

CONTEMPORARY CHALLENGES FOR ALTERNATIVE MEDIA:
LESSONS FROM THE AIDS MOVEMENT.

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ABSTRACT

Since the early 1980s, AIDS activists have developed their own alternative media projects in order to mobilize those infected and affected, challenge misconceptions regarding the disease, provide practical and useful information, and transform power structures which inhibit an effective response to the HIV/AIDS pandemic. This presentation looks at the challenges that AIDS media projects have faced over the course of the epidemic, specifically: (1) the professionalization of media projects; (2) the transformations in media technology; and (3) the marginalization of alternative media. How the experiences of AIDS media activists can provide insight into the current state of alternative media will be explored.

INTRODUCTION

Over the past thirty years the use of alternative media has expanded dramatically. A main factor contributing to this growth has been the emergence of new political and collective identities among those who feel excluded from, even oppressed by, the dominant social order. Contemporary social movements - the feminist movement, the civil rights movement, the gay and lesbian movement, the peace movement, the environmental movement, the AIDS movement - have served as a catalyst, and provided a frame of reference for this type of media activism. Independently produced media provides a means of raising awareness among oppressed or marginalized communities while at the same time challenging the meanings conveyed by social institutions like the mass media and the state. At the same time, there also has been a gradual increase in public access to communication technologies. This democratization has made the use of alternative media more available. Personal computers, publishing software, the internet, community radio and television provide the means for individuals and groups to participate in forms of cultural production previously reserved for an intellectual and political elite.

Media projects by and for people with HIV/AIDS can also be understood as being shaped by these recent social trends. The community-based response to HIV/AIDS has provided an organizational and ideological infrastructure through which those infected can become involved in media production. At this community-based level, activists have made use of whatever range of media technologies that were available. Publications, telephone hotlines, posters, fax, video, television, radio, and more recently the internet, have been used as a form of outreach and community development. At the beginning of the epidemic, alternative forms of communication were necessary given the lack of an institutional response to HIV/AIDS. Rather than relying on social institutions, media practices among people with HIV/AIDS have sought to exert control over the meaning of HIV/AIDS. Over the past fifteen years people with HIV/AIDS have continued to inform one another through various forms of media activism.

In this study I examine six media projects that have been created and sustained as part of the AIDS movement in North America. My approach is to examine media projects as one aspect of a broader strategy among those involved in new social movements to construct an alternative public sphere (Fraser, 1992). As Marshall (1991) has argued, contemporary social movements - feminism, environmentalism, gay liberation - have each created alternative public spheres, in part, through the use and development of communication media. In this regard, alternative media function on two levels. First, they provide a means for people to share and articulate a critique of

existing forms of domination and to seek social change. Second, they are a means for people to construct collective identities and to share experiences and knowledge. It is in this dual sense that alternative media are counter-hegemonic: in creating a public sphere they provide an alternative perspective to ideas and meanings legitimated and reproduced through the dominant social order.

The purpose of this paper is to identify several challenges that AIDS media projects have faced the over the course of the epidemic. They include: responding to the professionalization of media projects; adapting to transformations in the role of alternative media and to changes in media technology; and (3) overcoming the marginalization of alternative media. To conclude, I look at the extent to which the lessons learned by AIDS media activists can provide insight into the current state of alternative media in general.

METHODOLOGY

The media projects in this study were selected in order to reflect the general range of information that is produced for people with HIV/AIDS within the community-based response to the epidemic. Print media for people with HIV/AIDS can be divided into three main types: newsletters, treatment publications, and general interest magazines (including zines). Of the six projects in this study there are two from each type of publication.

BCPWA News is the oldest of the two newsletters in this study. It is a publication of the British Columbia Persons with AIDS Society, a Vancouver based organization that formed in 1985. The newsletter follows the mandate of the organization which is to “empower persons living with HIV disease and AIDS through mutual support and collective action.” *Body Positive*, the second newsletter, is produced by an organization of the same name. *Body Positive* began in New York in 1987 to assist people when they first acknowledge the impact of HIV/AIDS.

The two treatment publications in this study are *The Positive Side* and the *Treatment Information Flash*. *The Positive Side* was started in 1991 in Toronto. It was the product of a collective made up of people with HIV/AIDS who sought to create a forum for health information and viewpoints that placed emphasis on the different approaches that people with HIV/AIDS were using to manage their health. The *Treatment Information Flash* was initiated in 1994 by a group of people infected by HIV/AIDS and volunteers as part of the peer support program at the Hamilton AIDS Network.

POZ Magazine and *Diseased Pariah News* are the two general interest publications in this study. *POZ* is

modeled after a glossy mainstream magazine. According to the editor, it seeks to “simplify, popularize and broadly disseminate the huge volume of life-sustaining information – and inspiration – I had already found critical to my own survival.” *Diseased Pariah News* was started in 1990 in San Francisco by a group of gay men with HIV/AIDS. *DPN* is self described as “a patently offensive publication of, by, and for people with HIV disease. We are a forum for infected people to share their thoughts, feelings, ”

Despite being different types of publications, the projects selected for this study have several characteristics in common. First, they are directly informed by the political ideologies of the AIDS movement. A central feature of this ideology is that people with HIV/AIDS need to be in control of the decisions that affect their lives. As a result, the production and content of the media projects seeks to reflect perspective of those infected with HIV/AIDS. Second, the projects are supported, directly or indirectly, by the organized HIV/AIDS community. And last, there is an emphasis in the media projects on conveying or sharing useful information or practical knowledge.

The research on the six media projects in this study spanned between 1994 to 2000. The methodology used had three main components. First, data was collected from current and back issues between 1985 and 2000. A content analysis was conducted on the material in the publications based on predominant themes that emerged from the data. Second, interviews were conducted with those involved in media projects. Respondents were asked to talk about their history with the publication and their understanding of the publication’s historical development; the relationship between the publications and the AIDS movement; the overall purpose or objective of the publication; how the publication is produced on an issue to issue basis and how this production has changed over time; the rationale for the information in each issue and the role of the editors in this process, how people with HIV/AIDS are portrayed, and whether there is a particular emphasis placed on AIDS prevention, education, or support; and, how the publication is distributed, who the intended readers are, and what impact they thought the publication had among readers. Sixty interviews were conducted with people involved in the different media projects in the study. The third component of the methodology involved field work with two of the publications, the *Treatment Information Flash* at the Hamilton AIDS Network and the *The Positive Side* at the Community Treatment Information Exchange (CATIE). Throughout the study I volunteer as a member of each collective. My role in the publication included organizing meetings, planning and writing articles, developing connections with local AIDS stakeholders, developing strategies for dissemination, and advocating on behalf of the collective. During this participant

observation I kept field notes and sought to develop an in depth understanding of the process involved in producing and sustaining an alternative media project.

CHALLENGES FACING ALTERNATIVE MEDIA PROJECTS

Over the course of this research it became apparent that there several challenges that each of the media projects had to address over the course of the epidemic. First, there was a gradual trend toward the professionalization of media projects for people with HIV/AIDS as the epidemic expanded and the AIDS movement became increasingly institutionalized. Second, with changes in the societal response to HIV/AIDS, media projects had to adapt their role in the provision of information. Similarly, media projects have had to adapt to the changing technologies that have come available to convey information. Lastly, the media projects have had to struggle with their marginal position, on several different levels, as a means of informing people with HIV/AIDS and transforming institutionalized myths about HIV/AIDS. The extent to which the media projects have been able to effectively respond to these largely external challenges internally had determined their ability to strive and thrive throughout the HIV/AIDS epidemic.

Professionalization

The pressure for media projects to become increasingly professional in their production and content has been evident throughout the AIDS epidemic. This trend toward professionalization has been most evident in the two newsletters included in this study. Being tied closely to their parent organizations, publications like *Body Positive* and *BCPWA News* have had to follow broad transformations in the community-based AIDS movement. To keep up with the demands of the epidemic, AIDS organizing has gone through almost constant change, beginning initially as grassroots ventures, moving through a period of expansion, and lastly becoming increasingly formalized as the interests of AIDS organizers and activists have increasingly converged with that of the state and medicine.

The history of *Body Positive* and the *BCPWA News* is similarly divided into three periods: grassroots, expansion, and formalization. Initially they began as loosely structured and roughly produced projects, expressing the youthful exuberance and collective spirit of grassroots AIDS organizing. The tone, for instance, was informal and politically charged and the production emphasized participation over credentials. At the same time, though, they reflected the precariousness of the early AIDS movement. With limited resources to work with *Body Positive* and the *BCPWA News* appeared to be in a constant state of flux. The substance of issues varied considerably and they

were rarely produced in a predictable or coherent fashion. Overshadowing this uncertainty was the sense that the development of a public sphere – in terms of organizing and media – would bring about the emergence of a politically informed and politically active community of people with HIV/AIDS.

As AIDS organizations expanded their scope and mandate so did publications like the *BCPWA News* and *The Body Positive*. Between 1989 and 1994, they adapted as best they could to the tremendous growth in AIDS organizing during this period. Despite periods of precariousness and flux they expanded their role as strategies for communication between people infected and affected by HIV/AIDS. They became more legitimate forums for education, support, and advocacy. The introduction of more consistent funding, a larger readership, and greater involvement by volunteers provided the necessary resources and stability that was required for the publications to develop as forums for education, support, and advocacy. In constructing an alternative public sphere, the publications were reaching out, shifting from an internal focus (those involved in AIDS organizing) to one that tried to reach a broader more diverse community of people living with HIV/AIDS.

In recent years, the *BCPWA News* and *Body Positive* have continued to become more formal and professional following the general trend in the organizations that they are associated. The general tone of the publications has become less casual, intimate and focused on organizational issues. Instead, changes have been initiated that have made the publication more useful, formal, and public (in the sense of being generalized). A greater priority has been placed on producing a publication that reflects the organization status as a formal and efficient AIDS service agency (as opposed to a internally divisive grassroots coalition). To accomplish this, the publications have incorporated aspects of the mainstream media and even scientific or medical media (i.e., medical journals) while still trying to maintain, and even enhance, its commitment to self empowerment and self representation.

The move toward professionalization has posed a complex challenge for those involved in the AIDS media projects. Like AIDS organizations, print media by and for people with HIV/AIDS have struggled with the pressure to become more formal and accountable, not only to their clients but also to their funding bodies. Elements of the mainstream print media have been adopted in an attempt to produce a better quality, more respectable, and more appealing publication. At the same time, print media have also tried to renew their commitment to being a forum and as a resource for people infected and affected by HIV/AIDS. In some respects these revisions have been successful:

print media like *Body Positive* and *BCPWA News* have succeeded in moving beyond being grassroots publications. However, there has been an accompanying escalation in the implicit and explicit credentials required to participate “effectively” in creating a “quality” publication by and for people with HIV/AIDS. In other words, in many cases, the production of information has become less collective and more specialized. As a result, participation by those infected with HIV/AIDS has been limited to reading rather than producing publications like *Body Positive* and *BCPWA News*.

Broadly speaking, it would appear that one of the consequences of professionalization is that media projects, as constituting a public sphere for people with HIV/AIDS, have become less concerned with encouraging and supporting localized forms of political organizing and activism among people with HIV/AIDS; instead, greater priority has been placed on creating a supportive and instructive environment for a broad and diverse community of people infected and affected by HIV/AIDS. Also, participation in this public sphere has shifted as well. Initially, there were few barriers for those people with HIV/AIDS who were interested in becoming involved in grassroots media projects. However, as media projects have become more formal and professional in their approach, it has become harder for people with HIV/AIDS to be involved in forms of self representation unless they already have specific and often specialized skills related to publishing or journalism. Broader participation, as is the case with the mainstream media, has taken the form of consumption rather than production as readers are expected to treat publications as a source of practical information rather than an expression of their identities as people living with HIV/AIDS.

Such transformations in media projects, and in an alternative public sphere for people with HIV/AIDS, has come in response to pressures from the AIDS crisis itself, but also, from an increasing institutional investment in people living with HIV/AIDS and in the community-based response to HIV/AIDS. These changes suggest that print media by and for people with HIV/AIDS have become less overtly political (in the same way that there is often a distinction made between feminist media and media by and for women) though they are still products of the community-based AIDS movement. One key issue for the future direction of media projects for people with HIV/AIDS is the extent to which they rely on the corporate sector for financial support. While AIDS organizations continue to rely on dominant institutions, particularly the corporate sector, the disease is spreading at an alarming rate among those communities most disenfranchised in North America (and internationally). Such ties may make it

difficult for organization to remain accountable to those most in need of programs and services. According to many of those who are involved in media projects, the turn toward private industries is seen to be either a positive shift or an inevitability. It represents “the new terrain” of AIDS activism that does not particularly care who provides the resources for the community-based response to HIV/AIDS. They are confident that these ‘partnerships’ will not influence or ‘taint’ their commitment to the needs and concerns of those infected and affected by HIV/AIDS. Others involved in AIDS organizing are less enthused by the extent to which publications like *BCPWA News* and *Body Positive* have begun to embrace the involvement of dominant institutions in their work. They believe that AIDS organizing and AIDS activism is about, at some level, making public institutions accountable to the needs and interests of all publics - including the diversity of those infected and affected by HIV/AIDS.

Adaptation

Over the course of the epidemic, the media projects in this study have had to adapt their role of providing information and the means by which they perform this role. Of the media projects in this study, this process of adaptation has had the greatest impact on the two treatment information publications, *The Positive Side* and the *Treatment Information Flash*. One reason that treatment publications have had to work at adapting their role is because of the centrality of health care for people with HIV/AIDS and the quickly changing nature of AIDS medications. In the introduction to *Surviving and Thriving with AIDS*, an early guide to living with the disease, Callen (1987: 45) explains why so much attention is devoted to health care: “whenever people with HIV/AIDS get together, talk always turns to treatments. And when we are done talking about treatments, we talk about treatments some more.”

The challenges that AIDS treatment media have had to adapt to is the amount of information that is available and also the means available to convey this information. When looking back over the past fifteen years, treatment publications like *The Positive Side* and the *Treatment Information Flash* are best understood as transitional projects. They arose in response to the neglected information needs of people living with HIV/AIDS in the later 1980s and early 1990s. At this time, early in the epidemic, there were few treatment information resources available. People with HIV/AIDS relied on word of mouth, and on the handful of treatment publications just beginning to be produced at this time. A myriad of small treatment information projects arose in the late 1980s and early 1990s in communities across North America. Generally speaking, they were conceived of and produced by small groups of

people infected and affected by HIV/AIDS, usually volunteers for an AIDS service organization, looking to help others and to help themselves. In most cases, similar strategies of representation are used to convey information and opinions about managing HIV infection - a combination of lay investigative journalism and personal accounts and testimonials, always written from an empowered and positive perspective.

The role of treatment publications at this time was to provide information that was not otherwise available. As the epidemic grew, and the societal response to HIV/AIDS expanded, more treatment information became available to people with HIV/AIDS, not only from publications like *The Positive Side* and the *Treatment Information Flash* but from physicians, corporations, and government agencies. In Canada, for instance, one of largest AIDS organizations in Canada, the Community AIDS Treatment Information Network, supported primarily through government funding, is dedicated solely to collecting and providing information about HIV/AIDS. With this increase in information, *The Positive Side* and the *Treatment Information Flash* had to reinvent themselves not as providers of information but information filters. They became resources designed to help people with HIV/AIDS manage the overabundance of information that was available: scientific articles on clinical trials, information on new treatments and their benefits and drawbacks, news on the role of complementary therapies in managing HIV/AIDS, and so on.

A second and related challenge that has required significant adaptation for media projects like *The Positive Side* and the *Treatment Information Flash* has been emergence of new media technologies, like the Internet, and the growing use of existing technologies like the telephone and the fax, have raised questions about the efficacy of print media as a forum for people with HIV/AIDS. In years to come, especially as government support for AIDS organizing decreases, more energy may be devoted to providing direct education and support services as a more effective means of community outreach rather than relying on the production of print media.

Print media projects like *The Positive Side* and the *Treatment Information Flash* were limited as an effective ways of providing treatment information. However, they have played an important role in bridging the early social networks of people talking about treatments before there were any mediated forums to the current state of affairs in which there are social networks, publications, hotlines, treatment counselors and web sites all under the governance of AIDS service organizations. In particular, such small scale grassroots projects proved that it was possible and essential that people with HIV/AIDS be involved in and have control of (as much as possible) the

production and distribution of information about managing HIV infection. Currently, there are fewer opportunities for people with HIV/AIDS to start their own print media projects; however, there are greater opportunities for people with HIV/AIDS to become involved in providing information, for instance, as treatment counselors.

This new approach is seen to have several advantages, mostly connected to the idea that new media technologies are seen to be more consumer driven and interactive. One of the issues that plagued those involved in *The Positive Side* and the *Treatment Information Flash* was not knowing if the information that they were providing was what people with HIV/AIDS were interested in receiving and if they found the information useful when making health care decisions. Using electronic media, a person with HIV/AIDS can call, fax, or e-mail for specific information, rather than looking it up or waiting for it to be covered in a treatment publication. In addition, people living with HIV/AIDS are able to talk directly to another person about the treatment options that they are using or considering and discuss the potential advantages and disadvantages. Rather than simply receiving information, they are able to tap the knowledge of the person they are talking to about that information. In other words, speaking adds another dimension to the process of learning about how to make informed decisions about managing HIV infection. Also, from an organizational point of view, new media technologies provide a new means of collecting information about treatments and tracking the types of information that people living with HIV/AIDS were requesting. In the case of complementary therapies, for instance, the Community AIDS Treatment Information Exchange (CATIE) is now able to receive information about new treatments that people are trying when they call/fax/e-mail for information. And, they are able to identify what the demand is for information about particular complementary therapies (broken down by gender, ethnicity, sexuality, geography and so on) based on the calls that they receive from people living with HIV/AIDS locally and nationally. Even though the accuracy of this measure can be questioned, it does provide a guide for making decisions regarding the allocation of resources and the development of programs and services.

It would be inaccurate to say that this shift in the provision of treatment information is a rejection of print media or print media projects like *The Positive Side* and the *Treatment Information Flash*. There is a lineage between the two different approaches. First, with the use of new media technologies, AIDS organizations have kept and embraced a peer model of communication that has been central to the AIDS movement and to print media liketreatment publications. Again, the Community AIDS Treatment Information Exchange (CATIE) for instance,

like similar organization in the United States like Project Inform, has in place a peer treatment counselor training program in which people with HIV/AIDS advise and assist those who request information. Part of this program includes helping organizations across Canada train their own peer treatment counselors, as was the case at the Hamilton AIDS Network. Acquiring counselling and computer skills, documenting treatment information, and talking to other people living with HIV/AIDS is thought to be a more valuable and meaningful form of involvement and participation for people with HIV/AIDS than, for instance, contributing to or producing a treatment publication. However, it should be noted that prior projects that struggled to sustain a community-based or peer model of communication were influential in the development of this current approach to providing AIDS treatment information.

A second example of this lineage can be seen in the way that the turn to electronic media has not involved a rejection of print media, but instead, has been a way of emphasizing speech over print as the primary means of conveying information about managing HIV infection. Speech via the phone means that print is placed within a multi-media context. Treatment counselors, for instance, still rely on print media for information, although organizations like the Network have chosen is to subscribe to institutionally produced media (medical journals) over community-based media (organization newsletters and other AIDS publications). Guiding people with HIV/AIDS through this information can be done through print (there are fact sheets available) but it is usually done through conversations with peer treatment counselors.

The reliance on speech over print may be a response to the complexity, abundance, and ambiguity of current allopathic and complementary approaches to treating HIV infection. McLuhan (1964), for instance, has argued that new types of media emerge and predominate when societies increase in scope and complexity. In *Understanding Media*, he argues that there has been an evolution of media - from speech to print to electronic - as Western industrial societies have become more complex and more global. The dominance of electronic media, for McLuhan, was a return to speech and a move toward turning the world into a global village. On a more localized and specific basis, the provision of treatment information has followed a similar pattern - from small localized networks (speech), to treatment publications (print), to the use of fax, video, telephone, and the internet (electronic). For a generation of youth who have grown up with visual media rather than print, for instance, it makes sense to provide complex information about health care in a more familiar video format. In the case of treatment specific

AIDS organizations, the approach is less oriented towards privileging electronic media, but instead, trying to effectively integrate speech and print through new media technologies like the Internet.

Marginalization

A central organizing theme for the media projects in this study is reconstructing and reclaiming what it means to be a person with HIV/AIDS. This concern over the meaning of HIV/AIDS has been most integral to general interest publications like *POZ Magazine* and *Diseased Pariah News*. This struggle over meaning has occurred primarily through the construction and articulation of a collective identity. The concept of collective identity has been central in literature on culture and social movements. According to Melucci (1989), collective identity refers broadly to shared cognitive frameworks that enable individuals to formulate common goals and means for social actions and come to recognize themselves in one another – to foster a collective “we” that makes the group distinctive.

In *POZ Magazine* and *Diseased Pariah News* there have been three main themes in the work toward reconstructing the meaning of HIV/AIDS. First, people with HIV/AIDS are represented as living with HIV/AIDS not dying. HIV disease is not a death sentence; it does not have to be a terminal disease. Instead, HIV positive individuals are living with a chronic and manageable disease that may be life threatening. Representations around this theme included stories and images of people with HIV/AIDS who are open about their health, who understand their condition as chronic and manageable and are living accordingly, keeping their jobs, sustaining long term relationships, planning for their future, as so on. A second theme in media projects like *POZ* and *Diseased Pariah News* is that people with HIV/AIDS are survivors. What surviving with HIV/AIDS means is taking an active role in decisions that affect your life, asserting your own expertise regarding your body and your health, and refusing to be labeled a victim or accept discrimination on the basis of health status, sexuality, gender, or lifestyle. Lastly, the third theme in media projects is that people with HIV/AIDS are not shunned, alone and isolated members of society. Instead, they are part of a strong and diverse community of people with HIV/AIDS, and moreover, are active and valued members of many different communities within civil society.

The message of this collective identity is also to challenge and refute those myths and stereotypes about HIV/AIDS that exist in institutional structures and public discourse – in the media, the education system, the health care system, in the development of policy. As Marshall (1991) has argued, theoretically, alternative public spheres

have a dual purpose. By fostering and supporting the formation of collective identities, they have an internal function as part of contemporary social movements. At the same time, by providing the means by which dominant ideologies can be challenged and transformed through debate, alternative public spheres also serve an external function. One of the challenges that media projects have had to face as part of the AIDS movement is finding effective ways of moving beyond only reaching those that are already entrenched and involved in activism.

The alternative public sphere that has been constructed for people with HIV/AIDS through media projects like *POZ* and *Diseased Pariah News* have primarily performed an internal rather than external function. The focus of media projects has not been on challenging and influencing the beliefs of those who are not infected or directly affected by HIV/AIDS. Instead, the purpose media projects has been to give those infected a means of articulating and representing a supportive and empowered portrait of what it means to be HIV positive. This internal function of alternative public spheres is essential for the construction of collective identities in the context of social movements. However, the lack of an external focus limits the extent to which people with HIV/AIDS can work collectively to transform dominant social and power structures in North American societies.

There is evidence to suggest that media projects like those in this study have become more external in their orientation as the nature of the AIDS movement has changed. *POZ*, for instance, has tried to appeal to an audience that is located beyond the HIV/AIDS community. In using the conventions of mainstream magazines, those involved in *POZ* have tried to make the publication more attractive and familiar to a broader range of people and industries. Sean Strubb, the founder of *POZ*, has said that he will consider his magazine a success when a non-AIDS specific corporation like General Motors wishes to place an advertisement in *POZ*. The extent to which *POZ* has been successful in this regard is open for debate. The publication has certainly caught the attention of those working in the magazine industry, but its readership has remained limited in scope.

The emergence and growth of *POZ* can be seen as a response to the need for the AIDS movement to focus more on informing and engaging an audience other than those infected or directly affected by HIV/AIDS. In becoming broader in scope, the debate within the alternative public sphere for people with HIV/AIDS could potentially be more effective in order to challenge and transform dominant social and power structures. Most media projects by and for people with HIV/AIDS, however, are much more suited to performing an internal rather than external function. Alternative media in general have been criticized for only speaking to a relatively small and

already converted audience. It may be possible, however, for new types of hybrid media, like *POZ*, to break down the distinction between mainstream and alternative media and influence those who would not otherwise be exposed to the perspective of those infected and affected. It is a challenge is to accomplish this objective and still remain accountable to those living with HIV/AIDS and avoid becoming co-opted by dominant political or economic interests. In other words, in order to work toward revitalizing the public sphere, alternative media projects need to move beyond marginalized forms of communications in a way that does not result in a loss of autonomy.

CONCLUSION

In democratic societies it is important that citizens have the opportunity to put aside their differences and engage in critical debate about issues of common concern. Historically, such dialogue has occurred through participation in the public sphere. However, public spheres in most late industrial democracies are controlled by an economic and intellectual elite. As a result, the critical reason of those who are marginalized or oppressed is silenced or distorted in order to reproduce the dominant social order. A common feature of contemporary social movements is an attempt to revitalize the public sphere. From the perspective of social activists, the chance for all citizens to use their critical reason is considered to be central to redressing existing social inequities and forms of oppression. To reach this end, those involved in social movements have developed alternative public spheres so that a broader range of citizens can engage in meaningful public debate.

Altman (1993:1), in his book *Community and Power*, argues that the community based response to HIV/AIDS has been effective and subversive because “it has challenged the ‘expert’ control of knowledge and the state’s control of policy.” In many respects, organizing by and for people with HIV/AIDS has been at the forefront of this challenge. Using strategies of self empowerment, the AIDS movement has encouraged and assisted the involvement of those infected in all decisions that affect their lives. Being involved in the AIDS movement and in media projects has meant reworking and changing the societal norms and assumptions about what it means to be a person with an infectious, life threatening disease.

A common thread in the media projects in this study is the struggle to exert control over the representation of HIV/AIDS. Arguably, in recent years, such efforts have become more difficult as institutional discourses have adopted similar strategies of representation as those initially used by those with HIV/AIDS – like the portrayal of people with HIV/AIDS in a positive and empowered way or taking into consideration their needs, interests, and

perspectives in the provision of treatment information. The challenge that faces people with HIV/AIDS involved in media projects is to convince themselves, and those in positions of power, that their voice and their perspective is still essential to the way in which HIV/AIDS is represented and that they should be involved in the process of representing HIV/AIDS to some degree.

In this paper I have outlined three of the major challenges that faced media projects by and for people with HIV/AIDS. The pressure to professionalize, adapt to changing needs and technologies, and overcome marginalization have had a great impact on all aspects of the publications in this study. Indeed, the fate of the projects have been determined by the extent to they were able to successfully meet these challenges. Looking across the three challenges that I have identified, a common theme is the co-optation and incorporation of efforts within the AIDS movement by broader social and political structures. As HIV/AIDS as become a greater public health threat, as governments have become more involved, as a medicine has been able to develop more effective treatments, those working in the AIDS movement have had to struggle to sustain a critical and counter hegemonic focus to their activism without losing sight of their overall purpose. For the projects in this study, responding to co-optation and incorporation has meant having to learn to work strategically within institutional structures.

The analysis that I have provided is limited to the AIDS movement. However, the processes that I have been identified – professionalization, adaptation, marginalization – impact upon all forms of alternative media to varying degrees. It would be interesting to explore the extent to which those involved in different types of media projects have had to overcome similar challenges. Work in this direction may be useful in identifying why particular alternative media are able to resist the forces of co-optation and incorporation by dominant power structures.

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