & Bogdan, 1984). Transcripts were selectively coded according to the emerging themes (Neuman, 1997). The ultimate objective is to develop an in-depth understanding of PWA experiences in local AIDS service organizations.

Involvement and contribution

People living with HIV/AIDS bring a wealth of resources to community-based AIDS organizations. First, they bring a high degree of personal investment, motivation, dedication, compassion and commitment to the work. PWA involvement in agencies helps keep priorities and issues in focus. Respondents believe that they are a 'living reason' for the existence of AIDS agencies and that their presence has challenged, changed and sustained many organizations. An HIV-negative respondent stated, 'Their presence at work keeps us focused on our mandate. [People living with HIV/AIDS] bring a very creative life force to [our agency].' Having people with HIV directly involved in the organization helps make the epidemic more 'real.' They bring a greater sense of urgency and serve as a reminder of the importance of the work. The involvement of HIV-positive workers also helps organizations identify new and changing needs. Many agencies established in the 1980s largely to provide prevention education have needed to re-examine their mandate to provide more support services. The direct participation of those most affected by the epidemic was useful to agencies that struggled with recognizing and negotiating this shift: 'There were horrendous fights, really significant fights, over the issue of financing … If you look at our budget, [this agency] spends in direct services … something less than 2% [of the total budget]. It was felt that this was not really an organization for people living with HIV/AIDS.' PWA involvement can also provide agencies more credibility in the community. Increasingly, the involvement of service users has become an expectation of the communities of which they are a part. Government and corporate funders in Canada are also discovering a newfound respect for organizations that are consumer-driven. Aware of this, agencies are now careful to present themselves in this light: 'We consider our agency to be consumer-oriented and consumer-driven. We couldn't claim this philosophy without the direct involvement of PWAs.' User involvement also better enables ASOs to advocate for the needs of their service users. By involving people living with HIV/AIDS in leadership positions, AIDS organizations can more effectively speak as representatives of a PWA constituency, and therefore establish the credibility needed to influence the way in which policies are developed and services in other agencies are delivered.

The services provided by community-based AIDS organizations directly benefit from the involvement of people living with HIV. PWA have played central roles in AIDS education and prevention. HIV-positive speakers are some of the most effective educators. Peer education by someone who is infected is widely seen to help bring HIV and AIDS 'close to home' and has greater impact on audiences. Support services also benefit from HIV-positive staff and volunteers. Respondents indicated that people living with HIV/AIDS can relate to service users and offer peer support, which helps clients to feel that they are not so alone in their struggle. By having HIV-positive peer counsellors, many clients believe they will not be judged and can talk more freely: 'You don't feel the barrier. You also know that he is dealing with some of the same things you are dealing with. You can ask him anything. It is a totally open atmosphere. I'm not afraid to discuss anything.' Similarly, HIV-positive peer counsellors can quickly build rapport in ways not available to HIV-negative workers: 'It is like a bond and it's a common ground. So a lot of stuff is lifted … [HIV-negative counsellors] will empathize but they will never totally understand what we live.' The benefits of peer counselling can extend beyond a shared HIV status. Some people living with HIV/AIDS find comfort in talking to people living with HIV/AIDS of a similar cultural background. A respondent recalled the isolation he felt before finding another Black person living with HIV: 'I said there has to be another Black person living with this disease. For me, that's where Black-CAP [an AIDS organization in the Toronto Black community] came in.' One Aboriginal respondent discussed the importance of having someone who can appreciate the

importance of traditional approaches to healing. Women living with HIV often feel quite isolated and alienated from the male-dominated community-based AIDS movement: 'Often women want to talk to other women to know that they share a common experience as women.'

Workers and volunteers living with HIV can also have a broader cultural impact as role models: they can provide an image of an actively engaged person who is living a rewarding and happy life, despite their HIV infection. One respondent uses his AIDS position to help change attitudes in the Black community of which he is a part: 'Whenever I am needed, I am there. I man tables and pass out information at Carabana [a Carribean cultural festival]. For me it's like putting a face on AIDS because I'm reaching the Black community.' Such role models are also valuable to other people living with HIV/AIDS. Some people diagnosed with HIV suffer not only from poor physical health, but experience poor self-esteem, depression and suicidal thoughts. Many continue to see their diagnosis as a 'death sentence', at least initially. Having people living with HIV/AIDS in visible positions serves to remind others that those with HIV can continue to live productive lives and contribute to the community. They also serve as a reminder that PWA are not always viewed as pariahs: they can be valued and respected community members.

Barriers to involvement

Although our respondents described a wide range of benefits that they and their organizations derived from their active involvement, they identified significant obstacles. Almost all respondents noted that disclosure of one's HIV status was a significant barrier to involving more PWA in community-based AIDS agencies. This finding was consistent with Adam and Sears' (1996) observation that only a few of their participants were willing to 'go public' with their HIV status. Concerns about revealing their health status was a particular concern for respondents in smaller settings: '[This] is a small community. PWAs are very reluctant to associate themselves with our organization for fear of losing their anonymity. In one case, for example, family members pressured a certain person into withdrawing from our Board of Directors. The person complied to avoid losing his family's support.' Disclosure of one's status can indeed come with real costs, as one respondent discovered: 'I did Midday [a national television news show] last week. I've had death threats. I had to call the police. So your anonymity is a wonderful, wonderful thing to keep.' The fear of disclosure also exists in culturally specific communities in large metropolitan areas: 'For the longest time I was the only Native person involved in [the local PWA organization]. I remember walking up those stairs and just how horrible it was for me.' Many women also find it very difficult to disclose their HIV status. Some fear the child welfare system. Many women must respond to not only their own needs but to those of their husbands or boyfriends: 'I have a family. I've got a husband and a child. I was very quiet. My husband has started telling people at his work which is a big step. But that has only happened this year and I have been diagnosed for four years. You go through a long period of time when you need to protect yourself.'

Stereotyping of people living with HIV/AIDS occurs both inside and outside AIDS organizations. People with HIV/AIDS come from a variety of backgrounds, and as a result, they can bring widely different skills and experience to AIDS organizations. However, our interviews suggest that some workers have a very limited view of their potential contribution. Many agencies are seen to provide services primarily to poorly educated or very ill clients—or as one respondent graphically put it, 'the never-read or the almost-dead', with the result that many workers are seen to hold the view that PWA lack required talent, skills, education and experience. Indeed, some of our HIV-negative respondents believed that people living with

HIV/AIDS are only capable of low-level, task-oriented activities. One HIV-negative respondent stated that he feared that people living with HIV/AIDS would breach confidentiality. Others believed that people living with HIV/AIDS are too self-absorbed and, because they are 'too needy', they could not be helpful to others: 'Many [people living with HIV/AIDS] are self-oriented—"What can I get for nothing?" ' AIDS organizations in Canada are witnessing increasing social divisions between those who provide their services and those who receive them as a result of the shifting demographics of the epidemic. Many PWA coming for service experience various kinds of social disadvantage; many experienced problems before their HIV diagnosis and seek services to make up for inadequate social and financial supports. In contrast, many of those providing care in AIDS organizations are middle-class and relatively well educated. The perception of some workers regarding the limited contribution of people living with HIV/AIDS may be a product of class bias as much as anything else.

Negative attitudes towards PWA are apparent to many respondents in the hiring practices of AIDS organizations. One rationale for why PWA are not hired for key agency positions is that some people question the ability of workers with HIV/AIDS, whose health and energy might fluctuate, to maintain the required pace and volume of work. One respondent stated, 'Agencies need to hire "healthy" people, otherwise the demands of the job will further contribute to their illness.' Some agencies indicated that it was not easy to get qualified people living with HIV/AIDS to apply for positions, but a number of HIV-positive respondents felt that their applications for employment are not given serious consideration in hiring decisions or they are not asked to do meaningful work. Agencies are not seen to be providing opportunities appropriate for the skills people living with HIV/AIDS bring: 'You have [people living with HIV/AIDS] walking into a PWA group who are quite capable of doing stuff—working on computers. I know people who came in nine or ten months ago, filled out an application. They know computers inside out. They never even bothered calling these people. They walk in. They can't find anything to do. They walk out.' A number of respondents recognized a contradiction between the espoused commitment of agencies to PWA involvement and their actual practices: 'I don't want to work in reception. I want to do something that will challenge me. So you want to talk about empowerment? Don't give me this bull shit of empowering by sitting at a desk and stuffing envelopes. That's not empowering anybody.'

Beyond perceived attitudinal barriers, respondents outlined other obstacles to employment in AIDS organizations. Agencies need to offer more competitive salaries to hire those with the most skills and experience. People living with HIV/AIDS with established careers are understandably reluctant to compromise their income and benefits. Salaries in poorly-funded community-based organizations are not competitive with organizations, such as hospitals and schools, or many places of employment in the private sector. In Toronto, for example, teachers and social workers can earn as much as $20,000 a year more than educators and counsellors in AIDS service organizations who often have the same credentials. Even more problematic than low salaries is the inability of community-based AIDS organizations to provide adequate benefits for their employees: 'The health plan here is good until you become ill and then it is no good at all. When you go on long-term disability you have no drug coverage. It certainly doesn't encourage you to take the time to look after yourself.' PWA with secure jobs and good benefit packages have little incentive to work in a contract position. Even those who are not working but who possess a good disability pension are understandably reluctant to take a position with fewer benefits: 'I am on long-term disability through my past job, which makes it a bit difficult because since I own a benefit package, if I decide to take a contract position, then I would lose that benefit package. Then, when the contract was finished, what would I have? Nothing at all.' Because of the pre-existing

condition and the lack of portable insurance coverage, people living with HIV/AIDS often experience what is known as 'job-lock'.

Health concerns represent additional hurdles. Maintaining one's physical, mental, emotional and spiritual health is a full-time job for many people living with HIV/AIDS. Accommodating such needs can be particularly difficult in a small and poorly resourced community organization. Health, naturally, influences the participation of people living with HIV/AIDS. AIDS organizations can be very demanding workplaces. The health of people living with HIV/AIDS can be challenged by working in such demanding environments. Some HIV-positive respondents noted that the effects of long hours and a stressful work environment are a concern. One man stated, 'I think it may be, quite frankly, doing more harm than good in my life to be working in an AIDS organization as someone who is HIV positive.' Not only do such health considerations affect the PWA, they can affect the organization. Work continuity, high turnover, disruption of projects and lack of consistent service due to illness can all be problems in small organizations. Groups acknowledged difficulty in organizing work in ways that realistically accommodate sick-time or the loss of key members. Illness on the part of employees or volunteers can have an emotional impact on others in the organization. One respondent raised concerns about the morale of staff when a colleague died of AIDS: 'The repeated absence due to illness and finally the death of that member was very demoralizing to the group.'

Respondents identified other barriers that are more practical in nature. Transportation is a problem for anyone with a disability, including people living with HIV/AIDS. If an agency limits itself to standard business hours, people living with HIV/AIDS with daytime jobs often cannot volunteer, let alone access services. These agencies essentially eliminate any opportunity for many people living with HIV/AIDS to become involved: 'I have tried to get involved but I work full time during the day. Most of the [agency's] activities take place during the day. They cater to the unemployed. So basically, I have to wait until my health deteriorates before I can get involved.' The involvement of women requires the accommodation of needs like child care. Child care is difficult for families to arrange, even when they have the advantages of two parents, good health and adequate income. Many women living with HIV do not have these advantages: 'It's much more difficult for women to get in, particularly with children [...] If they are poor or are single moms there is just no way. The increasing need to get out to doctors to clinics, whatever. There are so many other things to do that this is just one more thing. You need child care.'

A broader concern was expressed by respondents who recognized that the needs of the organization may conflict with those of individual PWA. Some respondents recognized that PWA involvement may sometimes come at the expense of the individual service user, who may be 'set up' to take public positions on issues or to fight battles on behalf of their organization or other service users. Many, if not most, respondents indicated that one of the most important benefits from PWA involvement is the urgency they bring to the work, yet the passion expressed by some users is sometimes perceived as dysfunctional, uncooperative or unreasonable. Some PWA are invited to become involved to personally advocate for issues, and then may find themselves criticized for 'always complaining'. Given the growing differences between service providers and users, tensions relating to differences in working and advocacy style may reflect class divisions within organizations.

Negotiating boundaries can be a problem for PWA who work in both paid and unpaid positions. Several respondents indicated that once they became involved in AIDS work, they had trouble keeping limits around the work. They find that their organization can make excessive demands of their time and energy: 'I really wonder if becoming involved [in an AIDS organization] isn't a health hazard, isn't dangerous for the health of people with HIV,

because at some point you start to do one thing and then somebody wants something else, and something else again, and something else again, then all of a sudden you're living here and you have no life of your own.' The lack of a more supportive and balanced work environment sometimes leaves respondents feeling like they are there as a token effort on the part of their organization: 'Stop coming to me and asking me to sit on ten committees over here, being "schlepped" out as an HIV-infected person to make your organization look really good …' An HIV-positive woman experienced the same situation: 'One of the things that I find very difficult in being involved is the fact that there is too much to do … Being a woman there was all of a sudden this demand for HIV-positive women to be involved in everything.' Involvement in AIDS work can make some PWAs feel they are being judged by others if they fail to live up to some idealized image of a person living with HIV/AIDS. One respondent noted, 'When you are a PWA on staff, or volunteering at an AIDS organization, there is a lot of pressure to be a role model.' The pressure to be the 'perfect' PWA comes from all segments of the organization and applies to all aspects of the person's life. In the most extreme examples, people living with HIV/AIDS who are peer counsellors feel they cannot show signs of depression, and educators can not admit to taking any degree of risk in their sexual practices.

The community-based AIDS movement in Canada grew out of a highly political and mobilized lesbian and gay community. As AIDS affects a more heterogeneous community of people, mandates for agencies are becoming increasingly broad and the needs and interests of various constituencies can compete. People living with HIV/AIDS sometimes feel that serving the needs of PWA are secondary considerations for AIDS organizations and that political issues have eclipsed the provision of services to meet their basic needs. Although broader political issues such as racism, sexism and homophobia are undeniably linked to the fight against AIDS, people living with HIV/AIDS tend to focus more on issues that more immediately impact their lives. This stress on more practical needs can also compete with organizational needs for longer-term development and planning. Organizational climate can also be a barrier to greater involvement in AIDS work. In many ASO, there can be considerable stress and anger (Cain, forthcoming). This can take a toll on everyone, and lead service users, volunteers and potential employees to stay away: 'I don't want to go into that building because of all the politics … I don't want to go into this building because I will be forced to deal with other people's anger and I'd just as soon stay away because it is unhealthy for me.' This more combative climate can be enough to stop some PWA from getting involved either as a service user or as a worker or volunteer. 'I just find the political upheaval all the time in here—men against women, lesbian against gay, positive and negative. As a client, I feel it puts us second.'

Discussion

People living with HIV/AIDS have contributed to AIDS organizations in many ways. The involvement of people living with HIV/AIDS has been critical to assuring that agencies provide relevant and timely services. Perhaps the greatest asset that people living with HIV/AIDS bring to community-based AIDS services is the ability to provide peer support to other people living with HIV/AIDS, especially the newly diagnosed. HIV-negative counsellors have much to offer, but there are limits to their ability to support the needs of people living with HIV and AIDS. Moreover, agencies have found that the involvement of people living with HIV/AIDS is an essential part of their acceptance and success in meeting the needs of the community. The involvement of PWA legitimizes AIDS organizations. The increased politicization of people living with HIV/AIDS and the demands to be a consumer-driven

movement mean that community groups increasingly recognize the need to listen to and involve their service users. Finally, PWA bring a real humanity that can sometimes be missing in a workplace.

People living with HIV/AIDS are a diverse group: there is no singular PWA perspective. Our findings reflect the particular concerns—and social and political advantages—of Canadians living with HIV. PWA in other countries often do not share the same privileges of a universal system of health insurance. Even within Canada, there is a great diversity of experience with HIV that is shaped by sexual preference, gender, race and social class. As Ariss and Dowsett (1997) described in the Australian context, the PWA movement, like other identity-based social movements, are challenged by questions concerning who gets represented and whose needs and interests are pursued. We can anticipate diversity becoming more of an issue in coming years because of the shifting demographics of the epidemic. 'Users' are not a homogeneous group, and the different needs, desires and interests of users should be explicitly recognized. As Forbes and Sashidharan suggest, 'These differences emerge from particular positions in society and relate to a specific history and analysis which can be used to inform an agenda and strategies around which groups of users can effectively organize' (1997, p. 495). Diversity poses challenges, no doubt, but it also opens up new possibilities for organizational and political change. Many PWA in the Canadian AIDS movements have come with professional training and experience, and they have enhanced every aspect of the movement with their skills. But skills and knowledge that have been valued have often been defined exclusively in terms of formal education or professional work experience. PWA who lack this kind of background can still bring a richness of skills and experience: many people living with HIV/AIDS, even those with minimal formal education, have acquired extensive knowledge about the realities of living with HIV and the ever-changing world of AIDS treatments. Organizations need to somehow help people of a wide variety of backgrounds feel comfortable, valued and respected, even if they come in without professional, middle-class skills and experiences. AIDS organizations may need to provide additional support and training so that the contributions of a broader range of PWA can match the needs of the agency. It is far easier to train most people living with HIV/AIDS for a particular skill than it is to help someone not living with HIV to understand the experience of those infected.

Our data were collected before the advent of protease inhibitors, which leads us to speculate how the findings might be different today. Our experience suggests that immediate concerns of respondents about illness and death are less central today than was the case just a few years ago. But there are new issues to address. As many PWA now envision a longer career as an HIV-positive worker, they worry about their career mobility with AIDS organizations. Benefit packages for employees remain crucial concerns for workers, as they struggle to afford expensive and long-term medical treatments. Those who can afford the new drugs may be those more likely to have the opportunity to contribute to AIDS work. Being involved in AIDS work may be, in part, a function of one's access to effective treatment, which is, in turn, a function of one's social position (Mykhalovsky & Smith, 1994). This reality may further exacerbate divisions between those PWA who provide and those who receive services.

Finally, our study raises questions about the organizational structure of AIDS services and the goal of PWA involvement. Many AIDS organizations started as community-initiated alternatives to traditional health and social services. While many were originally driven and controlled by volunteers, they have slowly become organized along traditional staff-centred organizational models, where volunteers were seen as adjuncts to paid staff (Cain, 1993; Patton, 1991). This transformation can diminish the role and influence of volunteers and

PWA and, ultimately, of community input. There are costs to simply 'plugging' PWA into traditional agency structures by inviting them to serve on boards of directors, advisory committees and the like. The experience of mental health services to involve 'consumers' has been to coopt their energies and concerns, while failing to seriously challenge the profession-ally-dominated service system (Church, 1996). The promise of user involvement is not only that they will contribute to the development of more effective services, but that they will bring in critical voices. Service organizations, however, typically value calm work environments and smooth operations, so criticism and opposition will likely be discouraged. The PWA move-ment started with a relatively thorough-going analysis of the power relations in service delivery, but there are forces that will resist serious change and attempt to restrict the role of PWA to simply 'consumers'. Forbes and Sashidharan (1997) argue, 'It is not just that a consumerist approach is bound to fail if the objective is empowerment or "liberation", but that the introduction of such a model within state run welfare services poses the threat of dilution and co-optation' (p. 487–488). To help maintain the political analysis that has been so central to AIDS organizing, community-based organizations need to encourage the involvement of people with HIV/AIDS so that they bring engaged critical voices, rather than simply speaking about services and programmes.

By employing people living with HIV/AIDS as staff and volunteers, workers in com-munity-based AIDS services see the passion that PWA can bring to the work and their struggle for control over their lives. If the AIDS movement is truly going to be based on the principles of self-help and empowerment, there will be no room for those who want to experience the reality of AIDS from a distance. The foundation has been laid in the community-based AIDS movement for meaningful PWA participation. While much remains to be accomplished, much has been achieved in a short period of time. AIDS work is once again struggling with new questions and issues, so it is not surprising that workers are being challenged with the notion of how to better involve those who receive services. While it may sometimes create for conflict and disappointment, the goal of meaningful involvement of people living with HIV creates important new opportunities.

Acknowledgements

References

ADAM, B. & SEARS, A. (1996). *Experiencing HIV: personal, family, and work relationships*. New York: Columbia University Press.

AIDS ACTION NOW!/ACT-UP NEW YORK (1989). 'Le Manifest de Montréal'. June.

ALTMAN, D. (1993). *Power and community: organizational and cultural responses to AIDS*. London: Taylor & Francis.

ARISS, R. & DOWSETT, G. (1997). *Against death: the practice of living with AIDS*. Amsterdam: Gordon & Breach Publishers.

ARNSTEIN, S. (1969). A ladder of citizen participation. *AIP Journal*, July, 216–224.

ARONSON, J. (1993). Giving consumers a say in policy development: influencing policy or just being heard? *Canadian Public Policy, 19*, 367–374.

CAIN, R. (1993). Community-based AIDS services: formalization and depoliticization. *International Journal of Health Services, 23*, 665–684.

CAIN, R. (forthcoming). Devoting ourselves, devouring each other: tensions in community-based AIDS organizations. *Journal of Progressive Human Services*.

CALLEN, M. & TURNER, D. (1988). A history of the PWA self-empowerment movement. In: M. CALLEN (Ed.), *Surviving and thriving with AIDS: collected wisdom*. New York: People with AIDS Coalition.

CANADIAN AIDS SOCIETY (1997). *Canadian Declaration of Rights for People Living with HIV/AIDS*. Toronto, Ontario: Canadian AIDS Society.

CHURCH, K. (1994). *Forbidden narratives: critical autobiography as social science*. Amsterdam: Gordon & Breach Publishers.

CHURCH, K. (1996). Beyond 'bad manners': the power relations of 'consumer participation in Ontario's mental health system. *Canadian Journal of Community Mental Health, 15*, 27–43.

CROFT, S. & BERESFORD, P. (1989). User involvement, citizenship and social policy. *Critical Social Policy, 26*, 5–18.

CROFT, S. & BERESFORD, P. (1992). The politics of participation. *Critical Social Policy, 35*, 20–44.

FORBES, J. & SASHIDHARAN, S. (1997). User involvement in services: incorporation or challenge? *British Journal of Social Work, 27*, 481–498.

HALLORAN, J., ROSS, M. & HUFFMAN, L. (1996). Training people with HIV disease for involvement in the community planning process: Project LEAP. *Journal of the Association of Nurses in AIDS Care, 7*(6), 39–47.

HARDINA, D. & MALOTT, O. (1996). Barriers to consumer empowerment: implications for health and social services planning in Ontario. *Canadian Review of Social Policy, 27*, 1–19.

HEALTH CANADA (1998a). The Canadian strategy on HIV/AIDS: moving forward together. Ottawa: Minister of Public Works and Government Services Canada.

HEALTH CANADA (1998b). Ministerial Council on HIV/AIDS. Ottawa: Minister of Public Works and Government Services Canada.

INTERNATIONAL COUNCIL OF AIDS SERVICE ORGANIZATIONS (1996). Declaration of the Paris AIDS Summit. The Legacy of the Paris AIDS Summit, July.

KAYAL, P. (1993). *Bearing witness. Gay men's health crisis and the politics of AIDS*. Boulder, CO: Westview Press.

LOFLAND, J. & LOFLAND, L. (1984). *Analyzing social settings*. Belmont, CA: Wadsworth.

MYKHALOVSKY, E. & SMITH, G. (1994). Hooking up to social services: a report on the barriers people living with HIV/AIDS face accessing social services. Toronto: Ontario Institute for Studies in Education.

PATTON, C. (1991). *Inventing AIDS*. London: Routledge.

ROY, C. (1995). Living and serving: persons with HIV in the Canadian AIDS Movement. Ottawa: Canadian AIDS Society.

STOLLER, N. (1998). *Lessons from the damned: queers, whores, and junkies respond to AIDS*. New York: Routledge.

TAYLOR, S. & BOGDAN, R. (1984). *Introduction to qualitative research methods*. New York: John Wiley.

UNITED KINGDOM DECLARATION OF RIGHTS OF PEOPLE WITH HIV AND AIDS. (1991). Unpublished document.

WHYTE, W. (1991). *Participatory action research*. Newbury Park, CA: Sage.