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The sociology of AIDS activism, the case of ACT UP/New York, 1987–1992. (Volumes I and II)

Elbaz, Gilbert, Ph.D.

City University of New York, 1992

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A

THE SOCIOLOGY OF AIDS ACTIVISM, THE CASE OF ACT UP/NEW YORK, 1987-1992

BY

GILBERT ELBAZ

VOLUME I

A dissertation submitted to the Graduate Faculty in Sociology in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York

1992

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This manuscript has been read and accepted for the Graduate Faculty in Sociology in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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THE CITY UNIVERSITY OF NEW YORK

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ABSTRACT

THE SOCIOLOGY OF AIDS ACTIVISM,

THE CASE OF ACT UP/NEW YORK, 1987-1992

BY

GILBERT ELBAZ

Adviser: **PROFESSOR STANLEY ARONOWITZ**

The present dissertation is about an AIDS activist organization: AIDS Coalition to Unleash Power/New York (ACT UP/New York). The organization's self-proclaimed goal is to end the "AIDS crisis" using direct action.

Since its creation in 1987, the organization has matured. Only interested in drugs at first, it quickly diversified to include issues such as holistic medicine, issues of concern to white women and people of color with AIDS, national health care, drug use and high-school AIDS education, to name just a few.

Considered the most appropriate, the social movement perspective was elected to analyze ACT UP. The literature on social movements has moved from psychologistic to cultural emphasis via rationalism.

Special attention is given to Alain Touraine's Action Sociology, which represents the theoretical underpinnings of this research. However, disagreements with Touraine's view on the new social movements feeds the thesis of the present study.

Contrary to Touraine's contention that the new social movements are mostly cultural, defensive and post-industrial, the present analysis argues that ACT UP is equally political and cultural,

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offensive in its strategy and raises issues that are tied to the industrial character of society and in particular to biomedical research.

In order to comprehend the revolutionary character of ACT UP, a reconceptualization of the political realm is necessary. ACT UP's goal is not the take over of the state or the cultural patterns, to use Touraine's formulation, but the "communalization" of those cultural patterns by the social actors, which ultimately negates the power of the state.

Communalization is understood as the active input of a community affected by a specific issue; in the present work: AIDS.

Similar analysis, it is suggested, of other new social movements, such as the women's, the lesbian and the gay movements should be conducted in light of those new categories so as to reevaluate their political and politicizing effects on society.

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ACKNOWLEDGEMENTS

I WOULD LIKE TO THANK PROFS. STANLEY ARONOWITZ, MAXIME WOLFE AND MICHAEL BROWN FOR THEIR UNRELENTING TRUST AND PATIENCE, ESPECIALLY IN TIMES I THOUGHT I WOULD NOT BE UP TO THE TASK. I AM ESPECIALLY GRATEFUL TO ALL OF THEM FOR LETTING ME BELIEVE THAT ONE CAN INDEED BE A RESEARCHER AND AN ACTIVIST AT THE SAME TIME.

MY SPECIAL THANKS GO TO PROF. WILLIAM KORNBLUM FOR HIS FINANCIAL ASSISTANCE, AND PROF. CHARLES KADUSHIN FOR EXTENDING HIS EXPERTISE.

I ALSO OWE SO MUCH TO JONATHAN LANG FOR ALL THE THERAPEUTIC SESSIONS HE PROVIDED ME FREE OF CHARGE, AND TO YERACH GOVER FOR ALL THE TELEPHONE CONVERSATIONS THROUGH WHICH WE SHARED THE MISERIES OF BEING A GRADUATE STUDENT.

FINALLY, HEARTFELT GRATITUDE TO ALL MY FRIENDS IN ACT UP FOR LETTING ME BE THEIR RESEARCHER-IN-RESIDENCE FOR THREE YEARS.

GILBERT ELBAZ, SEPTEMBER, 1992.

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DEDICATION

I WOULD LIKE TO DEDICATE THIS DISSERTATION TO GLEN STAPLEMAN WHO WAS NOT ABLE TO ATTEND THE DEFENSE, BECAUSE HE DIED OF AIDS IN THE FALL OF 1991.

GLEN, I WILL NEVER FORGET YOU.

GILBERT ELBAZ, SEPTEMBER, 1992.

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THEORETICAL BACKGROUND AND SOCIOLOGICAL LITERATURE ON SOCIAL MOVEMENTS

The sociological literature on social movement theories stems from different traditions in sociology. Some theorists are more psychologically oriented, others are more structural in tone and the latest seem to follow a cultural path.

At the end of the nineteenth century, some social thinkers argued that people engaging in social movements were frustrated and acted out of passion. In crowds, individuals were thought to become barbarians unable to think rationally. (Le Bon, 1896) In fact, up until the fifties sociologists likened the behavior of crowd participants to a herd of animals. (Blumer, 1951)

The classical approach was refined in the sixties. Crowd behavior was no longer viewed as a homogeneous phenomenon but a hierarchical one. Emergent-Norm theory proposed that people in a crowd may have different reactions. Lest they be ridiculed or rejected, crowd participants followed the norms defined by few individuals. (Turner and Killian, 1972)

Other theories argued that social movements attract people who have personality defects and that membership in the movements meets their psychological needs by making them feel important and useful. (Cantril, 1941, 1963; Hoffer, 1951; Toch, 1965)

The common thread of all these theories is their stress on the social actor's psychology, leaving untouched the social system.

Unsatisfied with the psychological argument, some theorists pondered that, if they were "irrational" or "pathological", social

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movement actors would not be able to make specific choices as to which movements they would join. Furthermore, psychological theories could not explain why some movements, such as the civil rights movement, had been partly successful.

Obviously there was more to it. "Strain" or "Breakdown" theories, drawing on structural-functionalism, contend that the cause of social movements must be sought in some kind of strain in society. A strain surfaces when norms and social control are no longer adequate in the face of structural changes. Six conditions are thought to be necessary and sufficient to produce a social movement:

1) the social system must allow social movements.

2) Social structural conditions lead some segments of the population to view their condition as unfair compared to others (relative deprivation).

3) People try to find a shared definition of their perceived unfair situation, so that they can be ready for a collective action.

4) Precipitating events can support their shared definition (generalized belief), for example police brutality.

5) The emergence of a leader gives a sense of direction to the crowd participants.

6) The response of the authorities is crucial in determining whether or not the social movement will succeed (Smelser, 1962).

"Strain" theories born at the University of Chicago branched out into different versions. Although the premise of social malintegration is common to all of them, the "strain" models see different sources of malintegration yielding social protests.

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Thus, the "rising expectation" model met with temporary success. The reasoning was simple: as the social gains made by a social group increase, so do their expectations, which, if unmet, eventuate in a social movement. Davies' J curve or rise and drop model of revolution is a good visualization of the rising expectation model. (Davies, 1969) The civil rights movements, for example, was explained by the former political gains made by blacks.

The relative or absolute deprivation approach was also derivative of the breakdown model of the 60's. In this model, the civil rights movement was not stirred by earlier gains made by blacks, but by the frustration felt by the latter who considered their plight as unfair compared to other social groups. (Killian, 1972)

Mass society theory had the particularity of not sharing the assumption of pluralism, so dear to the other breakdown theorists. In this perspective, people do not have access to mediators who can relay their claims in the political realm. People are isolated and feel compelled to engage in social protest. (Kornhauser, 1959)

Following the Chicago school line, status inconsistency refers to the discrepancy between people's ranking on a variety of status dimensions, e.g education, income, occupation and their actual position in society. Their anomic conditions push those individuals into social protest.

The first criticism leveled at "breakdown" or "strain" theories is that although they devote more attention to the social sources of social movements, their focus remains fundamentally psychological.

The second concerns "breakdown" theorists' assumption that participants of social movements are essentially irrational. Social

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movement participants, according to this school are not able to use legitimate ways of voicing their grievances in a "pluralistic" system that would otherwise, according to the Chicago school thinkers, allow it. In this perspective, collective actions are crude and even neurotic; (Jenkins, 1983) they spread like an epidemic, through contagion and imitation. Protesters are construed as victims of social situations rather than in control of them.

The third criticism is that there is always a certain amount of strain or deprivation at one time or another in any society, yet this condition does not necessarily lead to the emergence of social movements. Thus, strain theories, like earlier classical theories, do not explain why the civil rights or the feminist movements emerged when they did.

Finally, most of the strain theorists tend to narrow down the concept of social movement to collective behavior, as this very concept gives way to very heated and interminable debates among today's social movement thinkers.

Realizing that the 60's movements could not be explained by the classical approach deemed too psychologizing, a new wave of theories rose in the early seventies. "Resource-mobilization" theorists decided to revamp the categories thus far used by classical theorists to analyze social movements. According to those social thinkers, grievances and feeling of frustration cannot be the motive force of social movements because they are "ubiquitous." Instead the variability of resources became the salient factor explaining the emergence of social movement. This approach had quite an impact in social movement theorizing, for it constituted the theoretical underpinning of 71% of the

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works published in the 80's.(ref) Another distinctive feature of those theorists was that many of them were sympathizing of, if not themselves involved in the social movements they were studying. (Jenkins, 1983)

This new perspective from inside the movements brought out new questions that earlier thinkers could not have thought about from their removed stance.

Resource mobilization theorists argue that social movements emerge when material resources become available. (Mc Carthy and Zald, 1977) Two major political orientations developed out of this premise. One that is conservative and business-like oriented, the other Marxist in inclination.

In the first orientation, social movements can be analogized to political parties, lobbies or interest groups. There is no real rupture between the political system and social movements. The latter partake of the pluralistic structure of society (Gamson, 1975) And for the first time social movement actors are construed as rational actors engaging in business-like calculations to join in the movement that will yield most social benefits to them.

> Assume that SMOs (Social Movement Organization) operate much like any other organization (J.Q. Wilson, 1973), and consequently, once formed, they operate as though organizational survival were the primary goal. Only if survival is insured can other goals be pursued. Second, assume that the costs and rewards of involvement can

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> account for individual participation in SMOs and that, especially, selective incentives are important since they tend to raise the rewards for involvement. Gamson (1975) and Bailis (1974) provide impressive evidence that selective material incentives operate to bind individuals to SMOs and, hence, serve to provide continuous involvement in their resource mobilization.[1]

Thus social movements are viewed as a real market or an industry to use resource mobilization's language. (Mc Carthy/Zald, 1977) This social social movement industry is divided into sectors, and each sector is comprised of social movement organizations (SMOs). Like any business firm, social movements are considered successful if they achieve institutionalization and measurable benefits. Great emphasis is placed upon the internal analysis of the SMOs, their hierarchy, their full-time paid organizers and effective mobilization of external support. (Mc Carthy and Zald, 1977; Zald and Mc Carthy, 1979; Obershall, 1973; Gamson, 1975; Tilly, 1978)

> Treating SMO target goals as products, then, and adherence as demand we can apply a simple ecomomic model to this competitive process. Demand may be elastic, and its elasticity is likely to be heavily dependent upon SMO advertising.

---

[1]John D. McCarthy and Mayer N. Zald, *Resource Mobilization and Social Movements: A partial Theory*, in American Journal of Sociology, No 82, May 1977.

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> Products may be substitutable across SMIs (Social Movement Industry). For example, while various SMOs may compete for resources from isolated adherents to the "justice for black Americans" SM (Social Movement), SMOs representing the "Justice for American women" SM may be competing for the same resources (to the extent that these two SMs have overlapping adherent pools). Some adherents may have a high and inelastic demand curve for a SMO or SMI, others' demand curves may show great elasticity.[2]

As a consequence, resource mobilization theorists tend to favor analysis of politically-oriented social movements, that is those who are most concerned with the distribution of political power. They also tend to neglect other social movements who are more critical of the power structure of society. The resource mobilization paradigm cannot assess the gains made by those politically "deviant" social movements.

The market metaphor used in resource mobilization's theory lacks rigor. It lumps together social movements with occasional upheavals without any consideration of the ideology that moves those different insurgencies. In fact, the ideological dimension of social movement has so little importance for resource-mobilization theorists that SMOs are construed as competing for the recruitment of members who are totally self-interested, if not disinterested, and without any

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[2]Ibid.

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political commitment. (Snow et al, 1986) Rank and file participants in a social movement are seen, in some versions of resource mobilization as largely irrelevant to the outcome of social protest. (McCarthy and Zald, 1973)

The latter strand of resource mobilization is more concerned with the structure of political opportunities and with the degree of organization within the deprived social groups. (McAdam, 1982,; Tarrow 1983)

In general the resource mobilization model discounts indigenous resources, and emphasizes external support opportunity. (Obershall, 1973) Instead, in the "political process" approach, members are very important. This approach stresses the importance of political opportunity prior to the movement. Thus, Blacks had already made some political gains before the civil rights insurgency erupted, and this reinforced their political efficacy. Emboldened by this new consciousness, blacks were now able to use extraparliamentary methods, and challenge the political structures of society.

According to this perspective, the decline of the civil rights movement was caused by disagreements over the goals of the movement and the movement's effective means of attaining them.

The "political process" approach does lend more importance to internal (indigenous) resources and political opportunity. However, political opportunity is defined in a very narrow way: ability to participate in the political institutions or right to vote. The model remains still very elitist for the stress it places on leaders. Thus Mc Adam impugns the decline of the civil rights movement to the:

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> lack of centralized organizational vehicles required to sustain the disruptive campaigns that earlier had forced supportive federal action.[3]

The improvement of McAdam's approach is to attempt to conceptualize politicization as a long time process as opposed to earlier resource mobilization models which viewed insurgency as the result of recent changes. One could question, however, the assumed discontinuity McAdam posits between the civil rights movement and the Black Panthers. The political process approach too quickly acknowledges the demise of the civil rights movement, when in fact the latter might better be viewed as the necessary ferment for the more radical 60's movements, and thus part of a larger movement of Black liberation.

Although more stress is placed upon political process, the eventual emphasis of the political process approach is on discrete organizations, which were part of the many manifest expressions of the Black movement.

Most of classical and resource mobilization theorists assume political pluralism. The former concludes that because movement actors do not use the legitimate political institutions, they are irrational. The latter considers the movement actors as mere part of a political system that is in fact larger than it appears.

Neither model question social production or reproduction. In each strand, the gains of the movement participants must be tangible.

---

[3] Doug McAdam, *Political Process and the Development of Black Insurgency, 1930-1970*, Chicago: University of Chicago Press p.186, 1979.

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Thus, the new social movements, where goals and means constantly negotiated and only understood in terms of process, are excluded from this paradigm. The individuals as political actors are totally ignored or equated to implacable rational thinkers. Both models espouse the concept of modernity and ignore alternative cultural expression. Ideology is left unquestioned, or if it is questioned (McAdam, 1982), it is left untreated. In many ways what makes the uniqueness of the AIDS movement is its critique of the ideology of science.

Most of the models proposed by theorists in the United States share the unquestioned assumption that the political system in this country is one of a pluralistic nature. Anybody can achieve political status; therefore, only the means used to achieve those political ends differentiate movements from one another.

Pluralism is precisely the assumption that European theorists do not share. Witnesses of the rise of the new social movements in the late sixties and early seventies, European thinkers disagree that the resource mobilization paradigm was sufficient to explain the emergence of those movements. They even disagree that it totally explained the how, since ideology has a lot to do with the way movements garner resources.

The European paradigm trades the stress on social movement organization for that on social movement construction with less emphasis on resource mobilization and more on identity and ideology. The disagreement with resource mobilization theorists is here obvious. Whereas the U.S. school assumes fixity of the goal and harmonious relationships as the sine qua non for the success of a movement, Melucci defines social movement as social construction whose unity is

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constantly shared and negotiated. In fact for him, unity is less a result than a departure. (Melucci, 1985)

A collective identity, for Melucci, is nothing else than a shared definition of the field of opportunities and constraints offered to collective actions. To consider a movement as an action system means to stop treating it as an empirical phenomenon. (Melucci, 1985)

Melucci defines analytically a social movement as a form of collective action based on solidarity, carrying on a conflict and breaking the limits of the system in which action occurs. (Melucci, 1985)

The organizational dimension of the movement becomes here really secondary. There is also the clear statement that the extant system is not able to absorb the demands of the new movements. The need to break it is made essential in the construction of a movement. If there is only breaking of the rule, then the action pertains to the realm of deviance and not social movements. (Melluci, 1985)

The actors in these conflicts are no longer classes, that is, stable groups defined by a specific social condition and culture. Melucci argues that the new movements have a growing symbolic function. They fight for different meanings thereby having more of a prophetic function.

> They (New Social Movements) do not fight merely for material goals or to increase participation in the system. They fight for symbolic and cultural stakes for a different meaning and orientation of social

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> action. Analysis ought to treat collective action as a sign and decipher its multiple significations.[4]

The characteristics of advanced societies require that control reach beyond productive structure into the areas of consumption, services and social relations. The mechanisms of accumulation are no longer fed by the simple exploitation of the labour force, but rather by the manipulation of complex organization system, by control over information and over the processes and institutions of symbol formation and intervention of interpersonal relations. The role of science and of information systems is growing in advanced capitalism. At the same time, the field of the public and political is subjected to the pressure of individual needs and demands. Birth and death, illness and aging have all become critical points capable of mobilizing collective action. (Melucci,1985) Criticisms are not focused on the political system because the new social movements are not interested in the conquest of political power or the state apparatus, but rather toward the control of a field of autonomy or of independence vis a vis the system. Hence the importance of direct action and of direct participation in the work of the spontaneous anti-authoritarian and antihierarchical nature of the protests. Identity is the main battlefield for the social movements according to Melucci:

> Eventually, defense of the identity, continuity, and predictability of personal existence is beginning to

[4]Alberto Mellucci, *The Symbolic Challenge of Contemorary Movements,* in Social Research 52, No 4: 789-817, 1985.

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> constitute the substance of the new conflicts. In a structure in which ownership of the means of production is becoming more and more socialized, while at the same time remaining under the control of particular groups, what individuals are claiming collectively is the right to realize their own identity: the possibility of disposing of their personal creativity, their affective life, and their biological and interpersonal existence. The control and manipulation of the centers of technocratic domination are increasingly penetrating everyday life, encroaching upon the individuals' possibility of disposing of his time, his space, and his relationships. Personal identity-that is to say, the possibility, on the biological, psychological and interpersonal levels, of being recognized as an individual-is the property which is now being claimed and defended; this is the ground in which individual and collective resistance is taking root.[5]

By overemphasizing the identity dimension of the social movements, Melucci and others (Pizzorno, 1978), it seems, lose sight of the structural constraints that those movements have to face.

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[5] Alberto Mellucci,*The New Social Movements: A theoretical Approach* in Theory and Methods, p.218.

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Instead, Touraine attempts to restore a balance between those two elements which shape the orientation of the new social movements. Touraine needs to redefine society in order to situate the importance of social movement. Society for Touraine is certainly not a system of class, conditions or status, as Marxist and Parsonian of different strands would have it. And it is definitely not dependent on any law, or evolutionism gearing toward an inevitably beneficent modernity. Society in Touraine's theory is an ensemble of relations. The main object of sociology is therefore to study those relations. This approach does not exclude the idea of system. But this time, social relations or social actions create the system, and not the opposite.

The second dimension of Touraine's perspective is that most of those relations are marked by power differentials. He then specifies the role of sociology as the analysis of people's actions to reverse power differentials. Touraine's sociology is then not only a sociology of relations but first of all a sociology of action.

Social relations and actions represent the fiber of society. The latter is no longer defined as a fixed entity dependent on universal laws of motion. It is a flow of movements constantly perturbing an apparent order.

In this context, the central role of social movements does not come as a surprise. They are not the disruptive product of maladjusted individuals, neither the programmed output of a studious cost-benefit analysis, they are the DNA of social life. They are social life.

Not all conflict, however, in Touraine's sociology, qualifies as social movement. A social movement is as much defined by the actions as the consciousness involved in it. He distinguishes three

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types of social conflicts. Collective behavior is the lowest form of conflicts. It is a form of conflict where people have not even been able to carry their claims to the political institutions. Because it is not well articulated politically, it does not carry a significant social input. Social struggles have a higher status in Touraine's conceptualization. They deal with distributive interests which can be resolved at the political level. This type of conflicts was the focus of resource mobilization theorists. Finally, come social movements per se with the highest form of consciousness, whose goal is to change the fundamental social relations of power. Before even changing those relations of power, they are in fact manifest expressions of pervasive power differentials.

The actor engaged in political struggles shares the vision that the United States is a pluralist society, where justice is a matter of distribution or redistribution. The actor engaged in a social movement believe that the premise according to which society is built must be questioned and changed. The former uses the rules of the game, the latter changes them.

Historicity is what distinguishes those two actors. One succumbs to social relations of power, and recurs to distributive compromise. The other challenges those relations and aims at controlling them. Touraine defines historicity as

> representation of society to itself not only with respect to images, but also with respect to its ethical projection for the future.[6]

---

[6]Alain Touraine, *The Return of the Actor Finish*, Minnesota: The University of Minnesota Press, 1988.

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The social actor is not only someone who acts, but also someone who has a visionary ethical social project. This is the Tourainian yardstick which assesses whether a conflict is mere collective behavior, political struggles or social movement. The definition of social movement in Touraine's perspective becomes:

> an action, both culturally oriented and socially conflictual, of a social class defined by its position of domination or dependency in the mode of appropriation of historicity, of the cultural models of investment, knowledge and morality, toward which the social movement itself is oriented.[7]

Social class is not understood as a Marxist concept referring to the fundamental contradiction between productive forces and the social relations of production. Class is defined as groups opposed to each other in a central conflict for the appropriation of historicity. (Touraine, 1988) More generally, for Touraine

> An industrial society is not defined by technologies but by class relations, by the capacity of a social category to transform the organization of labor and to appropriate the profits that result from this operation.[8]

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[7]Ibid.
[8]Ibid.

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Thus, a social movement is a conscious action whose aim is to force by way of social conflict a new model of economics, knowledge and ethics, what Touraine calls cultural patterns. Thus for him, the labor movement formed only when

> it went past the rejection of machines and recognized that mechanization and progress would save them from their slaving working conditions.[9]

The resurrection of the actor or the subject is a direct attack against modernity with its universalistic pretense as embodied in both the Parsonian and the Marxist grid. Touraine witnesses the lesser use of political representation by the individuals along with their more frequent recourse to social movement and direct action.

> The most visible result of this dissociation (between State and Society) is the weakening in representation of political institutions. Even in democratic countries an ever larger gap develop between the political actors who must find a mode of representation and the political forces that are supposed to represent them. Political parties are increasingly conceived as "political businesses" whereas social claims are expressed more directly

[9]Ibid. p.134.

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> through social movements quite distinct from the parties. There are no longer any political passions, whereas the French Revolution of 1848 or the Soviet Revolution were periods during which all passions were political.[10]

The claims of the new social movements cannot be carried out by traditional political institutions anymore. At heart, is a fundamental blurring of what is public and private. Fecundation, birth, reproduction, sexuality, illness and death are now construed by those new social movements as public problems. Claus Offe agrees with Touraine:

> The new movements politicize themes which cannot easily be coded within the binary code of the universe of social action that underlines liberal political theory, i.e. where liberal political theory assumes that all actions can be categorized as either private or public. The new movements locate themselves in a third intermediate category.[11]

The new social movements, for Touraine, are not formed through political action but far more by influencing public opinion. The women's movement and the ecology movements won an

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[10]Ibid.
[11]Claus Offe, *New Social Movements: Challenging the Boundaries of Institutional Politics*, in Social Research 52/4, p.819, 1985.

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audience never achieved by the labor union movement, and even all forms of labor action in the middle of the nineteenth century. (Touraine, 1988)

Touraine observes, however, that whereas the labor movement was concentrated, the new social movements are diffused. The ecological and antinuclear movements received a very small percentage of votes in the elections in which they participated. Thus, the French government's pronuclear policy went unchallenged for over ten year. Touraine does not believe that those new social movements really qualifies as social movements. Near the end of the Return of the Actor, he concludes:

> All of these observations lead to the conclusion that the present situation of Western industrialized societies is favorable to the emergence of protest movements, and even to their transformation into pressure groups, but the moment of their passage to the level of social movement has not yet come. This is why we often see the joint presence of strongly institutionalized claim-making forces and nonnegotiable 'emotional' residues, incapable of fueling by themselves a social movement.[12]

He then points to the necessity for those movements to coalesce and form a real movement capable of challenging central forms of

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[12]Alain Touraine, *The Return of the Actor*, Minnesota: The University of Minnesota Press, p134, 1988.

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social domination. None of the current movements, Touraine observes, is able to rally all the other movements behind it. None points to a central conflict. Taking the women's movement and the ecology movement as examples, he contends that neither one has a meaning general enough to rally the other protest movements behind it.[13]

Touraine recognizes that the women's movement has in fact two dimensions. One that is tied to modern concerns: the fight for equality with men; the other of a more radical nature: the refusal to see the world and oneself defined by men. Yet, Touraine still does not believe that even the radical branch of the women's movement qualifies as a social movement.

His confusion becomes more blatant when he observes that the new social movements question the values of culture and society. He recognizes that the connection between values and norm is of a coercive nature, thereby totally rejecting the Parsonian model. Yet, he does not recognize that the new social movements challenge a central form of domination (which should qualify them as social movements) and have here a ground for coalition.

Although the next excerpt reads as a recommendation, Touraine does not realize that this is what the new social movements are in fact doing:

> The more the new social struggles enter into the realms of culture and personality the more they

[13]Ibid p.135.

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> increase their chances of integrating the various struggles in a general social movement.[14]

Touraine believes that because their actions depend more and more on the state, social movements cannot keep their political integrity:

> They oscillate between an ethic based on convictions increasingly removed from concrete historical reality and a logic of efficacy which leads them to submit to the influence of political actors.[15]

He is particularly intransigent with the French workers' movement who, according to him, was not able to offer a political program and was coopted by political parties, even conservative ones. (Touraine, 1988)

Indeed the new social movements are engaged in a sort of subtle negotiation with the state. In the process of this negotiation, however, they are not necessarily coopted by political parties or by the state. They themselves can become harsh contenders in the political field without the help of political parties.

To be sure, the new social movements are not revolutionary in the traditional sense that they do not aim at overthrowing the state. The ultimate goal, Touraine witnesses, of the protests in Brazil, Argentina, Uruguay and Chile, is not revolution but democracy.

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[14]Ibid. p.120.
[15]Ibid p.136.

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However what is revolutionary, Touraine does not seem to recognize it, is the use those social movements are making of democracy.

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THESIS

Undoubtedly, ACT UP falls under the definition of new social protest. As mentioned earlier, Touraine denies the status of social movements to those new social protests such as the ecology and the women's movements.

The first contention of this thesis is that the categories used by Touraine and other proponents of the new social movement paradigm (Cohen, 1985; Offe, 1985, Habermas, 1985; Eder, 1985) are not adequate to understand ACT UP.

The key feature of a social movement for Touraine is its attempt to control cultural patterns. The thesis of this dissertation contends that ACT UP is interested neither in political nor cultural power, but in the communalization of those cultural patterns.

Power of any form entails domination by which freedom of choice finds itself severed. The main project of ACT UP is then to restore a communalized space where individuals, granted centerstage, can express and enact their choices. The first goal of ACT UP is the restoration of democracy at all levels of social life, whether it be science or decision-making with regard to healthcare policy, where individuals play an active role.

Because Touraine and others (Offe, 1985; Gamson, 1989; Touraine, 1988) do not acknowledge this fact, they render a very contorted version of the new social movements. According to them, new social protests are cultural. They are interested in autonomy from the State, and do not question the political and the economic realms; their concerns are postmaterialist and postindustrial, their goals and

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sometimes enemies (Gamson, 1989) are diffuse; their strategy is both defensive and extraparliamentary. Because he sees in the new social movements only concerns for specific issues, Touraine does not grant them the magnitude of a social movement:

> The new social movements are less socio-political and more socio-cultural. The distance between civil society and State is increasing while the separation between private and public life is fading away. The continuity from social movements to political party is disappearing; political life tends to be depressed areas between a stronger State in a changing international environment and, on the other side, socio-cultural movements. The main risk is no longer to see social movements absorbed by political parties, as in Communist regimes, but a complete separation between social movements and State. In such a situation, social movements can easily become segmented, transform themselves into defense of minorities or search for identity, while public life becomes dominated by pro- or anti-State movements.[1]

In response to this characterization of social movements, the present research argues that what appears to be diffuse goals or enemy

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[1] Touraine, Alain, *Introduction to the Study of Social Movements*, Social Research 52: 780, Winter 1985.

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(Gamson, 1988) is in fact the multifaceted confrontation ACT UP is engaged in to safeguard the democratic and communal project where the actor is center stage. Undoubtedly, this quest for democracy takes on different forms. AIDS activists thus are engaged simultaneously in the battle against racism, sexism, homophobia, classism, but also against the suppression of freedom of choice, whether it be sexual, biomedical or holistic.

In order to restore the democratic and communal project, AIDS activists have to watch closely the different state bureaucracies and their pronouncements and actions vis a vis AIDS. Thus, if they are not interested in political power, activists still need to closely watch this political power operate. In fact, they are in a constant relationship with the political institutions from an extraparliamentary stance. Thus, the claim that the new social movements fight defensively for their cultural autonomy ignores the complex relationship those new social movements informally enter with the political realm. The boycott of Miller beer company that sponsored Jesse Helms' senatorial campaign illustrates how new social movements can be involved in political fight from without the political institutions. Also the many zaps and direct actions organized at public officials' offices can not be simply dismissed as defensive strategy. One of ACT UP's recurrent logistical recommendations is that the organization be proactive, and counteroffensive and not wait for the *fait accompli.* Thus, the activists shut down the FDA, which finally promised to speed up its drug release process; they also chained themselves at the Burroughs-Wellcome building, causing the company to lower its price of AZT. These actions can hardly be called defensive.

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The claim that ACT UP would be postmaterialist and postindustrial is equally reductionist. One major aspect of AIDS activism has to do with people's biological survival. That in itself is enough to stress the materialist dimension of the AIDS movement. If ACT UP is also about choices of medicines, conventional and traditional, the present research will show that the dichotomy drawn between materialist and postmaterialist concerns is not a real one. Postmaterialist concerns reveal that consumption cannot be separated from production. Concerns about consumption not only impact on people's quality of life, but also survival, especially in the case of persons with AIDS. In many ways, consumption defines production from a social perspective and not an economic one.

Likewise the claim that the new social movements are postindustrial and uncritical of the economy silences what they are saying about work organization and unethical profit. One of ACT UP's claims is that biomedical research functions and reasons like an industry with the usual profit considerations. Activists often carry out a Weberian analysis to know who has real power in decision making and do not hesitate to denounce unethical profit-making, and to fight ever-rising medical costs.

In conclusion, ACT UP appears to be very fragmented and lacking focus, when in reality its unifying project is the communalization of the cultural patterns. Before fighting for this communalization, ACT UP begins by offering a cultural space where members learn the sometimes harsh rules of democracy. This cultural space hosts different groups, one might even say different social movements, which often collide with each other. Although those

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different social movements inside ACT UP may have different projects, they learn to dialectically integrate other groups' projects.

Self-empowerment of the members is at the heart of ACT UP's philosophy. It happens dialectically and begins with convincing members that they can ask any questions, through the process of direct democracy. Members realize there is nothing they cannot understand; they can make suggestions, organize an action and get funding for it.

When doing an action, the activists are in presence of the very institutions to which they attribute the cause of the epidemic's devastations. Here, another dialectical process occurs. The action will change the actors' view of the institutions; it will reinforce the belief that they can act upon themselves and act upon society, to use Touraine's terminology. A triad comes into place. The activist versus the institutions and finally the synthesis represented by a hightened consciousness. Likewise, when they deal with political institutions, which ACT UP sometimes does, activists are not necessarily coopted by the political game as Touraine would have it (Touraine, 1988). The activist's will to know and to act enter in a dialectical relationship with the political institution's will to coopt the activists. The result is, in the case of no cooptation, once again a new hightened consciousness.

The progress of the group then can only be measured by its dialectical integration of the diverse projects at work, and its ability to resist cooptation by the political institution and the State.

The present dissertation will systematically show that each group and committee addresses a central relation of domination, thus agreeing partially with Touraine's definition of social movement; that each group and committee function democratically and aim at

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empowering individuals involved, although regular power play occurrences must be dealt with dialectically; that self-empowerment is the main avenue leading activists into areas thought to be the closed battlefield of experts or politicians; that the main purpose of ACT UP is not the control of the cultural patterns but the democratic communalization of those cultural patterns.

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METHODOLOGY

Historical and comparative analysis was used to trace the cultural roots of ACT UP. Two cultures are historically tracked down: the Lesbian, Gay and the AIDS cultures. It is argued that ACT UP is a direct historical outcome of those preexisting cultures.

A survey was designed to collect socio-demographic information from a purposive (non random) sample.

Politicization and communalization are twin concepts. One cannot live without the other. Communalization of cultural patterns implies that individuals become politicized and are willing to risk their jobs, sometimes their lives. One of the research questions of the survey was to find out the level of politicization of the members before and after joining the organization. Politicization was limited to the number of meetings, actions and deliberate arrests in which activists participated.

Participant-observation was used to refine the concept of communalization, politicization and self-empowerment. For two years, research was conducted on the field, and at the sites of the actions and demonstrations. In addition, general Monday meetings were recorded for a year. The main object of this field work was to witness not only the making of a democratic communal space and the self-empowering process activists go through while in the organization, but also analyze the ideologies that move the group in so many directions.

Finally, one hundred in-depth semi-structured interviews were conducted with activists particularly involved in the organization. Here too, the object was not only to document the central relations of

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domination the organization addresses, but also to go beyond the "fact sheets" put out by ACT UP and hear the activists articulate their own ideologies and strategies.

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THE LESBIAN AND GAY CULTURES

ACT UP did not emerge out of the blue. Preexisting Gay, Lesbian and AIDS cultures made it possible. In fact, the history of the gay and lesbian movement can be summarized as a tenuous relationship with the medical establishment, physical and mental.

Foucault states in *History of Sexuality* that the "homosexual" appeared in the 19th century as a new medico-scientific category, a new object of research (Foucault, 1978). Interestingly enough the word itself was coined by a German, Magnus Hirshfeld, himself homosexual. This sudden interest in the matter occurred during the period of Victorian puritanism, characterized as much by its avowed disgust for sex as its hypocritical, hidden and interminable indulgence in it. Desire, sex, and pleasure became suspicious categories. Worse, they were construed as source of anarchy at a time when rationality and modernization were hegemonic. Anti-sex laws proliferated. In 1885, an English anti-prostitution bill was amended to criminalize male homosexuality. In 1889, an English Indecent Advertisements Act was passed banning publicity for venereal diseases. Those who were not able to turn around those laws were liable to harsh punishment. Thus, Oscar Wilde's trial in 1895 resulted in his condemnation as a corruptor of youth, and his conviction to two years of hard labor.

Women's sexuality "as a problem" was expeditiously resolved. Queen Victoria decided that "women could not possibly engage in this type of activity."

Further, the idea of controlling the multifaceted sex-related dimensions of human experience, which after all are free, was imbued

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with a sense of total power. Not only could rationality control the work organization, but it could also control the work force in what was construed as its most intimate aspects. Sexual repression was instrumental to power whether it be capitalist, socialist or religious. In most socialist countries, homosexuals are still liable to prison sentence. In Iran, a man can be stoned to death if discovered homosexual. For a long time many forms of power have pushed homosexuals into a deadly silence.

Finally, science was completing the work that Judeo-Christian tradition had not been able to perfect. It could now be "scientifically and medically proven" that sexuality was a core feature of social equilibrium.

It is no surprise that the first self-confessed homosexuals attempted to use a scientifico-rationalistic model to "justify" themselves-and some still do today. Yet, they were openly homosexual and realized very rapidly that they should be part of the debate around the medicalization of homosexuality.

In 1897, Magnus Hirshfeld formed the Scientific Humanitarian Committee in Berlin. This group sponsored research and discussion "in the view of changing laws against homosexuality." (Altman, 1971) Hirshfeld organized a petition signed by thousands of Germans, including leading political, literary and medical authorities in the Social Democratic Party. Smaller groups were formed in Holland and Britain whose respective leaders, Havelock Ellis and Edward Carpenter, formed in 1914 the Society for the Study of Sex Psychology. In 1919, Magnus Hirshfeld created the Institute for Sex Research, which will be burned by the Nazis in 1933.

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In France, the Napoleonic code did not contain any hostile regulations against homosexuality. Under the influence of Victorianism, however, the cultural and religious opprobrium would lay on any one avowing same-sex attraction. In 1923, a homophile movement following the German model was born in the United States. The Society for Human Rights was established in Chicago "to protect the interest of people who by reason of mental and physical abnormalities are hindered in the legal pursuit of happiness, which is garanteed them by the Declaration of Independence." (Altman, 1971). This excerpt reveals the internalized repression of the early homophile groups. The 1928 novel, Well of Loneliness, was also penetrated by much internalized oppression, although it certainly contributed to the rise of a lesbian identity.

The police raided the Society for Human Rights and no other organization was founded until World War II, as in Europe.

Hirschfeld was forced into exile by the Nazis and homosexuals were sent to concentration camps. Up until today the West German government refuses to compensate those who were in concentration camps because of their homosexuality.

Pioneering activists' self-recognition of mental illness was a political contradiction, but a productive one. By unraveling the central conflict of domination that the debate around sex and homosex posed, those 19th century scientifically driven homosexuals can be identified as the infants of the gay movement.

The heated debate around homosexuality stirred a frantic paradigmatic competition opposing behaviorists to biologists whose purpose was "to explain the cause of homosexuality." Behaviorists set

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up aversive methods to change individuals' sexual orientation in both the United States and the Marxist countries (Altman, 1971). Social pressure was then viewed as the "main cause" of homosexuality. But no similar reasoning was applied to heterosexuality. Behaviorally-oriented theorists were also concentrating on the socially perceived female appearance of some homosexuals. Yet it became apparent very quickly that very macho-looking men were also flamboyant homosexuals.

Biologists were-and are still concerned today-about hormonal disequilibrium. Their assumption was that homosexuals were suffering from an overdose of female hormones. In one experiment, to substantiate their theory, researchers added female hormones to male monkeys. The result was baffling: the male monkeys became more sexually active. (Altman, 1971)

Pre-second World War psychology needed to medicalize also the fact that many homosexuals knew they were homosexuals before they had any sexual contact. Psychoanalysis resolved this bind by arguing that homosexuality is caused by an improperly resolved Oedipal complex. If the father is too passive or the mother too domineering, then the child may be sexually misdirected. Sigmund Freud was the first to posit that sexual orientation was predetermined and had to be constructed through social pressure, basically the family. He even assumed the existence of a repressed or sublimated homosexuality in everyone's sexual development.

World War II caused people living in a rural environment to move to the cities. Women, in particular replaced men in factories, enjoying a certain degree of economic and social independence. This

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period represented an unprecedented situation, where gay men and lesbians could congregate, especially in ports like San Francisco and New York.

In 1948, the Kinsey Report confirmed that homosexual relationships were quite frequent. It showed that 32% of the male population had engaged in homosexual contacts up to the point of orgasm. Notwithstanding its methodological flaws, the Report certainly contributed to the rise of the homophile movement. Eight percent of the female population reported similar sexual behavior. What shocked many professionals or lay persons about the findings of the Report was not so much the number of men strictly homosexuals as the continuum it presented between homosexuality and heterosexuality. The greatest number of people were located in the middle.[1] To be sure, the homosexual movement, still shy, would use this "scientific" support to elaborate its strategy.

Gay activists soon realized that scientific discursive strategies were not sufficient to withstand the increasing medicalization of sex. It is during the Cold War that the homophile movement emerged. Although still embedded in the belief that they were abnormal, homosexuals did not want to construe themselves only in relation to their sexuality, but also on the basis of affective as well as political bonds. Homophile substituted the suffix 'sexual' by 'phile' which stands for sympathy or affective love. This was also a strategy, which allowed straight individuals to join the movement.

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[1]Kinsey, Alfred, *Sexual Behavior in the Human Male*, Philadelphia: W.B. Saunders Co., 1948.

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In the U.S., the first lesbian newsletter, Vice Versa, appeared in 1947. A year after was formed the first post-war group, the Bachelors for Wallace formed in 1948. Their basic principles were still centered around the notion of abnormality and hence the will to be better tolerated by society. During the same year, U.S. Congress drew up secret plans to identify and incarcerate homosexuals.

From the Bachelors for Wallace stemmed the Mattachine Society created by five men in secret. Mattachines were court jesters who told the truth to the king while hiding behind masks. Secrecy was all the more important that in the wake of the Mc Carthy era being homosexual or showing sympathy for homosexuals amounted to being labeled a communist with all the legal consequences this label entailed. The society issued its own publication Vector, the circulation of which exceeded 20,000 copies. For the first time statistics about gays and lesbians other than those of the police and hospital records could be obtained since the Kinsey Report.

in 1952, One Inc. was founded in Los Angeles, as a non-profit California corporation. They published their notoriously radical Bill of Rights advocating that homosexual marriages be recognized by the States; that homosexual couples be permitted to adopt children; that children be exposed to both hetero and homosexual ways of life in an impartial manner and allowed to make a free choice; and that homosexuals be allowed to serve in the armed forces (which they always had). One had its publication of the same name. Both the Mattachine Society and One used the model set up by the Civil Rights movement. Expression of the need of the disadvantaged people for "freedom", "equality of opportunity', "rightful place in the nation's

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society", and "equal protection under the law" closely paralleled the civil rights movement's claims. (Altman, 1971)

As all the homosexual organizations were male dominated, it became clear for women that to fight sexism, even within gay male organizations, required that they possess their own space. Thus, the creation of the Daughters of Bilitis in 1955 catered to the needs of women. Like earlier men's organizations, the Daughters of Bilitis was very concerned about respectability. Women had to behave and dress in certain ways. The Daughters of Bilitis too had its own publication: The Ladder.

The seizure of Alan Ginsberg's book, *Howl*, by the police in 1957, reflected the intensely repressive environment of the times. Yet, change was not totally perceived as impossible. Ginsberg won the subsequent court case against censorship. 1957 is also the year of the Wolfenden Report, Report on the Committee on Homosexual Offenses and Prostitution, in which criminality of homosexual relationships was removed.

Another important legal victory included "One" winning a court case vs. U.S. Postal Service. As a result Gay and Lesbian publications were now allowed to use the mail. Those punctual victories did not erase self-hatred among many homosexuals. Liberace, thus, sued the London Daily Mirror for libel for implying he was homosexual; he subsequently won $24,000 settlement out of court.

What passed as science in 1962 hit hard the homosexual community with Irving Bieber's book, *Homosexuality*, which would pathologize any sexual or emotional relationship among same-sex individuals.

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Against all odds, the first gay picket line in the U.S. was organized in 1963 by Randy Wicker and the Homophile League of New York. Twelve activists picketed the Whitehall Induction Center protesting violations of draft record confidentiality pertaining to homosexuality.

The same year, a middle of the road organization, Society for Individual Rights (SIR), Inc was born. It distanced itself from the conservativism of the Mattachine and the radicalism of One. The membership was about 1,000. It provided the staging of plays and reviews for education of the outside public. It was also the first to schedule speeches by political candidates for every election. SIR published the "Packet Layer", a booklet small enough to fit into a wallet with brief information on how to conduct oneself when being questioned or arrested by the police.

In addition to governmental harassment, religion has always weighed a heavy toll in the lives of gays and lesbians. As in the scientific debate, it was important for some activists to be part of the religious debate and show their faith. The Reverend Ted Mc Ilvana founded the Council on Religion and the Homosexual, Inc in 1964. He organized weekend long retreats, where representatives from both religious and homosexual communities roundtabled. The Pope, however, remained the leading figure, who set the position of the church with regard to homosexuality. And the Vatican (still today) condemned homosex with the reservation that people must be compassionate of the homosexuals' condition. Later on the Pope will announce that homosexuals had a chance to repair their sins (Le Monde, 1980).

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As if to build a scientific opposition to this political and religious mobilization, the New York Academy of Medicine Report of 1964 described homosexuality as an acquired illness susceptible to cure. The same year, Frank Kameny of the Mattachine Society addressed the 100th monthly lecture, arguing that Queers had to reject the medical establishment's view of homosexuality as pathology.

From then on, the activists' strategies became increasingly political. Gays and Lesbians picketed in Washington D.C. calling for an end to U.S. Governmental hiring discrimination against homosexuals. A year later, the clergy joined the battle. They demonstrated with the activists against those discriminatory practices.

Out of concern for the protection of the community, the Citizens for Alert was created in 1965 in San Francisco. It gathered evidence to halt police brutality and inequitable enforcement of laws regarding homosexuals. A 24-hour answering service was used and manned entirely by volunteers. The person in trouble was contacted by a list of volunteer doctors, ministers, photographers, and attorneys who had the responsibility of following up the complaint.

Later on the Tavern Guild was created as a way to reunite all organizations. It insisted upon a fund-raising system in order to face some of the legal expenses of battling police harassment of the bars and their patrons.

Up until the late sixties an ever-growing "visibility and politicization" of homosexuality had supplanted the scientific discursive and apologetic forms thus far used by the homophile movement. A greater sense of affirmation emerged with an intensified unwillingness to "have to" justify oneself in front of a

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cultural hegemony that served specific interests. In fact, several bars were raided by the police (well before the Stonewall Riot) which resulted in the resistance of the patrons. In 1967, for example, in Los Angeles, an intense assault on gay bars by police resulted in a rally of several hundred people , "where they listened to angry speakers intoning the phrases of confrontational politics."[2]

The same year saw the creation of Homophile Leagues at Columbia and New York Universities. Still in 1967, Craig Rodwell opened Oscar Wilde's Memorial Bookshop in New York City, the first gay bookstore.

Finally, in 1968, the Reverend Troy Perry conducted the first Metropolitan Community Church (MCC) meeting in his Huntington Park in California. Perry established the Committee for Homosexual Law Reform in 1969 as MCC's political arm.

This was the long historical staging for the upcoming Stonewall, too often presented as a sudden explosion of gay and lesbian affirmation, when in fact the latter had taken a whole century to simmer.

Like many other dissatisfied groups, gays and lesbians were witnessing and participating in the more general politicization of society. They were even able to coalesce-to different degrees-with other progressive movements such as the Civil Rights, the women's or some left-oriented movements.

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[2]Barry D. Adams, *The Rise of a Gay and Lesbian Movement* , Boston: Twayne Publishers, p. 75, 1987.

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THE STONEWALL RIOT: A TURNING POINT

The day of Judy Garland's funerals, June 27, 1969, as the police set out to raid the Stonewall, a gay bar in New York City, patrons, among whom drag queens and butch lesbians, decided to fight back and not let themselves be arrested as usual. Although the police were successful in emptying the bar, they would not have expected that the crowd would respond so aggressively from outside; so aggressively that the police had to barricade themselves from inside the bar. The second night, what came to be wrongly called the Stonewall Riot, metamorphosed into an organized action, which many thought would turn the page of the oppression against gays and lesbians forever.

The Gay Liberation Front (GLF) was formed out of Stonewall. A name chosen in homage to the Vietnamese guerillas. It created the first community center on 4th street in New York City. In December 1969, the Gay Activist Alliance was founded.

The Gay and Lesbian community was divided among different issues in the 70's. GLF argued that gays and lesbians had to work in a larger framework including economic, racial and gender oppression. Instead the Gay Activist Alliance (GAA) put the defense of identity before anything else.

The GAA approach had been more successful at bringing rights to gays and lesbians (Altman, 1982), but the debate remained open and the community kept diversifying itself. Most of ACT UP's strategies had already been used by both GLF and GAA for which direct action was also central. Zaps, leafletting, demonstration, civil disobedience and deliberate arrests were commonly used by the two groups. For

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example in 1970, GAA activists zapped the weekly TV show of Lindsay, the then Mayor of New York City.

Division was not absent from the gay and lesbian community. Some groups acted like any lobby groups, others refused to use political institutions, thinking that the system was corrupt at its core. Gay activists were not immune to sexism. Many lesbian activists quit GAA to form Radicalesbians.

Kate Millett became chairperson of National Organization of Women in 1970. As she came out as a lesbian, many female activists started to identify more with the women's movement, than the male-dominated gay movement. In fact, in 1973, Now appointed a National Task Force on Sexuality and Lesbianism. Yet, later lesbians realized that NOW was not immune to homophobia either.

Even if the oppositions were strong, the questions, however, were then about forms of gay and lesbian cultures, and not their survival anymore.

The number of groups which emerged since Stonewall was quite impressive and included grass roots organizations such as the Firehouse Community Center (a Gay and Lesbian Community Center), Lesbian Liberation Committee, Lesbian Feminist Liberation, Gay and Lesbian Youth of New York, Street Transvestite Action Revolutionary (STAR), and The Radical Faeries; religious organizations such Dignity, Metropolitan Community Church or Beth Simcha; professional organizations such as Gay Bankers and The Lambda Legal Defense and Education Fund; political organizations such as the Stonewall Democratic Club or the National Gay and Lesbian Task Force.

A year to be remembered is 1973, when the National Gay Task

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Force successfully pressured the American Psychiatric Association to remove homosexuality from the category of mental disorders.

Since then, what had been covered or unspoken forms of culture turned into a pervasive outpouring of gay and lesbian books, plays, bookstores, conferences, but also businesses and politics. In fact the area where the Stonewall riot took place was officially identified as a gay and lesbian area.

On the lesbian side, the Salsa Soul Sisters, organization of lesbians of color, was founded in New York City in 1974. This was also the year of the birth of Lesbian Herstory Archives founded in New York City. A year later was the first Michigan Womyn's Music Festival. The Gay and Lesbian marches throughout the country kept on attracting more and more participants, gays, lesbians and otherwise.

Conservative attempts at abolishing gay and lesbian legitimacy were unsuccessful. Thus, Irving Bieber, Charles Socarides and Lionel Ovesey relentlessly clung to their thesis that homosexuality was a pathology at the Association for Psychoanalytic Medicine Conference. A demonstration, including pickets, shouting the speakers down, and sitting down in the lobby disrupted the whole conference.

Lesbian activists demonstrated against CBS studio for misrepresenting lesbian realities. But, the Anita Briant's *Save Our Children Campaign* was probably the most organized challenge to gay and lesbian rights. Homophobia rose so much during that campaign, that Robert Hillsborough, a gay man, was stabbed to death in San Francisco. His mother named Anita Bryant in subsequent civil suit.

In the wake of those events, Harvey Milk, first openly gay City Council, was assassinated. The very light sentence that his murderer

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obtained stirred the angriest response of the gay and lesbian communities nationwide.

Already afflicted by an epidemic of sexually transmitted diseases in the middle of the 70's, the community saw health as a central issue. The first Gay and Lesbian Health Conference was organized in 1978. And right after the rape of a male youth in 1979, the Hetrick-Martin Institute was created including many programs geared to helping the gay and lesbian youth of New York. Its most famous program is the Harvey-Milk School, which caters to gay and lesbian runaways and throwaways.

Thus, although AIDS hit the community very hard at a time when full and productive social participation could be realistically envisioned, the gay and lesbian community was nonetheless historically and logistically prepared to face another 'medicalization' onslaught. This is where a major difference between other disease-related movements, such as the cancer movement, and the AIDS movement can be politically situated.

In addition, the 1986 Bower versus Hardwick, whereby the Supreme Court upheld that sodomy was illegal, stirred a real uproar in the community. Up to ten thousand people rallied in Sheridan Square at the historic site of the Stonewall to voice their anger. People organize a sit-in at a major intersection, blocking traffic for five and half hours.

Another demonstration involving over five thousand lesbians and gay men occurred at Sheridan Square on the 4th of July, 1986. Major conflicts between the leadership of GLAAD and the community made some activists think that the community was ahead of the

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leadership. The latter was thought to be more concerned about respectability.[3]

Almost immediately afterward, members of GLAAD's direct action committee formed the Lavendar Hill Mob, which used the "Zap" tactics of Gay Activists Alliance. The Lavender Hill Mob will form the bridge between gay, lesbian and AIDS activism. Already in 1986, the community was prepared for mass direct action. In this sense, Larry Kramer's speech, which many viewed as the originator of the radical AIDS movement, was more a reflection of the community's hightened anger, than its inspiration.

Right before the birth of ACT UP, the gay and lesbian communities were out, angry and vocal. And this is the cement that will shape ACT UP.

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[3]Maxine Wolfe, PhD, *The AIDS Coalition to Unleash Power, New York; A Direct Action Political Model of Community Research For AIDS Prevention*, Greenwood, in Press.

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THE AIDS CULTURES

It was the existence of this openly gay and lesbian culture that made the community response to the AIDS epidemic possible. Gays and lesbians were able to construct a social and political identity. The advent of AIDS was perceived as a threat to the Gay and Lesbian community as a whole, and not simply to isolated individuals as would have been the case a little over two decades earlier. This perceived threat prompted not only the large mobilization of resources necessary to combat the epidemic at all levels but, most importantly, the ideological underpinnings of this response.

Although some argue that the response was somewhat slow (Shilts, 1988), it would not have been possible without the existence of such a culture. In addition, the struggle with the medical structure was not new to the Gay and Lesbian communities, who had been fighting their way through mental legitimacy or normalcy since the birth of scientific medicine and psychiatry.

Not only were there preexisting gay and lesbian cultures, but there was also a gay-and lesbian-based AIDS culture, which also predated and triggered the emergence of ACT UP. In 1981, the Gay Men's Health Crisis was the first -and is, to date, the largest service-oriented AIDS organization. First catering to the gay community, it quickly expanded to the straight population as the AIDS cases multiplied. It now services over 3,000 men, women and children living with AIDS, ARC or other AIDS-related conditions, their families and carepartners. Since they began nine years ago, over 10,000 people

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have reached out for their services-that is more than one-third of the 28,391 New Yorkers that have been diagnosed with AIDS to date. In addition, 2,000 volunteers have joined GMHC in the effort to provide services for persons with HIV disease.

After much struggling, GMHC became funded by the government yet for a small amount only. This amount was kept low upon the consistent pressure by Senator Jesse Helms. This partial financial dependency on the government placed some constraints on the organization, which decided to keep a low profile in order to maintain its financial status.

One year after GMHC was created, gay and lesbian physicians formed, under the close scrutiny of the medical establishment, the New York Physicians Association for Human Rights, to provide support for its constituency.

Years before ACT UP's birth, the concern about research and treatment were central in the activist community. Advocating holistic medicine, Health Education AIDS Liaison (HEAL) was a self-help organization. The members of this organization were very critical of conventional Western medicine and looked into holistic medicine as an alternative. They thus provided members with the latest information on holistic and alternative treatments stressing the fact that only individuals can make their choice of treatments.

In the early eighties, another health center catering to Persons With AIDS opened up: the Community Health Project (CHP). Still, CHP was the product of a merge of two clinics dating back to the 70's--the St Mark's Clinic and the Gay Men's Health Project--dealing with

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sexually transmitted diseases within the gay community. Today, CHP is divided into two branches: general medicine and HIV/AIDS clinic. CHP had one of the earliest support groups for women with HIV, including lesbians. The need to create gay and lesbian-specific health institutions, therefore, predated the AIDS epidemic. And the National Gay and Lesbian Health Conference gave the focus on gay and lesbian health national visibility.

Rock Hudson's death in 1984 mobilized the Hollywood community and in 1985 the American Foundation for AIDS Research (amFAR) was created by the joint effort of Dr. Mathilde Krim, Dr. Weiss and Elizabeth Taylor. It would become the largest funding source for scientific research, outside the federal government.

In order to ensure that PWAs be represented at all levels of the AIDS-related decision-making process, Michael Callen, a long time survivor, created, The Persons With AIDS Coalition (PWAC) in 1985. It offered a self-empowering space for Persons Living With AIDS (PLWAs) at a time when they were coerced into silence about their HIV diagnosis. At that time, there was an absence of economic support for PLWAs as well as a lack of laws to protect them against discrimination.

The Denver Principles was a manifesto created in 1983 by PLWAs and PLWArcs at the Second National AIDS Forum in Denver, where the National Association of People with AIDS was formed. The manifesto put forward self-empowerment and self-help among the AIDS communities in order to foster their active participation in the diverse AIDS-related policies. PWAC, inspired by the Denver Principles themselves based on ideas from the feminist-health

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movement, could challenge the label "victim," which implies defeat. According to PWAC's own wording, PLWAs are only occasionally "patients." The manifesto is a prefiguration of the upcoming AIDS movement:

> We condemn attempts to label us as "victim," which implies defeat, and we are only occasionally 'patients," which implies passivity, helplessness, and dependence upon the care of others. We are "people with AIDS."
>
> We recommend that health care professionals:
>
> 1. Who are gay, come out, especially to their patients who have AIDS.
> 2. Always clearly identify and discuss the theory they favor as to the cause of AIDS, since this bias affects the treatment and advice they give.
> 3. Get in touch with their feelings (fears, anxieties, hopes, etc.) about AIDS, and not simply deal with AIDS intellectually.
> 4. Take a thorough personal inventory and identify and examine their own agendas around AIDS.
> 5. Treat people with AIDS as whole people and address psychosocial issues as well as biophysical ones.

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6. Address the question of sexuality in people with AIDS specifically, sensitively, and with information about gay male sexuality in general and the sexuality of people with AIDS in particular.

We recommend that all people:

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us, separate us from our loved ones, our community, or our peers, since there is no evidence that AIDS can be spread by casual social contact.

2. Do not scapegoat people with AIDS, blame us for the epidemic, or generalize about our lifestyles.

We recommend that people with AIDS

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda, and to plan their own strategies.

2. Be involved at every level of AIDS decision making and specifically serve on the boards of directors of provider organizations.

3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

4. Substitute low-risk sexual behaviors for those that could endanger themselves or their partners, and we feel that people with AIDS have an ethical

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responsibility to inform their potential sexual partners of their health status.

People with AIDS have the right:

1. To as full and satisfying sexual and emotional lives as anyone else.
2. To quality medical treatment and quality social service provision, without discrimination in any form, including sexual orientation, gender, diagnosis, economic status, age, or race.
3. To full explanations of all medical procedures and risk, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment, and to make informed decision about their lives.
4. To privacy, to confidentiality of medical records, to human respect, and to choose who their significant others are.
5. To live and die in dignity.[1]

Looking back at history reveals how the PWAC was visionary and prophetic in its stand, since everything that is recommended in this manifesto has materialized.

PWAC now offers support groups to meet different needs, including a support group for mothers of PWAs, and one in Spanish

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[1]The Persons With AIDS Coalition, *The Denver Principle*, Unpublished Document, 1983.

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for Latinos, and even a meal program. A drop-in center, called the "Living Room," has been set up in case of emergency. Newsline, the Coalition's newsletter written by and for Persons with Living AIDS, is distributed to 60,000 individual worldwide. In addition, thousands of PLWAs access their AIDS Treatment Information Bureau by a call to their PWA-staffed Hotline. SIDAhora, a quarterly magazine of the PWAC targeting the Hispanic community has a global circulation of 12,000. Likewise, the "Sister-to-Sister" Project was established to provide support for women of color who have AIDS/HIV.

In April, 1991, PWAC began a joint venture with WBAIFM 99, a New York City public radio station, to produce a weekly hour long radio program called PWAC Radio Newsline to literally give voices to PWAs, as well as promote the programs of PWA.

Very early on in the epidemic, PLWA's realized that some drugs, such as AL 721, were commercialized abroad, while the foot-dragging approval procedures of the Food and Drug Administration made it very difficult for those drugs to be approved in the United States. PLWAs decided to travel. Yet the majority of them could not afford the exorbitant traveling expenses to obtain those drugs abroad. Michael Callen decided to found the PWA Health Group, to import drugs approved abroad and not yet approved in the United States. This was a major step in the self-empowering process of PWA's.

In 1987, the PWA Health Group distributed large quantities of AL721-a compound made from eggs that showed promising anti-HIV activity *in vitro* without side effects. AL 721 was already available on the underground market in the U.S., yet the price was $3,500 a

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kilogram, which most PWA's could not afford. In contrast, the PWA Health Group was able to provide the drug at $200 the kilogram.

An alternative option for PWA's was a home recipe, using soy instead of egg. This home recipe was distributed at PWA's meetings and through the Native, a gay newspaper. Yet PWA's were never sure that they were using the right dosage. The PWA Health Group remained the most reliable source of supply for most PWA's in this country.

The work of this organization was a major step in the self-empowering process of PWAs. To turn around the prohibitive legislation of the Food and Drug Administration (FDA), the component was sold as a food additive. In doing this, the PWA Health Group was following the steps of other buyers' clubs predating it by a few months.

In October of 1987, the demand soared so high that PWA Health Group decided to incorporate and became People With AIDS Working for Health, Inc., a not-for-profit corporation in New York State, with a volunteer board of directors, comprised of PWAs and their advocates. Thanks to the Gay Men's Health Crisis, People With AIDS Working for Health, inc. now has a small office space.

Created in November 1987, Body Positive has the same function as the PWA Coalition except that its clientele is much larger, since it includes all persons with HIV. Like the PWA Coalition, it publishes its own journal, Body Positive, which presents for many the clearest explanation on the latest drugs and treatments. It also features the

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experiences of many persons, at different stages of the syndrome, who are able to deal successfully with the disease.

Mounting anti-lesbian and gay media coverage of AIDS in 1986, especially upon the closing of bathhouses, prompted the emergence of the Gay and Lesbian Alliance Against Defamation (GLAAD). GLAAD quickly expanded its goals to include all negative media coverage of lesbians and gay men. In addition, the few individuals, who started it, became a self-appointed board and the organization ended up with a top-down structure, leaving little room for member input. Its tax exempt status and hierarchical organization caused the departure of many activists.

Starting as a methadone treatment group, the Association for Drug Abuse, Prevention and Treatment (ADAPT) began to street outreach with bleach kits when the AIDS epidemic started to erupt. Yet, pressure from the city prevented the group from continuing to distribute bleach kits.

The communities of color had their networks as well. The Hispanic AIDS Forum, born in 1985. It translated AIDS-related information for the Latino communities and made available a bilingual hotline. Since its creation, many programs have been implemented: Entre Ombres for gay and bisexual men; Women's Program in the South Bronx and West Harlem using photo theater techniques; and a program dealing with HIV infection and alcoholism.

With a broader target in mind, the Minority Task Force on AIDS was created to outreach to all communities defining themselves as of color: Black, Latino/a, Asian and Pacific Islanders and Native

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Americans. Volunteers go out to known places where men or women in need of AIDS information may be found. Distinct AIDS literatures exist based on personal identification of the individual targeted.

On the West Coast, AIDS organizations existed as early as 1982 with the creation of the Kaposi Sarcoma Foundation, the San Francisco AIDS Foundation and the Shanti Project, which are basically the equivalent of GMHC. In 1985, Project Inform was created to provide treatment information. Although it created almost an uproar in the AIDS community for pushing aggressively for testing, it was one of the first organizations to provide medical information, at a time when Persons with AIDS could find none. Project Inform has its own research center, but research is not its only activity. It predates ACT UP with regard to AIDS research and treatment activism.

One of the boldest initiative of the AIDS movement was the creation of the Community Research Initiative (CRI) in 1987. A group of physicians, frustrated by the slow pace of government and industry research came together to form the nation's first community-based AIDS research sites.

The Community Research Initiative, which later on will become the Community Research Initiative on AIDS (CRIA) is a non-profit community based AIDS research center dedicated to the exploration of new methods for treating HIV disease and its associated opportunistic diseases. In conjunction with people with HIV disease, primary-care physicians, and recognized leaders in clinical research and treatment of AIDS, CRIA conducts clinical research on experimental therapies for HIV-related diseases, as well as studies which may assist in the further

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understanding of HIV disease and treatment. It develops private funding for the study of scientifically promising therapies for HIV-related diseases when no sponsor will finance research.

One of the commonalities among these organizations was their inability to demonstrate publicly their discontent with the government's inaction vis a vis AIDS. Many of them would receive funding from the government, and felt tied by this financial dependence. Others were too overwhelmed by the amount of services they had to provide. Others still preferred to operate in silence.

Public disruption was precisely the major strategy decided upon by ACT UP. The new organization owed a lot to the long tradition of gay and lesbian street activism, (See Section on Gay and Lesbian Cultures) which was revived by the July 1986 Supreme Court decision upholding sodomy laws.

Furthermore, the Lavender Hill Mob created in 1986 had already prepared the activist ground for ACT UP. Most of the members of this small group were part of GLAAD, which they deserted over disagreement about the increasingly hierarchical structure of the organization and its unwillingness to confront various agencies around AIDS issues. The Mob's structure was grass-roots using direct participatory democracy. Most of ACT UP's tactics had already been used by the Mob. For example Mob activists took over Senator D' Amato's office to force him to take up the issue of AIDS. The Mob held meetings with high powered officials at the major health bureaucracies such as the National Health Institutes (NIH) and the Food and Drug

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Administration (FDA). Well before ACT UP, the Mob had "zapped"[1] Cardinal O' Connor for stripping the Archbishop Hunthsauwn of Seattle of his authority. Archbishop Hunthsauwn was long a friend of the gay and lesbian community. Likewise, Cardinal O' Connor had dismissed the noted theologian Reverend Charles Curran from his teaching position at Catholic University because of his liberal views on sexuality and abortion. For this reason, the Mob organized an action against the Cardinal at the Alfred E. Smith Memorial Dinner-supposedly, the most dignified and charitable event-at the Waldorf-Astoria Hotel. Three days after the Vatican called homosexuality "an intrinsic moral evil," the Mob assembled at St. Patrick's Cathedral for the Cardinal's 10 a.m. mass. "The Church Ordains Bigotry" read the posters. Nine members walked inside as the Cardinal O' Connor was performing his homily and ostentatiously walked out arm in arm. O' Connor was advised not to give communion that night. ACT UP was not the first organization to zap the *New York Times*.. The Mob had zapped the *New York Times* for its lack of fair coverage of the AIDS epidemic and its refusal to use the words "gay" and "lesbian." Before ACT UP, the Mobsters organized actions at the first conferences on AIDS. They appeared at the CDC Conference on Mandatory AIDS antibody testing, dressed as concentration camp prisoners, in stripped costumes emblazoned with a pink triangle. Their demand to the Centers for Disease Control (CDC) was "Test Drugs, Not People." They called for the immediate release of Ribavirin and AL 721. Ribavirin

[1]Zaps grew out of the Gay Activist Alliance. It is a very quickly organized action, which consists in confronting an official person(s), sometimes using some visuals.

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was imported from Mexico and could be bought at $250 a week. This action met with unprecedented success and the Lavender Hill Mob gave 20 press conferences during each of those two days.

Finally, the New York State Health Commissioner, David Axelrod, was also targeted by the Mob. On February, 20th, 1987, when he was testifying at a New York State Assembly hearing on AIDS, the State Health Commissioner was charged with endangering the lives of women by denying the fact of heterosexual transmission.

Quite reasonably, three events can be assumed to have precipitated the emergence of ACT UP:

1) Mob activists had already established a correlation between the lack of proper research agenda and the spread of the AIDS epidemic. AIDS research had to become a target for activism.

2) A few gay men upset by the lack of government action created in 1986 the "Silence=Death" Project, a poster which will become the emblem of ACT UP and will wield international impact.

3) A letter by Larry Kramer, a famous gay playwright, who openly condemned GMHC's apolitical activism. And on March, 10 of 1987 a speech by Kramer successfully mobilized the gay and lesbian community. Kramer criticized the FDA and urged the 250 people, who filled the Gay and Lesbian Community Services Center, that changes were to be effected soon otherwise: "Two thirds of us in this room will be dead in five years."

Because no resolution had been passed the first night, another event was scheduled on March, 12. This time 350 people showed up.

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At the end of this meeting, a Wall Street sit-in was scheduled for March 24, 1987 at 7:00 am.

And a few weeks later, a new organization was born: The AIDS Coalition to Unleash Power, better known as ACT UP.

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PROFITEERING IN THE ABSENCE OF NATIONAL HEALTHCARE

In addition to the preexisting AIDS and Gay, Lesbian and AIDS movements, the formation of ACT UP must be viewed in the context of the huge amount of profit, drug companies make in a country where many million people still do not have any form of insurance.

This pharmaceutical reign is maintained by the lack of regulation around drug prices and drug profit. U.S pharmaceuticals are the most profitable industry, as they account for the largest share of the market worldwide.

This high profitability allows drug companies to offer the highest dividends to their shareholders. At the same time, the average cost per prescription for established drugs increase twice the rate of inflation.

The pharmaceutical industry claim that this profit is due to their spending on research and development. It is the partial truth only, since drugmakers spend twice as much on marketing. For example, American Home products, which exhibited the poorest record of innovation in 1990, still earned a 46% return on equity. It ranked 16th on the Fortune 500, thanks to its marketing strategy.

The reality is that the drug industry develops a number of drug products that offer little or no therapeutic advance over those on the market. In 1991, according to the pharmaceutical industry's own data, drug manufacturers spent $1 billion more on marketing and advertising than on research and development. Total research and development expenditures was 9 billion dollars, and total sales and marketing expenditures was 10 billion dollars. Thus, for the average

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company, advertising and marketing expenditures equalled 25% of the sales, while research and development expenditures equalled 22%.

Furthermore, the pharmaceutical industry receives hundreds of millions of dollars in tax credits and subsidies for researching and developing new pharmaceutical products. They, in fact, claim 45% of all tax credits granted to U.S. industries.

New drugs commonly sell at wholesale prices three to six times what they cost to make. For example, Squibb' ACE inhibitor, used to treat high blood pressure, has an annual global sales of more than a billion dollars. Druggists might pay $300 for a years' supply that costs only $50 to produce. And a person on an antihypertensive stays on it the rest of his/her life.

To top it all, drug companies do not hesitate to offer special gifts to doctors willing to sell their drugs. This practice was even condemned by the American Medical Association.

It is no wonder that, in a context of total laxism, dug increases outpace three times the general price inflation.[1] Drug companies experience growth, while most other companies are harshly hit by the recession. The average Fortune 500 industry in the U.S. had an average profitability of 4.6% in 1990. Yet, the average profitability of the top 10 drug companies had more than tripled that amount: 15.5%.

It is in a similar context of profiteering that ACT UP, (which did not have a name yet) organized in March 1987 its first demonstration. The action took place at Wall Street to denounce the unethical costliness of AZT. Indeed, Burroughs-Wellcome, the producer, was

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[1]Bureau of Labor Statistics from July 1980 through July 1990.

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benefitting from the Orphan Drug Act of 1983, which applied to rare diseases affecting fewer than 200,000 persons. Companies, which research drugs to treat those diseases, are offered many advantages. They are offered facilities to test their drugs, tax abatements and a seven year drug monopoly on the drug as well.

In 1985, AZT, then the only antiviral, won Orphan Status and came to market in March 1987. At $10,000 for a year's supply, it was the most expensive drug ever developed. The National Gay Rights Advocates, a Washington-based lobby, sued Burroughs-Wellcome for collusion with the U.S. Government. The company had donated $55,000[2] to pay for extra staff to work with Sam Broder of the National Cancer Institute at the same time the company was seeking Orphan Drug status.

In 1987, the Wellcome Foundation's profits were 169 million pounds, most of which coming from Burroughs Wellcome. By August 1987, sales of Retrovir in the four months since its final U.S. approval as an AIDS drug, amounted to 16 million pounds. Since work on Retrovir began, the company's stock exchange valuation had quadrupled.

About the same time Burroughs Wellcome began work on AZT, the CDC asked Lyphomed Inc., a small generic drugmaker in Rosemont, Illinois, to manufacture another AIDS-related medication, aerosolized pentamidine. This drug was for the prevention of pneumocitis *carinii* pneumonia, the major killer of PWA's. The only

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[2]The information had been obtained through the Freedom of Information Act.

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other prophylaxis on the market was Bactrim, a compound to which at least 50% of PWA's were highly allergic.

Aerosolized Pentamidine won Orphan Drug status in late 1984 and its price was $300 a year. By the year 1988, Burroughs Wellcome earned the AZT patent until the year 2005. After ACT UP's Wall Street action, pentamidine started to increase fourfold to $1,200 a year, even though manufacturing costs had fallen significantly and sales had swollen in volume. Lyphomed explained to Congress that the increase was caused by marketing expenses. Yet Lyphomed did not have to give further evidence since drug companies are not legally obliged to open their books and disclose financial information about individual products. And the newer aerosol version would belong to Lyphomed until 1996.

In reaction to this profiteering, the PWA Health Group, for which many ACT UP members worked, was able to provide the drug at 80% less than its cost in the U.S. drugstores.

Finally, two other drugs were not marketed because of poor profit prospect. Before AZT was approved, AL721 was believed to inhibit the ability of the virus to continue infecting the human cells. It was a cheap and natural anti-viral made from substances as commonplace as egg yolk. Ethigen Corporation of Los Angels, which held the AL721 patent license, had applied for government approval to sell it as an AIDS treatment, but ultimately refused to market it. Since AL721 consisted entirely of processed normal food substances, it could have been sold as food supplement only. The economic consequence was low level of profit.

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Likewise, dextran sulfate, a cheap drug which had been widely used for 20 years in Japan for blood clotting problems was not researched for economic reasons. Drug companies were not interested in arranging international trials because there was no prospect of profit.

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WHO'S WHO IN ACT UP

A survey was distributed to members attending the general Monday meetings at the Lesbian and Gay Community Services Center in New York City during the last two weeks of June and the first two weeks of July 1989. The findings are then only reflective of this population at this specific time. Out of 450 surveys distributed, 413 were returned. Questions were grouped in three major categories: motivations that prompted individuals to join the group, past and present political involvement, and lessons learned from their experience in the group. (See Appendix for Survey)

The results revealed that the group was predominantly gay, white male between 26 and 35. Surveyed members were predominantly seronegative, highly educated, and part of the new middle class.

Although it gives a sense of the profile of the group, the survey would have to be conducted again to assess the rapid changes that occurred in the constituency of ACT UP since 1989. The survey included the following background variables:

Gender: the sample surveyed was predominantly male with 329 (79.7%) males and 80 (19.5%) females.[1]

Sexual identification: the sample surveyed was predominantly gay: 240 (58.1%) of the members (including 2 women) defined themselves as

[1]If figures do not add up to 413 or 100%, it is due to missing values.

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gay; 55 (13.3%) members (including 2 women) defined themselves as homosexual; 44 (10.6%) defined themselves as lesbian; 39 (.94%) bisexual and 21 (.51%) heterosexual. (See Graph I and II)

Age: the majority of members surveyed, 220 (53.3%) were between the ages of 26 and 35; 89 (21.5%) were between the ages of 36 and 45. Finally, 19 (3.1%) were older than 45.

Race: the respondents were predominantly white with 324 (78.5%) Caucasians; 23 (5.6%) Afro-Americans; and 10 (2.4%) Hispanics.

Religion (of birth): the respondents were predominantly Catholic with 134 (32.4%) Catholic members; 121 (29.3%) Protestants; 71 (17.2%) Jews, and 32 (7.7%) claiming no organized religion at all. However, of the same total of members, 201 (48.7%) claim having presently no religion preference; 97 (23.5%) claim having their own personal religion; 35 (8.5%) prefer Judaism and 27 (6.5%) Catholicism.

Education: 5% of the respondents had completed less than college level; 60% had had some college or were college graduates (BA or BS) and 35% had completed some graduate work or actually held a graduate degree (Masters or Phd).

Occupation: ACT UP members in this sample were predominantly constituted of professionals or artists: 100 (24.2%) were professionals; 84 (20.3%) were artists; 71 (17.2%) were white-collar non professionals.

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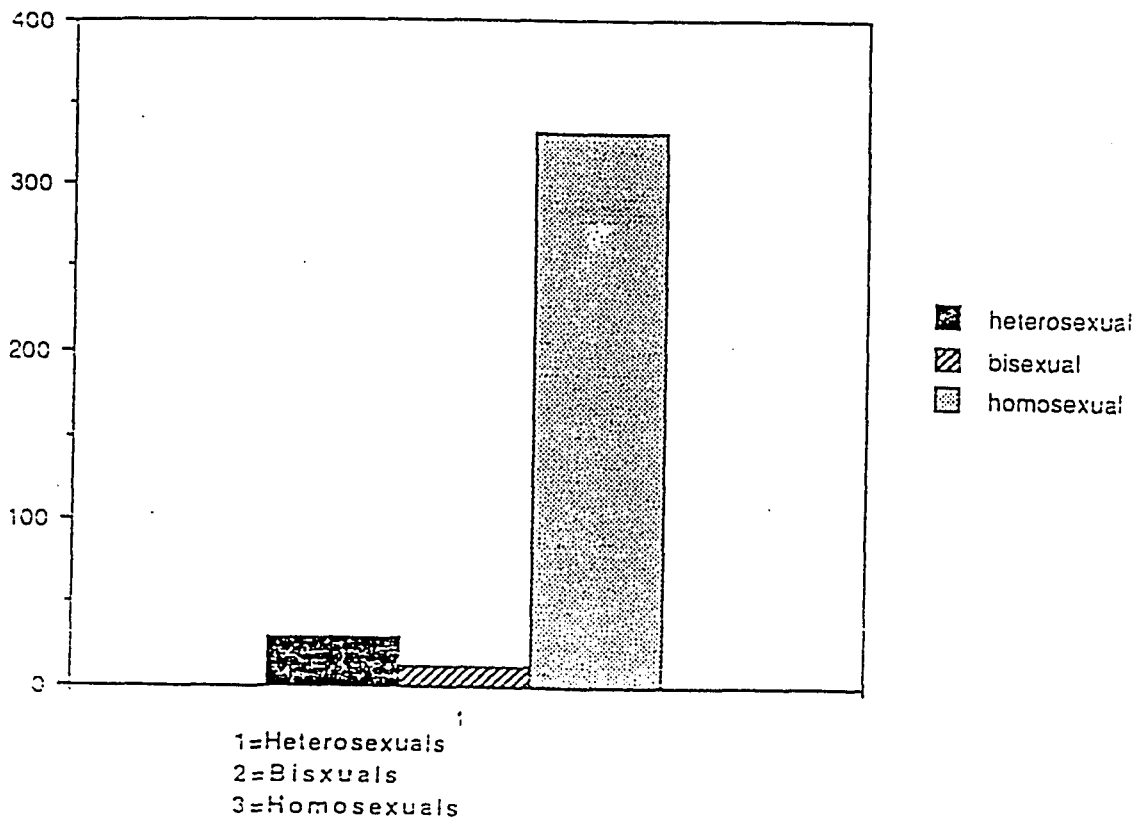
GRAPH I ACTUP Members' Sexual Orientation



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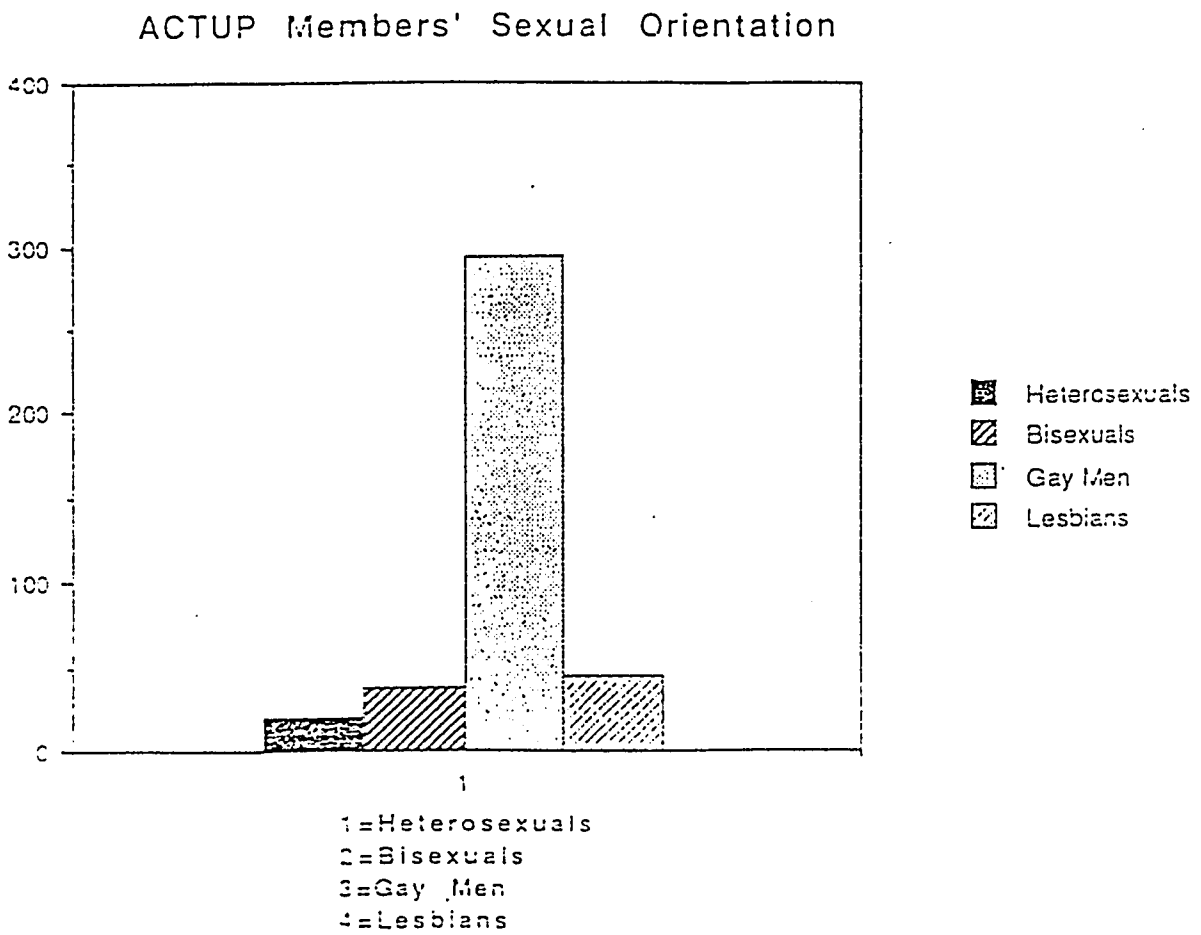
GRAPH III



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The rest was divided between 31 (7.5%) business (wo)men, 23 (5.6%) students, 21 (5.1%) health professionals, 12 (2.9%) service-oriented professions, and other fields in very small numbers.

Income: Although ACT UP members in this sample can be largely considered a middle-class organization with a quarter earning between $35,000 and $100,000 a year, 141 (22.8%), almost another quarter, earn between $0 and $25,000 a year; the rest, that is almost half the group, earns between $25,000 and $35,000 a year.

Time in the Organization: A the time of the survey, ACT UP had been in existence for two years and four months. 88 (21.3%) of the surveyed members had been in ACT UP for two weeks or less; 135 (32.7%) had been in the organization between one and twelve months; 120 (29.1%) had been in the organization between 13 and 24 months, and 52 (12.6%) had been members for more than 24 months.

Health Status: A the time of the survey, ACT UP did not have a consensus around testing issues. The group still does not have a consensus today. 225 (54.5%) of the surveyed members had been tested for HIV antibodies and 171 (41.4%) had not. The latter had indicated two major reasons for not being tested 1) they would rather not know their health status given the current state of health care, but would still take precautions as if they were seropositive; 2) they indicated not considering themselves at risk. Only 65.6% of the respondents answered the question about their seropositivity.

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80 (19.4%) members of the sample said they were seropositive, whereas 191 (46.2%) members said they were seronegative. Among the members in this sample 46 (11.1%) are HIV asymptomatic, 18 (4.4%) had ARC (AIDS-related complex) and 12 (2.9%) had full-blown AIDS.

Meeting Attendance: 302 (73.1%) of the respondents reported attending the Monday meeting regularly. 159 (38.5%) reported attending other meetings, mainly the Action Committee, Treatment and Data Committee, media Committee, PWA Housing Committee, and Women's Caucus meetings.

Electoral Participation: 341 (82.6%) surveyed members indicating voting during the last presidential election. 289(70%) voted for Dukakis.

Political Identification: 205 (49.6%) surveyed members identified themselves as Democrat; 76 (18.4%) as Independent, 45 (10.9%) as Socialist and 15 (3.6%) as Republican.

Attitude Toward The Government And Other Organizations: ACT UP members, who responded to the survey, tended to see the federal government as mainly responsible for the AIDS crisis and they favor coalition with other grass-roots organizations, unaffiliated to official political parties, such as the PWA coalition, ADAPT, but also GMHC (Gay Men's Health Crisis).

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MEASURING AIDS POLITICIZATION

The collection of data allowed for the assessment of the politicization process members go through while in the organization. Politicization was defined 1) by the members' participation in diverse activities such as voting, participating in legal demonstrations as well as civil disobedience actions which led to arrests; and 2) by their growing awareness that the AIDS crisis is not "just a medical problem," but one that affects most social areas and social groups, and thereby the very structure of society.

DATA ANALYSIS

Data analysis reveals an increase in the surveyed members' political involvement as a result of their experience in ACT UP. Before joining ACT UP, 53.5% of the surveyed members had participated in demonstrations and 7.8% of them had participated in civil disobedience leading to arrests.

After joining the organization, 71.8% of the respondents participated in demonstrations, and 29.6% of them had been arrested as part of civil disobedience actions, a fourfold increase. Since joining ACT UP, 64.1% of the respondents began supporting political struggles not related to AIDS, 55.2% of them contributed money to other causes, 36.5% lobbied (as opposed to 32% before joining), 50.4% demonstrated (as opposed to 53.5%), 13.7% participated in civil disobedience actions (as opposed to 16.7% before joining) and 7.3% were deliberately

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arrested for causes not related to AIDS (as opposed to 7.8% before joining), mainly feminist issues but statistics show that members are or were part of most of the progressive movements such as the Peace, Greens, and Anti-Vietnam war movements). (See Graph III)

To assess the overall effect of the organization on the politicization process of the surveyed members, a comparison was made between respondents' non-AIDS related past political actions with their present AIDS-related political actions. Data analysis shows that 27.8% of the respondents, who never were deliberately arrested before, decided to do so while in ACT UP; that 65.6% of those who had never demonstrated before, decided to participate in ACT UP's demonstrations; and that 23% of those who never voted before, decided to vote while in the organization.

In conclusion, after individuals become involved in ACT UP, their political activity increases in a variety of ways. On the most traditional level, more members will vote. But activity of a more radical nature, including street demonstrations and deliberate participation in civil disobedience also increases. For non-AIDS related causes, there is a slight decrease in the amount of demonstrations, civil disobedience actions and arrests. This can be explained by the large number of demonstrations and actions organized by ACT UP, preventing the members from being available for other mobilizations. The decrease, however, is not so great that the members have put aside their pre-AIDS activism. In fact, statistics show that AIDS activism has not affected the surveyed members' previous political involvement.

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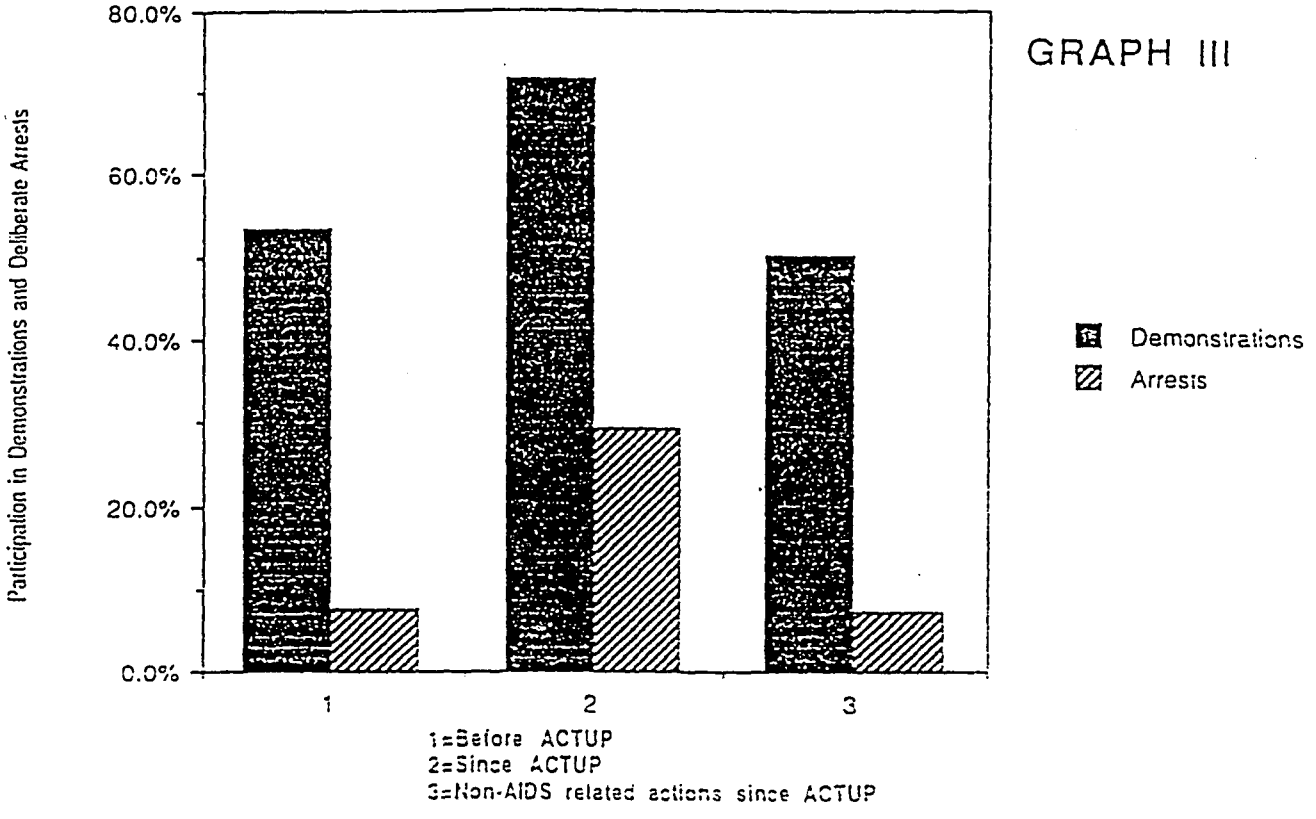
Participation in Demonstrations and Deliberate Arrests by ACTUP Members



GRAPH III

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A factor analysis of the motivation questions allowed for the construction of 10 indices of motivation, which brought individuals to ACT UP. The percentages that follow represent the rate of respondents who thought that the different concerns presented to them in the form of questions were significant enough to have motivated their joining ACT UP: 1) Fighting for the rights of PWAs (75.3%); 2) rights of lesbians and gays and PWAs (72.4%); 3) empower the community (48.9%); 4) help a cause (34.4%); 5) concern for sex-related issues (29.5%); 6) bonding (30%); 7) science (25.4%); 8) concern for politics and economics (13.8%); 9) concern for healthcare (13.6%); and 10) concern for oppressed groups (10.9%).

Among those ten indices, the first two, i.e. fighting for the rights of PWAs, and the rights of lesbians and gays, which are very similar, appear to reflect the reason the majority of respondents joined the organization: Crosstabulations by race, health status and gender failed to indicate any significant difference.

In turn, a factor analysis of the questions relating to what the individuals learned from their experience in the organization revealed an array of learning experiences. Nine indices were constructed measuring concern for: 1) science (58.6%); 2) sexual politics (55.9%); 3) politics (50.4%); 4) oppressed groups (50.1%); 5) medical drugs (33.2%); 6) gays and lesbians (28.3%); 7) more focus in the organization (24.2%); 8) rights of minorities and women (19.6%); 9) alienation in the organization (1%).

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A clear broadening of the surveyed members' consciousness (i.e. seeing the AIDS crisis not only as a medical problem, but also as a socio-political one) occurred after they joined the organization. For example "science" which was in the seventh position in the "motivation" set is catapulted to the first position in the "experience" set. "Sex related issues" is now in the second position, whereas it was in the fifth one in the motivation set. "Political concern" is now in the third position, and was in the eighth one in the motivation set. In addition, there does not seem to be any significant difference between male and female members, whether they are part of a minority group or not, and whether they are seropositive or not.

This broadening of consciousness is clearly related by the length of time the members have been in the organization. The longer they remain in the organization, the broader their consciousness is, and the more they are able to see the connection between the AIDS crisis and other issues. As with the previous case, there is no significant difference between male, female, minority, white, seropositive and seronegative members. For example, of surveyed members who have been in the organization for only three months, 68.9% agree that scientific concerns are essential to understanding the AIDS crisis. Of those who have been members for more than two years, 79.2% think that science is essential. Likewise, of surveyed members have been in the organization for only three months, 66.2% of them think that sexual politics is important to understand the AIDS crisis. In contrast, of those who have been in the organization for more than two years, 81% think that sexual politics is important. In fact most members, who

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were already somewhat open (out) about their sexuality before joining, become either more open or totally open about it during their stay in ACT UP.

IS THERE A DIFFERENCE BETWEEN MEN AND WOMEN WITH REGARD TO THEIR POLITICIZATION?

When genders are compared, 17.2% of the female respondents had participated in civil disobedience leading to arrests prior to joining ACT UP as opposed to 5.3% of the males. Before joining ACT UP, 67% of the female respondents had participated in demonstrations as opposed to 52.4% for their male counterparts. Finally, 63% of the females were voters prior to ACT UP as opposed to 73.1% of the male respondents. These statistics show that more of the women, who joined ACT UP, were already very politicized. They were ready to express their political conviction in radical ways such as participating in demonstrations or civil disobedience leading to arrests. This finding is in fact supported by in-depth interviews with ACT UP women, many of whom were involved in or informed by the feminist health movement and had already a long history of political involvement. Instead, to express their political views, more of the men engaged in traditional participation, such as voting.

After joining the organization, while women respondents increased their number of arrests by one and a quarter, men increased theirs by more than six-fold! Men reach the level of women with

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regard to the number of demonstrations attended while in ACT UP (76.7% versus 77.6%) and the number of arrests (29.9% versus 32.3%). Women, however, since the time they joined the organization, tend to vote even less than before (54.7% now versus 63.5% before) and definitely less than men (71.8%), more of whom seem to believe in the official political system. Women in ACT UP seem to express their "radicalness" by engaging in certain political activities, but also by refusing to engage in others. When it comes to non-AIDS political activities, women, once again, outdo men. More are arrested than men (10.6% versus 6.9%) and more participate in non-AIDS related demonstrations. (61.2% versus 50.2%) (See Graph IV)

In conclusion, women respondents were more radical than men when they joined ACT UP, and although male respondents increased their radical political activity up to the level of women, the latter remain more politically involved when it comes to actions non-specifically related to AIDS.

There is no difference between minority and white members with regard to the number of arrests and demonstration participation prior to joining ACT UP. There is a slight difference in their voting behavior for minorities tend to vote less.

Since the time they joined the organization, interestingly enough, minority and white members undergo a similar change. Six times more of them are arrested than before, and their demonstration participation also augments (64.3% for minorities and 77.5% for whites). Voting participation decreases in both groups, but remain

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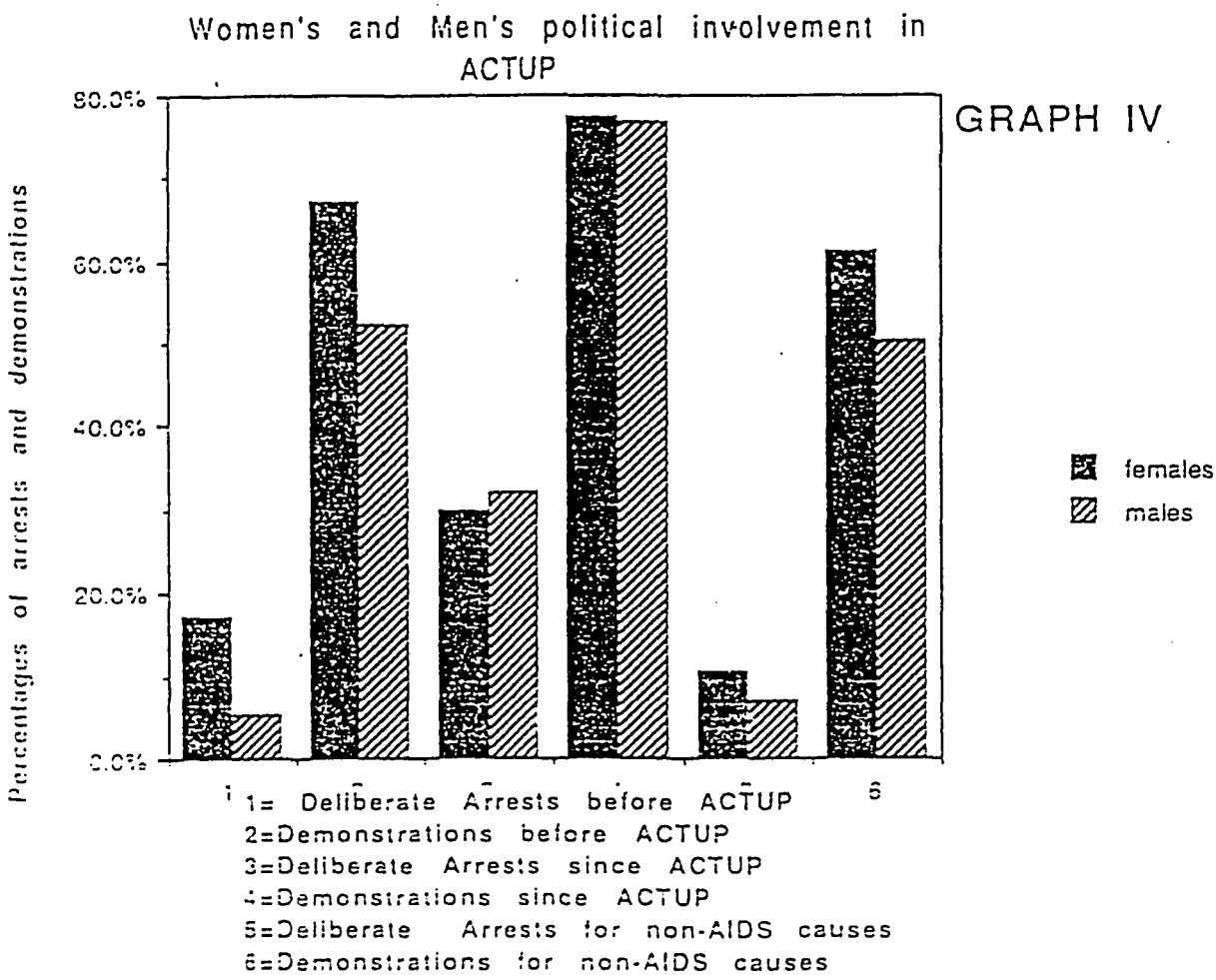

GRAPH IV

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higher among whites (51.2% versus 69.7%). More white members are arrested for non-AIDS related causes, but their demonstration participation for non-AIDS related events is similar to their minority counterpart. (See Graph V)

In conclusion there is hardly any difference between minority and white members before and after they joined the organization, and a slight one with regard to the number of arrests for non-related causes.

As strange as it may seem the surveyed members' health status does not make any difference in terms of their politicization process. (See Graph VI) The same percentage of people were arrested, demonstrated, and voted (with a slight difference: 69.6% for seropositive and 74.6% for seronegative) prior to their joining the organization. There is hardly any difference while they are in the organization. Their percentage of arrests is almost identical (31% seropositive versus 29.9% seronegative), slightly different for demonstration participation (72.5% for seropositive versus 78.5% for seronegative) as well as their voting behavior (69% for seropositive and 74.1% for seronegative). Their percentage of arrests for non-AIDS causes is strikingly the same and their demonstration participation for non-AIDS related causes is slightly different (46% versus 53.8%).

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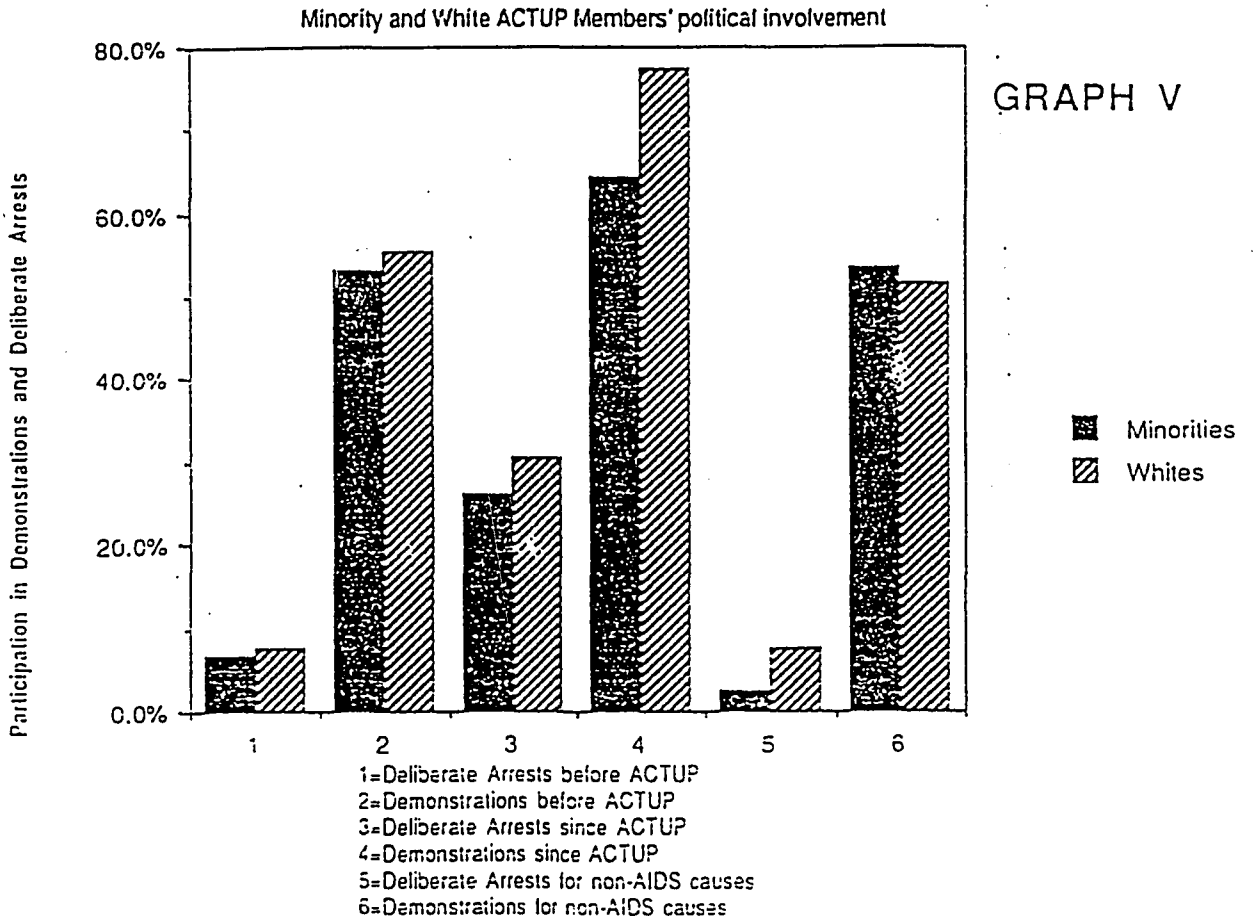

GRAPH V

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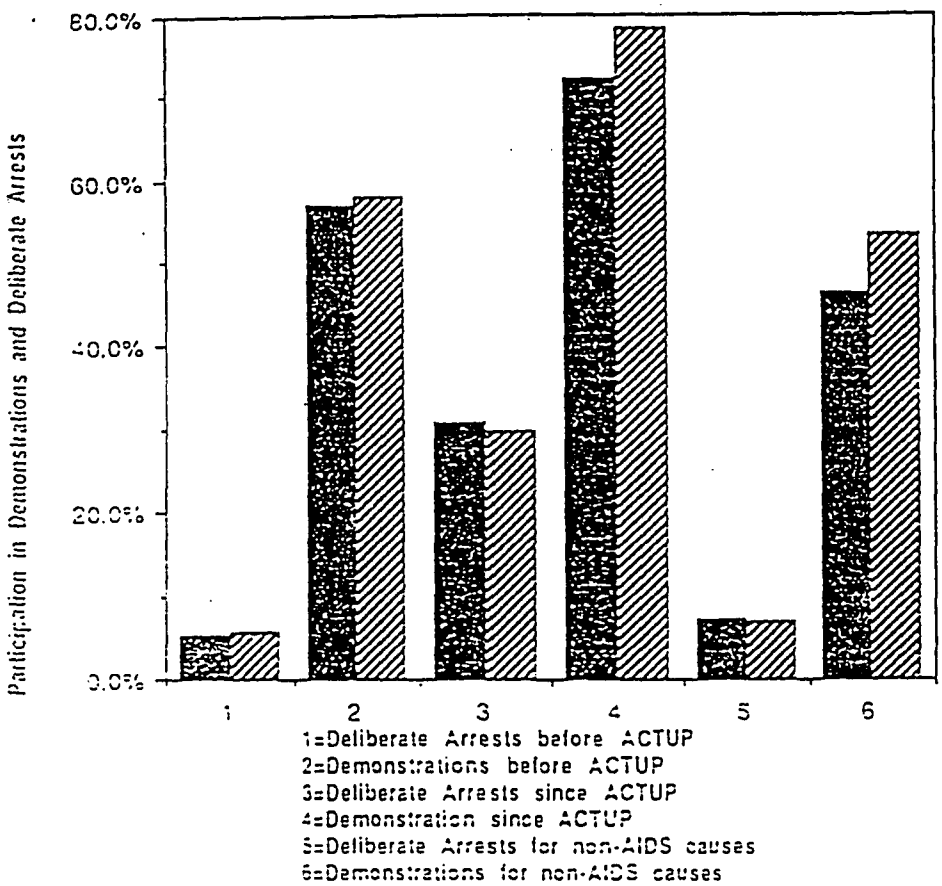
Participation in Demonstrations and Deliberate Arrests of Seropositive and Seronegative Members



GRAPH VI

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IN CONCLUSION THE PRESENT SURVEY HAS SHOWN THAT:

1) an increasing degree of politicization among AIDS activists has occurred through an increased volume of political activity and a change in attitude towards the AIDS crisis. The AIDS crisis is not only viewed as a medical problem affecting certain segments of the population, but also as a multidimensional problem affecting the very structure of society.

2) The surveyed members' present political involvement does not interfere with previous activism not related to AIDS.

3) Women in this sample were more politicized than men before joining the group, and while both of them have the same level of politicization in the organization, women are still more political than men with regard to non-AIDS causes.

4) The health status of members in this sample is not a variable that affects their politicization process within the organization, at least according to the way politicization is being defined in this study.

5) There is little difference between white and black members in this sample with regard to their political involvement in ACT UP.

Finally, the survey reveals that more than 50% of ACT UP members surveyed agreed that the organization dramatically changed

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their lives by being life-affirming, empowering and politicizing. Almost 90% of the members surveyed agreed that ACT UP should still exist in the event of a cure for AIDS, mainly to fight for gay and lesbian liberation, for a better health care system and human rights in general.

The present survey has measured, if not all of them, some of the items relating to the members' politicization process within ACT UP. The ensuing qualitative study provides a more in-depth view of the organization and its members. Together, they provide a basis for documenting the thesis of this research.

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STRUCTURE OF ACT UP

The structure of ACT UP flows from its stand vis-a-vis the AIDS crisis. No monolithic ideology dictates the politics of the group and the structure of the group facilitates direct action.

In order to avoid cumbersome procedural rules, a very simple Working Document has been written by ACT UP. Some positions are elected, (see figure 1) but in no way do they give elected members more rights or privileges .

FIGURE 1

ELECTED POSITIONS

Treasurer & Assistant Treasurer	Facilitators	Meeting Managers
Workspace Managers	At-Large Representatives	Coordinating Committee

Thus, Workspace and Meeting Managers as well as Treasurer and Assistant-Treasurer are elected, but their tasks are nothing more than logistical. The Coordinating Committee sets the agenda for the general meetings. This committee has a little more power because it can approve or deny projects that involve less than $1,000. Yet the Coordinating Committee operates by consensus, and if one person blocks the consensus, the issue must be resolved by the floor.

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Although the diverse committees (See Figure 2) are created by a vote from the membership, they do not have any power over the group. Nor are individual members bound to or by the committees. If an individual desires to raise money for ACT UP, for example, s/he does not have to contact the Fundraising Committee to do so.

FIGURE 2
ACT UP/NEW YORK COMMITTEES BY ALPHABETICAL ORDER

ALTERNATIVE AND HOLISTIC TREATMENT	CITY ACTION
COORDINATING COMMITTEE	FUNDRAISING
INSURANCE AND ACCESS	MAJORITY ACTION
MEDIA	NEEDLE EXCHANGE
OUTREACH	PWA HOUSING
SPANISH COMMUNICATION	TREATMENT AND DATA
WOMEN'S ACTION	YELL(YOUTH EDUCATION LIFE LINE)

What is important to remember is that committees do not follow, as in traditional organization, an ideology coming from the top.

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Each one is an autonomous structure and acts, at least this is the contention of this research, like an distinct social movement. Indeed all the major issues relating to the AIDS epidemic are addressed by those committees: biomedical research, holistic and alternative medicines, issues affecting persons of color as well as white women, homelessness, drug use, education, health care and city, state and federal politics.

If unsatisfied with the committee structure, individuals can form their own informal Working Group (see Figure 3) or Affinity Groups without the consent of the floor. Affinity groups have always been an important part of the self-empowering dynamic of ACT UP. They are the space where most of the work is done and bonds of solidarity created. In those informal groups, members learn to become full-fledged activists in a safe environment. They may ask questions which they might not feel at ease to ask during the sometimes intimidating and passionate general meetings. Another important function of Affinity Groups is the provision of a space where actions not necessarily approved of by the floor can take place. Thus, Surrender Dorothy, an Affinity Group set out to take over the office of Stephen Joseph who claimed that the number of AIDS cases were only half what they were in reality. This Affinity Group was deliberately arrested and eventually tried for property trespass.

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FIGURE 3

WORKING GROUPS BY ALPHABETICAL ORDER

THIS CHART IS CONSTANTLY SUBJECT TO CHANGE

ADAPT ACTION	ACT UP AGAINST THE NEW WORLD ORDER	CDC WORKING GROUP	DIVA TV	4TH ANNIVER-SARY ACTION	HEALTH CARE ACTION
HIV=AIDS?	MILLER BOYCOTT	ACT UP MOSCOW	NATIONAL LESBIAN CONFE-RENCE	ACT UP NETWORK LIAISON	POLICE VIOLENCE
PRISON ISSUES/ D.O.C.S. ACTIONS	STATE AND CITY ACTION	SYPHILIS WORKING GROUP	WOMEN AND AIDS BOOK GROUP		

Through the affinity groups, members, who are very shy, make the difficult transition to becoming participants or even initiators of actions. Some of the affinity group participants become, in record time, expert at analyzing and deciphering the maze of specific bureaucracies.

Not only instrumental to new comers, affinity groups allow older members to disengage themselves -- without leaving the

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organization -- from the sometimes constraining committee structure. One of the most successful actions of ACT UP was Day of Desperation in which thousands of individuals participated, organizing a myriad of actions throughout New York City. One affinity group, "The Affinity 500," jammed Grand Central Station in New York City during the evening rush hour. The main goal of Day of Desperation was to make New Yorkers and commuters realize that each day is a day of desperation for persons with HIV disease. ACT UP activists qualified this action as the most liberating because individual initiative was given full leeway.

More defined than affinity groups are caucuses (see figure 4), which, like affinity groups, do not need for their creation the approval of the membership. Typical of the caucuses is their closure to members who do not meet certain characteristics. Thus, there are caucuses for lesbians, persons with immune disorders, latinos/nas, and foreign nationals.

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FIGURE 4

ACT UP/NEW YORK CAUCUSES BY ALPHABETICAL ORDER. THIS CHART IS CONSTANTLY SUBJECT TO CHANGE

ADDICTS RIGHTS	ASIAN AND PACIFIC ISLANDERS	FOREIGN NATIONALS/ INS ISSUES	LATINO/A AIDS ACTIVISTS
LESBIAN CAUCUS	PISD (PEOPLE WITH IMMUNE SYSTEM DISORDERS)	ACT BLACK	

The very limited power of elected positions is at the heart of ACT UP's practice of direct democracy. Only the "floor" has real power to make policy or approve actions. In fact as Figure 5 reveals that if a project is voted down by the floor, members cannot go to the Coordinating Committee to have it approved.

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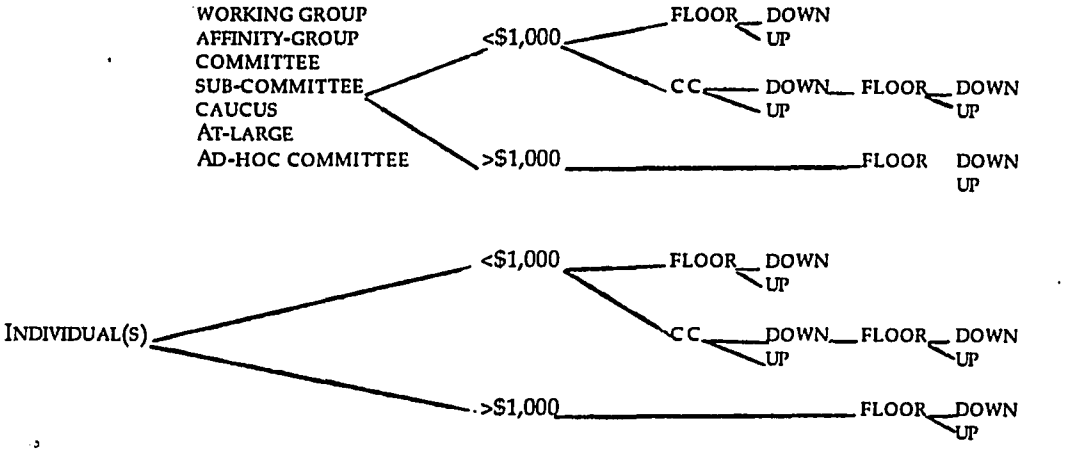
FIGURE 5
DEMOCRATIC PROCEDURE



The floor is represented by the 700 activists who used to meet at the Gay and Lesbian Community Services Center and now, by reason of growth, are meeting at the Great Hall of Cooper Union every Monday evening. To become an "ACT UP member," newcomers need to attend only three meetings, during which they are asked not to vote. Quickly enough, they realize that there is no "rite of passage" to become accepted by the group, just their participation in working groups or actions. Any work in ACT UP is volunteer, and everybody is judged according to the work done for the group. Not even professionals are given more prerogatives. They are as much at the service of the organization as the rest of the activists.

Meetings are run according to a loose version of Robert' s Rules of Order: loose because a literal application would reportedly take time that Persons With AIDS (PWAs), trapped in the urgency of the AIDS epidemic, cannot afford.

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AIDS RESEARCH REVISITED BY THE ACTIVISTS

In order to voice their anger and their frustration to the whole world, AIDS activists took over the stage during the opening session of the International AIDS Conference in Montreal in June 1989. Governments throughout the world had to understand that the AIDS crisis could not be resolved without the active input of the AIDS activists.

The Bill of Rights of Persons With AIDS based on the Denver Principles, among many other demands, required that:

> An international code of rights acknowledge and preserve the humanity of people with HIV disease. This code had to include:
>
> a) anti-discrimination legislation protecting the jobs, housing and access to services of people with HIV disease;
>
> b) active involvement of the affected communities of people with HIV disease in decision-making that may affect them;
>
> c) guaranteed access to approved and experimental drugs and treatments, and quality medical care;
>
> d) the right to anonymous and absolutely confidential HIV antibody testing. Pre-and post-test counselling had to be available;
>
> e) the right to medically appropriate housing;

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f) no restriction on the international movement and/or immigration of people with HIV disease;

g) full legal recognition of lesbian and gay relationships;

h) no mandatory testing under any circumstances;

i) no quarantine under any circumstances;

j) protection of the reproductive rights of women with HIV disease, including their right to freely choose the birth and spacing of their children and have the information and means to do so:

k) special attention to the unique problems and needs of intravenous drug users, including provision of substance-abuse treatment on demand;

l) special attention to the unique problems and needs of prisoners with HIV disease and guarantee that they receive the same standard of care and treatments as the general population;

m) the right to communication and all services concerning HIV disease in the language (written, signed or spoken) of his/her choice, through an interpreter if necessary;

n) the provision of reasonable accommodation in services and facilities for disabled people;

o) catastrophic/immunity rights-the

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> guaranteed right of people faced with a life-threatening illness to choose treatments they deem beneficial for themselves.[1]

Focal to the list of those demands was the refusal by activists to be treated like "helpless patients" as the Parsonian model traditionally describes them. Their *Treatment Agenda* distributed at the Montreal Conference also mandated the notion that AIDS activists had to be involved in all facets of the AIDS crisis, an idea already enacted by the Lavender Hill Mob.

Biomedical research was certainly not outside the purview of the activists' target. First moved by an urgent need to obtain treatment, the activists forced major changes in the field of science. Ironically, they were the last ones to expect to effect those changes.

When analyzing the research structure in this country, activists realized that several factors slowed the pace of research and access to treatment.

PARADIGMATIC MONOPOLY AND BUREAUCRATIC IRRATIONALITIES

Upon the discovery of HIV, the National Cancer Institute (NCI) competed against the National Institute of Allergy and Infectious Disease (NIAID) for AIDS research funding. While NCI was doing virological work, looking at the impact of the virus on the immune

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[1]ACT UP, *Bill of Rights of Persons With AIDS*, Unpublished Document, 1989.

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system, NIAID was researching opportunistic infections. Their tasks seemed to be well cut out at first. Yet both agencies were either paralyzed by their traditional functioning or lack of experience.

NCI had been one of the most financially endowed agencies in the early seventies, with Nixon's War on Cancer. Whether they produced results or not, NCI researchers were assured billions of dollars. They had successfully streamlined research procedures, making sure that most subjects would receive some form of treatment. However, their ideology was not attuned to the needs of PWAs. While in general researchers had relaxed their rigid position vis à vis the etiology of AIDS, the influential Robert Gallo would always start his speech at the world AIDS conferences with: "HIV is the cause of AIDS."

Since the discovery of the virus in 1983, the opportunistic infections, of which PWAs died, were of no research interest for federal researchers. In fact PWAs' healthcare was of no prime research interest for those researchers committed more to basic science. According to federal researchers, science progressed, even if they did not find a cure, and "this was what counted."

Thomas Kuhn had already explained this rigid attitude:

> The depreciation of historical fact is deeply and probably functionally ingrained in the ideology of the scientific profession, the same profession that places the highest of all values upon factual details of other sorts. The result is a persistent tendency to make the history of science look linear or cumulative, a tendency that even affects scientists

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looking back at their own research.[2]

The belief in the unitary character of science was (and is still)so strong that its historical construction would often be distorted to fit this belief:

> But Galileo said nothing of the sort. His discussion of falling bodies rarely alludes to forces, much less to a uniform gravitational force that causes bodies to fall. By crediting to Galileo the answer to a question that Galileo's paradigm did not permit to be asked, Newtons' account hides the effect of a small but revolutionary reformulation in the questions that scientists asked about motion as in the answers they felt able to accept. But it is just this sort of change in the formulation of questions and answers that accounts far more than novel empirical discoveries, for the transition from Aristotelian to Galilean and from Galilean to Newtonian dynamic. By disguising such changes, the textbook tendency to make the development of science linear hides a process that lies at the heart of the most significant episodes of scientific development.[3]

---

[2]Thomas S. Kuhn, *The Structure of Scientific Revolutions*, Second Edition, Enlarged. University of Chicago Press, p.138, 1970.
[3]Ibid p.140.

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The virologistic dominance of AIDS research led activists to qualify it as colonized by cancer-specific virology.

In turn, activists noted that NIAID was plagued with bureaucratic slowness and inconsistencies. For example, although it was more difficult for NIAID than NCI to obtain funds, it still managed to leave unspent 47 million dollars from its first appropriation.

A structural analysis by the activists made the slow pace of research obvious. The AIDS Clinical Trial Groups (ACTG's) were created in 1986, when the Reagan Administration finally decided to fund AIDS research for the first time. The ACTG's represented a cooperative clinical trials network established by the National Institute of Allergy and Infectious Diseases (NIAID) to evaluate promising therapies for use against the human immunodeficiency virus, the opportunistic infections and cancers that characterized AIDS. This network consisted of 47 AIDS Clinical Trials Units (ACTUs) located at universities and medical centers in 16 states and the District of Columbia.

The ACTG's were composed of six committees: 1) Primary Infection with a neurology subcommittee; 2) Pharmacology and Pharmacokinetics; 3) Biological Response Modifiers; 4) Opportunistic Infections; 5) Oncology, and 6) Pediatrics.

During the first five years, the Primary Infection Committee dominated the ACTG's. Its 36 trials enrolled 70% of all ACTG's research subjects. Only one drug came out of NIAID laboratories, AZT, with the strong support of Burroughs Wellcome. Although NCI relayed to NIAID several drugs, such as trimetrexate, tested *in vitro*,

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many of these drugs were still awaiting clinical experimentation.

Inconsistent with its mission to research infections, NIAID stuck to testing and retesting AZT, already licensed in early 1987. And of the 8 drugs approved for AIDS-related conditions since 1985, 7 were developed outside the ACTG's. (See Table 1) In turn, aerosolized pentamidine reviewed by the AIDS Clinical Drug Development Committee (ACDDC) as an agent that might prevent pneumocystis *carinii* pneumonia, was granted high priority. Still, it took over a year before the trial could begin because Anthony Fauci, Director of NIAID, claimed that he had one staff member missing. And during the thirteen months' wait, 16, 000 persons with AIDS died of PCP, to date PWAs' major killer.

A study in New York and San Francisco organized by the Community Research Initiative in New York and community-based research centers in San Francisco resulted in the record time FDA's approval of aerosolized pentamidine in June of 1989. Since that time, more than forty-five commmunity-based research centers sprang up throughout the U.S., including sites in Toronto, Puerto Rico and Hawaii.

An underground AIDS research movement was emerging as well. That same year compound Q, nickname for Trichoxanthin, a plant protein derived from the Chinese cucumber, showed some efficacy. It could selectively kill infected cells, and left alive healthy ones. Yet the FDA was taking forever to issue INDs, whereas patients could not wait. PWAs tried to obtain the drug from China, but in August 1989, the FDA ordered a ban on import of AIDS drugs from China.

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Compound Q was nevertheless made available on the street and was used irresponsibly. Six doctors, Project Inform, and a San Francisco-based group of activists decided to undertake an underground trial. Unfortunately, the result did not show that Q was a cure. What the activists wanted was a trial that was faster than the FDA's.

AZT: PRODUCT OF PARADIGMATIC MONOPOLY

In 1987 the AIDS Clinical Drug Development Committee (ACDDC) was created by Anthony Fauci. This committee would review candidate agents submitted by corporate sponsors or universities, and sort them as "high priorities," "medium priorities," "low priorities," or "not recommended for testing at this time." It included representatives from NIAID's Division of AIDS, the FDA, ACTG's, Committee chairs and ad hoc infectious disease specialists.

ACT UP 's *Critique of the AIDS Clinical Trial Groups*[4] demonstrated eloquently that this committee had been very arbitrary at selecting agents to be studied. (See Table 1) Indeed, many of the members were virologists, who embraced the "magic bullet" approach. And AZT, product of this ideology, was released in record time. First synthesized in 1964, NCI discovered its antiviral activity against HIV in 1984. It took only 2 years and one month from the discovery that AZT was active against HIV for the drug to be approved for marketing. And this, despite revelation that Burroughs Wellcome lost track of over a

[4]ACT UP, *A Critique of the AIDS Clinical Trials Group*, ACT UP, Unpublished Document, 1990.

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TABLE 1: DRUGS WORTH TESTING IN 1985: STATUS IN 1990

Agents believed "promising" in 1985	Tested by ACTG?	Outcome
Suramin	No	Too toxic; NCI is looking into suramin analogues.
AZT	Yes	Approved on basis of corporate study; then studied exhaustively in 50 ACTG trials.
Ribavirin	Yes	Doesn't work.
Alpha interferon	Yes	"A drug in search of a disease," IFN-alpha finally showed activity vs 1) KS in a subset of persons with high CD4 cell levels; 2) genital warts; 3) hairy cell leukemia; 4) hepatitis C.
HPA-23	No	Shown ineffective in France.
Foscarnet	Yes	ACTG anti-HIV trials results unknown; still unapproved.
Monoclonal antibodies	No	No known progress.
Interleukin-2	Yes	Led to infections in 1 study; still in 6 NIH trials; NIAID's favorite (and virtually only) potential immunomodulator.
Gamma interferon	Yes	Tested in 1985; didn't work; still being tested.
Isoprinosine	No	Unimpressive results, still in wide trials in Canada and Australia.
Thymopentin	No	Still in trials elsewhere.
Trimetrexate	Yes	Effective drug discovered at NCI; 5 years later it's languishing in ACTG trials so slow sponsor Warner-Lambert may be losing interest.
DHPG (BW 759)	Yes	Battle between sponsors (Syntex vs. Burroughs-Wellcome; Syntex "won" but in the meantime conducted no controlled trials); FDA rejected in 1987, approved in 1989, though no controlled trials were completed. Now finally being tested orally.
Ansamycin (LM427)	No	Lab anti-HIV activity contradicted in vivo. NIH never studied it; CDC distributed on Compassionate Use until FDA mandated more trials; will now be tested in community-based network.
Imuthiol	No	French study intriguing; ACTG interest minimal; FDA dismissive

courtesy: Mark Harrington's Critique of the ACTG's Unpublished Document.

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thousand (nearly 1/4th) of its compassionate release of AZT trial subjects.[5]

In order to understand why virology held such a prestigious place, it is necessary to step back in the history of medicine. Both sciences, virology and immunology, were born in the nineteenth century in the wake of the professionalization of medicine. With Pasteurs' germ theory, the face of medicine changed drastically.

Ever after this "medical breakthrough," medical researchers entered the "magic bullet" race to find a specific cure for each disease. The discovery of Penicillin in the 20's further reinforced this conception.

Kuhns explained that what characterized a paradigm is not its epistemological comprehensiveness, but a certain way of looking at the world:

> One of the things a scientific community acquires with a paradigm is a criterion for choosing problems that, while the paradigm is taken for granted, can be assumed to have solutions. To a great extent these are the only problems that the community will admit as scientific or encourage its members to undertake. Other problems, including many that had previously been standard, are rejected as metaphysical, as the concern of another discipline, or sometimes as just too problematic to be worth the time. A paradigm can, for that matter,

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[5]John Lauritsen, *Poison by Prescription: the AZT Story.*, New York: Asklepios, 1990.

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> even insulate the community from those socially important problems that are not deducible to the puzzle form, because they cannot be stated in terms of the conceptual and instrumental tools the paradigm supplies.[6]

Applied to AIDS research, this "magic bullet" paradigm implied that many of the principal investigators, who sat in the ACDDC, believed that HIV was the cause of AIDS. This explained their undivided attention on studying the virus.

Activists criticized this narrow virologic position. In their *San Francisco Research Agenda,* ACT UP noted that Joseph Sonnabend observed in 1982 the unusual presence of circulation of alpha interferon in the blood of persons with AIDS. He then proposed that alpha interferon might be a viral cofactor precipitating the activity of HIV, leading to AIDS.

Cindy Patton culturally framed the paradigmatic competition between virology and immunology:

> Immunology came to public attention in the 1960, at a time when holistic models of health were re-emerging in the U.S. The idea of a delicately balanced internal ecology nicely mirrored the growing perception of the human being precariously perched in world ecology.

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[6]Thomas S. Kuhn, *The Structure of Scientific Revolutions,* Second Editions, Enlarged, University of Chicago Press, p.37, 1970.

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> Immunology met the cultural needs of an "America" fascinated by a return to homeopathic ideas, but unwilling to abandon the miracles of modern medical technology. Moreover, immunology has radical implications for popular understanding of the body. The bacteriological body had been static before and after the assault by the germs; the endocrinological body ran hot and cold, oily and dry, not coincidentally (in the first anxious post-war years when endocrinology briefly had its heyday) maping the gendered tropes of emotionality. The immunological body was more gracefully fluid and fragile, like a dancer in a delicately balanced environment in which it was placed almost without boundaries.[7]

This paradigmatic monopoly in AIDS research fostered activists' awareness that science was not a unitary field but an arena of conflicts, analogous to the political arena. Each paradigm group purported to prove that its definition of reality was the "true" one, and waged costly fights to impose its "unifying or unitary concept." Through this awareness, the need for self-representation became focal to the activists.

Kuhn had already described the non-scientific ingredients which were also part of the scientific process:

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[7]Cindy Patton, *Inventing AIDS*, Routledge, New York and London: 1990.

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> We shall note for example, in Section II, that the early developmental stages of most sciences have been characterized by continual competition between a number of distinct views of nature, each partially derived from and all roughly compatible with the dictates of scientific observation and method. What differentiated these various schools was not one another's failure of method-they were all "scientific"-but what we shall come to call their incommensurable ways of seeing the world and of practicing science in it. Observation and experience can and must drastically restrict the range of admissible scientific belief, else there would be no science. But they cannot alone determine a particular body of such belief. An apparently arbitrary element, compounded of personal and historical accident is always a formative ingredient of the beliefs espoused by a given scientific community at a given time.[8]

Indeed:

> No period between remote antiquity and the end of the seventeenth century exhibited a single generally accepted view about the nature of light. Instead, there were a number of competing schools and subschools, most of them espousing one

[8]Thomas S. Kuhn,*The Structure of Scientific Revolutions*, Second Edition, Enlarged, University of Chicago Press, p. 11, 1970.

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> variant of Epicurean, Aristotelian, or Platonic theory.[9]

The issue for activists was not to ban research on nucleoside analogues altogether. The issue was to allow all perspectives to be heard and to be given a chance to be researched. In this regard, neurologists doing research on AIDS were very frustrated. Candace Pert from the National Institute of Mental Health, one of the inventors of Peptide T, could not get any funding to do clinical trials, reportedly because the drug did not come from the murals of NIAID or NCI. She was also perceived as being too holistically oriented. The work of activists then was also to empower researchers to do AIDS research, using a different paradigm.

ALL THE MEANS ARE GOOD TO SUSTAIN THIS MONOPOLY: CONFLICT OF INTEREST

Not only did the principal investigators hold those "magic bullet" ideologies, but they also represented pharmaceuticals' interests. Economically too, the magic bullet approach was more profitable. Indeed if a cure was found tomorrow by way of a drug, an estimated ten million people worldwide would be immediate consumers.

In order to back up their contention that principle investigators were guilty of conflicting interest, activists analyzed the structure of the relationship between principal investigators sitting on the ACTG's

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[9]Ibid p.12.

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committees and their consultative arrangements with private pharmaceuticals. (See Tables 2 and 3)

Interlockings between private drug companies were so egregious that the ACTG's conceived to be an alternative to the private research sector had really become an integral part of it. In fact some NIH officials themselves started to oppose conflict of interests by demanding that principal investigators not hold stocks in companies with which they had consultative arrangements. Here was the response of Martin Hirsh, one of the PIs of the ACTG's:

> Nearly all the ACTG's principal investigators have some industrial consultative arrangements. Such consultations facilitate, rather than impede, proper conduct of ACTG's trials by serving as a channel for communication and concerns for both industry and government.[10]

Thus the ACTG's were controlled by a minority of principal investigators, nicknamed by ACT UP the "gang of five," who were also sponsored by pharmaceutical companies. The principal investigators sitting on the Executive and the Primary Infection Committee controlled 22 trials or 60% of all the subjects under trial.

The emphasis on AZT and other antiviral nucleoside analogues caused the AIDS Program to deliver therapy to fewer than 5% of the cumulative total number of U.S. AIDS cases to date.

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[10]Anthony S. Fauci, MD, *AIDS Update* 2:24, 12.25.89, p.1 in *Critique of the ACTG*, ACT UP, 1990.

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TABLE II CONFLICT OF INTEREST, COURTESY OF MARK HARRINGTON IN CRITIQUE OF ACTG, UNPUBLISHED DOCUMENT.

Members of EC and Core PI Committees

Larry Corey, Chair, EC, Seattle
Margaret Fischl, U. Miami
Martin Hirsch, Harvard •
Stephen Lagakos, Harvard
Paul Volberding, UCSF

Executive Committee

Gerald Medoff, Wash U
Maureen W. Myers, NIAID •
John P. Phair, Northwestern
W. Kenneth Poole, RTI
Ruy Soeiro, Einstein
Catherine Wilfert, Duke •

Primary Infection Core Cmte.

Thomas Merigan, Chair, Stanford •
Douglas Richman, Vice Chair, UCSD
Paul Benninger, FDA
Sarah H. Cheeseman, U Mass Worcester
David J. Gocke, RWJohnson
John M. Leedom, USC
Donna Mildvan, Beth Israel
Carla Petinelli, NIAID
Peggy Weintrub, UCSF

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TABLE III

: TRIALS LED BY MEMBERS OF EXECUTIVE & PRIMARY INFECTION COMMITTEES[135]

PI	ACTG #	Drug(s)	Sponsor(s)	N/target[137]	%
Corey	010	AZT + Acyclovir	B-W	68/ 72	94%
	025	TNF + IFN-gamma	Genentech	25/ 30	83%
	063	AZT vs. AZT/ACV	B-W	65/ 600	11%
	121	CD4-IgG	Genentech	13/ 25	52%
Fischl	002	AZT hi vs lo	B-W	574/ 482	119%
	006	Adriamycin for KS	Adria	52/ 48	108%
	013	AZT + Alpha-IFN for KS	B-W	56/ 56	100%
	016	AZT in early ARC	B-W	714/ 538	133%
	106	AZT + ddC	B-W; H-L	39 / 48	81%
	116	ddI vs. AZT, AZT naive	B-W; B-M	279/1500	19%
	119	ddC vs. AZT on I-term AZT	B-W; H-L	0/ 320	0%
Hirsch	063	AZT vs. AZT/ACV	B-W	65/ 500	11%
	100	N-Butyl-DNJ	Searle	17/ 48	35%
Volberding	019	AZT in asx	B-W	3207/3200	100%
	117	ddI vs AZT on AZT	B-W; B-M	126/ 750	17%

Protocols headed by the Chair and Vice Chair of the Primary Infection Committee:

Merigan	012	ddC dose-ranging	H-L	61/ 64	95%
	024	IL-2 + AZT	B-W, Cetus	11/ 20	55%
	036	AZT/hemophilia	B-W	194/ 538	36%
	047	AZT vs. ddC vs. AZT/ddC	B-W, H-L	131/ 112	117%
Richman	004	AZT + DHPG	B-W, Syntex	41/ 60	68%
	007	AZT + Desciclovir	B-W	Withdrawn	
	016	AZT - early ARC	B-W	713/ 538	133%
	050	ddC alt. w/ AZT	B-W, H-L	110/ 96	115%
	106	AZT + ddC	B-W, H-L	39/ 48	81%
	112	AZT vs. ddC	B-W, H-L	18/ 120	15%
	117	ddI vs. AZT on I-term AZT	B-W, B-M	126/ 750	17%
	122	FIAC for CMV	Oclassen	4/ 78	5%

[B-W = Burroughs-Wellcome; H-L = Hoffman-LaRoche; B-M = Bristol-Myers.]

22 trials have PIs who sit on both the Executive and the Primary Infection Committees, or who are chair or vice-chair of the PI Committee. These 22 trials account for 5,818 of the ACTG's total 9,505 subjects (61%). They have accrued 66% of their target 8,805 accrual. This figure would be higher were it not for the unfilled totals of the new large ddC and ddI trials.

Courtesy: Mark Harrington's Critique of the ACTG's. Unpublished Document

[135] NIAID AIDS Program Protocol Overview, 10.13.89, pp. 1-12.

[137] Data from CTAAG, 2.2.90; total ACTG accrual = 9,505.

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Filled with a cynical irony, activists developed the prototype of a concept sheet that would in all likelihood be approved by the ACDDC. (See Table 4)

THE COMMUNALIZATION OF AIDS RESEARCH FROM TREATMENT TO EPISTEMOLOGY: PARALLEL TRACK

The criticisms levelled by the activists at the FDA were directed at the principal investigators who designed placebo-controlled experiments. For a long time such experiments had been criticized not only on humane grounds but on scientific ones as well:

> Even when the controlled trial does show a significant difference between new drug and placebo, we may know very little about what the drug will do in the real world, since the very factors that increase the discriminatory power of a trial (homogeneous population, control, drug intake, etc.) are those that do not generally obtain in ordinary medical practice. It is for this reason that I have sometimes urged "naturalist" studies as complement to controlled trials, in order to delineate more accurately a drug's true potential for good and harm in the universe of relevant patient candidates.[11]

[11]Louis Lasagna, M.D. *Placebos and Controlled Trials Under Attack*, European Journal of Clinical Pharmacology 15, 1979.

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-TABLE IV

TABLE A: HOW TO GET YOUR CONCEPT SHEET APPROVED AS A PRIORITY ACTG PROTOCOL:

1. **Have a seat on (choose one):**

   A. The ACTG Executive Committee
   B. The ACTG Primary Infection Committee
   C. The AIDS Clinical Drug Development Committee
   D. Any combination of the above

   [Hirsch sits on all 3 of these priority setting committees; Merigan and Corey sit on 2.]

2. **Have a background in:**

   A. Interferon trials
   B. Acyclovir trials
   C. Zidovudine trials

3. **Take a drug from list A or a drug from List B, or combine drugs from Lists A or B:**[139]

List A	Sponsor	List B	Sponsor[140]
AZT	B-W	IFN-alpha	B-W
ACV	B-W	IFN-alpha	Hoffman-LaRoche
ddC	H-L	IFN-alpha	Schering-Plough
ddI	B-M	IFN-beta	Triton
		IFN-gamma	Genentech[141]
		TNF	Genentech
		rsCD4	Biogen
		rsCD4	Genentech
		CD4-IgG	Genentech

4. **Mix them up however you please - in alternation, side-by-side, or compared against each other.** It doesn't matter which way you cut it, because any combination will benefit the sponsors, the "Program" - and you! - thanks to "consultative arrangements," "peer review" and the wonder of "investigator-initiated research!

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[139] List A is composed of nucleoside analogues. List B is composed of interferons or other recombinant human cytokines and other genetically-engineered substances.]

[140] At least 19 of the 31 trials slated for approval by the end of 1990 use agents made by the listed sponsors. EC Notes of 1.22.90 + 2.14.90.

[141] Hoffman-LaRoche recently purchased Genentech, drawing even tighter the circle of sponsors preferred by the ACTG.

Courtesy: Mark Harrington's Critique of the ACTG's. Unpublished Document.

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Exacerbating the rigidity of placebo-controlled designs, very strict entrance criteria, activists complained, were plaguing AIDS research and deterring thousands of PWAs from receiving therapies. In addition, subjects developing opportunistic infections were dropped from the studies.

As an alternative to placebo-controlled experiments and rigid entrance criteria, Parallel Track was proposed by ACT UP in 1988. It was a result of the very slow release process of the drug DHPG, used to treat blindness-causing cytomegalovirus, an infection occurring in 50-90% of PWAs (See Section on FDA.)

The concept of Parallel Track was simple: to allow subjects, who did not fit the entrance criteria to a drug protocol, to obtain the drug through expanded access, but without the usual bureaucratic and foot-dragging paper work. ACT UP proposed that data be drawn from Parallel Track so that the way the drug works in the real world could be more easily known. At first the concept caused much opposition from the research community, but then it was endorsed by Anthony Fauci, director of the National Institute of Allergic and Infectious Diseases, 20 AIDS groups and the FDA Anti-Viral Drugs Advisory Committee on August 17, 1989. Further, the National AIDS Program Office (NAPO) convened a task force, including members of ACT UP and Project Inform, to draw up detailed recommendations. Although expanded access had been forced on the pharmaceuticals, Parallel Track as conceptualized by ACT UP remained to be implemented.

The case of ddI was the closest a drug protocol came to Parallel Track. This drug was studied using data resulting from expanded access to the drug as well as formal trials. Until 1991, 20,000 individuals

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received ddI, more than any other AIDS-related expanded access program. In addition, it only took two years for the drug to obtain approval from the concept sheet.

ACCRUAL ISSUES

The first worry of the investigators was that expanded access might jeopardize accrual to the formal trials. Indeed Gina Kolata's 11/23/89 *New York Times* article publicized the hostility that arose around Parallel Track. On front page of the New York Times, she wrote an article--*Innovative AIDS drug Plan May Be Undermining Testing*--in which she asserted that Parallel Track threatened the entire clinical trial system. Kolata said that twenty times as many people were rushing to obtain ddI in the two new expanded access programs as in the three regular clinical trials of the drug. Kolata's major references however were principal investigators well known to be against Parallel Track.

In another article--*Odd Surge in Deaths Found in Those Taking AIDS Drug*--Kolata aimed at demonstrating that ten times as many people taking ddI in the Parallel Track trials were dying as compared to those PWAs taking the same drug in the regular clinical trials. Kolata argued that 300 people were dead because of Parallel Track. She did not understand that only those who did not qualify for the regular drug trials could benefit from Parallel Track trials. If those patients died, activists argued, it was because they were sicker to begin with. Of all the PWAs considered, 60% did not fit the criteria of clinical trials and 30% live too far away.

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To believe that Parallel Track was the cause for regular trials' lack of accrual was hiding the real issue, activists argued. Dr. Iris Long, a member of ACT UP, and founder of ATR, one of its spin-offs, studied for about three years enrollment at the various AIDS Clinical Trials Groups (ACTG's) at the national and state levels.

During its existence, the AIDS Treatment Resource (ATR now defunct for financial reasons) was engaged in several projects designed to make an impact on the enrollment problem in:

> 1) locating and collecting data on all government and drug company sponsored AIDS-related drug trials underway in the New York Area;
> 2) establishing a computerized database containing the most current and comprehensive information available on these trials;
> 3) disseminating this information in readily understandable printed reports and via on-line computer link to all persons who needed it;
> 4) developing education materials for assisting participants in making better informed decisions regarding enrollments in clinical trials.[12]

Iris Long's report led to one of the major ACT UP actions in 1987 at Sloan-Kettering Hospital, which had the worst record of enrollment of all the AIDS Clinical Trials Units (ACTUs). In her report, Iris Long

[12]ATR Report, Unpublished Document, 1987.

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demonstrated that the 32 ACTG's trials and 26 non ACTG's trials conducted by private companies were interested in four different axes of research:

> 1) The main axis of state or privately sponsored research were anti-retroviral drugs, which, as the name indicates, attack the retrovirus, such as AZT.
> 2) The second axis of research concerned AZT toxicity or the dosage tolerable by the subjects.
> 3) The third axis of research are opportunistic infections (OIs), to which persons with HIV may be exposed. This type of research focused on the prophylaxis and treatment of those infections.
> 4) The last axis of research was cancer treatment, clearly associated with AIDS research since Kaposi's Sarcoma and diverse Lymphomas were the cancers most associated with AIDS.[13]

The structure of AIDS clinical trials seemed to be evenly distributed among the different axes related to AIDS. With 14 drug trials, the anti-retroviral category was (and still is) the largest of the ACTG's trials, whereas 11 trials focused on the opportunistic infections.

In her study, Dr. Long, observed, firstly, that although the ACTG's had been the most funded clinical research groups in history,

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[13]Ibid.

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with 250 million dollars, there was no information about accrual, the patient population and where the drug stood in the approval process. Secondly, 44% of the sites, where the 22 anti-retroviral trials were conducted, were in Manhattan and 30% in Upstate New York. With only 4 trials in the Bronx, Blacks, Hispanics and women did not have even minimal access to clinical experimentation.

Upon pressure by the ATR, activists found out that that there was no accrual at the Bronx public hospitals. In fact, the same lack of information existed in cancer research. Cancer trials could (and still can) take up to four years to obtain decent accrual. Dr. Long's research revealed that 73% of 844 patients enrolled in clinical experiments were in 5 trials testing AZT, and the remaining 27% of the patients statewide were in the 32 other open trials. They represented fewer than 7 in a state that had hundreds of thousands of HIV-infected individuals. The situation was similar in New Jersey, where 60% of the patients were enrolled in AZT trials.

With this report in hand, ACT UP could assert that Parallel Track was not the cause for enrollment deficiency, but the lack of active publicizing and proximity of the drug trials as well as their poorly designed protocols. No PWAs would enroll in trials where they would have a 50% chance of obtaining the placebo. In fact, in December, 1989, ddI trials were enrolling at 35 subjects a week as opposed to 14 a week for AZT. In addition, it only took two years for the drug to obtain approval from the concept sheet.

The Community Research Initiative had shown that by designing trials in accordance with PWAs' needs, no accrual problem would occur. In fact CRI trials' accrual was greater than all the ACTG's'

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trial accruals combined.

COMMUNALIZATION OF THE BIOMEDICAL AIDS BUREAUCRACY

In contrast with Touraine's concept of control of cultural patterns,[14] the concept of communalization of cultural patterns is put forward in the present research.

Communalization is a two fold concept. It refers to a sense of identity, whereby individuals define their situation vis a vis their health and the social institutions. Out of this sense of identity emerges the need to mobilize with individuals sharing the same situation, or with individuals closely affected by the AIDS crisis, because their friends or lovers died. But communalization does not stop at this collective act of self-recognition. Communalization implies that AIDS activists fight to gain active input in the resolution of the AIDS crisis. The communalization of biomedical institutions for example means an increasing active representation of persons affected and/or infected by AIDS in those institutions.

As mentioned in the AIDS CULTURE section, this communalization process had already started with the creation of organizations such as Community Research Initiative. The need to be individually involved in the research process was already present very early on in the epidemic. What ACT UP did however was to render this fight more visible and actually impact on the biomedical research structure.

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[14]Alain Touraine, *The Return of the Actor*, Minneapolis: The University of Minnesota Press, 1990.

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As in the case of the FDA, it became clear to the activists that direct action would be the only way to impact change in the AIDS research structure. Many of the reasons that led to the FDA shutdown in 1988, led to the NIH action in 1989. Activists were frustrated by the fact that after ten years only one drug, AZT, was tested and approved. Placebos were killing people, without yielding significant information, and opportunistic infections were left out of the research agenda. Activists were accusing NIAID of practicing medical apartheid, because white women and people of color did not have access to the few trials available. When enrolled in a trial, PWAs were not provided with proper care or were asked to drop their prophylaxis or were totally abandoned when the study was over. Conflict of interest and secret meetings were plaguing AIDS research, while PWAs were given no representation in those meetings.

These are a few of the reasons which led to the "storming" of the National Institutes of Health (NIH) in May 21, 1990. In front of the National Institute of Health, 1,000 activists organized a rally and a die-in. A total of 82 protesters were arrested, shouting "Ten Years, One Drug Big Deal!," while 21 took over the office of Dan Hoth, Director of AIDS Research at NIAID to demand access for women to clinical trials and a women's health committee as part of the structure of the ACTG's.

At the time, the NIH did not even have a director. The latest one, James Wyngaarden, had been removed after seven years on the job because his views on abortion and fetal tissue transplant research-also of concern for persons with Alzheimer's and Parkinson's diseases-differed from the Bush Administration's.

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Subsequent to this demonstration NIAID approved the inclusion of PWAs in the ACTG's scientific research meetings. A Community Constituency Group (CCG) was also created to represent people with HIV and affected communities within the ACTG's. The CCG had members on every ACTG Committee including two voting members on the Executive Committee which passes votes on protocols. The CCG would have a broad range of responsibilities. It would meet three times a year for a conference lasting four to five days. CCG members would also serve as members of an ACTG's committee, such as the virology committee or the opportunistic infection committee, and would be responsible for attending all the meetings of that committee at the ACTG's conferences. Some CCG members would also serve as alternates to other ACTG's committees. Members would be required to submit a written report about the work of their ACTG committee within two weeks after the ACTG conference. This responsibility would be taken seriously, since CCG would serve at least a year, and if they missed one meeting they would have to leave, unless ill.

the ACTG Executive Committee recommended that each ACTU establish a Community Advisory Board. The Community Advisory Board would operate at the local level, in each hospital. At Cornell University Hospital for example, activists had been able to force the Principle Investigator to change his protocol. In the trial 135, a cocktail of drugs was used to treat MAI. But the PI did not want to tell prospective subjects that clarythromycin-a treatment for MAI as well- was available on expanded access. Ultimately he was forced to mention it in the form of consent.

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In April 22, 1991, NIAID's Anthony Fauci allowed 2 activists to be nominated for positions on the Community Advisory Board of the National Institute of Allergy and infectious Diseases. The board would advise NIAID on the selection of drugs for testing. Two community representatives were included in another important body, NIAID Advisory Council, which would review grant applications and priorities.

Finally, a Women's Committee was also included and was one of the greatest activists' victories (See Women's section.)

The direct result of the presence of activists at the ACTG's yielded better protocols and more research on OI's. And most of all, activists were viewed more seriously by the scientists.

THE FIRST AIDS TREATMENT ACTIVIST CONFERENCE

In November, 1990, the first AIDS Treatment Activists Conference (ATAC), organized by ACT UP/NY and ACT UP/DC, was held in Washington, D.C. It was the first national conference which convened treatment and research activists from all over the country. The first purpose of this conference was to establish the conditions to set up a national activist agenda. At heart of the communalization process of biomedical research by activists lies one of the most proactive and ambitious projects of Treatment and Data (T&D): the Countdown Eighteen Month (CD18M). Launched at the ATAC conference, it is a campaign to make the five deadliest AIDS opportunistic infections-PCP, Toxoplasmosis, CMV, Candidiasis, MAI-treatable within the next 18 months.

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CD18M has already achieved many successes. It has pressured the research establishment to set up a trial of 566C80 vs. pentamidine, which would meet the needs of individuals intolerant of sulfa drugs. 566C80 is a potential treatment for Pneumocystis *Carinii* Pneumonia (PCP), which is still a leading killer of people with AIDS and accounts for 43% of all opportunistic infections. The large number of cases of PCP were due to failure to prophylax because of toxic side effects of existing reagents, because of the exorbitant prices of these drugs, particularly aerosolized pentamidine. In fact, Aerosolized Pentamidine was still provided by the PWA Health Group, indicating that most PWAs cannot afford this drug.

With the help of other ACT UP members, they organized a boycott against Hoffman-Laroche, which subtly blocked expanded access of the drug ddC. Although, it granted expanded access of ddC, Hoffman-Laroche did not request a national Institutional Review Board (IRB), which made access to this expeditious program very complicated and "lengthy," between 4 and 7 months. ACT UP was swamped with doctors' phone calls because they could not obtain the drug. A boycott was organized against the products of the company and ACT UP informed doctors, by way of an ad in a medical journal, not to buy Hoffman Laroche's products, at least those which had substitutes. Much to the surprise of many, doctors followed suit. This boycott made visible, not only doctor's frustration with the research system, but their politicization and willingness to take action.

The same tactic was used to make possible the expanded access of clarythromycin by Abbot Labs. On the morning of February 18, 1991 members of T&D leafletted the New York Stock Exchange to educate

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investors about Abbott. A letter was sent to Abbott to inform that direct action, direct mail campaign to doctors, and a boycott of Abbott products would be used to gain access to clarithromycin for people with MAI. Soon enough, the company gave in to the demands of the activists. The expanded program began the first week of June, 1991. Doctors with patients, who were able to document that their patients had MAC, were allowed to call a toll free number to apply for the drug. Patients who were not geographically or physically able to enroll in phase II trials will be randomized to one of two doses of the drug. This constituted an important precedent: true expanded access providing useful safety and efficacy data. Abbot appeared to have agreed to implement ACT UP's "Middle Track" proposal from 1990, using expanded access for Clarithromycin to answer the question: which dose is best in a MAI treatment regimen, by randomizing patients on expanded access to 1 mg/day or 2mg/day of Clarithromycin.

Likewise, upon CD18M pressure, Pfizer also, provided access to azithromycin when its phase II trial began. Also, two of Pfizer's proposed azithromycin protocols allowed patients to be on other anti-MAC therapies.

Finally, only one agent was approved for Cytomegalovirus (CMV), ganciclovir, which had significant toxicities and had to be taken intravenously. Foscarnet, an important salvage therapy, had been trapped at the FDA, which has been procrastinating with the New Drug Application (NDA) for 9 months, 3 months longer than the statutory maximum. Astra, the manufacturer called on ACT UP's help to pressure the FDA to hold an advisory committee meeting which precipitated the approval of Foscarnet.

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These are but a few examples of the impact of CD18M on the direction biomedical research is taking in the area of AIDS. Communalization is then not just an abstract concept but can easily be assessed by concrete achievements of ACT UP's working groups.

FIRST RESULT OF THE COMMUNALIZATION OF BIOMEDICAL RESEARCH: SCIENTISTS' ACCOUNTABILITY

It has been an old saying that "science--meaning scientists--governs itself." This position has been one adopted by Congress which very rarely intervenes in scientific matters. With regard to AIDS, this is changing. In the future, the ACTG's will be funded in two parts: 2/3 of their funding will come as clinical core grants, awarded on the basis of budgets submitted by the site, which must plan for enrolling a minimum of 60 and a maximum of 150 participants per year in its trials. If the site exceeds accrual targets, or excels otherwise, it may receive extra cash in the form of "incentive funding" from NIAID. This novel formula spurred by long-term activist pressure, means that, for the first time, ACTG's funding will be tied to performance.

The first three years of the ACTG's can be regarded as the AZT years. Of the 101 trials opened before 1990, 50 tested AZT; these enrolled 85% of the total participants. The trials resulted in 1) lowering the dose of AZT by half 2) expanding the use of AZT for people with early ARC and asymptomatics with T4 cells under 500 and 3) approving AZT for children.

1989-91 were dominated by ddI. The three phase II efficacy trials opened in fall 1989 completed enrollment in March 1991 and were

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analyzed periodically until a difference between AZT and ddI was seen. Now, each AIDS Clinical Trial Unit (ACTU) will have to demonstrate its ability to study both "primary infection" (HIV) and opportunistic infections.

The ACTG's spent $375 million in 5 years to enroll 14,000 research participants for a total cost per subject of $25,000. In five years, no one at the ACTG's has ever discussed the cost of their trials, arguing everything solely on the basis of scientific merit. Now for the first time, protocols will be budgeted before trials are approved.

SECOND RESULT OF THE COMMUNALIZATION OF AIDS RESEARCH: DRUG TRIALS ARE MORE AND MORE ATTUNED TO THE NEEDS OF PWAS

In the view of streamlining the agonizingly long testing procedure, activists proposed 2 stages for phase 1: phase 1a and phase 1b. In phase 1a, subjects are given several doses of the new agent. At this level pharmacokinetic, safety and activity are assessed. In phase Ib, people are randomized to a series of doses found both safe and active in Phase Ia, and followed for changes in surrogate markers. The doses found best in phase Ib are then used to design phase II efficacy trials, and parallel track/expanded access, which, whenever possible, becomes a Middle Track with randomization to 2 or more doses. Phase Ib and phase II trials can also gather useful information more rapidly by including randomization to monotherapy vs. combination therapy.

The irony is that now that the FDA has become more open to releasing drugs more rapidly, it is the private pharmaceuticals that are

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blocking the release of drugs.

FROM COMMUNALIZATION TO PARADIGMATIC SHIFT

The preamble to the *Treatment and Research Agenda of the 1990 San Francisco AIDS Conference* showed that activists were then well aware of the epistemological strides they were making. Science could not advance without the input of concerned communities.

> It is often said that science is not a democracy. This is true. But if we are to have science in a democracy, the voices of those living with AIDS, the voices of potential and real trial subjects, must carry a heavy weight indeed.[15]

Further, the San Francisco conference organizers were actively pursuing the input of activists. Many ACT UP members gave presentations at this convention. The input of Mark Harrington, a long-term activist, was anxiously solicited to talk about AIDS activism. Even Derek Hodel, executive director of the PWA Health Group (where at least 50% of the staff are ACT UP members) was invited to present a paper called "Buyers' Clubs and the Legitimization of the AIDS Treatment Underground-- The PWA Health Group as Case study," along with an additional PWA Health Group poster, "When Safety Nets Fail: A Unique Guerilla Program to Provide Aerosol

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[15]ACT UP, *Treatment Research Agenda, VI International Conference on AIDS, San Francisco*, Unpublished Document, June 1990.

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Pentamidine to indigent Populations-- the PWA Health Group as a Model". Ultimately those two papers were withdrawn from the conference in support of the international boycott protesting restrictive U.S. immigration policies. In fact at this very Conference, another concept was proposed: Middle Track. This new concept would make Parallel Track usable with regard to research data. Middle Track is basically a Parallel Track treatment given on a randomized basis, at various doses, at appropriate sites, including community-based clinical trial and in some physicians' practices. Thus, Middle Track could provide useful efficacy data, while meeting PWAs' needs.

In 1989-90, AIDS research activism became more aggressive and focused. Treatment and Data of ACT UP formed a "drug buddy system," where self- selected members were responsible for specific drugs. They would research the drug, keep in touch with the manufacturer, and report to the group about the latest developments. This strategy proved to be an effective way of becoming acquainted with the pharmaceutical industry. Now activists know better the weaknesses and strength of drug companies. This new method has contributed to the access of the following drugs: ddI, EPO, Fluconazole, Foscarnet, ddC, and Clarythromicin.

While their initial intention was to obtain treatment, activists would not have expected to be the originators of a paradigmatic shift. AIDS activism has changed and so its goal. The activist's goal is now consciously epistemological. At issue is not only access to drugs, but the way research is conducted. And theory has a lot to do with it. One of the latest study groups formed by ACT UP is living proof to the new theoretical orientation of the group. Created in 1990, the Basic Science

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Working Group is looking into the role of HIV on the immune system. A basic science bulletin was proposed as an adjunct to the T&D digest at irregular intervals. Issues dealt with concerned cytokin dysregulation, auto-immunity, angiogenesis in Kaposi's sarcoma, chronic inflammation, herpes viruses, monocyte macrophage function, and allo-immunization. Members of this group worked on a list of questions to ask researchers at the 1991 Florence AIDS Conference.

It is now clear that activists have gone past requesting a reordering of priorities in biomedical research. They have, to a certain extent, taken over the role of scientists, who according to them, evolve in ivory towers and are not in touch with the experiential realities of the syndrome. This excerpt from the *AIDS Research and Treatment Agenda* distributed at the San Francisco AIDS Conference in 1990 is testimony to the new steps activists are taking toward the communalization of a thus far sovereign field--biomedical science:

> AIDS is causing an abrupt and seismic shift in biomedical research. The outlines of a new research order are emerging. Some scientists are changing, adapting to this new order. History will record the names of those who assist in creating a more equitable, humane and efficient research system, and it will record the names of those who resist. It is time to make one thing clear: people with AIDS will win this battle. Science will serve their needs. Either scientists will work with us in

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> advocating change, or they will be forced to step aside. It is time for activists from around the world to make research accountable to the needs of people, not profit.[16]

If communalization was not a core concept in Kuhn's writing, crisis as indicator of paradigmatic shift definitely was:

> Philosophers of science have repeatedly demonstrated that more than one theoretical construction can always be placed upon a given collection of data. History of science indicates that, particularly in the early developmental stages of a new paradigm, it is not even very difficult to invent such alternates. But that invention of alternates is just what scientists seldom undertake except during the pre-paradigm stages of their science's development. So long as the tools a paradigm supplies continue to prove capable of solving the problems it defines, science moves fastest and penetrates most deeply through confident employment of theses tools. The reason is clear. As in manufacture so in science-retooling is an extravagance to be researched for the occasion that demands it. The significance of crises is the

[16]ACT UP; *AIDS Treatment Research Agenda, VI International Conference on AIDS, San Francisco,* Unpublished Document, June 1990.

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> indication they provide that an occasion for retooling has arrived.[17]

ACT UP has unraveled a major relation of domination: the relation between science and lay individuals. Thus far, this relation was conceived unilaterally. Scientists were assumed to hold "the truth," and lay individuals had to listen. Lay individuals were not supposed to express any opinion, because of their alleged biased position and their lack of expertise. They were then expected to keep outside the therapeutic process.

Used to subjugate the communities affected by HIV, this relation of domination is shown by ACT UP to be coercive. People affected differently by HIV, according to the activists, need to be involved, for part of the epistemological process around this condition lies in the experiential knowledge acquired by persons living with the virus. Indeed:

> As in political revolutions, as in paradigm choice- there is no standard higher than the assent of the relevant community. To discover how scientific revolutions are effected, we shall therefore have to examine not only the impact of nature and of logic, but also the techniques of persuasive argumentation effective within the quite special groups that constitute the community of

[17]Thomas S. Kuhn, *The Structure of Scientific Revolutions*, Second Edition, Enlarged. University of Chicago, p.76, 1970.

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scientists.[18]

It is noteworthy that Kuhn's quote was not intended to encompass communities as understood in this research, that is communities affected by the disease. In his perspective, community means a specific group of scientists. AIDS activism reveals that this thought can be expanded from scientists concerned with a specific area of research to subjects personally affected by this area of research.

COMMUNALIZATION IS AN ONGOING PROCESS WHICH MUST CONSTANTLY ADAPT AS PROBLEMS MULTIPLY

The new ACTG's will enroll fewer than 4,000 persons with HIV each year into its trials at 20-25 sites around the country. Yet the "drug development pipeline" is full with scores of new drugs emerging from laboratories and phase I trials ready for efficacy studies. One or more of them could produce major advances in the treatment of HIV infection : Janssen's TIBO derivatives, Roche's tat gene inhibitor, and protease inhibitors for Upjohn, Merck, Roche and SmithKline, to name a few.

Between 1986 and 1991, the ACTG's have spent a total of $375,833,000 to enroll 14,046 participants in its 129 clinical trials, for a cost per participant of $26, 757-- almost 9 times the industry standard of $3,000. In order to resolve the costliness of drug research and make it more effective, activists suggest that the ACTG's should focus on phase I and on phase II trials. They also argue that community based research

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[18]Thomas S. Kuhn, *The Structure of Scientific Revolutionss*, Second Edition, Enlarged. University of Chicago Press, p.94, 1970.

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centers, in conjunction with the industry, should conduct phase III trials and expanded access programs, whenever possible in the form of large simple, rapid ethical and reliable trials.

HIV treatment research, in contrast, moves at a snail's pace. Disease is chronic and variable, not acute and predictable; virologic and immunologic endpoints are highly controversial, and clinical endpoints rarer especially in earlier stages of disease. By their nature, traditional randomized clinical trials exclude the population most at risk of death from AIDS.

Over 42,000 Americans were diagnosed with AIDS in 1990. Fewer than 4,000 of them entered ACTG's clinical trials. No new trials opened for asymptomatics, still the largest population of the HIV infected. For them too, AZT (Azidothymidine) is still the only available standard therapy and an inadequate one. And the current ACTG's have the capacity to competently develop just one antiretroviral at a time. Each period lasts 2-3 years: AZT from 1987; ddI from 1989-91.

175 is a new trial for asymptomatic HIV infected people with CD4 counts between 200-500. It will ask if combination nucleoside analogue therapy is better than monotherapy as early intervention. As already mentioned, AZT is the only FDA approved treatment for asymptomatic people in the CD4 cell range. The study intends to enroll 2600 people. Half of the people will have received prior nucleoside therapy. The other half will not have taken prior nucleoside therapy. The first half who have received prior antiretroviral therapy will be stratified by the amount of time they have taken AZT. The study duration is two years. It will probably take a year to enroll fully this

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trial. Therefore, it will be at least a major project in the ACTG's for three years. Once a person falls below 200, s/he will be followed until s/he develops AIDS or fall below 100 CD4 cells. At this time, s/he will be offered combination therapy compassionately.

This trial represents a huge cost, since it will swallow 20% of the ACTG's' financial resources. Researchers argue that it is going to determine CD4 as surrogate marker. Yet other studies are already using CD4 as surrogate markers. ACT UP organized a zap at the ACTG's against 175. The purpose of the zap was to obtain that the trial be funded by drug companies such as Bristoll Myers and Burroughs Wellcome.

THE LATEST EPISTEMOLOGICAL STRIDE: LARGE SIMPLE TRIALS

Current questions, activists argue, could be answered by large simple trials (LSTS). All AIDS LSTS should have the same inclusion criterion, and each arm of the trial should represent a valid treatment option. The endpoints should resemble decision points in HIV primary care. Enrollment should be completed in a year, with follow up completed in another year, and data review every 6 months.

Monitoring must be frequent enough to detect an unacceptable toxicity and otherwise not so onerous as to prevent primary care physicians from participating. Moreover, for those unable to participate in the LST, expanded access (the original Parallel Track) must still be available. Some FDA officials espoused the concept of large simple trials in which groups of HIV patients take new antivirals single or in combination to be compared to a control group taking the

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standard therapy: AZT.

It is ironical that now activists are fighting to obtain an FDA official to be part of the Lasagna Conference organized to speed up the drug release process. ACT UP is even proposing a boycott of the conference until the organizing committee includes an FDA representative. Who would have guessed such a coalition would have been possible a few months ago. What's more, Dr. Carl Peck, new head of the FDA AIDS Antiviral Advisory Committee, has requested ACT UP's suggestion for the replacement of Dr Cooper, Acting Director of the Division of Antiviral Drugs.

THE VIII INTERNATIONAL CONFERENCE ON AIDS, A FORUM FOR ACTIVISM

The 1992 VIII international Conference on AIDS, will be organized by Harvard University but will be held in Amsterdam, Holland, because of the U.S. immigration law barring HIV positive individuals from entering the country. Dana Van Gorder, one of the organizers of the conference paid a special visit to T&D. He acceded to such demands as 40% activists participation on committees, a special session on Countdown 18 Months, and a forum for officials on all levels to discuss "what it would take to solve the AIDS crisis."

The communalization of AIDS research is now a well established and accepted fact.

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FDA: AN ARENA OF CONFLICTS

Well before the creation of ACT UP, it was clear to the activists that one of the stumbling blocks to releasing drugs was the Food and Drug Administration (FDA). The Lavender Hill Mob had already demonstrated at the Federal agency. And criticisms of FDA regulations had already surfaced in ACT UP, even before the idea of shutting down the agency was first expressed. In fact, during the very first demonstration at Wall Street, ACT UP activists had burned the effigy of Frank Young, then FDA commissioner.

Conflicts with and about the FDA did not start with AIDS activists. In the past, the agency had been the arena of many controversies and battles. Many thought that the foot-dragging procedures of the FDA impeded the rapid process of drug release. In that regard, statistics are telling: between 1961 and 1977, 23.4% of all new drugs were discovered in the U.S., but only 8% were first introduced in this country.

The state of California had already taken emergency measures to counter the slowness of the FDA. On September 28, 1987, Governor George Deukemejian signed legislation permitting the approval of experimental AIDS drugs and vaccines developed in California. According to state Attorney General John Van de Kampl: "the law is a clear statement that in the midst of a killer epidemic-business as usual in the drug testing process just ain't good enough. " While California had already enacted legislation permitting clinical trials of drugs manufactured in California without FDA approval, the legislation had been used only for the cancer drug "laetrile." The new legislation could

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have been applied by California's Department of Health Services to handle applications for experimental AIDS drugs. Yet many firms were afraid to apply for approval under the new law, lest they antagonize the FDA.

U.S. Governmental officials, themselves, were critical of the agency's regulations. In 1980, Democratic representative James Sheuer of New York, chairman of the House Subcommittee on Science and Technology, charged that: "the FDA is contributing to needless suffering and death for thousands, because it is denying them life-saving and life-enhancing drugs that are available abroad far sooner than they are here." He specifically cited the cases of Propranolol--a drug that significantly improved the treatment of hypertension--available in the U.K. seven years earlier than in the U.S., and Adriamysis--the second most widely prescribed cancer medication in the world, introduced in Britain in 1971, but not until 1974 in the U.S.

Despite all evidence that drug lag caused needless suffering, regulatory policy remained unchanged other than the 1983 passage of the Orphan Drug Act, which provided drug firms with special incentives to relieve the plight of those suffering from diseases too rare to make drug development and marketing profitable.

The Gay community's criticisms of the FDA were reiterated by the report of the Presidential Commission for the Human Immunodeficiency Virus. Retired Admiral James D. Watkins, the Commission's Chairman, worried that "we don't have a system to move drugs rapidly into clinical trials." He predicted the troubles the FDA would have to face, and proposed that FDA be given more resources to handle the flood of new applications. He also proposed

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that the agency eliminate placebo drug trials for AIDS patients, on grounds that it was unfair to give desperately ill patients sugar pills.

The PWA Health Group was trying to meet the ever-growing demand of desperate individuals while fearing FDA's crackdown. The demand for "AIDS drugs" was so high that the PWA Health Group's sales approached $1 million by the end of 1988. Still, some individuals could not afford the very competitive prices of the PWA Health Group and had to manufacture their own drug, such as AL721.

Recently, the opposition to the restrictive FDA regulations has become generalized. Of all the medical professionals, 88% wanted the FDA to change its regulation. Feminist activists and major family planning organizations, such as the Planned Parenthood Federation of America, campaigned to make RU486 available a drug developed in Europe, and proven highly effective in terminating pregnancy.

GETTING DRUGS INTO PEOPLE'S BODIES

Deciding to 'get drugs into people's bodies,' to use a slogan of the time, AIDS activists heightened the pressure. At the 1988 Lesbian and Gay Health Conference they organized a die-in, subsequently to which Frank Young, then FDA commissioner decided that:

> US residents may buy unapproved drugs from foreign countries as long as the drugs are for personal use and not for profit. If the custom officials seize such a drug, the patient must produce a doctor's letter recommending the substance.

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> People may import only a three-month supply of such a substance for personal use.

This new regulation certainly helped. It decriminalized the activities of the PWA Health Group for example. Yet one of the requirements of this new regulation was proof that the person in need of a drug had a prescription. This restriction severely limited the application of this new regulation.

For some people the fastest way to have access to drugs was-if they could afford it- to fly abroad. But the U.S government decided to restrict the international AIDS drug market, although the latter was totally legal. Thus, it pressured the Japanese government to ban the sales of Dextran Sulfate to U.S. visitors, so that they would be forced to participate in trials which did not necessarily meet their needs. PWAs rushed to the PWA Health Group, which had to expand to meet the ever-growing demand. Yet the FDA started to clamp down on buyers' clubs selling AL-721 and Dextran Sulfate.

In response to that restriction, ACT UP New York decided in June of 1988 to organize a sit-in at the subsidiary of KOWA, the Japanese manufacturer of Dextran Sulfate. Although the New York branch did not manufacture any chemical component, the message came through--the Japanese government reversed its policies--and U.S. PWAs visiting Japan were subsequently able to buy Dextran Sulfate.

Sporadic actions like the one against KOWA, although very effective, could not bring about the necessary structural changes which would fundamentally change the drug releasing system. The agency which had the power to yield such a change, activists realized, was the

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Food and Drug Administration, itself part of the gigantic Department of Health and Human Service (See figure I and II).

FROM PATERNALISM TO CONTROL: FDA'S HISTORICAL BACKGROUND

The FDA defines itself as being in the business of consumer protection. Its job is to see that foods, medicines, cosmetics and medical devices are suitable for use by the public.

Each year, FDA's specialists make 50,000 inspections among some 120,000 establishments that process, store or transport foods; process or deal with distribution for drugs; formulate cosmetics or manufacture medical devices.

The law enforced by the FDA, the Food and Drug Act, dates back to 1906. The law forbade manufacturers from making unsubstantiated claims on medicine labels.

In 1937, the so-called Elixir of Sulfanilamide caused 108 deaths. This disaster led to the passage of the 1938 comprehensive Food, Drug and Cosmetic Act, which still governs the FDA today. The act required that drug be proven safe before marketing.

Still with this new requirements, drug companies could thrive fairly rapidly. Drug trials were inexpensive, and the FDA took an average of 7 months to approve a drug. There were also many abuses on the part of drug companies such as the unregulated use of antibiotics (Eigo et al., 1988). Between 1959 and 1962 Senator Kefauver attempted to enforce an efficacy requirement before the marketing of drugs, but to no avail. The pharmaceutical lobby was too influential.

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FIGURE I

THE BUREAUCRACY

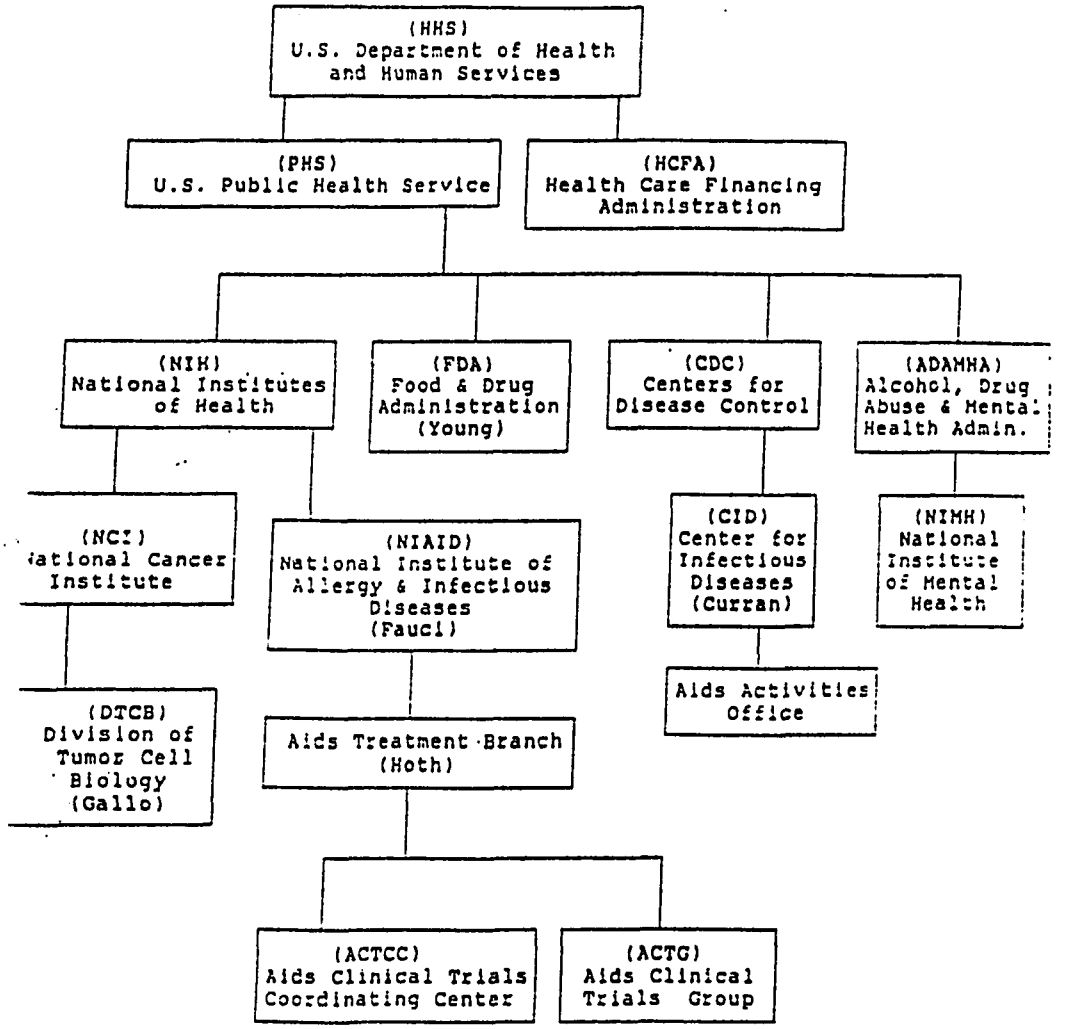

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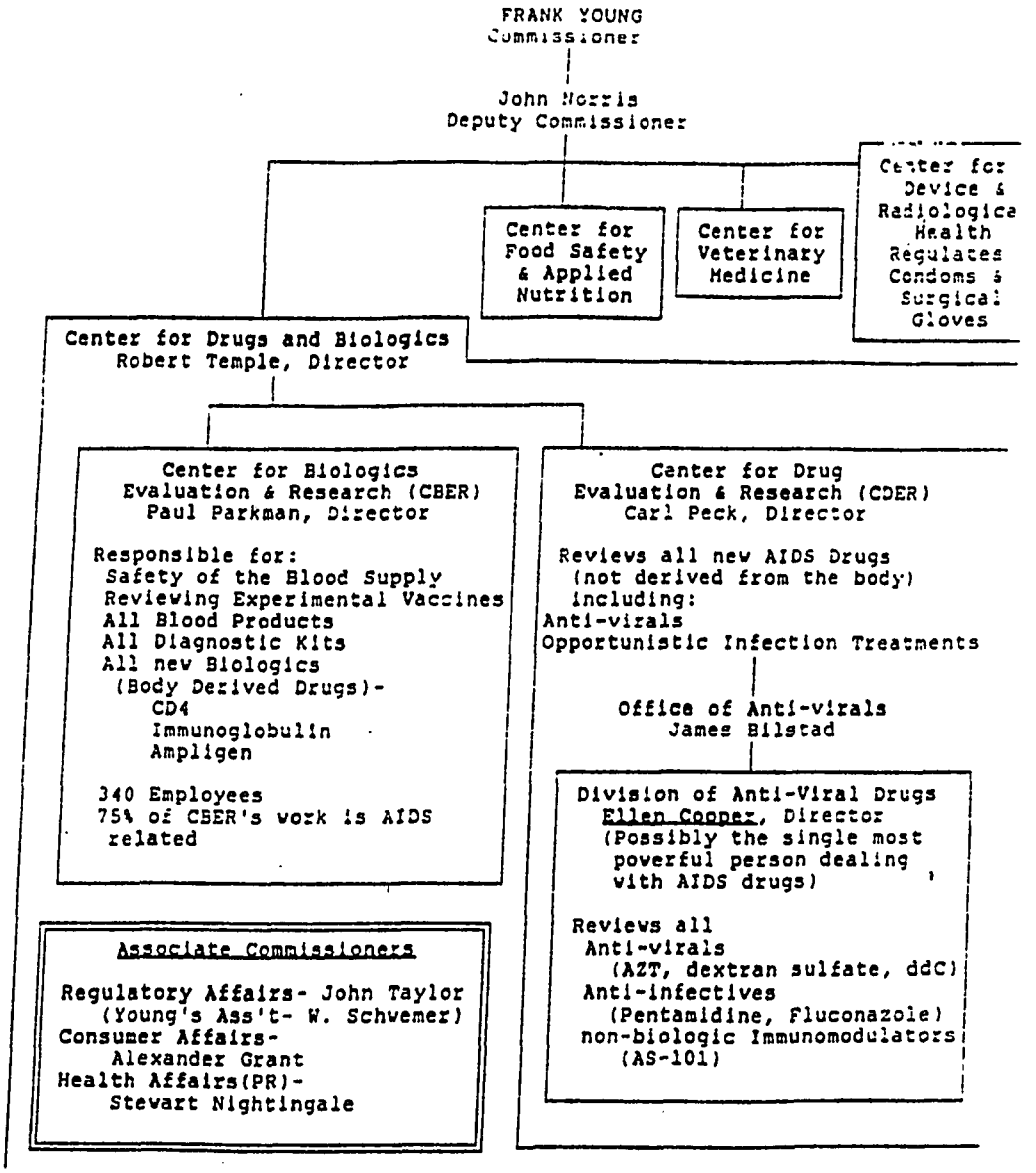
FIGURE II

THE FOOD AND DRUG ADMINISTRATION



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It took another disaster, this time in Germany, for a change to occur. Thalidomide, although tested in the U.S., was never sold in this country thanks to a woman on the FDA staff who stopped its sale on time. It was a very effective sleeping pill but caused birth defects. The discovery of babies born without arms nor legs set the stage for the Kefauver's Amendment, which was endorsed by President Kennedy in 1962. Activists noted that Congress paradoxically passed the efficacy requirement because of a drug which was actually efficacious, but unsafe.

In studying both the history and bureaucracy of the FDA, activists came away with 3 conclusions:

1) the role of consumer protector that the FDA was proud to brandish was, in actuality, a role of control and coercion. This role did not meet the needs of persons with AIDS, who could not afford the average 10-year wait it took to pass all the draconian requirements of the FDA. The premise according to which activists were operating was that clinical trials are also health care:

> The imperatives of science, law, bureaucracy and corporate property, which result in 8-10 year testing periods for most drugs, must yield to a synthesis with the needs of seropositives and PWAs who, untreated, will often live far less long.[1]

[1]Eigo et al. *FDA Action Handbook*, Unpublished Document,1988.

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2) For this change to happen, community representation at all levels of the drug releasing process was fundamental.

3) The history of FDA revealed that the agency was open to change, only when forced. Direct action was the only avenue of communication.

As they elaborated their analysis, activists realized that although it is not directly involved in the research process itself-the FDA does not test drugs-its regulating power extends over all the stages of drug testing and most definitely over drug access.

The three ways a person with HIV has access to drugs are through a doctor, a clinical drug trial or the underground market. Although other federal agencies are involved in the research process, the FDA has a great deal of control over the three of them. The second way is really the battlefield of activists, because if drugs are approved more rapidly then doctors can prescribe more safe and effective drugs and seropositive individuals will not feel compelled to form buyers' clubs to import illegal drugs.

Yet according to the activists:

THE FDA SLOWS DOWN THE DRUG TESTING AND RELEASE PROCESS

Not included in the Kefauver Amendment, but mandated by the FDA are the three phases of an excruciatingly long drug-testing process, which occurs after animal and preclinical trials have been successful (See Figure III.)

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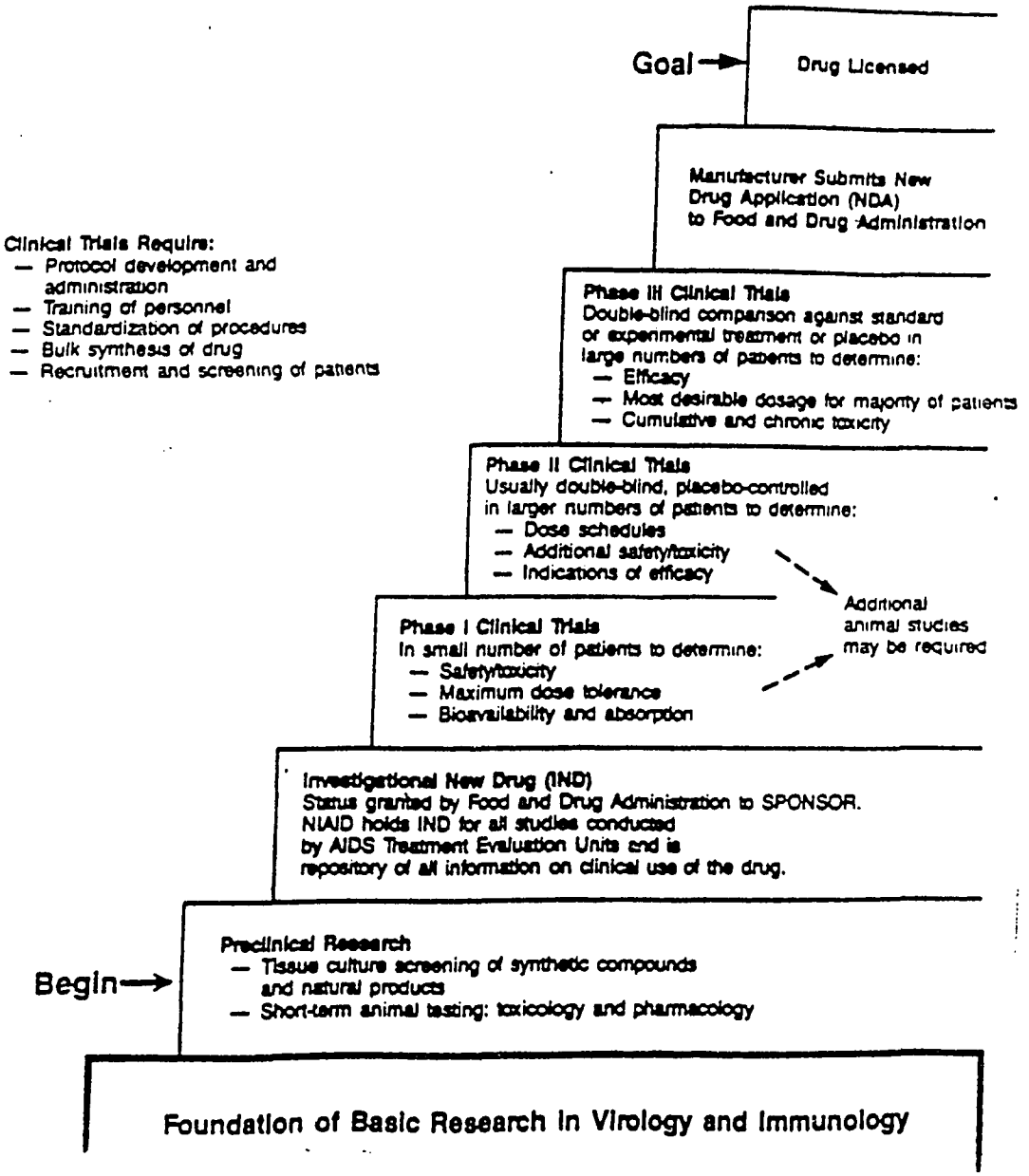
FIGURE III

National Institute of Allergy and Infectious Diseases

Steps in AIDS Drug Development and Testing



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Phase I trials study the safety of a drug, and also observes how it is absorbed and distributed within the tissue, how it is eliminated and how long a dose acts on the body. These trials involve fewer than 100 subjects and are completed within a year. Of all the Investigational New Drugs (INDs), 70% are successful in this phase of trials. The review process takes between 2 and 3 years.

Phase II trials study safety and efficacy. They also detect major adverse effects. They take between 2 to 3 years to complete and between 100 to 1,000 subjects are involved. In this phase, only 33% of all INDs are successful.

Phase III trials study efficacy. Several thousand subjects are involved in those trials in order to assess the generalizability of earlier findings. These trials can take up to several years. Between 25 and 30% of all INDs are successful in these trials. Noteworthy is the fact that most drugs successful in the first two phases of the testing process also survive successfully the last phase, the longest of all.

The FDA had already started to address the issue of the long drug release process in the case of serious and incurable diseases with two procedures:

1) Treatment IND (Investigational New Drug) is an FDA program that makes experimental drugs available to seriously ill people through their doctors. The people must meet certain criteria. Only Phase II or III drugs qualify for this program and they are released at the FDA's discretion before then end of a trial.

2) Compassionate Use IND is a program, under which people who are seriously ill can have their doctor ask the drug company to give them an experimental drug they believe will help them. The drug

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may have little data as to its effectiveness and safety. Although this is not a formal drug trial, some data about the drug' s effects is collected. The drug company has the final say over whether the person receives the drug or not. Very few drugs are available through this program. Drug companies never charge for the drug.

There are three reasons why activists do not like Treatment IND and Compassionate Use. The first one is the requirement of a private physician, to whom most people with AIDS, who are very poor, do not have access. The second is the delay involved. Weeks can pass before the FDA replies. In 1988, Trimextrate, an anti-PCP agent, became the first AIDS drug released under Treatment IND. The criteria of inclusion was life-threatening toxic reactions to both Bactrim and IV-Pentamidine, the existing treatments. In July 1988, only 89 people were able to benefit from this Treatment IND. An uproar from the AIDS communities and a lawsuit threat by the Lambda Legal Defense and Education Fund caused the FDA to expand access to Trimextrate. The drug was offered free of charge and expanded to those who did not have results with either Bactrim or IV-Pentamidine.

PWAs were also successful with Fluconazole, an experimental drug used to treat blood fungus associated with AIDS. Individuals, who applied for compassionate use of Fluconazole in 1989 had to use the approved therapy Amphotericin B, called "amphoterrible" by many PWAs because of its horrific side effects and complex, intravenous administration. The lucky ones were able to receive Fluconazole through the buyers' clubs. Pressure was placed on the FDA and in January 1989, after much delay, the FDA approved fluconazole for use in the U.S.

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The third reason why activists do not like Treatment IND is that drug companies may impose a fee on access to the drug. This is however rarely the case since companies would have to exceptionally open their books to justify why they are charging PWAs. FDA officials themselves could not hide these realities anymore. Former FDA commissioner Frank Young estimated that, at its optimum, Treatment IND would get drugs to those who need them only 20 to 30% faster than normal approval.[2]

In 1988, The Presidential HIV Commission also characterized FDA's treatment IND program as a failure for persons with AIDS. In two years only three drugs had been released. Likewise, DHPG or ganciclovir, a drug to halt progression of an AIDS-related blindness, was made available only to the most severely ill. The less seriously ill were forced into placebo-controlled experiments.

The FDA's failure to approve DHPG (Ganciclovir) caused a nationwide outcry from AIDS advocates. Despite overwhelming agreement among frontline doctors, ophtalmologists and patients whose sight and lives had been saved by DHPG, the FDA went along with the recommendation of an October 1987 advisory committee to reject efficacy data "since it was not collected from adequate and well-controlled trials." The Committee's two ophtalmologists supporting approval of DHPG were totally ignored. Already 3,500 Americans had received DHPG, and the National Institute of Allergic and Infectious Diseases (NIAID)'s own treatment protocol noted that the drug was effective in 80% of people treated. Although DHPG was already

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[2] ACT UP, *FDA Action Handbook*, Unpublished Document, 1988.

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approved for use in Britain, Holland, Belgium and West Germany, Dr. Dan Hoth, NIAID AIDS Program Director, arranged a delayed treatment arm of the controlled protocol (ACG 071). The logical consequence of this trial was that subjects would experience progression to CMV retinitis. Activists realized the real function of the FDA:

> In its obsession with "clean data," the FDA is protecting not the public but its own beleaguered status as arbiter of its arbitrarily-applied rules governing drug approval. Only full New Drug Approval (NDA) of DHPG can protect the sight and lives of immunocompromised patients.[3]

The FDA, part of the biomedical bureaucracy, was acting like any other bureaucracy. Its ultimate purpose was not to implement a substantive end, to use a Weberian terminology--i.e. to service the public, but to implement an instrumental one--i.e. to reproduce itself. In effect, there was no real difference between the biomedical bureaucracy and say the Board of Education. Old officials were holding on to old values and spent most of their time attempting to justify the indispensability of their existence, instead of implementing changes attuned to the need of Persons With AIDS.

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[3]*FDA Action Handbook*, ACT UP, Unpublished Document 1988.

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THE FDA DEFINES BIOMEDICAL SCIENCE IN A VERY RESTRICTIVE WAY

The FDA and drug companies are usually reluctant to give drugs on a treatment IND basis. Because, officials argue that patients are no longer willing to participate in drug experiments. The case of ddI, a nucleoside analog first reported in 1986, contradicts this assertion. This antiviral drug was distributed in September 1989 to 20,000 persons through an expanded access program as a result of the National AIDS Treatment Research Agenda proposed by ACT UP at the Vth International AIDS Conference in Montreal in June, 1989. At the same time the ddI trial had one of the largest accruals. In fact while AZT trial accrual was 14 persons per week, ddI enrollment was about 35 patients per week in early December 1989.

In the meantime, two major drug trials (ACTG 005, ACTG 019) testing AZT were unable to obtain sufficient accrual and suffered from a sizable attrition rate. Further, when subjects decided to remain in the study, they were at the same time using other drugs.

Activists disagree with the FDA on the centrality of placebo to prove a drug's efficacy. Their claim is that placebo-controlled experiments are not always the perfect design to test a drug. During the experiment, principal investigators can check the mean corpuscular volume (MCV) which measures the size of the red blood cell count. In fact in some AZT trials, the MCV level was not erased from the patient chart.[4]

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[4]Mark Harrington, Village Voice, 1990.

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Likewise, anemia, a common direct consequence of AZT absorption, requires transfusion and is a clear indicator for principal investigators that the person is on the drug and not the placebo. In fact, anemia was becoming so critical in some trials that investigators had to take some patients off the drug for a while. Experiments involving a prophylaxis would be the only case activists would agree to the use of a placebo, because it does not jeopardize the subjects' lives.

Drug trials should be, according to activists, health care. Even if PWA's have insurance, most insurance companies will not pay for experimental treatments. And, experimental treatments may be the only treatments available to a PWA for HIV or for certain opportunistic infections. Therefore, activists argue that requiring a placebo is inhumane and unethical.

A drug can be measured against itself at different doses or against another approved drug which has been proven safe and effective. It could also be tested against other experimental therapies as is currently done in cancer research. Another option is to look at the natural progression of a disease in a specific population who has been given the drug. This way researchers can assess how the drug works in the "real world." This method combined with any of the previous methods allows for a large number of possibilities. The drug may thus be tested at different dosages on diverse populations, who all receive a safe amount of it. Top research authorities, such as Mathilde Krim, recognized the need to have a sense of how drugs function in the "real world."

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> Ethically and scientifically satisfying alternatives to placebo-controlled trials have been devised for the study of experimental drugs in cancer patients. They consist of designing trials so that no one remains untreated. For example, one option consists in comparing the effects of two experimental drugs, one better known than the other... One can also compare two or more doses of the same drug, or else alternate, in the same patient, periods of drug administration with periods when treatment is withheld... Good science can be done, and objective data obtained, with trials that are not placebo-controlled.[5]

Little by little, Anthony Fauci, director of National Institute of Allergic Disease (NIAID), himself recognized the ingenuity of the new trial concept offered by activists:

> I'm looking to the next two years. Asymptomatic combination research with nontoxic treatments is a major doable goal.[6]

The case of ddI is the examplar of how expanded access can be used not only by patients for treatment but also for scientific purpose as

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[5]Mathilde Krim, PhD, at the Weiss Committee, 13-14, 1986.
[6]Personal conversation between Anthony Fauci and Mark Harrington, one of the authors of *A Critique of the AIDS Clinical Trials Groups* p.9.

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well. The expanded access, a joint work between ACT UP, FDA and NIH was vehemently criticized by principle investigators and *The New York Times.* In 1991, Bristol-Myers, which was granted the license to develop and market ddI by the U.S. government, submitted its New Drug Application (NDA) to the FDA. The findings, based on 8,000 subjects, resulted from two trials, one in phase I, the other in phase II, and the expanded program.

Unlike DHPG in 1987, ddI was granted approval. Although Bristol-Myers researchers did not use randomization, they used "historical control" cohorts. The placebo arms of Burroughs Wellcome's Phase II AZT trials, of ACTG 001 and 016, and the Dextran Sulfate arm were considered a placebo.

FDA DEFINES ETHICS IN A VERY ARBITRARY WAY

FDA officials oversee the work of Institutional Review Boards (IRB) which approve proposed research involving human subjects and see to it that the design is ethical and that subjects are treated with dignity. They also ensure that subjects are given correct and detailed information about the experiment as well as an informed consent form to sign.

Activists argue that IRB's for AIDS have been inadequately sensitive to the needs of persons with HIV. For example, IRB's allowed trials where subjects had to discontinue all outside treatments only to receive a placebo.

Secondly, the FDA had approved research in which subjects had to discontinue PCP prophylaxis when joining an antiviral or

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immunomodulator trial. In a similar situation, someone in the Phase I ddI trial was expelled when he developed cryptococcal meningitis. He was reinstated only after ACT UP intervened. Nonetheless, due to his temporary expulsion, data were lost to determine what would occur in someone treated with both ddI and Amphotericin-B, a combination certain to recur in the future. In fact, activists argue that obliging subjects to drop their prophylaxis is unscientific because use of a preventive anti-infective should not skew the results of a drug trial for an antiviral or an immunomodulator or for many other antinfectives; National Cancer Institute's Samuel Broder had already conducted such a study (sequential weekly AZT/ACV, ddC+ddI). Even Anthony Fauci, director of National Institute of Allergic Diseases (NIAID), confessed that he would be on PCP prophylaxis were he HIV infected, even if he had to obtain it on the streets.[7] Fauci finally gave in to the demands of the activists and pledged that no design trials would ban concurrent prophylaxis for opportunistic infections.

Thirdly, although FDA guidelines put forward the idea of equitable representation among groups, the FDA has blatantly discouraged the inclusion of women, persons of color, and drug users in clinical trials. In particular, the geographical location of the trials, their requirement that women not be of childbearing age or be sterilized were evidence of discrimination against those populations. Yet the FDA has the power to make the principle of equal representation a requirement.

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[7]*FDA Action Handbook*, ACT UP, Unpublished Document 1988.

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Finally, part of AIDS clinical research's atrocious realities, was that FDA allowed placebo-controlled experiments involving babies. Intravenous immunoglobulin (IVIG) was tested as immunomodulator geared to boost up babies' immune system. This was the most enrolled of the four trials available to babies in 1988. The way the placebo was administered threatened to infect the control group with infections it sought to prevent in the treatment group. The injection took from 2 to 8 hours, biweekly and some infants had to be restrained while being injected. Although the duration of injection was mentioned in the protocol, the consent form failed to mention it. Further, IVIG was available by prescription. Thus, parents, who could afford a private physician, were able to obtain the drug, whereas poor parents were being coerced into the trial in exchange for better medical are.

Central to the activists' demands was the inclusion on the IRB's of representatives of the affected communities. Only with them, activists argued, could a change in the face of biomedical research be accomplished.

FDA'S INACTION WITH REGARD TO THE DRUG COMPANIES' ABUSE OF THE ORPHAN ACT IS DUBIOUS

Whether or not a drug company decides to conduct a drug trial hinges for the most part on economic considerations. Will profit be yielded by the manufacture of the drug? Small companies are usually pushed out of the research market because of the length and the costliness of the process. The only option left to those small companies is to sell their rights to a larger one. HEM, developers of AMpligen, an

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expensive drug requiring 80 steps to produce, sold its rights to DuPont. However, because of the potentially small number of consumers, the latter stopped researching the drug.

As already mentioned in the Profiteering section, the Orphan Drug Act was passed to help companies develop drugs to treat diseases that affect under 200, 000 people, which would not allow the companies to recover their expenditures from the sales. This Act stipulates that criteria for drug release be simplified. For example, a large sample is not mandatory, since only a limited number of people will use it. The FDA, according to the Act, is supposed to help put the drug on a fast-track priority and is also supposed to assist the sponsor in designing the protocol as a means to determine in advance the potential cost of testing. Up to 63% of the cost may be claimed as tax credit by the company which can also be granted an exclusive license for marketing the drug for up to 7 years. Burroughs Wellcome was granted this license for AZT in a record time, for the drug had already been tested in the sixties for cancer. In addition, the pharmaceutical company took out a 17-year patent that extends its monopoly of the drug. The remaining testing of the drug was done at the expense of the National Institutes of Health.

The fight around Pentamidine illustrates how the FDA is an arena of conflicts where bureaucratic inconsistencies and financial alliances are many. Pentamidine is the only drug to be effective both in preventing and treating pneumocystis *carinii* pneumonia (PCP), the leading cause of death among people with AIDS.

Pentamidine Isethionate is a fairly simple organic salt easy to manufacture. As the epidemic spread, the Center for Disease Control

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(CDC) found its imported supply diminished and overseas manufacturers unwilling or unable to provide a reliable supply. It took until October 1984 just before the Presidential election, an interesting coincidence for Secretary of Health and Human Services Margaret Heckler, to announce FDA approval of intravenous pentamidine. Still, injected pentamidine had severe side effects, including abscesses at the injection site, persistent nauseas and appetite loss.

Aerosolized Pentamidine was put on the list of high priorities by the National Institutes of Allergy and Infectious Disease (NIAID). Under activist pressure a Congressional Hearing was organized, where Dr Anthony Fauci was made to appear. He admitted that he could not start testing aerosol pentamidine for 13 months because he lacked "one single staff person".[8] This drug is a prophylaxis for PCP, the leading cause of death in AIDS.

Because the large drug companies were not interested in doing research on pentamidine, FDA turned to the small company Lyphomed and granted it an Orphan Drug license guaranteeing the exclusive right to market intravenous and intramuscular pentamidine until 1991.

Usually drug trial research is covered by anticipated future drug trial drug reimbursement. LyphoMed decided to charge the patients receiving pentamidine for the research into aerosolized pentamidine. This resulted in a 300% price increase for IV pentamidine, from $24.94 a vial to $99.95. Meanwhile the price the company paid for the drug dropped from $6 to $1.8. The compassionate intent of the Orphan Drug

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[8]*FDA Action Handbook*, ACT UP, Unpublished Document 1988.

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Act was once again transformed into source of unethical profit. In addition, Lyphomed did not think to apply for Orphan status for aerosolized pentamidine until 1987, three years after it claims to have begun development and only after its competitor, Fisons, was given orphan status. This would suggest that Lyphomed did not need the incentives of the Orphan Drug Act to continue its research.

The AIDS death caseload increasing, companies suddenly started to enter the AIDS drug research market. Trials started in Europe and the USA on a large scale. Fisons, Inc. a giant British multinational pharmaceutical began pentamidine trials in England, Canada and the USA. Rhone-Poulenc, the French manufacturer, who denied the CDC supplies of Pentamidine three years ago, became also interested.

The activists charged the FDA torpor with killing thousands of lives. In the 27 months that elapsed between the AIDS Clinical Drug Development Committee (ACDDC)' s designation of aerosolized pentamidine for testing as a high priority drug and its June, 1989 FDA approval based on 2 community-based clinical trials, over 16,000 Americans died of pneumocystis.[9] The sad reality, activists point out, is that a year long of aerosolized pentamidine costs less than one hospital day.[10]

Although the Act was passed to help the relatively small number of people affected by the disease, the high price that Burroughs Wellcome and LyphoMed imposed came from a quite different intention. Several other drugs have been granted Orphan Drugs status:

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[9]Michael Callen, *Testimony to the Antinfective Drug Advisory Committee of the FDA* May 1, 1989.
[10]ACT UP, *AIDS Treatment Research Agenda, 6th International Conference on AIDS, San Franciscop.5, June 1990* .

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Dextran Sulfate, Ampligen and DHPG. The activists were and still are asking why the FDA remains motionless in front of those blatant abuses. Does the agency receive perks?, some activists ask. This would not be the first time, since the famous briberies from the generic drug companies. One drug company's private investigator found that at least three genric drug companies were getting preferential treatment on drug approvals in exchange for payoffs. One year later came reports that more than a dozen genric drug companies and scores of individuals were under suspicion of fraud and bribery.

An ACT UP working group is currently in place to reform the Orphan Drug Act following the steps of Congressman Henry A. Waxman (D/CA), who already introdruced two bills in April of 1990. Waxman's amendments provide that drugs lose will their exclusivity once a disease is no longer rare, or where multiple manufacturers are competing to develop a drug.

FDA CONTROLS THE UNDERGROUND MARKET

Controlled by the Food, Drug and Cosmetic Act, the underground AIDS market has not been harassed or prosecuted criminally as had been and still is Laetrile for cancer. One explanation for this difference in attitude on the part of the federal agency is due to the existence of a strong underground AIDS network supported by the very large AIDS movement. The cancer movement had (and still has) a much less organized social base.

A certain number of drugs have been openly available on the underground market through the New York Based PWA Health

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Group (the largest underground buyers' club), where 50% of the staff are New York ACT UP members.[11] Some of those drugs are: AL 721, egg lecithins, German Enzymes, ribavirin, dextran sulfate and DNCB. A number of them have been tested by community-based organizations. For no scientific reasons, the FDA delayed the testing of those drugs, even when they had already shown efficacy. Such is the case of Ribavirin, an anti-infective treatment, which had been around as far back as 1980, yet was not allowed to be released by the FDA. Such is also the case of bactrim and Septra against PCP. Margaret Fishl, one of the ACTG PIs insisted that a double-blind placebo controlled experiment be arranged to prove the efficacy of Bactrim, which had already proven efficacious. Community-doctors could not wait for the FDA approval and were already prescribing those drugs. By 1988, there were over sixty drugs being discussed in the drug underground as possible treatments against AIDS. Many were already available through buyers' clubs.

Relaxing the drug regulations does not imply total deregulation. Most activists are in favor of a seriously regulated drug market. They caution against the total drug market deregulation advocated by certain drug companies' lobbies. In this sense, ACT UP does not wish to see the FDA eradicated, but demands that its function be performed more effectively and rapidly. The recent debate around the Campbell Bill, in this regard, is illuminating. This Bill intends to speed up the drug approval process by eliminating the efficacy requirement. Many activists are against it because it would be like going to a store and

[11]Personal Interview with a Staff member.

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buying products without any label. Currently, most drugs are not even tested for safety on women and people of color. Activists insist that enough efficacy data be gathered before commercializing the drug.

THE SHUTDOWN OF THE FDA

Aware of the FDA history, ACT UP knew that changes in the regulatory policy of the agency could not happen without revealing publicly the deficiency of the agency. A member revealed in one of the ACT UP handbooks that:

> "Budget cuts worsen the burden of the FDA. Because of lack of personnel, FDA cannot assume its basic tasks: monitoring Institutional Review Boards, inspecting clinical trials sites, dissemination of information about these trials, cannot thoroughly examine phase I on trial protocols, cannot prepare the drug approval summaries required by the Freedom of Information ACT, cannot audit informed consent forms until a drug meets approval, cannot check if researchers are complying with their protocols. FDA does not have its own building.
>
> In turn drug companies complain that they do not understand the data requirement of the FDA. Data had been collected on the drugs DHPG, ribavarim and Imreg-1 only to be rejected by the

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> FDA. The requirements are so unclear that certain companies are not even sure of the definition of an efficacy trial and have resorted to their lawyers on that matter. There is no good common definition of what an HIV-related immunomodulator might be or do.[12]

Frustration resulting from a dysfunctional FDA fraught with stringent regulations became unbearable to the activists and in October 11, 1988 ACT NOW with ACT UP organized a four-day action in Washington D.C., which included a demonstration at the Department of Health and Human Services under the banner "Health Care is a Right." The culmination of those four days was a large action--Seize control of the FDA--during which the agency was shut down. Some of the banners read "this Government Has Blood On Its Hands", "One AIDS Death Every 30 Minutes", or "Silence=Death."

The FDA action yielded concrete results. The protocol of the drug trimetrexate was made less stringent to make the drug available to many more people. Also, PWAs would be, from then on, included in the Institutional Review Boards to determine the ethical character of a trial

The symbolic ramifications of the FDA action were even more staggering. It was the first time in history that the agency was shut down. That alone brought the news to the front page of most newspapers, except the *New York Times*. The news intrigued many

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[12]*FDA Action Handbook*, ACT UP, Unpublished Document, 1988.

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people because they did not understand how a biomedical institution could be treated as a political organization. One of the major consequences of the FDA action was the inclusion of PWAs in the biomedical discourse of AIDS. And This inclusion process will intensify with the years to come.

Most importantly, the FDA action made activists realize that indeed there was a growing AIDS movement, as it gave momentum for other ACT UPs to be created throughout the country.

On February 2, 1989, ACT UP along with other AIDS organizations demonstrated at the National Institutes of Health (NIH) to protest the unethical character of the DHPG trial. They demanded that Institutional Review Boards and that FDA advisory committees include an ethicist and a person living with the disease. Some members took over Anthony Fauci's office who ultimately came out in favor of the release of the drug and personally pressured Frank Young to approve it.

Ellen Cooper, Acting Director of the Division of Antiviral Drugs was declaring: "We can't get into the business of approving drugs on the basis of testimonials... But if I was out there treating patients, I would use it. It's a different role. You need different data."[13] Eventually, Cooper accepted the release DHPG on a non-placebo controlled results, because the clinical evidence was so stunning. The sight-and life-saving drug was thus released without passing a formal Phase II on May 1989.

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[13]*FDA Action Handbook*, ACT UP, Unpublished Document, 1988.

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With the release of DHPG, the conflicting and political nature of the drug release system reached its apex. If Burroughs Wellcome was the victor in the AZT race, the AIDS activists had been the victor in the DHPG one.

Two years after the FDA shutdown, the new commissioner David A. Kessler in his opening remarks confessed that:

> we have learned much from the AIDS community. We have recognized that the FDA is, that we must be, accountable for what we do...

Since then, activists have been part of all the hearings leading to the release of the drugs Foscarnet, ddI, and ddC. And they are now part of all the major discussions relating to drug release.

OPENING AND LIMITATIONS

Most activists would agree that the agency has become more open to quick drug release. Yet, even after its shutdown in 1988, vestiges of the old system persisted. On March 30, 1990 the FDA denied the manufacturer of Imuthiol Investigational New Drug status, despite results from a trial of 389 people, which showed that the drug reduced the incidence of life threatening opportunistic infections by 50%. Although three subsequent trials have confirmed the drug's promise, the FDA and the drug's manufacturer have argued for a full year over what constitutes valid study endpoints.

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Aerosolized pentamidine is still sold by the PWA Health Group, which purchases it in England, because the price of the drug is so exorbitant in the U.S. It is the first time that the Group sells a drug that is already approved in the country. The reason is obviously economic. It can offer the drug for $40 per dose, substantially less than the $125-175 charged in the United States, and accuses the U.S. manufactuere of price gouging.

In March, the Public Citizen Litigation Group files suit in U.S. District Court in the District of Columbia on behalf of the PWA Health Group, challenging the validity of the patents held by Burroughs Wellcome for AZT (Retrovir). The suit contends that U.S. patents held that government scientists should have been named as co-inventors for the use of the drug in treating AIDS. It is widely acknowledged that should the suit prevail, generic (and considerably cheaper) AZT could become available.

The conclusion is that the FDA is becoming more open. Yet, activists must keep on watching the agency. The federal agency now wants to investigate buyer's clubs.

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FEDERAL EPIDEMIOLOGY: WOMEN DON'T GET AIDS; THEY JUST DIE FROM IT

In January 1988 an issue of Cosmopolitan Magazine featured an article by a psychiatrist claiming that women with "healthy vaginas" did not have to worry about contracting HIV even if they engaged in unprotected vaginal intercourse with an HIV infected man. Yet the Centers for Disease Control had already registered 2,000 cases of women with AIDS, 26% of which were attributed to unprotected vaginal sex. One of the consequences of the lack of educational campaign about AIDS in general and women and AIDS in particular was that 1 out of 61 newborns in New York City was HIV positive. In addition, in New York City, the male to female ratio of AIDS cases among adults was eight to one. With teenagers, however, it was anywhere from three to one to virtually equal.[1] Those statistics heralded a major pandemic, given that one in ten teenage girls becomes pregnant.[2]

In response to that irresponsible article, ACT UP women wrote a critique of the article and requested an appointment with the Chief Editor of the magazine, who refused to speak with them. They were however able to meet with the psychiatrist, Dr. Gould, who maintained his position. When asked about the two thousand women who contracted the virus and developed the disease, he responded that "they were either prostitutes or liars."

The ACT UP's Women's Caucus organized an action at the

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[1]Gina Kolata, *New Trends Alarming to Experts,* The New York Times, October 8, p.1., 1989.
[2]Center for Population Options, *AIDS and Adolescents: the Time for Prevention is Now,* October, 1988.

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office of Cosmopolitan Magazine. Along with 300 ACT UP members, they distributed 5,000 fact sheets in icy cold weather. The fact sheets concluded with a call for a boycott of Cosmopolitan Magazine. Two months later, Cosmopolitan had its first article on safer sex. A video was made, based on the Cosmopolitan action-*Women, Doctors and Liars: AIDS Activists Say No to Cosmo*-and sent throughout the country. One result was a drastic increase of the women membership in ACT UP.

In order to reinforce the visibility of women in the AIDS epidemic, the newly formed Women's Caucus organized an action as part of Nine Days of Action planned by ACT NOW, a network of all the ACT UPs around the country. The event they chose was the New York Mets baseball game, a way or directly reaching 22,000 New Yorkers, and millions more through its broadcast. No fewer than 400 activists participated. Information leafletted focused on women and AIDS, the risk they ran by engaging in unprotected sex, and the responsibility of men in using condoms. Activists handed out 5,000 condoms and 10,000 fact sheets. And all the banners were consonant with the ball game terminology: "DONT BALK AT SAFE SEX," "HERE'S THE SCORE," "AIDS IS NOT A BALLGAME," "AIDS KILLS WOMEN," "MEN USE CONDOMS!," or again "NO GLOVE, NO LOVE."

The need for these types of actions were the result of the Centers for Disease Control (CDC)'s long silence about women and AIDS. The agency, constructing the disease as gay-specific, was consistently omitting the collection of data about women and AIDS.

In order to understand why the CDC focused so much of its energy on the condition of gay white men, a step back in history is

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necessary. In 1981 nobody knew the cause of AIDS. Some conjectured that the environment was the main cause, others an overloaded immune system, others again an infectious agent. Because the first individuals identified with the symptoms were gay, AIDS was first called Gay-Related Immune Deficiency (GRID) or gay cancer. Epidemiologists posited a strong correlation between the "gay lifestyle" and the disease. The fact that the disease was labeled after a group of people rather than specific behaviors denoted the biased nature of epidemiological research. Gay identity was confused with homosexual practices, and homosexuals were all believed to engage in the same type of sexuality. At that point, activists realized the political nature of epidemiology, which defined itself as a scientific field.

As early as 1982, the medical literature reported cases of what would eventually be called AIDS among women, who had been diagnosed in 1981.[3] The same year, the *Morbidity and Mortality Weekly Report* had reported that 22% of patients with Kaposi's Sarcoma and/or Pneumocystis *carinii* pneumonia were heterosexual, the majority of whom were intravenous drug users. And almost a third of the heterosexual patients were women.[4][5] Yet, the CDC would only focus on the gay white male community.

The persistent and monolithic focus on gay men was partly drawn from the assumption that their "uncontrolled promiscuity"[6]

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[3]Masur, et al. *Opportunistic Infection in Previously Healthy Women. Initial Manifestations of a Community Acquired Cellular Immunodeficiency,* Annals of Internal Medicine, 97: 533-539, 1982.
[4]Don C. Des Jarlais et al and Samuel R.Friedman, *AIDS Among Intravenous Drug Users: Current Research in Epidemiology, Natural History and Prevention Strategies*
[5]Gerald M. Oppenheimer, *In the Eye of the Storm* from *AIDS, Burdens of History.* ed. Elizabeth Fee and Daniel M. Fox, Berkeley: University of California Press, 1990.
[6]*No Need for Panic About AIDS,* Nature 302, p 749, 1983.

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was more amenable to venereal diseases, and henceforth the real originator of the epidemic.

John Langone suggested that the:

> virus enters the bloodstream by way of the "vulnerable anus" and the "fragile urethra." The "rugged vagina" (built to be abused by such blunt instruments as penises and small babies), in contrast, provides too tough a barrier for the AIDS virus to penetrate.[7]

Langone concludes:

> AIDS isn't a threat to the vast majority of heterosexuals. It is now and is likely to remain the fatal price one pays for anal intercourse.[8]

And this was titled *AIDS: The Latest Scientific Facts.*

Thus, the federal epidemiology as well as its recommendations to implement mandatory testing and name reporting relied heavily on cultural stereotypes. Although Thomas Kuhn was interested in non-scientific components in the constitution and practice of science, his analysis was still confined to those components which can be classified as scientific. He did not investigate the ways in which scientists could

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[7]John Langone, *AIDS: The Latest Scientific Facts,* Discover, December, 1985, quoted by Paula Treichler in *Burdens of History.* ed. Elizabeth Fee and Daniel M. Fox, Berkeley: University of California Press, 1990.
[8]Ibid., pp. 27-52.

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also be influenced by the culture of their own time.

The CDC's approach violated an important principle in the history of epidemiology defined as the search of common behavior patterns leading to disease transmission. The old *Kinsey Report* had already demonstrated that homosexuals and heterosexuals alike engage in virtually the same sexual practices, the only difference being the sexual partner. (Kinsey, 1948) *Cunnilingus*, a potential route of transmission, can be equally practiced by lesbian, heterosexual or bisexual couples. Whether homosexual or heterosexual, individuals who engage in these types of activities without precaution risk infection equally.

A statement by James Curran, Head of the CDC' s Venereal Disease Prevention Division, may partially explain why CDC researchers were hesitant to list sexual practices: "It was apparent that some research scientists were completely ignorant about the sexual habits of homosexuals."[9] The other reason was obviously the constant pressure of the administration and conservative groups to prevent this type or research.

It is through a long study of Hepatitis B that the CDC started to know more about gay male sexuality. Yet, women and lesbians in particular remained invisible.

CDC scientists knew before the identification of the virus in 1983 that, people were suffering from specific opportunistic infections, which, as their name indicates, take advantage of a weakened immune system. After the discovery of HIV, they defined AIDS as the presence

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[9]Talbot and Bush, *At Risk, AIDS: Downplaying the Plague.*

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of the virus in the person's body, along with any of the opportunistic infections and cancers listed by the CDC.

The identification of HIV, however, did not fundamentally change the paths of research. Although the name was different, and the knowledge increased, the profile of the typical person with AIDS, in the minds of the CDC's epidemiologists, was still gay white male.

In 1985, the CDC changed its 1982 definition by adding HIV and some cancers. Yet the change was minimal since it affected only less than one percent of previously reported cases and added only 3-4% of new cases.

The same year, the U.S. Government, through NIAID, began a study--Multicenter AIDS Cohort Study (MAC)--including over 5,000 gay/bisexual men, most of them white and not injection drug users--a study which is still ongoing. Women will have to wait a decade before a large scale study was even conceptualized.

Because of new prophylaxis and treatment certain opportunistic infections had started to decline, leaving the way to others such as HIV Wasting Syndrome or HIV Dementia, which were believed to be end-stage infections, likely to occur just prior to death. The CDC definition soon proved too narrow and led the agency in 1987 to revise its 1982-surveillance definition with changes in both the adult and pediatric definitions. For adults, additions included HIV encephalopathy, HIV Wasting syndrome and certain lymphomas, perceived as more advanced stages of the disease. In addition, the CDC added diagnoses made presumptively (without having to do laboratory tests) when the person was found to be HIV positive. The presumptive conditions included esophogeal candidiasis, CMV retinitis with loss of vision,

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Kaposi's Sarcoma, Mycobacterial disease, PCP and toxoplasmosis of the brain.

This revision had a significant impact on reported cases of AIDS. Expanded, CDC-defined AIDS allowed numerous people to pass from the category AIDS-Related Complex (ARC)-milder HIV-related conditions-to AIDS. (SEE APPENDIX FOR EXPANDED DEFINITION) Placed in the new category, those same persons could benefit from Medicaid (for which most people with ARC did not qualify) and participate in more adequate drug protocols. In fact, to many activists, the distinction between ARC and AIDS is a questionable one, for many individuals with ARC, many of whom are women, die without ever receiving a diagnosis of full-blown AIDS. According to the activists:

> Symptomatic HIV-related disease should become the term used in determining eligibility for medical, housing and social services. Anyone with an HIV-related condition which causes partial or total disability should be able to get benefits. All conditions now known as ARC would be subsumed under the new definition, and so would conditions like endocarditis or tuberculosis if found in HIV-infected drug users, gynecological conditions found in HIV-infected women. CDC-defined AIDS should be widened to include all complications of HIV which can cause illness or death. City surveillance should be expanded accordingly.[10]

[10] ACT UP, *ACT UP Hand book*, Unpublished Document, 1989.

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Despite CDC estimates that there are ten times more ARC than AIDS patients, that as many as 30 to 50 times more ARC patients might eventually develop AIDS, and that ARC patients are probably the most promising candidates for medical intervention, there is no listing of ARC cases.

In the first year following the revision, the percentage of persons who were reported to the CDC as having AIDS and who were intravenous drug users, both homosexual and heterosexual, increased to 43%. Blacks increased from 24-36%, Hispanics from 13-16% and women from 2.6-3.6%.

As of 1989, nationally, approximately 30% of new cases fit only the 1987 definition. In the latest New York City Surveillance Report of cases diagnosed since January 1990, 30% of all cases fit only the 1987 revision. Furthermore, 38% of IDU cases fit only the 1987 definition and 26% of heterosexual transmission cases fit only the 1987 definition.

The CDC itself recognized that

> Compared with patients who meet the pre-1987 definition, a higher proportion of patients who meet only the 1987 definition were female, black or Hispanic or were intravenous drug users."[11]

The dramatic increase was accounted by the fact that most people with AIDS, who did not have a family doctor and used clinics, could

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[11]HIV/AIDS Surveillance Report, August 1990.

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now be presumptively diagnosed. In addition, the opportunistic infections, now allowed to be presumptively diagnosed, were end stage infections, the diagnosis of which would often occur after death.

Yet despite these additional cases, recent studies indicated that 35-40% of the serious HIV-related diseases treated in hospital in-patient settings do not fit the CDC definition of AIDS.[12] And, in one CDC study of the death certificates for women which listed HIV/AIDS, 48% died from conditions not listed in the DC definition.[13]

In addition the CDC itself admits that:

> diagnosed AIDS cases do not represent all cases of severe morbidity associated with HIV infection. Many HIV positive persons suffer from illnesses that are not reportable as AIDS even under the current definition and some persons may not have access to medical or diagnostic care. The number of persons with severe HIV related morbidity exceeds the number of diagnosed AIDS cases.[14]

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[12]New York City Department of Health AIDS Case Projections, 1989-1993.
[13]Chu, S. et al. *Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States.*, Journal of American Medical Association, July 11, 254(4): 225-229, 1990.
[14]Mortality Morbidity Weekly Report Supplement *AIDS and Human Immunodeficiency Virus Infection in the United States*, 1988 update, 5/12/89.

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WOMEN-TO-WOMEN TRANSMISSION: IMPOSSIBLE SAYS THE CDC

Until now, the CDC has not listed women-to-women transmission, the direct consequence of which is the greater rate of unexplained transmission among women as compared to that of men. According to the CDC itself, the rate of unexplained transmission among women was 8% versus 2.3% for men. Still, from 1981 to 1984, there were 101 reported cases of AIDS in which the women self-identified as lesbians or bisexual. The CDC decided not to collect this information any longer because there were not enough cases. While many cases of lesbians with AIDS are among lesbians who are also or were intravenous drug users, there have been documented cases of women to women sexual transmission.[15, 16, 17, 18]

The most obvious way a women may transmit HIV to another woman is through oral-vaginal unprotected sex during menstruation. Yet, this type of blood is not considered as regular "blood" by the CDC.

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[15]Ribble, D. *HIV Infection in Lesbians.*, Poster presented at the 5th. International AIDS Conference, Montreal, 1989.
[16]Cohen, J.B. and Wofsy, C.B.: *Women and IV Drugs: Parenteral and Heterosexual Transmission of Human Immuno-Deficiency Virus*: The Journal of Drug Issues, , 19:39-56, 1989.
[17]Marmor, M., Weiss, L.R., Lyden, M., Weiss, S,H., Saxinger, W.C., Spira, T.J., and Feorino, P.M. *Possible Female-to-Female Transmission of Human Immunodeficiency Virus* (Letter): Annals of Internal Medicine: 105:969.
[18]Mondanaro, J.: *Treating Chemically Dependent Women.*, Lexington Books, 1988.

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SEX WORKERS: HISTORICAL SCAPEGOATS

In contrast, health officials have concentrated their attention on prostitutes whom they thought are transmitters of the virus. In Nevada, the only state that regulates prostitution, all prostitutes must submit to HIV testing. It is a felony for a prostitute to work after she or he is informed of a positive test result. These laws do not distinguish between high risk sex and no risk sex. Almost no laws require proof of transmission. Yet studies done on prostitutes show that they are not anymore likely to be infected than women who are not in the sex-industry. In fact they tend to become infected from their lovers, while they use protections with their customers. Along with gay and bisexual men and IDU's, prostitutes have been blamed for AIDS. Yet most professional sex workers routinely use condoms for both oral and vaginal sex.[19] In fact sex workers are far more likely to practice safe sex than other sexually active women.[20] And studies have shown that women, who are paid for sex, do not contract HIV more than women who are not.[21]

Yet history keeps repeating itself. During World War I, the government quarantined over 30,000 women in response to soaring numbers of syphilis cases, rather than distribute condoms to servicemen.[22] Any woman under suspicion was forced to test for venereal diseases, with devastating personal consequences. Syphilis

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[19]Federick Delacoste and Priscilla Alexander,eds., *Sex Work Writings by Women in the Sex Industry*, Pittsburgh, PA: Cleis Press, p.189, 1987.
[20]Ibid, p.248.
[21]Ibid, p.33.
[22]Allan M. Brandt, *The Syphilis Epidemic and Its Relation to AIDS*, Science, vol. 239, p.377, January 1988.

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rates continued to soar.

Therefore, besides the numerous studies that focus on women working in the sex-industry or women as vector of transmission, the absence of statistical information on the way the disease develops in women illustrates the total lack of interests the CDC has displayed concerning the impact of HIV on women.

THE COMMUNALIZATION OF FEMALE AIDS EPIDEMIOLOGY

Activists demanded an epidemiology that takes into account the cultural environment in which risky behavior may occur. Data collected this way would not only assess the prevalence of the disease, but also help set up preventative programs. Such an epidemiology would logically require the input of the communities affected, which the CDC was thus far unwilling to accept.

A real preventative approach would require data on early stages of the disease, which the CDC was not ready to effect. Only interested in terminal cases, the federal agency ignored the sometimes very slow progression of the disease. Until now, the CDC has not reported opportunistic infections or only at the end-point of AIDS. With these omissions, the federal agency was really breaking away from its traditional multifactorial paradigm. Indeed, epidemiology has always been interested in the impact of socio-cultural factors in the spread of diseases. In the case of AIDS, the CDC adopted a position closer to that of virologists whose interest lies more in the deadly aspects of the disease. This criticism is echoed by the Presidential Commission on AIDS in June 1989 which stated that:

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> Medical, municipal, political and community-based organizations must direct their attention to the total course of the HIV infection rather than concentrate their attention on the last stages of AIDS. Attention focused on AIDS rather than the whole spectrum of HIV-related diseases has made our nation unable to deal with this epidemic.[23]

To be sure, the Commission was not hired by the government to coalesce with the activists.

The irony is that before the discovery of the virus, patients were identified by those very opportunistic infections. Kaposi Sarcoma had been diagnosed in twenty-six male homosexuals in 1981 and although no real research was conducted on this cancer, it stirred interest among the medical community.

Upon the discovery of the virus, the CDC dropped its interest in opportunistic infections, important markers in the pathogenesis of the disease, and started to focus its energy on the final aspects of the disease. The yet-to-be proven assumption was and still is that HIV causes AIDS.

In conclusion, the CDC perceived the epidemic as affecting only certain segments of the population, the "general population" being immune to the virus. In addition to minimizing AIDS expenditures and AIDS prevalence, the activists claim, the government perceived

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[23] Presidential Commission on AIDS in June 1989.

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the populations infected as "expendable," thus denying them the treatment usually granted the socially defined "average American." They take history as proof. When Legionnaire's disease was identified in 1976 or the Tylanol scandal broke out in Illinois in 1982, emergency funds were released almost overnight.

The data collection of the CDC was heavily criticized even by the General Accounting Office which audits the work of other federal agencies, and concluded that: "The CDC underestimated by 40% the number of persons with AIDS." With over 160,000 declared cases, more than 40, 000 people had never been counted with the very definition of the CDC itself.

A partial explanation for this difference is offered by Sandra Panem:

> Under current procedures, only the states, through their police powers, can make a disease reportable. As there are fifty states, there are fifty different reporting providers. It is the states that decides what will be reported. CDC has no authority to require reporting, nor can it impose penalties if its requests are not met.[24]

Sandra Panem concludes:

> Thus the process by which a disease becomes

[24]Sandra Panem, *The AIDS Bureaucracy*, p. 48, Cambridge Mass.: Harvard University Press, 1988.

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> reportable, thereby allowing the collection of data needed to develop a national strategy, require voluntary cooperation of a myriad of institutions, each using unique procedures.[25]

The CDC estimates that there are presently between 945, 000 to 1.4 million seropositive people in the United States. Epidemiologists project that in 1992 there will be 365,000 people with full blown AIDS, but only 80,000 cases will be declared.

It is important to specify that ACT UP was never for mandatory testing or reporting. Activists wanted people with AIDS, in particular women and injection drug users with serious and life-threatening illnesses, to have their opportunistic infections count as AIDS.

According to New York City AIDS Surveillance Unit statistics, AIDS is now the leading cause for women aged between 25 and 34 in New York City, and women represent 10% of all cases of AIDS in the country placing it fifth in the list of lethal diseases for all women aged between 15 and 44. Women die twice as fast as gay white men and women of color die ten times as fast as gay white men. Their death rate from AIDS quadrupled from 1985 to 1988. Even the Centers for Disease Control in Atlanta has declared AIDS "a leading cause of death in women of reproductive age." Most women with AIDS (not to mention those with HIV illnesses not officially recognized as AIDS) are mothers. Unofficial estimates range from "over 50%" to 99%. Yet CDC does use those statistics to plan HIV services nationwide.

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[25]Ibid.

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THE CENTERS FOR DISEASE CONTROL BESIEGED

To translate their anger into creation, women in ACT UP organized teach-ins on Women and AIDS within ACT UP, which eventually became a book *Women, AIDS and Activism* published in the Fall of 1990 by South End Press, by far the best piece on the matter. The teach-ins and subsequent research formed the basis for the first CDC action.

On the 5th of January, 1990, activists went to Atlanta and in conjunction with ACT UP/Atlanta, they protested in front of the CDC. About two hundred people participated and fifty arrests were made. Reminiscent of 1960's demonstrations, civil disobedience actions such as die-ins at the foot of one of the CDC buildings or sitting across the street to block the traffic, were used to cause disturbance, dramatize the event, and obtain more media coverage. For example a flag was hoisted on the flag pole that read: Cunnilingus Counts and an affinity-group--the Condams--staged a die-in bringing attention to the gynecologic infections of HIV.

Activists were able to meet with the CDC scientists. When asked by a French reporter what type of research was undertaken concerning lesbian and AIDS, the CDC official responded: "We are studying a number of lesbians artificially inseminated with the sperm of gay men." With those few words, he confirmed one of the theses of this chapter: the CDC officials were still conceptualizing the disease as gay-male specific.

Women's second attempt failed. When they presented data on women's opportunistic infections and their correlation to AIDS, the

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administration--including Gary Nobles, Deputy Director of HIV at the CDC--remained motionless. As a result, another demonstration at the CDC in Atlanta was scheduled on the 5th of December 1990 to coincide with World AIDS Day, the theme of which was Women and AIDS. Over 500 people, from around the country--including large contingents of women from HIV support groups--attended the demonstration. Over one hundred people were arrested, and fifty of them were dragged out of Gary Nobles' office. Women with HIV organized a speak-out, announcing to the nation what it means to be a woman with HIV.

The ACT UP CDC Working Group, who wrote a critique of the CDC AIDS epidemiology, sent a "Call to change the CDC surveillance Case Definition of AIDS" to thousands of groups around the country. Some activists took over the office of Gary Nobles, Deputy Director of HIV. They demanded that the CDC definition be modified to include both women's and injection drug users' opportunistic infections. One activist changed Nobles' answering machine message to: "Gary Nobles' office is being taken over by ACT UP. Change the definition of AIDS!."

After ample negotiation, in August 1991, the CDC decided to expand its definition of AIDS by including PWAs with a CD4 count equal to or below 200, and also by including the opportunistic infections specific to women. Still, instead of making CD4 count part of the surveillance system, the CDC made it part of its classification system. This system is intended for clinical management and not for surveillance purposes. The classification system is not used for national listing. Therefore, the list of opportunistic infections in the monthly surveillance reports did not change. In addition, women's OIs were included in the B-list, which defines ARC cases only, and do

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not entitle PWAs to benefits.

This modification was far from satisfying the activists. They argued that CD4 counts are inaccurate, unreliable, and costly. Indeed research shows that a measured T-cell Count of 150 could really indicate a count of as low as 89 or as high as 292.[26] Furthermore, its use is not covered by legislation requiring anonymity or counseling. Insurance companies can use it to discriminate against individuals with t-cell counts below 200. Finally, CD4 count has no predictive value. In fact, this definition, the activists argued, was developed as a compromise between those favoring mandatory HIV reporting and those against it, in the last minutes of a meeting of the Council of State and Territorial Epidemiologists.[27]

The CDC working group became more determined than ever to force a significant change in the federal definition of AIDS. They organized a postcard campaign, beginning what would become one of ACT UP's largest endorsement campaigns. ACT UP/New York sent one thousand postcards with a picture of James Curran with a bright orange target above his head. Postcards read: "Hey Curran! We are sick of meeting with you--these are our demands: Change the definition, support anonymous testing, stop stigmatizing people's identities, and study routes of transmission instead."

On an ACT UP Women's Network Conference call, the CDC-Working Group of ACT UP/New York, in March 1991, decided to refuse meetings with the government regarding the AIDS definition

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[26]CAMACS Report, Data Working Group Meeting, 9/12/91.
[27]Maxine, Wolfe, *Testimony Before the National Commission on AIDS, December 9, 1991. Hearings on the Proposed Revised Classification System for HIV Infection and Expanded AIDS Surveillance Case Definition for Adolescents and Adults.* Unpublished Document, 1991.

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and instead educated and organized as many people as possible about the issues. The same month, the CDC-Working Group obtained the endorsement of officials such as Ruth Messenger--Borough President of New York City--and San Francisco Mayor Art Agnos for their "Call for the Immediate Revision of the CDC's AIDS Definition."

A teach-in was organized in April 1991 at the Graduate Center of the City University of New York, followed the next month by an action held at Federal Plaza in lower Manhattan to protest the definition. About five hundred ACT UP/New York members attended the demonstration, carrying big signs that read: "The CDC is a Dead End and Undercounting AIDS Cases Kills." Other actions were held at the same time by other ACT UP's throughout the country.

As the demonstration was unfolding, a Working Group-based affinity group took over the office of Norman Miller, who was a CDC employee deployed to the New York State-Department of Health AIDS Surveillance office to help keep track of the epidemic in New York. About 16 people were arrested. The next day, another group of 10-15 activists descended on the office again, forcing Norman Miller to vacate the premises for the day. The day after, another group went back to his office. Each group attempted to remain in the office until the demands were met, one of which was that he sign the endorsement letter for the change of the CDC-AIDS definition.

In June 1991, groups around the country staged actions at their local CDC offices, and while the 7th International Conference on AIDS was unfolding in Florence, Italy, ACT UP placed an ad, endorsed by 300 different groups, in The New York Times: "Women Don't Get AIDS. They Just Die of It."

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That same month, the New York State Assembly and both Houses of the Maine Legislature passed a resolution--written with the help of women in ACT UP--addressed to President Bush and Louis Sullivan, Secretary of HHS calling for a change in the definition of AIDS by the CDC.

Dr Alan Greenberg, CDC HIV epidemiologist who assists AIDS surveillance at New York State-Department of Health was invited to speak in August 1991 on "The Changing Face of AIDS." The CDC-Working Group zapped him, and demanded that he sign the Call for the Change of the CDC-AIDS Definition. He refused to sign "under duress." As the endorsement campaigned is pursued throughout September of 1991, the CDC-Working Group decided to meet with William Roper--Director of the CDC--as he arrived at JFK Airport. Activists carried signs and flies reading: "Big Fat Liar". Those same banners will be used during a conference that Roper attended at the New York Academy of Medicine.

Near the end of 1991, the CDC finally gave in to the pressure of female activists to design a pilot study at four sites--New York, Detroit, Baltimore and Providence), which will use the data collection plan and instruments that eventually will be modified and used for the Women's Interagency HIV Study (WIHS). The WIHS will be conducted in 1993 by the National Institute of Allergic and Infectious Disease (NIAID). Before the WIHS, two other studies about women and AIDS had been conducted--the Heterosexual AIDS Transmission Study (HATS) and the Women and Infant Transmission Study (WITS). HATS is not a transmission study because no woman seroconverted. WITS showed that HIV positive women had gynecological infections.

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For example 57.3% of the women had vaginal candidiasis; 26.2% have unusual headaches and while 11% of the women had CD4 counts below 200, only 5% had experienced a CDC-AIDS defined symptoms.[28] But even the WITS study does not ask questions about menstrual difficulties. The questions about sexual practices are not specific enough, and women are all assumed to be heterosexual. Thanks to activist pressure, NIAID will not repeat the same mistakes in WIHS.

At the ACTG's meeting of January 1992, the ACT UP Network's Women's Issues Committee sent a letter to Connie Woofsey of the ACTG's Full Women's Health Committee, asking the Committee to take a stand regarding the expansion of the AIDS definition. During the meeting, women activists handed out their last critique of the CDC definition. They also pointed out that a young man of 25 years old with Kaposi Sarcoma, a rare form of cancer, led researchers to use KS as an AIDS defining condition. Researchers were therefore guilty of sexism for not using the case of a 16 years old girl with cervical cancer as AIDS-defining for women. They cited Mitch Maimon's research as scientific documentation.

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[28]Maxine, Wolfe, ACT UP Network Women's Issues Committee Meetings with NIAID (National Institutes of Allergy and Infectious Diseases) Epidemiology Branch, December 3, 1991, and December 6, 1991, Unpublished Document.

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FEMALE AIDS RESEARCH: FEMALE MICE HAVE BEEN MORE RESEARCHED THAN HUMAN FEMALES

The flawed epidemiology of the CDC had a tragic impact on female AIDS research. Used by research centers which are federally funded, CDC-defined AIDS entails the elimination of whole communities of people infected with the virus from the research protocols. They are excluded from the drug clinical trials, which for the majority of persons with HIV in the United States are the only hope to obtain medical care. The United States with South Africa are the only two industrial nations that do not offer a national health care system.

Thus, the percentage of women enrolled in ACTG drug trials in August 1988 was about 5%. Of the 200 women included in drug trials in 1988, 72% were enrolled in AZT trials, a drug they could have obtained without entering a trial. By the end of 1989, a review of trials as published by the American Foundation for AIDS Research reveals that there were still trials excluding women or requiring infertility.

Some drug trials explicitly exclude women, because FDA regulations allow the exclusion of women of "child bearing potential." The reasons given by the FDA are that women have historically been thought to be undesirable research subjects in clinical trials for non-reproductive oriented drugs; women exhibit cyclical hormonal fluctuations which may influence the results of clinical trials; the drug may only be good for men since men and women have hormonal differences; women may become pregnant which results in the loss of a test "subject" and puts the fetus at risk; and the disease may be different in women than and men.

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While each of these statements is true, the conclusion should be different. In fact, it would be more sound to include women to study the differences.

In addition, almost all ACTG trial use male levels of hemoglobin as entry criteria. They use a level of liver enzyme which excludes IDU's. They do not allow people with active disease in trials.

Even when women are recruited, they are not usually recruited in large enough numbers so that the inferences are statistically significant.

It is clear that under these guidelines the risk to women in taking a drug is not discovered until the drug is released which exposes many more women to risk than the trials themselves. AZT, for example, was tested on female mice and in December, 1989, Burroughs Wellcome researchers found out that the drug had carcinogenic effects on the reproductive system of the females.

These guidelines are designed to protect the fetus and to protect the government and pharmaceutical companies from liability resulting from potential "damage" to the fetus, but leaves the woman totally unprotected.

During the AIDS Clinical Trial Groups' meetings of January 31, 1992, women organized two actions around the exclusion of women and injection drug users (IDU's) from clinical trials. They attended the session on Foscarnet--drug used against CMV. At the end of the presentation they presented a slide and read it aloud:

> This drug is nephrotoxic. No IDU's were allowed in this trial. IDU's are: 51% of women with CDC-

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> AIDS; 39% of people of color with CDC-AIDS; 10% of gay/bi men with CDC-AIDS. This drug costs $30,000 per year. NIAID: Test Drugs for All PWA's.[29] (Emphasis original)

The second action consisted of a small affinity group, who had made fortune cookies, which they placed on the tables for the coffee break. As they broke the cookies and unfolded the papers, researchers could read: "Congratulations, your research has not saved the life of one PWA."; " It's 1991. Is there a gyn oncologist on your team? Can you say vagina?" "Large randomized trial designs will never tell us anything about women." "Why isn't your trial accruing?" "Why are so many women dying of lymphoma?"

CLINICAL TRIALS OPEN TO WOMEN ARE NOT OPEN TO WOMEN

In general, only women, who are willing to undergo a hysterectomy (removal of uterus) or sterilization, can enroll in clinical trials.

If they decide to go ahead and enroll in a clinical trial, women may be hindered by the location of the clinical trial. Indeed, of all the AIDS clinical trials, 74% are in NYC. There are none in Newark, New Jersey where 27% of all AIDS cases are women.

Women may be excluded also because of costs involved. In some trials patients must pay for their own preliminary physical

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[29]Maxine, Wolfe, the ACT UP Network Women's Issues Committee at the December ACTG Meetings, January, 1991, Unpublished Document, p.2.

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examinations and tests.

Finally, the lack of child care may also exclude women from clinical trials. As they were meeting with the National Institutes of Allergy and Infectious Diseases, the Epidemiology Branch, activists from the ACT UP Network's Issues Committee Meetings proposed that mobile research team be constituted to reach women, who could not commute to the research centers.

076: THE CLINICAL TRIAL THAT EPITOMIZES THE MEDICAL THE MEDICAL ESTABLISHMENT'S GAZE AT WOMEN

New trials have opened for pregnant women. Yet these are geared to give treatment to the fetus, not the mother. 076 for example tests if AZT, using escalating dose slows down vertical transmission, that is prenatal transmission in 700 women. Women AIDS activists find this trial totally unethical, because as already mentioned, AZT is carcinogenic to female reproductive organs. And, a pediatrician, but no gynecologist, sits on the review committee of 076. In addition, the pediatric ACTU's do not have Community Advisory Boards, so that no activists can monitor directly the conduct of this trial.

During the ACTG's meeting of January 31, 1992, the Principle Investigators indicated that to be effective the drug should allow a 10% HIV transmission rate. Yet their baseline was 30 to 40%, which is the regular rate of vertical HIV transmission. Female activists argued that HIV positive women usually take AZT, which should already lower the level of transmission. The baseline then should be different. Further, they argued that a European study showed that with good

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perinatal care the transmission rate would be as low as 15%. They then questioned the usefulness of 076.

Controversy around 076 also reflected how differently from male, female activists are treated by the researchers. When male activists deal with researchers they are generally assumed by those researchers to be HIV positive. When female activists deal with the researchers, they usually have to face blatant sexism and lesbophobia of these researchers. The assumption is that the woman is a lesbian, HIV negative, has never been pregnant. As a white woman AIDS activist started criticizing ACTG 076 during the ACTG meetings in the Spring of 1991, the researcher responded: "

> You wouldn't understand. These women are pregnant. These women care about their children. But you wouldn't understand.[30] (Emphasis original)

The white woman activist, who identified as a lesbian, responded:

> No, you don't understand. I found out I was HIV positive when I was 6 months pregnant and I gave up my child so that she could have someone to raise her when I die and I still think this trial is unscientific and unethical.[31] (Emphasis original)

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[30]Maxine, Wolfe, The ACT UP Network Women's Issues Committee at the December ACTG Meetings, Unpublished Document, January, 1991.
[31]Ibid, p.1.

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Pregnant women may also be pressured to have an abortion. This is a Catch 22 since there are very few clinics which will perform an abortion for an HIV+ woman who wants one. Among all the states, 37 do not allow public funds to be used for abortions because of the Hyde Amendment, which left it to the States to fund abortion.

When pregnant women are drug users, there is virtually no treatment program in NYC and only four or five in the country. And there is total lack of data regarding the pharmacokinetics of AZT in male or female drug users (See Section on IDU.)

In conclusion, women cannot enter clinical trials because they are defined by the biomedical establishment primarily through their reproductive system.

WOMEN BESIEGE CONFERENCE AND DECLARE BILL OF RIGHTS FOR WOMEN AND HIV

Upon consistent refusals by Dr. Daniel Hoth, Director of the ACTG system, to receive women activists, a sit-in was organized at his office during the storming of the National Institutes of Health, in May 1990. The sit-in was organized by an ACT UP N.Y. and ACT UP/D.C. lesbian and gay affinity group as well as an all women's affinity group--Invisible Women--at the NIH Campus. Civil disobedience resulted in twenty arrests. In addition, letters were sent and phone calls to request an appointment with Dan Hoth and Anthony Fauci remained unanswered. Therefore, a few months later, right in the eyes of an audience of 5,000 spectators, a "zap" of Daniel Hoth was organized during his speech at the 6th International Conference on AIDS in San

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Francisco in June 1990. Banners read "NIAID Form a Women's Committee Now." Another demanded the creation of a Conference on Women and HIV. These actions finally yielded the meeting requested.

Reportedly, scared by further image-wrecking strategies, Hoth agreed to stage the first governmental Conference on Women and HIV, free of charge and including child care, in December of 1990.

The conference attracted 1,200 participants. Disappointed by the basic level of the speeches, a couple of hundred of women invaded the stage, and took the microphone away from James Curran. HIV positive women and their allies demanded changes in the CDC definition, changes in the disability regulations and the inclusion of women in clinical trials. At the same time, the first *Women's Research and Treatment Agenda* was being circulated. Chants were reminiscent of the storming of the Montreal Conference in 1989. The second day of the Conference, a Bill of Rights for Women with HIV and AIDS was declared.

DIFFERENT AIDS SYMPTOMATOLOGIES FOR DIFFERENT PHYSIOLOGIES

Given the lack of information on women and AIDS, ACT UP/New York, in conjunction with other AIDS organizations, undertook their own education by producing a critique of the CDC-AIDS definition and federal AIDS research-*Women's Treatment and Research Agenda* (ACT UP Women's Network, 1990). This handbook revealed to many women how they could be differently affected by the virus.

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Transmission as well as the effect of the virus on women depend on their physiology. Thus, transmission occurs when semen, blood, (including menstrual blood) and vaginal discharges enter the bloodstream through the mouth, anus, vagina or any opening in the skin. Vaginal secretions, sweat, tears and saliva are not considered high risk, because the concentration of HIV is low. On the other hand, vaginal discharges, e.g. yeast infections, do have a high concentration of white blood cells which, if a woman is HIV infected, could harbor enough HIV to create a risk. The problem is that most women have small vaginal infections quite frequently and often do not know about them.

Female activists recommend that women should learn to examine themselves by using a plastic speculum and a flashlight and a mirror; by having their partner look at their labia before they engage in oral sex, they can identify infections and other conditions such as sores, bleeding or cuts that may increase the risk of being exposed to or transmitting HIV.

Women can also transmit the virus by breastfeeding their child (studies are underway, but it is recommended not to breastfeed the child if the woman is HIV positive). Studies show however that 75% of the children will receive the mother's antibodies and only 30% will go on developing the CDC defined opportunistic infections. It is only 15% in countries where good prenatal care is provided.

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BIOLOGICAL DIFFERENCES BETWEEN WOMEN AND MEN

AIDS is a syndrome or a condition which is defined by its symptoms. This set of symptoms differs and keeps changing, depending on who contracts the virus. AIDS symptomatology may depend on one's state of health, mode of HIV transmission, endocrine differences, age, geographic location, economic status, to name a few variables.

Women are subject to unique organ-specific diseases and conditions (e.g., pelvic inflammatory disease (PID), endometriosis, uterine tumors, cervical cancer and vaginal candidiasis), and a higher incidence of some diseases (e.g., simple urinary tract infection, breast cancer, human papillomavirus infection [HPV], MAI). For example, Dr. Mitch Maimon, a gynecological oncologist from State University of New York downstate clearly demonstrated that that HIV positive women had higher rate of cervical cancer and more advanced stated. His research showed that the youngest case of cervical cancer was a young girl of 16 years of age. In addition, Maimon showed, that women with HIV are more likely to have high grade as opposed to low grade cancer, their lesions are multifocal rather than unifocal and those lesions tend to be at more than one genital site. Maimons' research revealed that women with HIV had multiple types of HPV.[32]

Women die of complications related to pregnancy and to diseases of reproductive organs (e.g., cervical breast, ovarian, and uterine cancers). The incidence of ectopic pregnancy (a pregnancy that

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[32]Maxine Wolfe, ACT UP Network Women's Issues Committee at the December ACTG Meetings, January 31, 1992.

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grows outside of the uterus, usually in the fallopian tube) has increased dramatically since 1970, and this reflects, generally, an increase in sexually transmitted disease (STDs). STDs such as gonorrhea and chlamydia often cause asymptomatic infection in women who later develop a condition called pelvic inflammatory disease. This acute problem often leaves scar tissue in the genitalia tract and greatly increases the risk of ectopic pregnancy, which in turn can rupture, causing hemorrhage and death.

Both men and women contract STDs, but the symptomatology is different. In gonorrhea and chlamydia there is often a long silent phase in women (sometimes from three to six months), whereas men frequently show symptoms much sooner, such as a drip or burning during urination.

Further research is needed to know what increases a woman's risk for HIV infection. What is known is that a woman with an STD, a genital ulcer disease (herpes, chancroid, syphilis, lymphogranulaom verum), condyloma (warts), or cervical dysplasia (an abnormal pap smear result) is at increased risk of acquiring HIV if exposed.

Besides persistent vaginitis, we know very little about how women are affected by HIV. Chronic vaginitis, especially recurrent monillia or yeast infection, was noted in 24 percent of HIV positive women in one study. Of these women, 86% progressed to AIDS.[33]

The mechanisms of exposure differs where vaginal intercourse occurs. The cervix, which at certain times of the month allows the

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[33]J.L. Rhoads et al., *Chronic Vaginal Candidiasis in Women with Human Immunodeficiency Virus Infection*, Journal of the American Medical Association, Vol. 257, no. 22, pp. 3105-3107, June 12, 1987.

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sperm to travel into the uterus, is susceptible then in a unique way to infection. Any condition affecting the health of the vagina, genital tract, and rectum undoubtedly affect transmission rates and degree of exposure in all women.

Despite all those obvious biological differences, the opportunistic infections contracted specifically by women were never included neither in the national CDC definition, nor in the international classification system.

Given the biases of the CDC definition of AIDS, women are more likely be diagnosed with ARC than AIDS. They consistently die of ARC without being diagnosed with AIDS. In New York City alone about 50% of those hospitalized for AIDS/ or HIV-related reasons, are chronic ARC patients. It is difficult to determine which opportunistic infections affect women in particular, because neither the CDC nor the NYC AIDS Surveillance Unit give exact breakdowns of opportunistic infections by gender, and the number of people who are affected by ARC is unknown because only AIDS diagnoses are tracked statistically.

Studies have shown a strong correlation between vaginal infection and HIV-seropositivity. In her Newark-New Jersey study Dr. Patricia Kloser reported that out of a pool of 400 women with AIDS, "more than half had gynecological symptoms, including 25% with chronic vaginitis and 7% with PID (pelvic inflammatory disease) that is often so severe as to require immediate hospitalization. Associated with gynecological infections are the problems of syphilis and other STDs.

Health officials themselves recognize the need to include vaginal infections in the AIDS definition for women: "Sten Vermund,

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Chief of the Epidemiology Division for NIAID (National Institute for Allergy and Infectious Diseases) believes that advanced HPV (Human papillomavirus) should be considered an AIDS-defining opportunistic infection, but medical professionals refuse to take this seriously.

The CDC claims that the diseases activists wanted added to the definition affect other women as well and there is no causal relationship between those infections and AIDS. Yet gay men contracted many of the OIs they contract with HIV before they contracted the virus, such as syphilis or gonorrhea.

Another argument used by the CDC is that those infections are not life threatening. But neither are some of the OIs contracted by gay men. If they use prophylaxis or other treatments they can survive many opportunistic infections.

In addition to the opportunistic infections listed above, recent research bears out the claims AIDS activists' claim that a list of possible HIV-related infections includes: Syphilis, salmonella, herpes(simplex/zoster), toxoplasmosis, CMV-urinary tract or genital infection, tuberculosis, obstructive pulmonary disease, septicemia, rare parasitic infection chronic obstructive pulmonary disease, pelvic inflammatory disease, chlamydia.

The lack of acknowledgment of women specific opportunistic infections also has repercussions for women's ability to monitor their own health, and for health care provider to be alert to and diagnose AIDS in women before they are so sick and they die quickly. Yet it has been shown that women receiving primary health care live longer than those who do not. In contrast, the CDC pushes for "routine testing", confidential testing, mandatory testing, partner notification

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and contact tracing. According to Maxine Wolfe from ACT UP New York:

> If we consider that women died of AIDS six times as fast as men in 1990, it is clear that women are diagnosed too late to receive vital medical treatment. And minority women have presently the fastest rate of infection.[34]

Pressured by activists to study the disease among people other than gay men, the CDC claimed that a new study-the Spectrum of Disease Studies- would include women. The sites of the study were Atlanta, Dallas, Detroit, Seattle and Denver. Yet, they did not include Newark, Brooklyn, Miami, San Juan or other cities with the largest numbers of reported cases for women or intravenous drug users.

In Atlanta, representatives of ACT UP were allowed to participate in the design of the study. As a result, that particular site provided 60% of the female participants. Yet activists realize that, despite their repeated requests, only 7% of the 4,000 individuals involved in the study were women. Activists also found out quickly that the CDC was not interested in collecting data on vaginal thrush because many of women would get it.

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[34]Maxine Wolfe, *CDC Working Group Fact Sheet*, Unpublished Document, 1990.

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VIOLENT SEXISM INCREASES WOMEN'S RISK OF INFECTION

If women can contract the virus, they should, like men, engage in safe sex. Dental dams (first designed by lesbian activists) are now widely recommended, or else latex glove and condoms. In Europe, a condom for women has been devised, but its commercialization is awaiting in the U.S.

Knowing what the risks are is not enough for women. Many times they have to negotiate safer-sex with their male partners. It is difficult in a society where women are taught that the pleasure of their male partner comes first.

Violence against women is one of the most heinous aspects of a male dominated society. One out of three women in the United States will be raped during her lifetime.[35]

In this context, negotiating safe sex may become very dangerous for a lot of women.

HETEROSEXISM INCREASES LESBIANS' RISK OF INFECTION

Although Randy Shilts begins his chronicle of AIDS-*And the Band Played On*-with the 1976 case of the Danish lesbian surgeon Grethe Rask, who became ill working in Zaire (Shilts, 1988), the CDC and other professionals took a long time before understanding that lesbians could be at risk. Here again cultural bias is at the root of the problem: James Curran, Head of the CDC' s Venereal Disease

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[35]Federal Bureau of Investigation, *Uniform Crime Report: Crime in the United States, 1980*, p.15.

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Prevention Division asked: "Do lesbians have sex?" (Wolfe, 1991.) And one gay male writer went as far as saying that lesbians-those who are AIDS activists-had AIDS envy.[36]

Yet, like many straight women, some lesbians are drug users and share needles; some have been married; some have babies; some are in prisons, some have sex for money, and some get raped. Some women who self-identify as lesbians still have sex with men. According to an ongoing Kinsey study 46% of the self-identified lesbians surveyed reported having sex with men since 1980.[37] Activists stress again that it is not who you are which puts you at risk, but what you do. And women who have sex with women exchange bodily fluid.

The percent of "undetermined risk" cases for women nationally is twice that of men: 7 vs. 3% in New York: 10% vs. 5%. The CDC itself recently acknowledged that this is where women to women cases would be listed.

Conscious that AIDS education for lesbians could not be obtained from the government, women AIDS activists undertook their own education and organized their first public safer sex forum for lesbians in New York at the Lesbian and Gay Community Services Center. Approximately 300 lesbians attended. Two more teach-ins on women and AIDS were offered, during which was distributed a handbook, the title of which was very revealing: *The ACT UP Women's Caucus Women and AIDS Handbook or a Reassessment of Reality.* Soon enough, 1,500 copies were sent throughout the country

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[36]Darrell Yates, *The Deadly Costs of an Obsession,* The Nation, p. 181, February 13, 1989.
[37]Donna Minkowitz, *Safe and Sapho: An AIDS Primer for Lesbians,* Village Voice, p.21, February 21, 1989.

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and around the world. Even now, NIAID is beginning what they call a "heterosexual transmission study in women." Women lesbian activists confronted Dan Hoth about his inability to assert that these women were definitely heterosexual, because no question on women-to-women sexual behaviors was asked, he finally agreed to include the following question: "Have you ever had sex with a woman?"

ECONOMIC SEXISM INCREASES WOMEN'S RISK OF INFECTION, AND DEATH RATE UPON INFECTION

Women's inferior economic status is solidly built in the socio economic stratification system of the U.S. While women's participation in the paid labor force has increased by over 20 % in the past three decades, women's wages have not risen comparably. For example, white women who worked full time in 1988 earned about 65% of what white male full time workers did.[38] Black and Latina women's incomes are even lower than those of white women, averaging 59% of what white men make.[39]

While women's earnings are generally two thirds of men's, women are often responsible for more dependents. Only 23% of divorced mothers receive any child support payments at all. And for those lucky enough to receive child support, the average amount is only $1,200 per year.

Women's inferior economic status means that they are less likely to

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[38]U.S. Department of Commerce, Bureau of the Census, *Money Income of Household, Families, and Persons in the United States:*, 1986.
[39]Ibid.

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have health insurance, less likely to be able to afford the consistent and high quality medical attention necessary for early detection of HIV infection and opportunistic infections and less likely to be able to afford quality treatment for themselves and their children. A full time working women performs an average of 35 hours of physical housework labor per week in addition to her 40 hour paid job.[40] This labor is not paid nor is it counted in the GNP.

Too often services for mothers and children are not only inadequate , they are also divided among multiple agencies, each with its own regulations, visits and paperwork. If there are adolescents in the family, still more agencies can be involved. For example, a childcare worker, sent by one agency to a Bronx family, would make lunch for the children but not the mother and a homecare worker sent by another agency would make lunch for the mother, but not the children.

DEAD BUT NOT DISABLED

One of the most deadly consequences of the inadequate definition of AIDS by the CDC was the Social Security Administration's use of this definition to deny many women their otherwise due benefits. Many of them would die without ever obtaining their disability entitlements.

In response to this lethal situation, two actions were organized. An ACT UP member, who is also a lawyer, filed a suit against the

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[40]Joseph Pleck, *Working Wives, Working Husbands*, Beverley Hills, CA, Sage Publication, 1985.

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Social Security Administration. Secondly, in October 1990 an action was organized by ACT UP/DC at the Health and Human Services Building in Washington, DC. Activists carried banners reading "DEAD BUT NOT DISABLED." They also used "stink bombs" to show that "Louis Sullivan's Disability Benefits Stinks!"

A speak out was organized where self-identified HIV positive women revealed that they had been denied Social Security benefits. Laying down on the floor, activists were carrying tombstone signs such as: "Died of Pelvic Inflammatory Disease," or "Cash, Not Caskets." Even the American Medical Association came out in support of the change in the CDC definition of AIDS.

In August, 1991 the ACT UP lawyer received a draft of the Social Security's proposed new HIV Listing. Although the new listing included many of the activists' demands, it remained very deficient, since it omitted gynecological conditions. Thus, pelvic inflammatory disease (PID) was still missing from the list. The standard for cervical cancer was too stringent since the listing contained a stage II standard for cervical cancer, extending beyond the cervix into the vagina or uterus. Other disabling HIV-related conditions, the ACT UP lawyer noted, had gynecological implications and were missing. Examples cited included recurrent herpes with lesions which have not been documented to last for four weeks, but which recur more often than every eight weeks, or which are incompletely suppressed despite continuous maintenance therapy; abscess of an internal organ or body cavity, caused by known or unusual organisms; chronic genital ulcers, caused by a sexually transmitted disease, which fail to respond to treatment and persist more than four weeks; neurosyphilis or syphilis;

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recurrent vulvovaginal candidiasis which interferes with activity of daily living. The requirement of a T4-cell count of 200 or below in Section M(3) is too high a standard; chronic anemia with the following medical criteria should be included in the Listing without any functional test.

Evidently, a battle had been won, not the war.

LINK BETWEEN THE AIDS MOVEMENT AND THE FEMINIST MOVEMENT: WHY WOMEN ARE MORE RADICAL THAN MEN IN ACT UP

As the ACT UP Survey revealed, women in ACT UP are more politicized. Coming out of, or informed by, the feminist health movement, many of these women came to ACT UP already very politicized.

Feminism for these women refers to:

1) the rejection by women of the way they have been represented and treated by men, and in particular in the present research, the male dominated medical establishment

2)the attempt by women to take control over their fate by taking control over their bodies.

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THE AIDS AND FEMINIST HEALTH MOVEMENTS: COMMON FIGHT FOR THE FREE USE OF ONE'S BODY

The concern to liberate themselves through the liberation of their bodies from the control of the male-dominated medical establishment is a central one for women in the midst of the AIDS crisis. Most women are barred from clinical trials, because they might, according to doctors and scientists, endanger the fetus. For women, then, the AIDS crisis is as much a battle for the liberation of their bodies as the pro-choice movement is.

The concern to liberate themselves through the liberation of their bodies has been present throughout the history of the women's movement.

Women fought hard against the Comstock law passed in 1873 forbidding birth control. In fact, the passage of anti-abortion occurred at the same time of the professionalization of medicine. Not only did women loose control over their bodies, but they were barred from the healing profession of which they had been long date practitioners. This is not to say that before the professionalization of medicine, women were totally free of using their bodies. But, this interdiction was made "scientific", which broadened the control of men over women's bodies.

At the turn of the century, Emma Goldman and Margaret Sanger understood that birth control would free women from unwanted motherhood, what Emma Goldman called the "slavery of motherhood." In 1912, the average women in the US had between 5 to 11 children.

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AIDS ACTIVISTS WERE NOT THE FIRST TO PUT FORWARD THE IDEA THAT WOMEN WERE VIEWED FIRST AND FOREMOST AS REPRODUCTIVE MACHINES BY THE MEDICAL ESTABLISHMENT

The New York Medical Society took the first formal position in 1916, stating that "indiscriminately employed," contraception would undermine personal morality and national strength. This position summarized men's view of women as being essentially immoral beings and suppliers of population and military force. Meanwhile 22,000 women a year were dying from pregnancy-related causes and Sanger was receiving 1,200 letters a week.

In 1936, contraception laws were repealed, and in 1937 the AMA recognized birth control as part of medicine. With the rise of fascism, the birth control movement was coopted by the "eugenicists" or else called scientific racism, which claimed that character traits and physical traits were inherited and that sterilization of "problem people" would eliminate those problems. Women were then used to purify the race.

By 1935, 27 states had passed sterilization laws applying to at least 34 categories of people. Courts ordered nearly 64,000 women to be sterilized from 1907 to 1963. And between 1973-76, 3,406 Native American women were sterilized. Consent forms were in English, although most of the women sterilized were non-English speakers. Finally, the anti-sterilization movement started when women of color began to expose their experience in their own communities.

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AIDS ACTIVISTS WERE NOT THE FIRST TO DEMONSTRATE IN FRONT OF THE FDA

If they were not "unresearched," women could become guinea-pig for very dangerous experiments. The birth control pill was marketed in the US in the 1960's after a trial of 132 Puerto Rican women in which two women died and were excluded from the study report.

The experiential use of DES to prevent miscarriage in approximately 3 million pregnant women between 1945 and 1970 resulted in cancer and death for thousands of their daughters, and testicular cancer in their sons (although in smaller numbers).

On December 15, 1975, the newly formed National Women's Health Network held its first demonstration-a memorial service in front of the Food and Drug Administration (FDA), in Rockville, Maryland-to commemorate the thousands of women who had died from synthetic estrogen related to complications.

MISTREATMENT BY THE MEDICAL ESTABLISHMENT: COMMON EXPERIENCE OF FEMINIST HEALTH AND AIDS ACTIVISTS

The feminist health movement developed as part of the women's liberation movement of the late 1960's. Through Consciousness Raising (CR) rap sessions, women realized they had experienced humiliating, and often abusive mistreatment from their male doctors.

The publication in 1969 of *Our Bodies, Ourselves* by the Boston

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Women Collective was sent across the country to tell women about their health history. Prior to that period it was very difficult for women to get information by women and for women's health. Women started to talk about sex, birth control, abortion, childbirth and lesbianism.

The organizing principle was that women would be free if they could control their bodies. Thus far, and still in many quarters of medicine women's health had been defined according to their reproductive organs, and that is how, feminists thought, the medical profession viewed the totality of women's experiences.

AIDS activists were, in a different way, opposed to the way PWAs were used by the medical establishment. They did not want to be tool of science; they wanted science to be their tool to better their health.

WOMEN'S AND GAY MEN'S BODIES VIEWED AS ESSENTIALLY SICK BY THE MEDICAL ESTABLISHMENT

The feminist health movement set out to change the traditional medical model which viewed women as essentially sick. If woman was not sick she was vector of transmission for sickness.[41]

Barbara Ehrenreich explains that doctors view events, such as menstruation, childbirth, as natural anomalies which places a woman in a constant state of sickness. According to Ehrenreich and other feminists the representation of childbirth as a sickness allowed doctors

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41 Allan Brandt, *No Magic Bullet, A Social History of Venereal Disease in the United States since 1880*, New York: Oxford University Press, 1985.

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to eradicate midwifery. In 1950, 50% of childbirths were conducted by midwives. In 1974, the rate fell to 1%. Noteworthy is where midwives are used such as in the Netherlands and Denmark (85%), the rate of infant mortality is lowest.

Gay men and lesbians, likewise, are still considered as essentially sick by many doctors, although the American Psychiatric Association removed homosexuality from the list of mental illnesses.

SELF-CONTROL AND SELF-EMPOWERMENT: COMMON STRATEGIES OF FEMINIST AND AIDS MOVEMENTS

The feminist health movement was teaching principles that were contrary to the ones taught in medical schools. Activist substituted the traditional disease model taught in medical school for a health oriented one. People could learn about their own health, they could take care of themselves, they could examine themselves, they could actively participate in the process of healing. It also stressed prevention.

The feminist health movement was attempting to return women to their tradition as healers. Feminist health projects developed educational workshops and training programs for lay women to be health workers or educators. Likewise, many AIDS activists became AIDS educators.

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THE COMMUNALIZATION OF CARE, COMMON EXPERIENCE OF THE FEMINIST HEALTH AND AIDS MOVEMENTS

After the publication of *Our Bodies, Ourselves* in 1969 and the establishment of two feminist clinics in 1970 -the Emma Goldman Clinics for Women in Chicago and the Elizabeth Blackwell Women Health Centers in Minneapolis-there emerged 35 women's clinics, and 116 women's centers in 1973. By 1974, more than 1200 women's groups across the country provided health information. Those clinics continued to grow in the mid-70's and started to decline in 1980's. Here again, AIDS activists followed the example set by the feminist health movement in creating their own clinics and community-based research centers. The AIDS movement also produced its own health care workers and a voluminous literature to document or research the epidemic.

ACTIVE UNDERGROUND ORGANIZING TO SOLVE THEIR PROBLEMS CHARACTERIZES BOTH THE AIDS AND THE FEMINISTS HEALTH MOVEMENTS

The Jane Collective represents one of the most radical project of the feminist health movement. Organized by 40 women from Chicago's Women's Liberation Union in 1969, Jane advertised "call Jane for abortion information." The Jane collective arranged safe and illegal abortions (but legalized in New York in 1970). Jane members handled the medical preparations and very often were doing everything, but the abortion itself.

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Early abortion is an easy operation, requiring no anesthesia or cutting and any one can learn the basic sterile techniques. They fired the doctor (who turned out not to be a real doctor), cut their prices to $50 dollars and provided 11,000 women with safe abortions from 1969-1973. They had no fatalities, and practiced anonymously in semi-underground. Likewise, AIDS activists who are seropositive have learned to prepare drugs that are not legal in this country, but in other countries.

The use of the speculum was another such project. Women used a speculum, a flashlight and a mirror to examine their own cervix (narrow lower portion of the uterus) and vagina. Lorraine Rothman traveled across 25 cities in 1971, demonstrating vaginal self-examination and distributing speculums. The idea was that if women were able to see their cervix they would be able to detect vaginal infection more rapidly.

Women who are HIV positive are also encouraged to examine their cervix to prevent the spread of vaginal infection. The concept that the persons with AIDS should be involved in the healing process is a central one in the AIDS movement. Indeed, the average person with AIDS knows more about the disease than the average doctor.

Feminists went on to establish full-service clinics, and once abortion was legalized nationally they determined the type of abortion to be used, they trained lay women to provide all aspects of health care except abortion and they created an atmosphere free of shame for women to get an abortion as well as information about their bodies. In Florida, the cost of an abortion in a feminist clinic was $150, when doctors were charging $300. The latter had to lower their prices.

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Similarly, the PWA Health Group provide aerosolized pentamidine because the drug, although legal and approved, is still too expensive to acquire by many PWAs

REJECTION OF HIERARCHY TYPIFIES BOTH THE AIDS AND FEMINIST HEALTH MOVEMENTS

Offshoot of the feminist movement, it was natural that women's clinics chose the collective as a model for operation. The collective was also a rejection of what was viewed as a male model of organizing wherein individuals vie for power, privilege and control.

The collective stresses consensus decision making among the members. It was used not only as a way to combine and share skills and ideas and thus empower other women in different places, but was also, in some cases, applied to services as well. The Federation of Feminist Women's Health Centers (9 centers in all) used self-help models until the early 1980's. Women would come in for pregnancy tests and a health worker would show them how to do the tests themselves. In the Participatory Well-Woman Clinic, a health worker would demonstrate to 3 or 4 women together how to do a vaginal and breast examination. The abortion decision, deprivatized and politicized, was put in a context of empowerment rather than guilt.

In ACT UP too, individuals, or the floor, are the ones who make decisions.

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INTERNAL PROBLEMS IN THE MOVEMENT: RACISM, CLASSISM, HETEROSEXISM, AND SEXISM

Like most white dominated movements, the feminist health movement and ACT UP did little to eradicate racism. Although, there is a large membership of latino activists in ACT UP, their work is very isolated, and they certainly do not consider ACT UP as "their" movement, but a space where they can do specific work. Black activists have almost disappeared from the group.

Although ACT UP cannot be considered a heterosexist group, since the majority of the members are gay men, the group is not immune to sexism. Women complain of unfair treatment by men. Their issues as well as their strategies are not taken as seriously as the ones put forward by the male activists. For example during the storming of the Conference on Women and HIV, some male activists decided to have dinner with Federal officials. Many women have dropped out. In fact, some lesbians are talking about separatism again.

As in society at large, women in ACT UP have less access to financial resources. And the economic affluence of some of their white male counterparts determines the sometimes tense relationship between the two groups. Although a Women's Action Committee was created in the summer of 1990-with two representatives to avoid tokenism-sexism has not disappeared.

As of January 1991, some women in ACT UP have been harassed for several months. They would receive obscene phone calls such as "I want your pussy," or as they picked up the phone, people would hang up, or again a third person would interfere in a two-party conversation.

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Another member had a swastika posted on her door. But, according to a female activist, the male membership has not been very concerned, and no strategy has been put in place to protect the women being harassed.[42]

Arguably, women are being harassed because they certainly represent the most radical section of the group, with a strong past of health activism. In fact, some women feel that AIDS has been institutionalized, and male activists are more concerned about dialoguing with famous scientists or bureaucrats.[43]

In January 6, 1991, women proposed a moratorium, according to which ACT UP would not dialogue with any governmental representatives for six months. The proposal was vehemently rejected by the male-dominated floor.

RESOURCES: A MAJOR DIFFERENCE BETWEEN THE FEMINIST HEALTH MOVEMENT AND THE AIDS MOVEMENT

Lack of resources has always plagued the feminist movement. Some feminist clinics had a budget as low as $25,000. Low wages meant high turnovers and little commitment.

In contrast, ACT UP can hold a fundraiser and collect a quarter of a million dollars in one day. Although, the group is always concerned about money, there has not been a sense of total economic deprivation yet.

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[42]Personal Interview with female activist, 1991.
[43]Personal interview with female activists, 1991.

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THE SEX CONNECTION BETWEEN THE FEMINIST HEALTH MOVEMENT AND THE AIDS MOVEMENT

Up until the 20th century, women have been denied sexual pleasure. Women who would indulge in it were either whores or perverse. Thanks to the 1970s feminism, women deprivatized sex and were encouraged to cultivate clitoral orgasmic pleasure. Vaginal orgasm was demystified. The move to affirm female sexuality gave visibility to lesbian and bisexual women. The pill removed other awkward forms of birth control and abortion was legalized upon Roe versus Wade. Yet, women have undergone two government onslaughts: the 1977 passage of the Hyde Amendment, which cancelled federal Medicaid funds for abortions, and more recently the 1989 Webster decision, upon which states could determine their own restrictions around Roe vs. Wade.

The movement for reproductive rights grew, in part out of the movement for abortion rights. Reproductive rights encompass far more than abortion rights. Reproductive rights include the right to sex without punishment and without unplanned pregnancy, the right to have sex with whom women want, and the right to have sex without risk of illness.

The fight for reproductive rights is, among other things, a fight for sexual pleasure. Women live in a world where many of them are ashamed of their bodies, even speaking about it.

Likewise, gay men have been stigmatized for their sexuality. Like women's sexuality, their sexuality was defined as not real or perverse. Safe sex has been the greatest response the gay community

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has provided to fight off heterosexist onslaughts. Safe sex was not only designed to save lives, but also to safeguard a whole culture.

AIDS AND FEMINIST HEALTH ACTIVISTS BESIEGE ST PATRICK CATHEDRAL, CULMINATION OF THE CONVERGENCE OF BOTH MOVEMENTS

Attacking reproductive control by limiting abortion rights reduces the independence of all women and by extension polices sexual desire. Eroticism from a reproductive rights perspective is power.

Both the AIDS and reproductive rights movements have been hounded by the moral specter sex guilt. For women, in particular, sex has never been safe because of the threat of unwanted pregnancy, rape and sexual harassment. Women have therefore a stake in fighting for sex to be safe.

After Cardinal O' Connor denounced condom distribution and announced that he would partake of an Operation Rescue action, ACT UP/New York and the New York based Women's Health Action Mobilization (WHAM!) planned a Stop the Church demonstration at St Patrick's Cathedral in New York City on December 10, 1989 with joint demands against the church's opposition to abortion and its lack of AIDS policy. Anticipating the presence of Operation Rescue members, some ACT UP activists dressed up as clowns to form the Operation Ridicule affinity-group.

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AND THE SIMILARITY BETWEEN THE FEMINIST HEALTH MOVEMENT AND AIDS MOVEMENT CONTINUES

Abortion rights activists are now considering underground distribution of the new abortion pill, RU486, currently available only in France, using PWA Buyers Clubs as a model.

Both movements are about the communalization of biomedical science and healthcare, the decolonization of their bodies and the retrieval of their sexual culture.

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HOLISTIC ACTIVISTS, A DIFFERENT VOICE IN ACT UP

"Getting drugs into people's bodies," the slogan which typified the early years of ACT UP did not sound totally right for every body in ACT UP. Not everybody agreed with the dominant line that HIV was the cause of AIDS. Some of the activists even thought that HIV had very little to do with AIDS. To formalize the difference, in the fall of 1988, the Alternative and Holistic (A&H) Treatment subcommittee of the Treatment and Data (T&D) committee of ACT UP was created.

A & H endorsed the Denver Principles adopted by the National Association of People With AIDS in 1983, according to which individuals should have the right to freedom of informed choice of treatment. The stated purpose of the subcommittee was to share information and plan actions to broaden scientific knowledge about treatment for AIDS/HIV. Its approaches included acupuncture, herbs, diet changes, nutritional supplements, homeopathy, body work, mental/spiritual healing, and unconventional medical treatments such as typhoid vaccine and aqueous penicillin. The subcommittee worked to achieve freedom of choice among treatments, challenging obstacles by the insurance companies, drug companies, state laws and federal agencies, and to advocate for broad inclusion of alternative treatments in any proposals for state and national universal health care.

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CONFLICTING PARADIGMS WITHIN ACT UP

As there was no consensus around the cause of AIDS in ACT UP, there was no unanimous consensus around AIDS treatment either This lack of agreement created (and still does today) much tension from within ACT UP. In this regard, the internal ideological difference within ACT UP, reflected ideological differences which have torn apart the medical field for the most part of this century.

In order to understand the ideological tension between holistic and allopathic activists, a step back in history is necessary.

FOR HOLISTIC ACTIVISTS, THE AMA DOES NOT EQUAL KNOWLEDGE WITH POWER, BUT WITH POLITICS

Before the creation of the American Medical Association (AMA), holistic practitioners could flourish in total liberty. Among those were the herbalists, acupuncturists, homeopaths, botanists, and naturopaths, to name just a few.

Although, they displayed significant differences, they shared a common ground. They all predicated their approach on the idea that the body had to be viewed in its integrality with itself, but also with nature. They all followed the Hippocratic Oath that one "first, do no harm."

Homeopathy, for example, was introduced to the United States by a Danish Homeopath and quickly became very popular. In 1844, the American Institute of Homeopathy was formed. Rather than being considered merely unpleasant manifestations of illness, from which

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people should protect themselves by any means possible, symptoms, physical, mental or emotional, were seen as expressions of the steps the body is taking to heal itself. In addition, homeopathy considered all aspects of a person's condition. Temperament, habits, occupation and mental attitude, all combined with the physical complaint to create a comprehensive picture.

In 1846, the "non regular" Popular Health Movement with its emphasis on gentle botanical and herbal remedies, to aid the body's natural healing powers, had gained great popular support. The AMA found its allopathic monopoly threatened and attempted to introduce licensing laws to restrict non-allopathic practitioners. Through political action, groups such as Samuel Thompsons' Friendly Botanical Society, the Popular Health Movement stopped the passage of those licensing laws.

Louis Pasteur's germ theory, however, established allopathy as the dominant model. The irony is that Pasteur's vaccination principles borrowed from the Principles of Similars and microdoses. Yet homeopaths have long warned of the dangers of vaccination, in which the amount of the substance far exceeds the content of any homeopathic dilution. Vaccines have been implicated in immune suppression and in contamination by extraneous viruses and bacteria during the manufacturing process.

The main distinction between the allopathic and the holistic models lay in the fact that the former was interested in eliminating the symptoms, whereas the latter was interested in the multifactorial origin of the disease.

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To suppress symptoms with drugs, according to the homeopaths, brings temporary relief of that symptom. Furthermore, bacteria can develop resistances against drugs, especially if individuals have been exposed to those drugs before. The resurgence of sexually transmitted diseases in the 60's is a good example of drug-resistant diseases. Finally, anti-biotics non selectively destroy beneficial bacteria as well as others. Protective skin bacteria which are part of the innate immune system are destroyed as well as important intestinal flora.

From a homeopathic perspective, the use of antibiotics is not only damaging to the immune system, it is ineffective because bacteria are not the cause of the disease, but merely a by-product of it. Far from curing the underlying disorder, drug suppression actually throws off the healing mechanism. For example, in the homeopathic treatment of asthma in children, a frequently seen progression in health history is an earlier skin condition which is suppressed by drugs.

In contrast, homeopathy follows the Principles of Similars. According to those principles, homeopaths administer a drug that would produce similar symptoms to the disease intended to be cured. Heavily diluted, the drug would only be administered in microdose, following this way the Hippocratic Oath.

The advent of penicillin in the 20's, however, consecrated the reign of allopathic medicine. Since then, the two paradigms have been in struggle. The allopathic paradigm maintains that a foreign agent can cure the body, or the "magic bullet approach." Allopathy also believes in using invasive procedures (surgery) and often toxic pharmaceuticals in order to cure the body of diseases, as described by this statement from a holistic activist:

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> The virus-oriented ideology of the medical establishment has produced a militaristic strategy, which has damaged the body instead of healing it. The body has been bombarded with a chemotherapy abundantly documented to be toxic.[1]

The holistic practitioners, in turn, believe that the whole person's experience has to be considered. They tend to favor the body's own immune-enhancing abilities. A corollary to that principle is that medicines people need occur in nature. In the case of the allopathic treatment, for example, the drug itself, is supposed to cure the patient from the disease. In the homeopathic perspective, the drug, injected in microdoses, is supposed to enhance the immune system, which in turn, heals the patient.

Symptoms were then viewed in drastically different ways by the two paradigms. For allopathic practitioners, symptoms had to be eliminated. For holistic practitioners, symptoms had to be encouraged, because they were precisely the response of the body to the disease.

Those two approaches carried with them two different economies as well. The allopathic approach tended to be very expensive, whereas the homeopathic tended to be very cheap.

Persisting today, these differences in looking at the disease have been harshly divisive in ACT UP as the following statement by an activist reveals:

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[1]Personal Interview,1991.

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> Even if T&D members are interested in cofactors and opportunistic infections, all they did was to divide the syndrome in ten or twenty different diseases and find a "wonder drug" for each disease.[2]

Yet more attention had to be brought to alternative treatments, argued the holistic activists, because more and more PWAs, discouraged by standard treatments, were using some form of alternative or holistic treatment.

THE MAJORITY OF PWAS WERE AND ARE STILL USING SOME HOLISTIC FORMS OF TREATMENT[3]

Many persons with AIDS used alternative treatments with standard therapies, others alone. Many of them had philosophical objections to toxic drug interventions, believing holistic approaches are sounder on theoretical grounds. Others were impressed with the generally more personal atmosphere of care offered by holistic practitioners, especially their efforts to respond to both emotional and physical issues and to individualize each treatment. Growing numbers of PWAs, who had found antivirals such as AZT and ddI ineffective or too toxic had then turned to alternative treatments. Others chose to try non toxic treatments first, leaving the more intrusive drugs as a last

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[2]Personal Interview, 1991.
[3]This Chapter relies heavily on discussions held with, and Outweek articles written by Robert Lederer from the Alternative and Holistic Committee of ACT UP.

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resort. Finally, there were the swelling numbers of impoverished PWAs--many from communities of color--who lacked health insurance and could not obtain basic primary care, but were able to self treat with diet and lifestyle changes and inexpensive herbs.

Way before the creation of A&H, PWAs were using holistic forms of medicines. Some were using Ayurvedic Medicine, which is the over 4,000 year old traditional medicine of India. This type of medicine holds that optimal health and illness are at either extremes of the health continuum and that people are capable of optional health and well being once their bodies' biological needs are met.

The Ayurvedic doctor understands that the body is capable of curing itself. The goal of this approach is to eliminate the causes of the illness, the recuperation of vital energy, the natural elimination of accumulated toxins, thus allowing the body to reestablish its harmony. The biological necessities are provided, including pure air and water, and proper hygiene.

Other PWAs were using orthomolecular medicine which holds that the administration of certain nutrients given frequently and in megadose can aid the body in reestablishing its internal balance, thus restoring health. Orthomolecular medicine has been used successfully, holistic activists argue, against AIDS using megadoses of vitamin C, beta carotene, and flavinoids accompanied by other vitamins and minerals.

Homeopathy was also used by many PWAs. As already mentioned, homeopathy views symptoms as a manifestation of the body's attempt at purification against disease, and as such, the doctor's role is to encourage them as a way of allowing the body to heal itself

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naturally. Homeopathy, activists argue, has shown some effectiveness with certain conditions related to AIDS such as CMV, Epstein Barr virus, parasites, candida and syphilis among others.

Of all the holistic approaches, Traditional Chinese Medicine (TCM) was probably a modality of predilection for PWAs. It is an over 5,000 year old practice. It utilizes herbs, diet, massages and acupuncture to correct deficiencies of vital energy or Qi that runs through the spleen, lungs and kidneys, often affected by AIDS.

TCM is an ancient, complete medical system serving over a billion people in China, Japan and southeast Asia. Its clinical therapeutic properties were formulated 1800 years ago by Zhang Zhonging. His writings are still adhered to today. TCM views the body's natural immunity as a function of the individuals' vital energy, or zehng qi. In this view, there must be a deficiency of zheng qi when an environmental pathogenic factor successfully attacks the body.

TCM arrives at a diagnosis by analyzing the observed patterns of symptoms, or symptom complex.

The symptom pattern is called the patient's zheng or conformation, in which the location, nature and probable cause of the patient's condition, together with his or her response to treatment, are all taken into account. Conformation is not to be confused with disease; it is rather a total picture of the patients' psychological, mental and emotional states.

Integrating the Western diagnosis of disease and the TCM diagnosis of conformation to formulate a better treatment protocol is standard procedure in the Chinese health care system. Using both

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systems has yielded much more efficacious results than are achieved by either system in isolation.

AIDS is perceived by TCM advocates as a constellation of varying symptoms, which make it especially appropriate TCM.

People with AIDS can benefit from a number of TCM strategies, including the use of antiviral herbs to reduce the potency of the virus; the use of herbal immune regulators to rebuild the immune system; the use of herbs which treat specific AIDS-related opportunistic infections and malignancies; the use of antiviral substances such as hepric, which is an extract from the Chinese herb Huericum and Trichosanthin, known in the U.S. as Compound Q, a purified extract from the Chinese herb trichosanthes Kirilowii; the use of therapies for non specific symptoms, and herbs which often prevent the adverse side effects of Western medications.

TCM herbal formulas are usually composed of 8-12 different herbs in four classes: imperial, ministerial assistant and servant. The imperial herb is the primary herb of the formula, the ministerial herb is ancillary to the first, the assistant herb augments the actions of the preceding two or diminishes their side effects and the servant herb coordinates the actions of all the herbs.

Other forms of alternative treatments were used by PWAs, such visualization, positive thinking, and macrobiotics among others. The commonality of any holistic perspective PWAs elect, is that they all share self-love as a predicament for treatment and the notion that the individual is the center of attention for the practitioner, and not a tool of science.

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Access to alternative treatments, however, is sharply limited by both legal restrictions faced by acupuncturists, homeopaths and herbalists (in most states, they are not licensed and must practice illegally) and the lack of trained personnel (largely due to inadequate funds for alternative medical schools). Self-administered alternative treatments (herbs, vitamins, etc.) can only be obtained in the few localities with health food stores. Insurance policies deny reimbursement for most expenses of unconventional modalities, leaving such treatments out of reach from many PWAs on limited incomes.

THE MAINTENANCE OF A PARADIGM TO DOMINANCE REQUIRES THE DEPLOYMENT OF AN EVER INCREASINGLY POWERFUL ARSENAL OF COERCION

Holistic activists argue that this limitation, even suppression, of holistic and alternative modalities does not occur haphazardly but has a long history behind it. Once again, a step back in history is helpful in contextualizing this argument.

The American Medical Association was created in 1848 and was a direct response to the founding of the American Institute of Homeopathy in 1844. An adage of the time was that it was better to see a patient die from the orthodox remedies than live by homeopathy.

In 1855, the AMA established a consultation clause whereby members would be expelled if they even consulted with a homeopath. Women, in particular, were affected by the AMA's monopolization of

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medicine, as Barbara Ehrenreich and Dierdre English describe in *Witches, Midwives, and Nurses:*

> "women have always been healers. They were the unlicensed doctors and anatomists of Western history. They were abortionists, nurses and counsellors. They were pharmacists, cultivating healing herbs. They were midwives. For centuries women were doctors without degrees, barred from books and lectures, learning from each other, and passing on experience from neighbor to neighbor and mother to daughter. They were called "wise women" by the people, witches or charlatans by the authorities. The suppression of women health workers and the rise to dominance of male professionals was not a "natural process, resulting automatically from changes in medical science. It was an active takeover by male professionals...And it was not science that enabled men to win out: the critical battles took place long before the development of modern scientific technology."[4]

In 1868, the AMA refused to admit well-qualified women M.D.'s. And by 1906, the infrastructure of the industrial medical complex was

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[4]Ehrenreich, Barbara, *Witches, Midwives and Nurses: a History of Women Healers,* Old Westbury: The Feminist Press, 1973.

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already in place. All but one medical journal was subsidized by drug advertising.

Then came the Flexner Report. In 1910, the Carnegie Foundation released a report titled "Medical Education in the U.S. and Canada," authored by Abraham Flexner in collaboration with the AMA. Homeopathic schools, which tended to be small and poorly funded were, as expected, denied accreditation.

Until today, the AMA has deployed all of its energy to stop the advertising or prescriptions of alternative treatments by holistic practitioners, even by doctors who are classically trained. In 1987, a federal court ruled, in a lawsuit filed by chiropractors, that the AMA was guilty of "conspiracy to contain and eliminate the chiropractic profession." The decision, upheld on appeal in February 1990, supported the chiropractors' charges that AMA policy prevented doctors from referring patients to chiropractors or taking referrals from them, and prevented chiropractors from treating patients at hospitals. controlled by doctors. The ruling ordered the AMA to stop "restricting, regulating or impeding" its 275,000 members from associating with chiropractors. However, in the absence of similar lawsuits by acupuncturists, herbalists, etc., AMA anti-competitive practices towards those professions continued unabated. Thus, any PWAs are denied the right to obtain the services of these holistic practitioners.

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THE SAME INFRASTRUCTURE OF COERCION WAS USED AGAINST ALTERNATIVE CANCER AND AIDS ALTERNATIVE PRACTITIONERS[5]

The crusade of the medical establishment was most virulent against the alternative cancer movement. Yet, the medical establishment was repeatedly inconsistent in its attacks. When radiology was first discovered, Dr. Emile Grubbe, its originator, was bitterly denounced by leading surgeons in 1896. Thirty years later, however, it was legitimated as one of the main treatments for cancer by the American College of Surgery. Another example is the misevaluation is Hyperthermia or heat therapy developed by Dr. Donald Coley, MD. Hyperthermia is a therapy based on heat which stimulates the body's production of antitumor immunological substances. It then focuses on the ability of the body to use its immune system enhancing qualities. The approach was for a long time derided by the American Cancer Society (ACS) and now is held as an approach that may play a vital role in future cancer therapy. It was even tried on persons with AIDS. This inconsistency confirmed that the ACS's rejection of a treatment was politically and not scientifically grounded. And many holistic cancer practitioners saw their careers ruined by the medical establishment, or had to relocate abroad.

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[5]This Chapter relies heavily on discussions held with Ralph Moss, from the Alternative Cancer Movement.

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AND HISTORY REPEATS ITSELF LIKE A FARCE

Historically the suppression of ideas has never been the best way toward the conquest of truth. Thus, although the arsenal of coercion deployed by the medical establishment against alternative and holistic practice was quite impressive, holistic practitioners never stopped from discretely flourishing.

As in the cancer movement, there is overlap between the mainstream ideology of AIDS and the alternative ones. The difference is then not of a scientific nature, but depends on what the orthodoxy is willing to accept. Like in cancer, it moved from a near fundamentalist position which stated that HIV only was the cause of AIDS to HIV plus other microbial co-factors as the cause of AIDS. Like in the alternative cancer movement, the medical establishment never attributed any credit to the influence of alternative theory. The recommended treatment by the orthodoxy is AZT, ddI or ddC, reasoning that by killing the virus, health is restored.

Like in the alternative cancer movement, holistic doctors see AIDS as symptomatic of an organism that is seriously imbalanced and overstressed. Since holistic medicine holds that the physical, emotional, and spiritual are interconnected, there could be a myriad of explanations, i.e. chronic malnutrition, long term abuse of over the counter as well as illegal drugs and alcohol, long term exposure to environmental toxins, sexually transmitted diseases, exposure to immuno-suppressive vaccines, even unresolved psychological trauma and/or long term locked up emotions. From this perspective, all these factors in addition to HIV could contribute to a weakened immune

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system. There is controversy within the holistic community as to the exact role of HIV in AIDS. All holistic practitioners, however, would agree that it could not be the sole cause of AIDS.

Like in the alternative cancer movement, most researchers who came up with alternative theories were, in the great majority, classically trained doctors very well respected in their own field.

Some alternative AIDS treatments had even been studied scientifically. Yet those studies have been ignored by the medical establishment. Examples include such studies as the one conducted in San Francisco AIDS alternative Healing Project in conjunction with the Oriental Healing Arts Institute in March of 1988, which involved a six-month clinical trial of herbal therapy for AIDS patients.

Alternative treatments for AIDS have been scientifically studied by community-based centers such as the Community Research Initiative (CRI) and the Community Consortium of San Francisco. But then again the medical establishment has not paid much attention to the results. In some cases, NIH has delayed indefinitely or rejected outright proposals by respected scientists to study non pharmaceutical treatments. Examples include Lentinan (an extract of the Japanese Shiitake mushroom, used in Japan as a cancer treatment for five years) and megadoses of Vitamin C, used in cancer and AIDS treatment with encouraging clinical results for several years.

Since most companies developing herbal extracts, vitamins, minerals and nontoxic drugs are small and have low research budgets and since many of their products are unpatentable, the result is very few clinical trials of alternative treatments. This leaves PWAs and their practitioners with little more than anecdotal reports, sporadically

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reported or spread via the PWA grapevine, as a basis for decision-making about alternative treatments.

THE FIRST CONSEQUENCE OF THE PARADIGMATIC EXCLUSION IS LACK OF ACCESS TO LIFE-SAVING OR PROLONGING TREATMENT

Many health insurance policies and the federal programs of Medicaid and Medicare systematically exclude from reimbursement such alternative practitioners as acupuncturists, chiropractors and homeopaths. Even when policies pay for office visits to such practitioners, they rarely cover the costs of the substances prescribed, such as vitamins, herbs, homeopathic remedies, etc.

In addition, most states have no licensing system for acupuncturists, herbalists, homeopaths, naturopaths and several other categories of holistic health practitioners. Lacking a system of state recognition and regulation, some potential practitioners are unwilling to risk critical sanctions and thus never enter the field. Others do so quietly, unable to advertise legally. Meanwhile, PWAs are subjected to an unregulated field of practitioners, some of whom may be unqualified. The lack of licensing of these professions also becomes an additional justification for insurance companies to deny coverage for those modalities.

Finally, several physicians across the U.S. have been prosecuted or threatened with license revocations simply for practicing unconventional approaches to life-threatening illnesses such as cancer and AIDS.

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SECOND CONSEQUENCE OF THIS PARADIGMATIC EXCLUSION: LACK OF EXPOSURE OF, AND RESEARCH ON, ALTERNATIVE LIFE-SAVING OR PROLONGING TREATMENTS

Many medical personnels and increasing numbers of PWAs rely on a range of conferences, newsletters, directories and training programs to keep up with the state of the art developments in treatment. Yet the same systematic bias against alternative and particularly holistic treatment, which characterizes the research establishment, also pervades these public or private institutions. For example, the federal government's toll free hotline on AIDS clinical trials and the widely respected quarterly directory of experimental AIDS/HIV treatments published by AmFAR lack any references to available alternative treatment, not even those which are in small, private clinical trials.

Gay and Lesbian conferences were not immune from this bias. ACT UP had to zap the National Gay and Lesbian Health Foundation in George Washington University, Medical Center. Although a number of papers and posters were submitted on alternative and holistic treatments for AIDS, only one was accepted. The year previous nine papers were delivered. Perhaps the sponsor of the program, Burroughs Wellcome, had some influence.

Most medical conferences or training programs on AIDS do not include even a single speaker representing these medical disciplines. The annual International Conferences on AIDS, billed as the most comprehensive and prestigious gathering of AIDS researchers, have almost never had more than a tiny number of posters and virtually no

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panels or symposia on alternative treatments. For example, at the 1989 Montreal Conference, there were fewer than two dozen posters on nutrition, a handful on herbs, and none on a wide range of alternative medical systems, including the indigenous healing approaches being experimented with in Africa and Latin America.

Yet the interest in those treatments was not lacking. At the Montreal Conference in 1989, over 200 attendees met at a spontaneous workshop on the practical applications of African traditional herbal remedies.

THE COMMUNALIZATION OF HOLISTIC AND ALTERNATIVE TREATMENTS

Like in any other area of AIDS, it was clear to the activists that only they could rehabilitate and promote research on alternative treatments. The historical example of the 15 year-old Lincoln Hospital Acupuncture Clinic in New York City's South Bronx was in this regard quite telling. It was established by Black and Puerto Rican community activists and became renowned for its successful detoxifying of thousands of heroin, cocaine, crack, and alcohol addicts. It has been treating PWAs (both IDUs and non users) for seven years. An interim study by the Clinic in 1987, together with the experience of hundreds of PWAs, indicates that many have obtained symptomatic relief, fewer opportunistic infections, and increase mental calmness and balance. Furthermore, acupuncture and herbal treatments are quite inexpensive.

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Holistic activists in ACT UP had to fight two opponents. They had to persuade a large number in ACT UP, who were virulently opposed to what they viewed as quackery, a view they shared with the medical establishment. And holistic activists are still struggling today to convince other members that alternative treatments can be as viable, if not more viable than conventional ones.

> We were at a different level of consciousness. T&D wanted the machine to function quicker, A&H was much more critical of the medical establishment.[6]

While T&D wanted to reconceptualize AIDS using the conventional model, A&H wanted to reconceptualize medicine.

The second opponent was obviously the medical establishment, with its official arm against quackery: the National Council Against Health Fraud(NCAHF). NCAHF was founded in 1984 as an outgrowth of the Southern California Council Against Health Fraud, Inc--along with affiliated groups and wealthy allies among pharmaceutical and insurance companies and the medical profession. All these institutions formed the core of the quack busting movement in the U.S. which traced its origins in the anti-chiropractic campaign of the 60 and 70s. Today their goal is to eliminate a host of health practices that they find unacceptable. Even now, despite the widespread acceptance of chiropractic, NCAHF's founder, Dr. William Jarvis confirmed that the NCAHF believes that the AMA was right in restricting

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[6]Personal Interview, 1992.

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collaboration with chiropractors and had a duty to try to eliminate chiropratic pseudomedicine in 1987.

In its promotional material, the National Council Against Health Fraud, Inc. claims to oppose misinformation, fraud and quackery in the health marketplace. They define fraud as the portion of a medical remedy that does not work or has not been proven to work. Noteworthy is that many FDA approved or experimental drugs often fall into this same category, but are never called fraud by the NCAHF.

Among NCAHF's biggest supporters are petrochemical giants Shell, Mobil and Amoco; General Motors, Ford, Alcaoa, U.S. Steel, Proctor and Gamble, General Foods (a subsidiary of Philip Morris), and Coors Beer. Each of these companies contributes between $5,000 and $15,000 annually to NCAHF's efforts to "educate consumers."

The NCAHF is a well coordinated, well funded nationwide network of self-proclaimed quack busters who hold periodic conferences and offer a constant array of public events, media interviews, booklets and guest editorials.

A working relationship often exists among the National Council, local American Medical Association affiliates, the health insurance industry, the Food and Drug Administration (who co-sponsored the 1988 Health Fraud Conference in Kansas City) and, behind the scenes, the pharmaceutical industry. For example, in 1990, AMA was co-sponsoring the Health Fraud Conference with the Health Insurance Association of America and the Association of Food and Drug Officials.

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The NCAHF have become the leading force in the continued effort by the AMA and large pharmaceutical companies to suppress their competition and insurance companies to reduce their coverage and thus, according to holistic activists, deny all people freedom of treatment choice. NCAHF's conferences--often used as strategy/training sessions for the medical establishment--are a major tool for identifying their propaganda campaign against alternative and holistic health care, falsely lumping it all under the terms quackery and fraud often cleverly mixing worthwhile treatments into lists of real scams to blur the distinctions.

According to holistic activists, the actions and tactics of these "qack-busters" revealed that their real intention is not to "protect consumers", but rather to suppress information critical of the medical establishment. In fact, the NCAHF offers a wide variety of services to anyone who wants to discredit, attack, or mount legal assaults on alternative health practices that they label "quackery." They offer everything from lawyer referrals to financial grants to legislative advisement.

In 1985, Dr. John Renner, a National Council official and coordinator of the Health Fraud Conference in Kansas City, successfully pressured a radio station in that city to remove from the airwaves a chiropractor/nutritionist who had a popular weekly health program. According to the NCAHF's literature, one of the services they provide is aid in cancellation of newspaper columns and media broadcasts advancing health misinformation.

A leading official of the NCAHF, Victor Herbert, filed a multi-million dollar lawsuit in 1988 against 26 individuals and organizations

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advocating alternative health care, charging slander, libel, defamation and conspiracy for publicly exposing his biased stance and distorted presentation. In a preliminary ruling in January 1990, a federal judge dismissed charges against 22 of the defendants and stated that Herbert had failed to show any conspiracy. The ruling was later upheld on appeal.

THE BLACKLISTING STRATEGY OF QUACK BUSTING MOVEMENT, SUCCESSFUL IN RESTRICTING THE ALTERNATIVE CANCER MOVEMENT, FAILED THE AIDS MOVEMENT

In 1989, this campaign reached insidious new heights when a for profit corporation, directed by insurance industry consultants, launched an effort to create a blacklist of alternative AIDS treatments. Emprise, Inc. of Washington, D.C., headed by Attorney Grace Powers Monaco (who represented several leading insurance companies in suits against alternative doctors) proposed to hand-pick "peer-reviewers" to "evaluate" the most commonly used alternative treatments so as to "warn" doctors and PWAs against "worthless and dangerous approaches." The results were to have been computerized and made broadly available to the public and the insurance industry. Careful study of a similar Emprise project on cancer treatments found that it had been riddled with conflict of interest and entrenched bias. Its openly declared goals included supporting insurance exclusion, and discouraging federal funding of clinical trials of alternative treatments.

The National Institute of Allergy and Infectious Disease granted Emprise a $47,000 pilot grant. The company's follow up request for an

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undisclosed amount was to have been considered at an May 21 NIAID advisory Council meeting.

Meanwhile, over 30 AIDS service, PWA and activists groups had signed ACT UP's anti-blacklist Open Letter; the National Association of People with AIDS revoked its 1989 letter to NIAID endorsing the project; the ACLU AIDS Project was helping with legal research; Lesbian/Gay and AIDS publications nationwide were debating the issue; Congressman Ted Weiss was investigating conflict of interest by Emprise. And ACT UP/NY was readying a much broader campaign of letter writing, phone calls and press releases to culminate at the May 21, 1990 council meeting where stop the blacklist would have been an added demand at ACT UP's Storm the NIH national demonstration targeting the agency's virtual refusal to broaden treatment research beyond AZT and its analogues.

In early April, 1990 Grace Powers Monaco withdrew her Emprise corporation's application for federal funding of a computerized data base of unproven AIDS remedies-five months after ACT UP/NY launched a national "Open Letter" campaign to defeat it.

Undaunted, Emprise announced plans to pursue the database under university sponsorship and return later for NIH funding. Any evaluation of alternative treatments, holistic activists argued, must be done by unbiased individuals, with a major input from the AIDS community and from alternative practitioners themselves.

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NOW THE QUACK BUSTING IS THE TARGET OF THE ALTERNATIVE AND HOLISTIC MOVEMENT

A three day action in January 1990 provided another example of the struggle between government bureaucrats and community activists over freedom of choice of experimental HIV/AIDS treatments, particularly non toxic ones. The controversy concerned a food derivative called lentinan. The FDA tried to choke off its availability to people with HIV-related conditions, but a nationwide AIDS community rebellion forced it to back down. For years, this extract of the shiitake mushroom has been manufactured and used effectively in Japan as an immune booster for people with cancer, with studies showing dramatic life extension. Laboratory and animal research suggest that lentinan can stimulate the functioning of such key immune system parts as natural killer cells, macrophages and T-Cells.

In May 1990, after national cable TV station NBC set up a panel discussion on AIDS Treatment Fraud: "Grace Powers Monaco (an insurance industry consultant/attorney) and federal "quackbusters" refused to allow an invited member of ACT UP/NY to appear with them, or to have any activists in the audience (also invited). The station then tried to begin the program without the activists, but their opposition forced the station to cancel the broadcast.

In protest of the convention of the National Council Against Health Fraud, A&H co-led with ACT UP/Kansas City the National Action for Freedom of AIDS Treatment Choice in Kansas City, Missouri, on September 15-18, 1990. A counter-conference was convened including cancer and AIDS activists which allowed them to

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evaluate the possibilities of joint actions. The result was the creation of the AIDS and Cancer Freedom of Choice Task Force," a coalition of seven groups dedicated to coordinating lobbying and activism around these issues.

On September, 16 a silent vigil at the hospital employing conference organizer John Renner, MD was followed by a picket at the hotel hosting the conference. On September 17, a downtown march, a rally picket and a civil disobedience action were organized at the hotel.

Some picketers wore Donald Duck suits. One placard read: "John Renner is a quack." Outside the heavily policed building, one affinity group ran into the driveway, released mountains of feathers and staged a die-in while another group blocked traffic. Meanwhile, numerous other activists infiltrated the hotel past the lines of riot police and sneaked into the conference ballroom. The first group stormed the stage and took the microphone from the startled speaker, blowing duck calls and chanting, "Arrest the Real Criminals!" Shortly after the first group of arrests, two other waves of chanting protesters caused further disruptions. Police used choke holds and dragged some activists by a painful under the chin grip. Several arrestees filed brutality charges against the Kansas City police.

Later that day a local Kansas City action at City hall protested the mayor's opposition to AIDS budget increases and the City Council's refusal to pass a gay- and HIV-positive rights bill. Two protesters were arrested after hanging the mayor in effigy and throwing fake money around the building. All 25 arrestees were released within several hours on $25 or $50 bails and will face minor charges with low fines.

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On September 18, 1990 ACT UP/NY spokesperson Jon Greenberg, an HIV positive person using Chinese medicine and vitamins, rejected an invitation to participate in an AIDS quackery panel with three National Council leaders. The activist's statement said, in part:

> Under no circumstances will I legitimize your action by appearing in this heavily weighed and one-sided panel designed with malicious intent to unfairly represent me and the types of treatments that I have chosen to keep me alive.[7]

Jon Greenberg also denounced efforts by conference organizers to divide the coalition of AIDS and cancer activists which helped plan the protests. The previous day, National Council board member Victor Herbert, a New York physician at Mt Sinai hospital, publicly charged that alternative cancer treatment advocacy groups had paid airfares for "35 misguided gay activists" to come from New York to attend the protest.

The latest actions of A&H is targeted at the Health and Hospital Corporation which runs all the city hospitals in order to have it change its meal plan policy. The hospital food includes much sugar and fat, and according to holistic activists, poison the patient population. In fact, during the "Day of Desperation" action, an A&H affinity group protested its way into the office of Dr. Emilio Carrillo, President of the

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[7]Jon Greenberg, Alternative and Holistic File, Unpublished Document, ACT UP, 1990.

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Health and Hospitals Corporation. Carrillo agreed to devise an immune enhancing diet for persons with HIV diseases and to make this available to the general public in English and Spanish at all city-HIV testing sites. A&H activists also obtained his support for subsidized access to and information about acupuncture to help people with HIV disease de-toxify from drug addiction. Finally, he committed himself to lobbying Medicaid and insurance companies to cover acupuncture as a way to treat many ailments related to HIV diseases.

THE COLLUSION AND COLLISION OF TWO PARADIGMS: THE COLLAPSE OF THE CONCEPT OF PARADIGM, THE EMERGENCE OF THE CONCEPT OF STRATEGY

Reflecting changes in the culture of science, a split occurred in A&H. The committee was becoming more and more polarized over whether to use the scientific methodology to test alternative treatments. Some argued that the scientific methodology could not be adapted to test alternative treatments, others said it could.

For analytical purpose, activists who want to combine the scientific methodology with alternative treatments will be called scientific-alternative activists. They argue that no research has been conducted on those alternative therapies because no sponsor has been willing to spend the money. Riddled with bias, possible pharmaceutical sponsors view those therapies as suspect. Yet, even if there is hope of efficacy, the potential sponsors are still not enticed to produce it, because being natural, those components are not patentable and therefore no major profit can be expected to be reaped from them.

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An excerpt from a scientific-alternative activist's report is, in this regard, informative:

> PWAs have a fundamental right to make informed choices about their treatments.
> PWAs need reliable information in order to decide how best to use limited treatment funds.
> Reliable information is most efficiently and convincingly generated by scientifically reproducible controlled clinical studies.
> A treatment is only universally accessible if either it is free or reimbursable by third-party payees (insurance or Medicaid).
> Insurance companies, both public and private, base their decisions on which treatments to cover based on controlled clinical studies or large body of empirical evidence.
> WE NEED RELIABLE CONTROLLED STUDIES OF ALTERNATIVE AIDS TREATMENTS.[8]

Yet scientific-alternative activists argued that many PWAs[9][10] were using these therapies without really knowing what was in them, and their possible side effects. A national survey in 1989 by the

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[8]Jon Greenberg, Alternative Treatment Action File, Unpublished Document, 1991.
[9]Proceedings of the Ninth Annual Symposium of the Oriental Healing Arts Institute, *Immunity and Chinese Medicine*, Long Beach, Ca. 1989.
[10]Rabinowitz N. *Acupuncture Treatment of AIDS*, American Journal of Acupuncture, 15, 1987, pp. 35-42.

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Physicians Association for AIDS Care[11] revealed that over half of clinicians reported that their patients were using one or more alternative treatments, either in addition to or instead of conventional treatments.

In May 1991, activists formed a group called Treatment Alternatives Research Project (TARP). It is a group of PWAs, PWHIVs, AIDS activists and scientists, formed to address the need for *reliable* information on commonly used and promoted "alternative" and non pharmaceutical AIDS treatments with the specific goal of stimulating further research on these therapies. TARP is a working group. TARP members do not discuss theory, but they work and help each other with their individual projects. To this end, they gather information on the proposed treatments, separate the reliable data from that which still needs to be confirmed, create fact sheets for community education, and write formal concept sheets which clearly outline the rationales for and design of controlled clinical studies to generate the necessary answers. Additionally, they meet with "alternative" treatment advocates, community-based researchers and clinicians to stimulate interest in testing those treatments. Furthermore, TARP identifies possible sponsors for promising treatments and funding sources for proposed clinical trials. One of their governmental targets for funding is the the federal Community Program for Clinical Research on AIDS (CPCRA), which was designed by the government to meet the needs of the communities. In fact a study on peripheral neuropathy, long neglected by NIAID, is being currently conducted by the CPCRA.

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[11] Physicians Association for AIDS Care Notes, July-August, 1989.

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For TARP activists, it was necessary to redefine both "alternative treatments and holistic approaches. Alternative refers to treatments which have not been developed in a pharmaceutical laboratory and/or are not included in the established research system. Alternative treatments may include (but do not necessarily include) one or more of the following characteristics which keep them out of the established research system:

1) It is a natural substance and therefore unpatentable.

2) It does not have a major pharmaceutical company to sponsor its development and marketing

3) It is a mixed, not purified substance

4) It may be considered a food product

5) It is not a new agent.

6) It is a technique, not an agent at all and therefore there may be no research model for it[12]

Holistic approaches, in contrast, involve healing on three levels: mind, body, and spirit. Healing occurs, when it occurs at all three levels. Holism is a philosophy of health, it is not a specific treatment. Alternative treatments may be used in holistic approaches but they are not, in themselves, holistic unless they work on all three levels at once.

Alternative treatment practitioners, users and producers, according to scientific-alternative activists, do not know how to access and do research. They have no knowledge of rigorous clinical trial designs, and are unable to cut through the bureaucracy.

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[12]Alternative Treatment Action Fact Sheet, Unpublished Document, ACT UP, 1991.

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In turn, the research establishment is not knowledgeable about alternative treatments, as well as the different models of disease. Scientific-alternative activists want to apply requirements of new pharmaceuticals with unknown toxicities and effect to long used treatments with no known toxicities and effects and sponsors.

TARP's project includes scientific research on:

Glycyrrhizin

Hypericin

Vitamin B-12.

Iscador-- an extract from European mistletoe, immunodulator,

Zinc supplementation

Slenijum

Vitamin A (Betacarotene)

CoQ10

Amino Acids

Vitamin E

Stress Reduction

Massage

Acupuncture

Chinese Herbs

Sb 73 (mushroom extract from Brazil)

Carnoivora

Blue-gree algae

SST

PCM-4

714X

Thymus extracts

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Hydrotherapy

Astragalous

Maitake Mushroom

Ozone therapy

Homeopathy

Chiropractic

Dietary management (for the control of fungal infection and as possible OI prophylaxis)

Thymus extracts

Hypnotherapy

Astragalous

Maitake Mushroom

Ozone therapy

Homeopathy

Chiropractic

Dietary management (for the control of fungal infections and as possible OI prophylaxis.

Just about any treatment, whose relationship to AIDS management is not fully understood.[13]

There have been few clinical trials of the efficacy of alternative treatments. Those undertaken are mostly small, primarily due to lack of funds and staff time available to the underfunded institution (whether local clinics or small health food companies), which administers them. The situation of the Community Research Initiative (CRI) is indicative of the difficulty small research centers face

[13]Treatment Alternative, Unpublished Document, 1991.

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in their quest for funding. In October, 1989, the NIH was forced by Congress to make grants available to community-based AIDS research centers. It rejected all funding for CRI/N.Y., and several other well established independent groups.

Preliminary studies, however, show some positive results for such particular products as Chinese herbs, plant extracts, and nutritional supplements; a few food and herbal extract--lentinan (shiitake mushroom) and hypericin (St. John's Wart herb) are in community-based trials.

After growing PWA interest in lentinan and the refusal of the National Institutes of Health to do studies, the Community Research Initiative in New York and the University of California, San Francisco Medical Center, each began community-based clinical trials of its efficacy in March April, 1989.

With 50 east coast and 40 west coast subjects-all HIV or people with ARC having 200 to 500 T-cells the 12-and eight week trials, respectively are scheduled to be completed in the Spring of 1992. The New York trial includes two groups on different doses and one group on placebo, all receiving weekly intravenous injections. According to former CRI's Executive Director Bernard Bihari, M.D. preliminary results at both sites show that after a full course of treatment well over a fifth show clear rises in T4-cells, often by over 50% ,and stabilizing after discontinuance with only occasional minor and transient side effects. He cautions, however, that until the study is unblinded it is unknown how many with increases are on lentinan and how many are among the 20% on placebo.

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The New York trial like all trials run by CRI follows strict guidelines of ethics and compassion set by its board of PWAs, AIDS advocates and community physicians. The co-sponsor of the trial is the Lenti-Chemico Pharmaceutical Laboratory, a subsidiary of the large Japanese drug company Ajinomoto which manufactures lentinan.

TRAVELING, THE NEW EPISTEMOLOGICAL PATH

A trip to the West Coast by Jon Greenberg remarkably synthesized the problems within both the holistic and the allopathic paradigm. The following excerpt shows that the activists' intention was clearly epistemological:

> We had to motivate conventional, established AIDS researchers to initiate studies of commonly used and/or promising "alternative" AIDS treatments. At the same time, there was a need to educate "alternative treatment practitioners" on the rationale, principles and methods of clinical research. Along the way, the hope was to gather enough community support so that once I had left, the work on these issues would continue.[14]

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[14]Jon M. Greenberg, *Report From West Coast, or 3 Cities, 4 AIDS Researchers, 8 Alternative Treatment Advocates and Countless AIDS Activists in 14 Days,* Treatment Alternative File, ACT UP, Unpublished Documents, 2/6/1992.

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In Stanford, Greenberg met with Dr. Thomas Merigan, one of the ACTGs' Principal Investigators, who, did express an interest in Vitamin C, but did not want to commit his laboratory to doing the PCR for the trial. He indicated that he did not want "to ruin his reputation" the way that Linus Pauling had by attaching himself to Vitamin C.

In San Francisco, Greenberg met with Robert Gorter, who is an AIDS researcher at San Francisco General Hospital (SFGH) and is involved with the development and testing of Iscador, an extract from the European mistletoe. For 3 years, Iscador has had a treatment IND status from the FDA. It is the first, and only whole plant extract which the FDA has granted a treatment IND. Yet no trial had been set up yet.

This is what Greenberg observed about two establishments:

> Our basic questions about appropriate dosages and achievable and maintainable plasma levels of Vitamin C remain unanswered but at least we have a strategy for answering them. It has been like a treasure hunt finding and putting together the various pieces of the puzzle.
>
> What was learned:
>
> 1.We need consistent activist pressure in this area. Pressure on both the AIDS establishment to initiate studies and on the "alternative" medical community to do reliable, useful, ethical studies.
>
> 2. People can get excited about research when they realize why it's necessary and how it relates to them.

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3. The "alternative" medical community has not been blameless for the appalling lack of reliable information on these types of treatments.
4. People with AIDS want and need the information.
5. It is possible to engage even the most close-minded researcher if she/he is presented with something concrete.
6. We need more people to work on this.[15]

Leanna Standish is the head of AIDS Research at Bastyr College, the largest and most respected school of naturopathy in the US. A couple of years ago she completed a study which was entitled H.A.R.P (Healing AIDS Research Project). HARP was intended to show that "with effective natural medical treatment and a sense of control over their health and future, people can become long-term survivors of HIV infection."[16] It was a complicated protocol which was more appropriate for a model of care than it was for a model for research, according to Greenberg. It included four therapeutic modalities: nutrition, hydrotherapy, psychotherapy and either botanical medicine or homeopathy. Because the last modality was the only controlled variable, it was also the only part of the protocol which could have possibly be read. According to Greenberg, the sample was not large enough, not randomized and the endpoints were nor clear enough.

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[15] Jon M. Greenberg, *Report From West Coast or 3 cities, 4 AIDS researchers, 8 alternative treatment advocates and countless AIDS activists in 14 days,* Alternative Treatment Action, ACT UP, Unpublished Document, 1992.
[16]Standish, Leeanna : HARP. Bastyr College Research Department, September 1990.

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Except for some very raw toxicity data , very little useable information was gathered from the "trial". Overall, the HARP study was a very good example of what is wrong with most "holistic" treatment research projects. They may be very good guidelines for a treatment regimen, but they are not designed to answer questions.

The next morning Greenberg spoke to Subhuti Dharmananda the director of the Institute for Traditional Medicine in Portland, Oregon. They are the distributors of Seven Forests brand of Chinese Herbs. One of their products, Composition A, is in wide use in the HIV community and is sold over the counter in many pharmacies and health-food stores in impacted communities.

Greenberg wanted some information on the quality and composition criteria used in the formulation of Composition A. Without such information, it would be impossible to design a trial of the substance which would give any meaningful data. Dharmananda refused to provide such data saying that the compound was formulated on the principles of traditional Chinese Medicine which were so "involved" that he could not possibly explain them to him over the phone. Greenberg replied that to test for efficacy, there has to be some basic information about what the compounds were made of. Dharmananda argued that they were not making any claims on the bottle; that the herbs were effective so they did not have to do any of the studies. Greenberg replied that people were spending their limited treatment dollars on these herbs based on, the perhaps rumor, that they were effective treatment against HIV disease. Dharamanada replied that the herbs were being delivered by practitioners schooled in the principles of Chinese medicine so any specific questions of toxicity and

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/or efficacy would have to be formulated within the context of the principles of traditional Chinese medicine.

Dharamanada would not answer Greenberg's questions about possible toxicities or drug interactions. He would not answer Greenberg's questions about the standards he used to determined recommended dosages. Yet he was not unfamiliar with the concepts of consistency of product and quality control. It was also evident that Dharamananda understood the concepts of pharmacokinetics, pharmacodynamics and bioavailability. He simply refused to acknowledge that these principles applied to his products.

Greenberg's trip to the West Coast really exemplifies the new trends of activism that is developing. A critical spirit targeting any form of fundamentalism, whether it be allopathic or holistic. Each perspective for the scientific alternative activist entails some form of fundamentalism. Because of its long standing dominance the allopathic paradigm has used science not only to show a method of inquiry, but also to impose the object of research. In other word allopathic doctors and researchers dictate how to study and what to study.

In contrast, holistic fundamentalists declare that their treatment are effective for specific diseases, yet their methodology is so obscure that only "they" can test those products.

The response of scientific alternative activists is that any treatment should be given an equal chance of being tested. But all treatment should be tested according to the scientific methodology.

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Science in this instance steps down from its level of paradigm and is reduced to the humbling level of being a strategy used in the quest of finding a cure to a disease.

Allopathy has been the dominant model for over 100 years. Now the relationship between allopathy and holistic perspective is more of a dialectical nature. Allopathic proponents are more drawn toward the alternative modalities because their approach has lamentably failed many of the major diseases that kill most people in society. Allopathy is now more held in check.

For many holistic activists, AIDS is viewed as a metaphor: AIDS is the breakdown of the universal defense system at the physical, intellectual, epistemological, sexual, racial, social, political, economic levels:

> AIDS is the breakdown of the medical system, of the ideas of science, of faith in science.
>
> We must create a culture in order to defend ourselves against racism, homophobia, economic disparities, which were created out of the fear of others.
>
> Today's religion is the religion of science. Today's high priests are researchers and scientists. They have created the institution in order to keep the secret of science away from the masses. The real secret of science is that there is nothing to be afraid and that everyone is capable of doing science.

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That's what the scientists are guarding. If that comes out, they lose power.[17]

The revolutionary thing about ACT UP is that we're about empowering people with the knowledge, and the belief that there is nothing to fear. We' ve fought the economic system at Wall Street. We've fought the government, the Church because they all made us afraid. The last frontier is science, today's new religion.

Treatment Alternative is dedicated to breaking down, destroying the separation between science and the masses, by telling people very clearly how to understand, in a way not done until now that they can create their own science.

Treatment Alternative has to take away the ritual trappings to get to the core. Science is holy in a way anything else is holy.

We use the method of scientific inquiry and apply it to holistic.

Likewise holistic practitioners must be submitted to the same scrutiny. Holistic practitioners are afraid, because their principles can be exposed.

We demystify the information that we make available to the masses. They learn to be their own

[17]Personal Interview, 1991.

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doctors. And that's a very threatening ideas for experts.

The only way we can break our fear is through vision and sharing information. The power of ACT UP is giving people the support structure that individuals need to confront their fear. Arrest situation for example have two functions:

1) external function with media attention, to change public opinion or create public opinion.

2) internal function with empowering ourselves, and allowing ourselves to confront our fear of authority, police, jail, handcuffs.

We must get over our fear or death and authority of any forms. Death is healthy, because we are part of the universe.

The cancer movement has not fought for scientific research of their treatment. But Cancer activists helped create the confusion, and lay down the foundations for the work I do.

I do not see AIDS as an enemy. It is like deconstructionism, it shows old forms of knowledge, and suggests new ones.

By broadening the concept of treatment, and attaching it to the requirements of science (now reconstructed as a strategy only), scientific alternative activists bring new heights to the concept of

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communalization of medicine, and more generally to that of epistemology.

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PEOPLE OF COLOR, MINORITY IN NUMBERS, MAJORITY IN RATES

In 1987, people of color were most hit by the epidemic. Since then, the situation has not changed. In fact, it became even worse as current statistics reveal. In November of 1991, the total number of AIDS cases nationwide passed the 200,000 mark, and approximately 50% of those cases were persons of color. Yet people of color represent only 20% of the U.S. population. The proportion of gay or bisexual men in each category was quite significant. Among all the Black men with AIDS, 44% were gay or bisexual, as opposed to 46% in the Latino community and 81% among Asian and Pacific Islanders (API's) and finally 64% among Native American/Alaskan (NAA's).

In New York City, Black men represented 32% of the total of AIDS cases, Latinos represented 27%, API 1%, and NAA's 1%. White men represented 40% of all the AIDS cases in New York City. Added together, AIDS cases among communities of color represented 60% of all the cases. In New York City the proportion of gay and bisexual men with AIDS was also significant. Among all Black men with AIDS, 36% were gay or bisexual, as opposed to 36% in the Latino community and 78% among API's, and finally 27% among NAA's.[1]

Statistics about women and AIDS reflected the same picture. Black women represented 35% of AIDS cases among women of all races. Latinas 28%, APIs 1% and NAA 1%. White women represent 36% of AIDS cases among women of all races. As in the case of men of color, if all AIDS cases among women of color are added, they

[1]All those statistics are drawn from the AIDS Surveillance Update, Fourth Quarter 1991, New York City Department of Health Office of AIDS Surveillance, Issued January 1992.

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represent, with 64%, the vast majority of AIDS cases among women of all races.

In both gender categories, intravenous drug use held a special weight. Black and Hispanic men are almost three times more likely than whites to contract HIV through unsafe drug sharing. Black women were three times more likely than whites to contract HIV through unsafe needle sharing, and two times more likely than Hispanic women.[1]

AIDS: JUST ANOTHER PROBLEM FOR THE MOST DISENFRANCHISED COMMUNITIES OF COLOR

When AIDS hit communities of color, the pre-existing social, economic and medical epidemics plaguing those communities. Medically for example, communities of color lagged far behind the rest of the population, although medicine had made tremendous progress allowing people to live much longer. Wornie L. Reed has argued that if Blacks benefit least from those medical improvements, it is due to institutional racism.[2] Reed defines institutional racism as those established laws, customs, and practices which systematically reflect and produce racial inequities in American society.
With regard to the health of persons of color, one product of institutionalized racism expresses itself through the ever increasing

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[1]All those statistics are drawn from the HIV/AIDS Surveillance Report Issued by the CDC, U.S., U.S. Department of Health and Human Services, Public Health Service, *AIDS Cases reported through November 1991.*

[2]Reed, Wornie L., *Racism and Health: The Case of Black Infant Mortality*, in Conrad, Peter and Rochelle Kern, Eds., *The Sociology of Health and Illness, Critical Perspectives*, New York: St Martin's Press, 1990.

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infant mortality rate. Infant mortality is the indicator usually used to assess the mother's health status and the overall socio-economic situation of the family. The U.S. still ranks very high in infant mortality, due mainly to the high death rate among nonwhite children. In 1986, the rate for all Americans dropped to 10.4 deaths within the first year of life per 1,000 live births, the lowest ever recorded in the United States. For whites, the figure was 8.9 per thousand births, a decline from 9.3 in 1985, but the rate for blacks was 18.0, compared with 18.2 in 1986.

Birthweight is well established as a factor influencing infant mortality. Birthweight is also affected by the number of prenatal medical visits. Pregnant women should have 13 prenatal medical visits. In actuality, only 60% of African American and Latinos/as receive prenatal care.[1]

Reed argues that even African-American with the highest socio-economic status have a higher infant mortality rate than whites with the lowest socio-economic status. Race, then, would correlate more than class with infant mortality.

In addition, cutbacks in Maternal and Child Health (MCH) Funding by the Reagan administration in 1981 had adverse effects on infant mortality. The tragic consequences of these cuts included the realization that the Black infant mortality rate today is equivalent to the white rate in the 60s, and some 6,000 black infants die each year whom otherwise should be living.

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[1]Malcolm Gladwell, *Life Expectancy of Black Males Falls to 64;* The Washington Post, April 9, 1991.

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Institutionalized racism also expresses itself through the high mortality rate of persons of color. Before the AIDS epidemic was identified, African American individuals had an overall mortality rate 47.4% higher than whites among persons 45 years of age. Of this "excess death," 26.9% were due to infant mortality. In addition, among the leading causes of death during this period, homicides and killings in police confrontations increased 8%, the first increase in this category since 1980. While the death rate for such killings increased 5% for whites, it went up 15% for blacks.[1]

The gap between black and white mortality rates has increased although the overall mortality rate has decreased. In 1950, the black rate exceeded the white rate by one third; in 1980 the black rate exceeded the white rate by one hundred percent. Yet the rates for Native Americans, Chinese, Japanese and other races decreased by 499%, 206%, 193% and 228%. The decrease among Native Americans was the result of a crash health program, which demonstrates the capability of the Federal Government to decrease the mortality rate among racial groups.

POVERTY INCREASES RISK OF INFECTION WITH HIV, AND RISK OF DEVELOPING AIDS

Impc rtant factors associated with poor infant health include low income, inadequate insurance coverage, preexisting disease condition, poor nutrition, inadequate housing and crowded living conditions,

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[1]National Center for Health Statistics, Report 1988.

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limited maternal education, stressful work environment, problems of transportation, and childcare.

But, according to Reed, the one single most important factor contributing to poor health is economic discrimination, that is the consistent location of a high number of blacks in the lower socio-economic classes. Of the black population nationwide, 30.1% survive under the level of poverty, defined as annual income of $12,000 for a family of four. When they are under 18 years of age, 43.2% of the blacks survive under the level of poverty. Of all the Latinos nationwide, 27.8% survive under level of poverty.

It is no wonder that more than 20% of blacks and nearly 40% of Mexican Americans lacked health insurance.[1] In addition, blacks and Latinos/as have more teenage pregnancies than whites. This socio-economic backdrop certainly contributed to the overrepresentation of communities of color in pediatric AIDS cases. Indeed in 1992, over 90% of the pediatric AIDS cases hit babies of color.

Residential segregation of black population is another processes that contribute to the black population being so greatly "at risk" for infant mortality. Ghettoization affects infant mortality by overcrowding, poor housing, lack of sanitary environment, and preclusion of blacks from health facilities, as is the case in the AIDS clinical trials. Ghettoization also affects the mortality rate of adults. A study showed in 1990 that the life expectancy rate of African-American males in Harlem to be lower than the men of Bangladesh.

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[1]Hilary Stout, *Life Expectancy of U.S. Blacks Declined in 1988*, The Wall Street Journal, April 9, 1991.

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In 1910, 73% of the Black population were living in rural areas. Fifty years later the proportion reversed, 73% of the population lived in urban areas.

The Federal Housing Administration, created during the New Deal in the 1930's, had an official policy of segregating residential areas. Although the Housing Act of 1937 brought housing to the poor, few blacks were permitted to occupy public housing. And racial restrictions in housing purchase contracts were permitted until the 1950's. Nowadays, segregation is more subtle. Criteria such as family size are used to prohibit blacks from living in white neighborhoods.

Worse than residential segregation is homelessness. In 1990, 46% of the nation's homeless were black. This is what a survey of mayors in 30 major cities revealed. And this other scourge is not about to disappear in the midst of the economic recession that is plaguing the country. The survey also revealed in 70% of the cities, shelters were forced to turn away homeless families, because they lacked the resources to meet the growing demand for housing.

HOW INSTITUTIONALIZED RACISM OPERATES IN THE MIDST OF THE AIDS EPIDEMIC

The treatment of PWAs of color is the carbon copy of their treatment in society as a whole. Although they are overrepresented in the AIDS epidemic, with over 40% of AIDS deaths, they receive hardly medical attention. When they actually do, many of them are not diagnosed with the disease. And when they are, it is too late for them to benefit from life-saving treatments.

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The lethal consequence of this lack of health care is that persons of color die three times as fast as Caucasians. Women of color in particular may die six times faster. As already mentioned, children of color represent over 90% of all pediatric cases. And those children are subjected to terrible experimentations or receive no treatment at all.

The CDC definition excludes women of color, the way it excludes Caucasian women. But in addition, it excludes opportunistic infection specifically contracted by indigent people. Pulmonary tuberculosis is a good example of how the poorest communities are left to die without treatment.

Pulmonary tuberculosis is actually the most common opportunistic infection worldwide. Worldwide, AIDS is increasingly a disease of the Third World, or a disease of poverty. In the U.S., therefore, it affects particularly persons of color, IV drug users and poor people who live in infested and polluted environments. Yet the CDC does not list it as an opportunistic infection.

The first tragic consequence of this omission is the preclusion of PWAs of color from Social Security entitlement programs. The second is their preclusion from drug trials, some of which could be life-prolonging for many PWAs. Indeed, although over 30% of all PWAs are Black, they represent only nine percent of the subjects in all federal AIDS trials.

Yet when they are admitted in clinical trials, PWAs of color are not treated like white PWAs. The gaze of the biomedical establishment toward communities of color is still one of distrust and disinterest. Persons of color are viewed as "unreliable subject populations."

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THE COMMUNALIZATION OF ISSUES AFFECTING PEOPLE OF COLOR

WE DIE, THEY DO NOTHING

The committee in ACT UP that dealt with issues related to persons of color was the Majority Action Committee (MAC) created in the Spring of 1988, out of the Nine Days of Action organized by ACT UP/N.Y. and ACT NOW (umbrella network encompassing all the ACT UP chapters in the U.S.). The name "Majority Action Committee" was chosen, because not only are communities of color found in larger number in New York City than Caucasian ones, but they also comprise the largest number of AIDS cases. In this sense, the term "minority," according to some activists, would be quite demeaning and unrepresentative of the social reality.

MAC's goal was:

> Participating in AIDS educational forums within our communities
>
> Distributing information on "clean works" and other issues pertaining to IV drug use.
>
> Distributing explicit safe sex information on the streets of our communities.
>
> Demanding a national program for dealing with AIDS in all minority communities as well as demanding leadership from our elected officials.

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> Fighting for the participation of minorities, women, and IV drug users in the drug protocols to be administered by doctors we can trust. Monitoring the situation of children with AIDS in hospitals and stopping the inhumane experiments upon them.[1]

Thus, MAC members went to the CDC National Conference on the Prevention of HIV Infection and AIDS among Racial and Ethnic Minorities in the United States, held in Washington, D.C., from August 14th through August 17th, 1988. Although no action was held during the conference, MAC members passed out personal testimonies of their experience as persons of color with HIV or having friends of color with HIV. The response was so huge that it represented a good measure of the urgency felt by present delegates.

They criticized the Conference for focusing only on prevention, rendering invisible the many persons of color already infected with HIV. Because persons of color are often faced with more immediate concerns such as employment, income, housing, food and child care, it would be erroneous to expect that most of these individuals would be influenced by pamphlets and advertisements to effectuate behavioral changes, much less coming to a center for testing and counseling. In this context, knowledge of antibody status does not elicit behavioral change, but creates new levels of discrimination and oppression. Consequently, activists of color's demands included the convening of a

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[1]Majority Action Committee Fact Sheet, Unpublished Document, 1988.

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Conference that would include issues relating directly to the experience of communities of color.

THE CONNECTION OF AIDS MOBILIZATION AND THE CHURCH IN THE AFRICAN AMERICAN COMMUNITY

The single most influential institution in Communities of color in the U.S. is the Church, whether it be Catholic or Protestant. Activists of color understood from the beginning that if they wanted to reach to their own communities, they would have to use the medium of the Church. This would not be an easy task, because of the heavy religious interdiction around sexual and homosexual issues.

As a result, they decided to participate in a panel on "AIDS Agenda-Genocide," convened, at the Abyssinian Baptist Church in June 25, 1988, by the Reverend Calvin Butts and other public figures of the African American communities. MAC members thought it would be a wonderful opportunity to expose the views of ACT UP and offer collaborative efforts to face the epidemic. Little did they know they would not be allowed to speak.

Their first failure at the Abyssinian Baptist Church could not stop the activists' effort to reach the African American communities faced with one of the most lethal scourges in their history. Thus, in August, 1988 MAC wrote to the Reverend Jesse Jackson. In this poignant letter were elucidated many crucial problems facing the black communities.

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It comes as no surprise to us that few politicians have decided to assume the responsibilities of addressing AIDS issues, for to address these issues is to address all the politically unpopular issues of our era: discrimination, racism, sexism, homophobia, sexuality, poverty, public health care, homelessness, prisons and IV drug use. All of the communities affected by AIDS are socially and/or economically oppressed. No one cares. Latinos, Black, lesbians and gay men--we are all "disposable" populations, somehow deserving of the ravages that AIDS wreaks among us. Blacks and Latinos make up less than 20% of the U.S. population but over 40% of AIDS-related deaths. 84% of women and 92% of children with AIDS are people of color. Although a white male lives an average of 18 months after an AIDS diagnosis, people of color live an average of only 6 months after diagnosis. We are targets of blame for spreading the disease-- for being "vectors of transmission"--not targets of treatments and services to mitigate the damages of AIDS. It is not a virus alone that is killing us. Public apathy, political negligence, and medical profiteering all come together to cause what is tantamount to genocide. [1]

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[1]Excerpt of a letter sent by the Majority Action Committee of ACT UP/N.Y. to Reverend Jesse Jackson, in August 29, 1988, Unpublished Document.

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The Reverend Jackson's support of MAC was the flip side to the more conservative wing of the Church. As an activist of color puts it:

> The Church can help you as much as it can hurt you. But the Church holds a special place among the black community, even the gay black community. It offers a sanctuary where we can experience our spirituality, even our gay spirituality. And to be religiously spiritual should not be equated with being conservative. We have in our churches individuals who are far more radical than in ACT UP. We derived this radicalness, not from our political orientation, but from our historical and current oppression.[1]

It was with the support of other churches that an action was organized at St Luke's Hospital in the Winter of 1990. The City had decided to move its pediatric AIDS unit Harlem down to Roosevelt Hospital. Black Ministers and activists marched together to have the unit reinstituted.

In contrast, Secretary of Health Louis Sullivan was pressing more people to be tested for HIV. MAC members went to Harlem and passed out petitions demanding that a hearing be held at the federal level so as to assess the impact of the epidemic among communities of color, and to sponsor concrete, comprehensive and effective

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[1]Personal Interview, 1992.

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legislation in the areas of AIDS education, prevention, treatment and care. The petition also called on elected representatives to introduce and sponsor bias crime legislation protecting and providing remedies to individuals who have been targets of violent attacks or property damage because they were or were perceived to be affected by AIDS and HIV infection.

THE CHEMISTRY'S JUST WRONG!

As already mentioned, AIDS was just another problems for the most disenfranchised communities of color. And AIDS, in fact, worsened other forms of discrimination. The role of MAC, from the activists' point of view, was therefore to remind ACT UP that racism did not only operate through the (mis)handling of the AIDS epidemic by the government and institutions in power, but was a much more pervasive process. For example, an investigation by Senator Leichter and Assemblyman Farrell revealed that ChemBank was one of four New York area banks that practiced discrimination against women, African-Americans and Latinos especially in the area of new accounts.

The study, entitled "Limited Access" found that 77% of the time ChemBank, Chase Manhattan, Marine Midland and Citybank waived a "rule" requiring a checking account applicant to live or work within ten blocks of the branch office if the applicant was white, and waived this "rule" only 2% of the time for Blacks and Latinos. White women were given waivers only 50% of the time. Waivers were consistently offered to white men.

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Furthermore, while Chemical bank publicly declared that it was opposed to the racist Apartheid regime of South Africa, activists asserted that it actually assisted South African interests in an attempt to increase their foreign investments and strengthen their cartels. Minorco, a subsidiary of the Anglo-American/ De Beers group (a corporation controlled by white South Africans) was attempting to take over Consolidated Holdings. ChemBank was lending the money to carry out this transaction with powerful Apartheid-controlled cartels.

As a result, MAC proposed that ACT UP remove its account from ChemBank. In addition ACT UP demanded that the bank reveal all its accounts with South Africa which to date are not covered by the Anti-Apartheid Act of 1986.

MAC AGAINST HOSPITAL GENOCIDE OR THE APARTHEID HEALTH CARE SYSTEM OF THE U.S.

In June 17, 1989, more than 100 furious protesters, carrying gravestone-shaped signs and led by a hearse, marched on Kings County Hospital Center to decry what they called dangerous conditions at the huge Brooklyn Medical Center. Present were AIDS activists and members of civic organizations, complaining that the Brooklyn hospital was desperately overcrowded, that emergency-room patients sometimes had to wait hours to see a doctor, that treatment of AIDS patients was inadequate and that the hospital's administration was insensitive to the communities of color. Protesters also complained that Kings County Hospital, which had one of the highest AIDS caseloads in the city, did not use key drugs for the treatment of the

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deadly disease. When asked about aerosolized pentamidine, the commonly used treatment for PCP, the director of the Hospital revealed that he was not aware of its existence. Protesters also accused hospital administrators, 12% of whom were black or Latinos/as, of not caring about the patients, 77 percent of whom were persons of color.

As a result of the Kings County Hospital's protest, Majority Action created its own manifesto, the focal concept of which was the central involvement of AIDS activists of color in the resolution of the crisis affecting their communities.

GOVERNMENTAL CONCERN FOR COMMUNITIES OF COLOR?

As a result of the pressure placed by different organizations of color the government created the Community Program for Clinical Research in AIDS (CPCRA). This was a new funding program designed to create clinical trials in community-based sites, because PWAs of color had been so far excluded from the official protocols. The new trials would be close to the communities and involve them in the design of the protocols.

Two reasons still deterred black people from participating in those trials. The first one involved the recollection of past experiments which left harsh imprints in the memory of the community. For example 60 years ago, 412 poor black sharecroppers suffering from syphilis were rounded up in Tuskegee, Alabama, for what would become the most horrific example of human experimentation funded by the United States Public Health Service.

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For 40 years, the men were never told what had stricken them, while doctors observed the ravages of the disease, from blindness and paralysis to dementia and early death. Even after penicillin proved to be an effective treatment for syphillis, they were given aspirin, a free examination and $50 for burial. And the study was funded by the United States Public Health Service. After a class-action lawsuit filed by the subjects and their families, in 1974, the Government agreed to award $37,500 to the 70 subjects then living and $15,000 to the heirs of each of those who died.

The second reason was that NIAID may not have been so much interested in the community's needs as its own protocols. In March of 1989, the National Institute of Allergic and Infectious Diseases (NIAID) released a Request for Proposals (RFP) for contracts with the Community Program for Clinical Research on AIDS (CPCRA). But ACT UP realized quickly that NIAID's real intent was to dictate what the so called "community protocols" would be. In other words federal researchers were more interested in funding their own research than meet the needs of communities of color. Activists are still working on the issue.

As all this politicking was going on, the situation of the black population was worsening. In 1989, driven by drug use and inner-city poverty, there were about 37,000 new cases of syphilis among African-Americans, more than double the 16,000 of four years earlier. The increase alarmed health officials because of the close association of syphilis and AIDS. Because both diseases are spread through the same sexual behaviors, the rise of syphilis indicated that people were not practicing safe sex, and as a result were highly susceptible to HIV as

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well. In addition, genital ulcers caused by syphilis greatly increased the chances of HIV infection.

MAC'S DEMISE

MAC attempted to outreach to all the communities of color. But as time went by, it became clear that the group could not address the multiplicity of issues encompassing the reality of the many individuals who identify as individuals of color. In addition, MAC members fell short of representing the ethnically diverse communities of color.

As a result, three different groups emerged in 1990: the Spanish Translation Committee, Wipe out AIDS and Racism (WAR,), and the Asian and Pacific Islander Caucus.

The Translation Committee was actually a mix of ethnically diverse activists. Yet Latinos felt that they needed their own caucus and a month or so later the Latino/nas AIDS Activists Caucus of ACT UP was created. As in the other caucuses, Latino/as could meet and express themselves in their own language, addressing the issues in their own terms, without fearing the intervention of other members ignorant of problems facing the Latino/a community.

THE COMMUNALIZATION OF LATINO/A ISSUES

In order to make the Spanish Translation Committee more attuned with the purview of ACT UP, the committee changed its name from Spanish Translation to Spanish Communications. The difference lay in the cultural emphasis that the second name placed on

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translation, seeing translation not only as the activity of transferring a sentence from one language to another, but also of transferring the cultural context in which the sentence is expressed. In this sense, the Spanish Communications Committee was as much direct action oriented as the Treatment and Data Committee of ACT UP. The ultimate purpose of the committee was to stir the Latino/a individuals' political consciousness and engage them into direct action.

Thus, the Latino Caucus, as it was more commonly called, went to countless fairs, forums and conferences to make AIDS a first priority. In 1990, Latino members went to the Latino Conference-Somos Unos- in Albany, but were evicted because they wanted to bring up the issue of AIDS in the Latino community. That same year, they asked for a permit to participate in the Puerto-Rican Parade, but were turned down again, because, according to the organizers, *this was neither the place nor the time.* As expected, the activists did not wait for the permit to be granted, and *broke in.* In fact, even now, the Latino Caucus has never been allowed to march in the parade. Some Latino/a activists argue that this may not be unrelated to their being AIDS activists and their self-identification as gay or lesbian.

Being part of a special Caucus does not mean that latinos/as were divorced from the rest of the group. They participated in all the major actions of ACT UP. Thus, during the National Institutes of Health (NIH) action on May 21, 1990, they formed a group called Las Locas Radicales whose demands were equal representation in clinical trials; research of infections, such as toxoplasmosis, particularly affecting Latinos because of their socio-economic status; more

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systematic accrual in the Latino community and finally translation of protocols into Spanish.

Latino/a activists were also present at the Centers for Disease Control action, where many Latina women revealed their seropositive status to the media, and described the plight of being a poor Latina woman with HIV without any hope of receiving Social Security benefits because of the denial by the Centers for Disease Control that they could develop AIDS.

In the Spring of 1990, they organized the first People of Color and AIDS Activism Conference with the collaboration of other activists of color in ACT UP/N.Y. and other ACT UPs throughout the country. The Conference was held in Chicago, to decentralize the importance of New York City. Interactions between the different groups was intense and filled with emotions. The direct result of this conference was a strengthening and expansion of the network of activists of color.

Activists of color also participated in the huge demonstration on April, 1990 stirred by the racist regulation of the FDA to ban Haitians and Africans south of the Sahara desert from donating blood, even if the blood had been tested and proven uncontaminated.

Expanding their networks allowed activists of color to organize an action during the 6th International Conference on AIDS. Dr Louis Sullivan was slated to speak with other health officials. Because he sustained the ban of HIV positive immigrants, and denied the expansion of the CDC definition to include women, activists of color, with the support of others, had decided to shut down his speech. During the logistical preparation of the action, it was decided that black activists would lead the action, so that Sullivan could not say that

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shutting down his speech was an racist act on the part the predominantly white constituency of ACT UP.

The whistling and hissings lasted during the length of his speech, which he persisted to give, although no one could hear a word he was saying. Activists of color were, according to one WAR member, all the angrier that Sullivan was himself black and totally unable to display compassion for his own community.

Back in New York, the Latino/na activists started to be interested in the AIDS situation in Puerto Rico. When Latino/a activists got a copy of the Confidential Report on the situation in Puerto Rico, commissioned by the American Foundation for AIDS Research, their immediate reaction was: *we've got to go there, and organize a direct action.*

AIDS IN PUERTO RICO, WORSE THAN HURRICANE GILBERT[1]

Puerto Rico, with a total of 7,659 cases, has the second highest incidence of AIDS in the Unites States (after Washington DC) and represents 27% of adult cumulative cases. The Island currently has the nation's second highest rate of AIDS, with 53.2 cases per 100,000 population and a total of 6,092 cumulated AIDS cases. The San Juan area alone has more than 2,000 known AIDS cases. In terms of per capita rate of new cases, Puerto Rico has the nation's highest rate, more than three times the national average.

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[1]Statistics in this section are drawn from the Confidential Report on Puerto Rico mandated by amFAR in 1990, Unpublished Document.

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Approximately 60% of all AIDS cases in Puerto Rico are intravenous drug users, 18% are gay/bisexual, 10% are gay/bisexual IV drug users, and 8% are heterosexuals (primarily women).

AIDS is the leading cause for death among Latino/a men and women between the ages of 25-44. To top it all, 60% of Latino/a youth in Puerto Rico do not know how HIV is transmitted, according to a study funded by the CDC.

Dr. Johnny Rullan, Puerto Rico's epidemiologist and appointed chief AIDS coordinator, acknowledged that the official count was underreported by as much as 40%. By this estimate, Puerto Rico's AIDS incidence would be 63 per 100,000, more than one and half times New York State's and almost five times that of Massachusetts. Nearly one in every 20 adults between the ages of 25 and 44, seen at the San Juan Municipal Hospital for non-AIDS related illnesses, was found to be carrying HIV. Among San Juan residents of all ages, an average of 2% are already infected. The Island's blood donors, considered a cross-section of lower-risk Puerto-Ricans, have HIV infection rates 27 times the United States average. Dr Rullan estimates the number of HIV-infected people Island-wide at up to 70,000.

The following statistics were drawn from a study[1], which looks at the connection between drug use and AIDS, funded by the federal government and conducted by sociologist Hector Colon. This sociologist also runs the Puerto Rico AIDS Prevention Department and the San Juan municipal government, and is funded through a $900,000 grant from the National Institute on Drug Abuse.

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[1]Confidential Report on Puerto Rico, AmFAR, 1990.

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Of 1,713 addicts tested for HIV, 45.8% are positive. The Puerto de Tierra precinct (including Old San Juan, Santurce and Barrio Obrero) has the highest AIDS incidence. Fifty-two percent of addicts tested there have been exposed to HIV. The trend is followed by Rio Piedras, with a 47% positive rate, Bayamon 44%, and Catano 41.7%.

THE HEALTH CARE SYSTEM (OR LACK THEREOF) IN PUERTO RICO IS INSEPARABLE FROM ITS COLONIZED STATUS

First named Boringuen by the Indians, Christopher Columbus renamed the Island San Juan Bautista in 1493, and it was finally given its present name in 1508 by Juan Ponce De Leon. When Ponce de Leon took power, he eliminated all the Indians.

Spain surrendered Puerto Rico to the United States in 1898 after the Spanish American War. In 1917, the Jones Act gave all Puerto Ricans the right to U.S. citizenship. The people of Puerto Rico were not satisfied with this form of government and after much debate the Commonwealth of Puerto Rico was established in 1952.

Commonwealth for many Latino activists was the new word invented to mean neo-colonialism. Illustrative of this new form of colonialism was the preclusion of Puerto Ricans from participating in the continental elections, although they are officially part of the U.S. Furthermore, the economy of the Island is largely dominated by the U.S., as the presence of many pharmaceutical companies reveal. Those companies were drawn to the Island by tax exemptions and made of Puerto Rico a major pharmaceutical center.

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Another aspect of this neo-colonialism was involved population control campaigns through either sterilization or lethal experiments. In fact, for many activists, the inaction of the federal government with regard to the situation in the Island, looks very much like an extension of its population control policy.

Because of its "Commonwealth status," Puerto Rico only receives a block grant of $79 million under Medicaid. In contrast, a continental state receives from the federal government a fixed percentage of the total expenditures the state makes for medical services.

Of the 79 million dollars received, 12 million are used for running the bureaucracy of the Department of Health. The remaining 67 million are divided up into $11 million for the Municipo de San Juan, and 56 million for the other 72 municipalities throughout the Island.

Yet, 60% of the Island's population qualifies for Medicaid. In fact, of Puerto Rico's approximate 3.3 million residents, 2.3 million are deemed "indigent" and approximately 1.87 million are covered under Medicaid. However, if the United States' minimum economic qualifying standard was used, 80% of the Island's population would qualify for Medicaid.

As a result of this institutionalized discrimination, the health care system in Puerto Rico for indigents is abysmal. Medicaid recipients are forced to wait for hours, and even days, for substandard care in dirty, understaffed, and overwhelmed hospitals.

Unlike the Continent, Puerto Rico's Medicaid program does not provide for reimbursement of private physicians, who provide services

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to Medicaid recipients, or reimbursement of private pharmacies, which dispense medication. Instead, Puerto Rico's Medicaid program requires that Medicaid recipients be treated in specially designated public hospitals and that they acquire medication from so-called public pharmacies, usually located in the same public hospitals (except for emergency cases).

Furthermore, Medicaid has published a list of drugs that should be or should not be purchased by Medicaid pharmacies in Puerto Rico. In particular, Medicaid does not cover medication such as AZT or pentamidine, whereas it covers certain chemotherapy and radiation treatments for cancer patients if such treatments are available at the hospital. If the individual is hospitalized, then s/he can receive pentamidine. But it is very difficult for someone with AIDS to be hospitalized.

The irony is that Puerto Rico is a major pharmaceutical center where companies such as Abbot or LyphoMED (producer of Pentamidine) do not pay taxes. In the meantime, individuals with AIDS are frequently turned away from hospitals because they are deemed "incurable."

Logically, the very limited number of Puerto Rican PWAs, who can afford the Puerto Rico-New York City bridge, fly to New York City to receive better medical care, albeit by no means perfect.

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TREATMENT ISSUES IN PUERTO RICO EQUALS NEW YORK CITY TEN YEARS AGO

Since Medicaid does not cover AZT in Puerto Rico, the only way for indigent individuals to obtain AZT is by enrolling in one of the very few clinical trials programs. These programs provide free AZT to approximately fewer than 250 patients throughout the entire Island.

Federal funding for the largest clinical trials program, the Latin American Center for Sexually Transmitted Diseases (CLETS is the acronym in Spanish) ran out on December 27, 1990 when its federal grant expired. To make this situation worse, the head of CLETS, Dr. Rivera Castano, did not take steps to replace the grants.

As in the U.S., active IV drug users are automatically excluded from participating in CLETS' clinical trial program because they are considered "unreliable."

Castano also admitted that they had aerosolized pentamidine, but it was not dispensed because they did not have--and they take steps to obtain--the ventilators (nebulisers) which must be used to administer it. In addition, Dr. Rivera Castano returns funds that he does not use back to the Puerto Rican government every year.

The Confidential Report includes interviews with a variety of government officials, community-based activists and physicians. Their response and attitude shed light on the reasons why the AIDS situation in Puerto Rico is increasingly devastating.

Representative Mabel Velez Acedevo is a member of Puerto Rico's Camara de Representantes (House of Representatives) and chair of the health care committee. She is the only female member of the

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House of Representatives who belongs to the ruling party, the Commonwealth Party.[1] Although Representative Velez is sympathetic to AIDS issues she knows very little about Medicaid as it relates to access to medication for HIV infected individuals. She also cautioned against making "too much noise," which would jeopardize the Commonwealth's funding for various AIDS projects. She presented the Commonwealth' s proposed budget, which showed that no money had been allocated for the Fundaciòn SIDA for the next fiscal year.

Laura Torres is the Director de la Administraciòn de Facilidades y Servicios de Salud (AFASS), Departamiento de Salud. The AFASS is the Department of Health 's service that distributes the funds, including Medicaid funds, to Puerto Rico's various public clinics, hospitals and health agencies.

Mrs. Torres was evasive, but admitted that Medicaid does not cover AZT and pentamidine "because they are too expensive and would deplete most of the $79 million dollars that Puerto Rico receives under Medicaid." She admitted that AIDS is "somewhat neglected because it is a relatively new disease." Worse, the Commonwealth government was sitting on a warehoused supply of $900,000 of AZT, that expired in March of 1991, reportedly because it had no "protocol" by which to dispense the therapy that is already approved and available by prescription. According to Dr. Rullan, over 20,000 people on

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[1]The three major parties in Puerto Rico consist of the Governor's Commonwealth Party, the Statehood Party, and the Independence Party. A 1991 plebiscite was called to decide whether Puerto Rico should declare independence, become the 51st state, or retain--albeit in a more precisely defined and updated form--its singular status as a commonwealth. The pebliscite has been called off since then.

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medicaid would have qualified for this anti-HIV therapy in Puerto Rico. Torres argued that "some psychotropic drugs are not supplied for psychiatric patients, and so therefore it is justifiable and rational that AIDS patients would be denied treatments. Mr. Torres may not know that those treatments might be life prolonging, activists argue.

Puerto Rico is under the jurisdiction of Region II of the Department of Health and Human Services, based in New York. Ms. Guzman admitted that Puerto Rico is not in compliance with the provisions of the federal Medicaid statute because sub-standard health care is provided.

Los Servicios Legales de Puerto Rico, Inc. were interested in challenging the Department of Health's policy for refusing to provide Medicaid recipients with AZT. However, their knowledge of Medicaid is poor and they practice in the state courts and have almost no contact with the federal court system. In Puerto Rico, attorneys appearing in state court practice in Spanish while those appearing in federal court practice in English.

Dr. Clemente Diaz and Dr. Licette Flores, Centro Medico, both ran a clinic for 35 HIV-infected children and babies at Centro Medico's Children's Hospital. The children, ranging in age from one month to 12 years, were given varying doses of liquid AZT. Burroughs-Wellcome provided the AZT free of charge. However, the drug company notified Dr. Diaz that the free supply of AZT could end at any time. Burroughs-Wellcome gave them one month's notice to allow the clinic to come up with an alternative source of free AZT. Dr. Flores claimed that thousands of HIV-infected children in Puerto Rico were receiving absolutely no treatment.

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Representante Jorge de Catro Font is a member of Puerto Rico's Camara de Representantes. He is also chair of the Youth Committee. Although considerably ignorant on AIDS issues, Font was sympathetic to AIDS and was very influential. He was instrumental in persuading the Department of Health to conduct an investigation of HIV-prevalence in the IV drug user community.

Fundaciòn SIDA and Hogar Crea Las Americas is an AIDS residence for approximately 100 recovering drug addicts and the only one of its kind in Puerto Rico. None of Hogar Crea's residents receives AZT or pentamidine.

The Confidential Report recommended a lawsuit against Puerto Rico's Department of Health to challenge its policy of precluding Medicaid recipients with AIDS from obtaining AZT. A state may not arbitrarily deny or reduce the amount, duration or scope of a required service to an otherwise eligible recipient solely because of the diagnosis, type of illness or condition. (Article IV of the Social Security Act)

PUERTO RICO, TOO, HAS A CARDINAL

In addition to being politically and economically colonized, Puerto Rico has other cultural problems. Because most of the AIDS cases in Puerto Rico are believed to be caused by IV drug use, most research focuses on this type of transmission. It is important to note however that sex, let alone homosexuality, is still a heavy taboo in this predominantly Catholic Island. Cases due to unsafe sexual practices are undoubtedly undercounted.

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Cultural and religious bias against condom use can also exacerbate this transmission. Indeed, Cardinal Aponte Martinez of San Juan warned that *it is a greater sin to use condoms than to get AIDS.* The lack of condom use is particularly problematic since Puerto Rican men have a long tradition of bisexuality, and recent studies suggest that 30% of heterosexuals engage in anal intercourse (Boston Globe, 1990).

Angel Meaux, a case manager for Puerto Rico's AIDS Foundation said that his organization is forced to buy boxes of condoms from the U.S. because religious leaders and others will not allow condoms to be distributed on the Island for the purpose of AIDS prevention. "We've seen some changes since we first began in '88 but we still have a long way to go," said Meaux.[1]

TOURISM, FIRST CONCERN IN THE GOVERNMENT'S AIDS PLAN

Stigma associated with the disease, fear of losing tourism, infighting among the various political parties have made a terrible problem even worse.

Dr Rullan's proposed plan to combat AIDS was approved by Governor Rafael Hernandez Colon. The plan calls for

1) increasing the number of people on AZT to 900

2) aggressive AIDS testing

3) tracing of sexual contacts of HIV-infected persons

Sarah Andrew, *City Unprepared For Puerto Rican AIDS Influx,* Manhattan Spirit, May, 1991.

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Obviously, the last two propositions were highly unpopular among local community-based groups such as Fundaciòn SIDA and ACT UP.

COMMUNALIZATION OF AIDS IN PUERTO RICO

Activists criticized Colon and Rullan's plan for mandating sexual partner contact tracing, notification and name listing. The public health system is not equipped in Puerto Rico to make the offers necessary for responsible follow up of those persons who test positive for HIV, and will not be for some time to come. The message that PWAs receive is *you are going to die any way.* In this context, the only rationale for testing is to find out who is positive and who is not, and let die those who are.

In contrast, activists proposed mass education on how HIV is and is not transmitted. Gross misinformation was being distributed such as *AIDS is transmitted through mosquitoes and the virus can live for 7 days in swimming water where it will give you AIDS.*

The Latino Caucus blasted the budget of only 6 million dollars requested by the government. This figure, activists argued, would not even pay for the lab work for the first year, let alone salaries, administrative costs, the vague and abstract education plans, Rullan's proposed epidemiological studies, the establishment of medically appropriate facilities for the clinics, psycho/social support programs, or pre- and post-test counseling components.

The activists urged the government: to use the CARE (Ryan White Comprehensive AIDS Resources Emergency Act) bill; early

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intervention treatment and support for those already infected with HIV and still asymptomatic; viable and accessible treatment options; organized, sensitive and appropriate long term support services, including emotional support, home health care and housing.

The Latino Caucus urged Colon to declare Puerto Rico as an AIDS disaster Area. They wanted him to call for a one-time emergency expansion of the $79 million Medicaid ceiling specifically for funds to cover legally required medications for all people living with AIDS.

Finally, activist condemned the Commonwealth's Medicaid office for providing a guide for medicaid pharmacies listing which drugs they should and should not carry. Blacklisting of disease or diagnosis specific medications, activists recalled, is illegal, and should stop immediately.

Activists understood that negotiations and recommendations would not be enough. In August of 1990, ACT UP/N.Y. members flew down to Puerto Rico and demonstrated at the International Conference on AIDS Education. The Conference was in English only, with no translation. Because activists threatened to disrupt the Conference if no translation was provided, the organizers agreed to provide translation the last day of the Conference.

At the end of the Conference, activists disrupted the last speech to announce that a demonstration against the governor of Puerto Rico would be held. A large number of people from the audience followed them.

The direct outcome of this action was the creation of ACT UP/Puerto Rico, which is currently actively involved in the AIDS situation of the Island.

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A second action was organized simultaneously in New York City and Puerto Rico. In New York City, activists demonstrated in front of the Puerto Rican's Commonwealth office building. In Puerto Rico, activist marched toward the Governor's Palace.

WHEN A COMMUNITY-BASED ORGANIZATION DOES NOT DO ITS WORK, THE COMMUNALIZATION PROCESS MUST CONTINUE

Back to New York, Latino/as activists were shocked at the realization that their own, those who considered themselves community activists, were not on their side. For example, in January 1991, during the Day of Desperation action, a group of Latinos went to the office of President Ferez, the Borough President of the Bronx. His response sounded familiar to the activists: *This is not the time, this is not the place.*

Likewise, the only organization, that claimed to do work on AIDS for the Latino community, the Hispanic AIDS Forum (HAF), became the focal target of the activists.

Upon research, activists found out that the Board of Directors was (and still is) comprised of bureaucrats who did not represent any of the groups affected by AIDS/HIV in their community. No one was out with regard to their HIV status or sexual orientation, and no one was an openly recovering addict.

The agency had no position on holistic treatment and clinical trials for the community, or national health care. It had no agency policy regarding Latinos with histories of chemical dependency (i.e

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needle exchange, harm reduction, the quality of drug treatment, different drug treatment modalities, risk reduction strategies of IVDU's, support and education services for IVDU's.). It had no agency policies regarding Latina women with HIV infection or AIDS (i.e. the limited CDC case definition, treatment issues for women, exclusion of women from entitlement programs, support and education service for women.). It had no agency policies regarding the discriminatory practices of the Immigration and naturalization Service (INS) (i.e. HIV testing of undocumented individuals, entitlement program for undocumented individuals, deportation of HIV undocumented individuals, support and education for undocumented individuals). Finally the Hispanic AIDS forum was widely unknown by Latinas/os in the area.

On January 9th, 1991 the Latina/o AIDS Activists (LAA) of ACT UP met with the board of directors of HAF, to confront them on what they had not done to address AIDS in the Latino community. Members of LAA who are HIV positive and/or have been diagnosed with AIDS were present (including women, people in recovery, gay men and lesbians and straight men and women) to denounce HAF's lack of leadership and unresponsiveness to the needs of their community

In this meeting, members of LAA posed a fundamental question to HAF's board of directors: "how many people with AIDS and HIV infection are currently represented on the board?" To which Paul Ruiz-Salomon, President of the Board, responded: "that this information is none of your business", "asking for this information is

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inappropriate,"and "this criterion is totally irrelevant to the work of the agency."

LATINO/AS INDIVIDUALS WITH HIV/AIDS IN THE SOUTH BRONX, EL BARRIO, LOISAIDA, JACKSON HEIGHTS AND QUEENS HAVE TO GO TO CHIC SOHO TO BE SERVICED

The Latino Caucus (LAA) was wondering how many dying Latinos/os from the South Bronx, East Harlem or the Lower East Side would go to Soho to obtain services. Soho is where HAF's CBO office is located.

LAA accused the Executive Director of being homophobic, because he would not reveal who was gay, or say if there was openly gay directors. The response he gave was similar to the one he gave about the members' HIV status.

The entire board of directors have been taken to the Human Rights Commission for Bias Discrimination based upon AIDS /HIV disability and sexual orientation by gay and lesbian staff members of HAF, some of whom are HIV infected and /or have been diagnosed with AIDS.

HAF continues to remain passively silent regarding the Condom Distribution Plan proposed by Chancellor Hernandez of the New York City Board of Education. In the meantime, a study conducted in 1990 by the Boston University School of Public Health and financed by the Federal Centers for Disease Control, found that 60% of the Hispanic adolescents who were interviewed did not know how AIDS is usually transmitted and 90% had one or more

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misconceptions about AIDS. One of the most common misconceptions was that there is a cure. Another was that one can identify people infected with HIV by simply looking at them. Of the people interviewed, those at the highest risk of infection were often the least informed. The study showed that 45% of the intravenous drug users surveyed and 40% of the gay men did not know how AIDS is transmitted. Misconceptions about the disease were found among 90% of the drug users and 80% of the gay men. The interviewers spoke with 2,541 people in Connecticut, Massachusetts, New York, Pennsylvania, New Jersey and Puerto Rico.

Even Miguelina Maldonado, executive director of the Hispanic AIDS Forum in New York City recognized this tragic situation situation: "This represents a snapshot of what's going on in terms of knowledge, attitudes and behavior within our communities."[1]

HAF receives most, if not all, of its funds from Centers for Disease Control (CDC), the New York City Department of Health (NYC DOH), New York State AIDS Institute ($320,000 for 10 salaries). It offers the following prevention and education programs:

Entre Hombres Project is supposed to be a peer education program which offers risk reduction workshops for Latino gay men. However, HAF has not been able to meet contract compliance with the NYC DOH, because they do not have any relationship with the Latino gay male community and therefore are unable to gain access to the individuals they are supposed to be providing services. After two years

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[1]The New York Times, *Study Finds Many Hispanic-Americans Are Ignorant About AIDS;* Wednesday, October 31, 1990.

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in existence, the project continues to flounder without any focus or results to show the services they have provided.

De Mujer a Mujer is supposed to be an education and support service program for Latino women who are chemically dependent and/or HIV or who have been diagnosed with AIDS, and/or who are sex partners of IVDUs. However, HAF has not been able to meet contract compliance with CDC because of the lack of expertise, sensitivity and commitment to Latina IV drug using community. After one year in existence, this project continues to fall behind on every contract deliverable and should be providing direct support service to women in the South Bronx.

HAF's Citywide Project is supposed to be a citywide prevention education program targeting the general Latino community. However, HAF continues to place an emphasis on professional training efforts rather than directly working with community groups, and CBOs. Additionally HAF operates a bilingual AIDS information and referral hotline, which only receives an average of approximately 12 calls a week. Also, HAF's distribution of bilingual AIDS prevention literature to CBOs, which is, according to activists, outdated, addictaphobic, homophobic and AIDSphobic. HAF, like the NYC DOH, also continues to not make condoms available to the constituencies whose lives they say they are tying to save.

Queens Expansion Project is supposed to be a prevention education and social support program targeting the Latino gay male community which operates out of a satellite office in the Jackson Heights area of Queens. It took a very long time for HAF to even begin the project.

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Noteworthy is the fact that the attacks against HAF by the Latino Caucus did not proceed without fracas within ACT UP. Many activists were opposed to demonstrating disagreement toward a community-based organization. The Latino Caucus itself split over the idea of demonstrating in front of Latino agency. Yet, the demonstration did take place on February, 1991 and the most sung slogan was: *He He, Ho Ho, HAF What are you doing in Soho?!*

ACT UP/AMERICA

The creation of the ACT UP/Americas Committee was the last initiative of Latino/as activists in 1991. As the name indicates, they are interested in the AIDS situation in Latin American countries. ACT UP/America adds a new international dimension to the organization. First a caucus, it quickly became a committee. Since then, it has been involved in many actions. Activists disrupted a press conference given by the Mexican Consulate at the Plaza Hotel. They also disrupted a prize-giving ceremony gathering the most famous artists in the Latino community. In the middle of the ceremony, they unfurled a banner: "Latinos are dying."

On February 5th, 1991 they went to the Argentinean Consulate to protest its mistreatment of PWAs and gays and lesbians. Finally, the committee was instrumental in helping a gay man obtain legal status in Canada based on his being harassed by the Argentinean authorities. And this was a first in the international history of the gay and lesbian movement.

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THE ETHNIC COMMUNALIZATION PROCESS OF AIDS GOES ON AND ON

The Asian and Pacific Islander (API) Caucus was created a little after the Latino Caucus in 1990. The fight of API activists was as much outside ACT UP as inside. They had to fight their invisibility. As one activist expresses it:

> Although, the number of AIDS cases among APIs is still low compared to other ethnic groups, the rate of increase is the greatest, and no one seems to care[1]

Racism can also occur inside ACT UP. As this activist recalls:

> During the Florence conference I was not invited in planning meetings relating to women's issues. I even had to remind the white women in ACT UP, that, I, too, was a woman, and should be given the right to express myself.[2]

Another instance involved a journalist from Britain.

> A journalist approached a white female from ACT UP to interview her about women's issues. I decided to go over to her, and told her that if she

[1]Personal Interview with an API activist, 1992.
[2]Personal Interview, 1992.

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> wanted to talk about women in the U.S., it was ok with me, but if she was asked questions about women of color, then I would be more qualified to answer the questions. She agreed to let me speak with the journalist. But the journalist insisted to speak with her. He said: 'I am not interested in women of color and AIDS. And even if I was, I would interview an Afro-American woman." I was not surprised by the racism of the white journalist. What blew me was the fact that the white woman, who had observed the whole situation, went on with the interview as if nothing had happened.[1]

Many other individuals, even groups in ACT UP, were accused of racism by activists of color. Frustration within and outside ACT UP led API members to declare their own manifesto. The Manifesto decried the U.S. Immigration policy for mandating all immigrants applying for residency to be tested for HIV. If tested positive, the applicant would be subject to deportation. Under such status, he/she would not be eligible for any public assistance or health care, especially HIV/AIDS treatments that are only available in the U.S. In the past eight years, during the height of the AIDS crisis, Asians and Pacific Islanders were the largest immigrant group entering the United States.

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[1]Personal Interview, 1992.

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The API Caucus joined in an action organized by the Foreign Nationals Caucus of ACT UP. The action took place during the reopening of Ellis Island inaugurated by President Bush, who was blasted for laying the blame and guilt of the epidemic on one of the most disenfranchised populations in the U.S.

APIs are made invisible, because they are lumped together, when in fact there are over a 100 different cultures with as many different dialects, as their Manifesto declares:

> WE ARE
>
> People descended from Bangladesh, Bhutan, Borneo, Burma, Cambodia, China, Guam, Hong Kong, India, Indonesia, Japan, Korea, Laos, Malaysia, Mongolia, Nepal, Pakistan, Philippines, Polynesia, Singapore, Sri Lanka, Taiwan, Thailand, Tibet, Vietnam, and countries and territories in the Polynesian, Micronesian, and Melanesian Islands.
>
> WE ARE CULTURALLY DIVERSE, MULTILINGUAL, AND WE ARE ALL LIVING WITH HIV, THE VIRUS THAT CAUSES AIDS.

It took until 1988 for the CDC to give APIs their own category in the AIDS breakdowns. However, due to their relatively small number, in New York city's statistics (as of October 1990), there were still grouped together with Native Americans and Alaskan Natives. In New York State's epidemiological studies, they are still classified as "Others."

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Funding for Asian and pacific Islander specific HIV prevention materials and services were denied on the basis of insufficient statistics and therefore insufficient needs. Yet, between 1988 and 1992, there was an increase of 158% of AIDS cases among APIs as opposed to 86% for whites. According the CDC itself, APIs are the fastest growing "minority group" in full blown AIDS cases in the U.S.

Up until 1990, there was no Asian HIV specific advocacy and social service agency in new York. As a result, neither New York City nor New York state has any culturally relevant HIV prevention materials in Asian and Pacific Islander languages, and no outreach effort into the communities.

Confronted with language and cultural barriers, the fear of deportation, lack of affordable health care and drug treatment, no guarantee of anonymity, and no information about AIDS, Asians and Pacific Islanders infected with HIV do not seek help and are not counted.

Finally, there is only one community-based clinic targeted toward APIs, located in China Town of New York City, and only one Chinese speaker on the New York City AIDS Hot Line.

COMMUNALIZATION OF APIS' ISSUES

The API Caucus in conjunction with the Foreign Nationals Caucus of ACT UP demanded that United States Government abolish its racist and AIDSphobic mandatory HIV testing policy imposed on immigrants; that the U.S. government fund for the production and distribution of HIV prevention information, including safer sex and

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safe IV drug use information, that is culturally relevant and in languages specific to the Asian and Pacific Islander communities; that the U.S. government fund and establish community-based advocacy and service provider agencies for API living with HIV, and that these organizations be created with active involvements of APIs with HIV and their advocates; that community-based health care and drug treatment clinics be instituted; that health care and drug treatment be provided regardless of ability to pay and/or legal status, and that anonymity be assured; that the U.S. government conduct accurate and specific epidemiological studies with regard to HIV transmission in APIs, and that these studies be sensitive to confidentiality and follow up by providing counseling and health care services.

The direct result of Asian and Pacific AIDS activism was the creation in 1991 of an Asian and Pacific Islander Coalition on HIV/AIDS (APICHA.) funded by the Department of Health of New York City.

MOST OF CHILDREN WITH AIDS ARE EITHER AFRICAN AMERICAN OR LATINO/NA

There are approximately 2,000 children with AIDS in the U.S. and at least 20,000 infected with HIV. Approximately 80% were born to mothers infected with HIV. Others were exposed through blood transfusions, blood products, and a few cases have resulted from breast feeding and sexual abuse. Over 80% are children of color. Like their adult counterparts, children of color have to struggle to survive the consequences of racism, poverty and inadequate health care system.

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Only 30% of the babies who tested positive for the HIV antibody test will go on to develop AIDS. But compared to their adult counterparts, babies with AIDS tend to develop the symptoms much faster and die much faster as well.

Research has been almost non-existent when it comes to young people infected with HIV. A recent survey looked at attitudes among health care providers in neonatal intensive care units.[1] A majority of providers would treat children known or suspected of having HIV differently than children not at risk for HIV. Two-thirds of these clinicians agreed with the statement that HIV positive women should not carry pregnancies to term. The majority would not recommend treatment for these children for non-HIV related conditions on the basis of knowledge that the infant's mother was infected, and an even higher percentage would not treat if the infant was "known" to be infected. Most also agreed that women and infant at risk should be routinely tested, a practice which could potentially result in widespread, inappropriate withholding of treatment. And many practitioners lack up-to-date information on treatment and transmission. Because of fear of liability, new treatments are often out of reach of the children.

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[1]Jono Weiss and Lisa Auer, *Pediatric HIV Disease*, PI Perspective, October, 1990.

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ONE CASE WHERE COMMUNALIZATON CAN ONLY WORK VICARIOUSLY

The abysmal situation of children with HIV, whether it be with regard to treatment or research, led ACT UP members, natural parents and foster parents to create a Pediatric Committee in December, 1990. The common thread tying all the members of the committee was the experience of witnessing children and their parents die of AIDS.

Three immediate needs were delineated. Firstly, clinical trials geared towards children were urgently needed. The few clinical trials open to children with HIV included the comparison of nucleoside analogues such as AZT vs. ddI or AZT vs. ddC, types of trial too well known by AIDS activists. Peptide T, a natural compound with very little toxicity, which has shown to have anti-viral activity, has not been experimented on children yet. Activists are pressuring to arrange a peptide T trial for children.

Secondly, one of the most disenfranchised pediatric populations were foster children, mostly children of color. They are totally dependent on the state and not the biological parents. Those children are mandatorily tested an left to die since the Child Welfare Administration does not provide for the set up of pediatric clinical trials. These children cannot even expect to be helped by activists organization, because their ultimate authority is the state.

Thirdly, parents needed to receive HIV/AIDS information.

Like women, children are left unresearched because drug companies as well as the government are afraid of potential legal liability. In this sense, as the situation of women with HIV sheds light

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on the powerlessness of women in society, so does the situation of children with HIV.

Out of those three needs were developed a list of 25 demands relevant to HIV infected children and their families. (See Appendix)

Although the committee has not organized any pediatric specific direct action, it went to several meetings to make pediatric AIDS a priority. During the Pediatric AIDS Conference in Washington, DC a split occurred between parents of hemophiliac children and natural and foster parents who were themselves HIV positive. It seems that even among children-considered "innocent victims by the media and governmental institutions-hemophiliacs were considered more innocent than those who contracted HIV through their mothers. The example of Ryan White, a very courageous child victimized by the worst form of ostracism, is illuminating in this regard. He was white, middle class and contracted HIV through a transfusion. In this sense, he was quite unrepresentative of most seropositive children, who were defined as children of color, poor and infected perinatally. Yet, the Bush Administration decided in 1990 to pass the Comprehensive AIDS Resources Emergency Act, which it called the Ryan White Act. As an ACT UP member of the Pediatric Committee suggested: "Would it have called it the Vito Russo Act?".[1] It took the "image of total innocence" as constructed by the Bush Administration to decide on national funding of the epidemic. The criticism of the division between the "innocent child" and the "guilty homosexual" is then not totally accurate. In the eyes of the administration, children who

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[1]Vito Russo is held as one of the most vocal AIDS activists by the Gay and Lesbian Community.

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contracted HIV through transfusion are the "real innocent victims." Even in ACT UP, some members did not see the distinction and refused to support the existence of the Pediatric Committee.

The Pediatric Committee went to the Minority Awareness Day, Washington DC, the 7th International AIDS Conference, Milan, Italy and finally the Community Forum, West Harlem, in New York, where a father spoke on the way to care for HIV infected children.

The committee plans to develop a National AIDS Plan to present to the National Institute of Child Health and Development. (NAICHD) Pediatric AIDS activists want to meet with drug companies, publish informational booklets written by parents on how to care for an HIV infected child and how to organize an activist group in the community in order to obtain treatment and services for children. Finally, their agenda includes working with staff members to prevent the closing of day care center for HIV infected children and preventing the possible closing of a pediatric AIDS unit in a Bronx hospital.

MOST PRISONERS WITH AIDS ARE PEOPLE OF COLOR

AIDS is the leading cause of prison deaths in New York State. Yet there is no comprehensive health care, education or prevention program in place for prisoners affected by the AIDS crisis. And with the greatest number of infected prisoners in the nation, New York State has the worst situation. Approximately 10,000 of the over 54,000 prisoners housed in New York States' 61 prisons are living with HIV disease, and 800 prisoners are symptomatic.

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One in four young black men and one out 10 Latinos are under the control of the system.[1] Approximately 80% of crimes are drug-related. Nearly 90% of HIV-positive prisoners are African American or Latino, and women are the fastest growing numbers of prisoners with AIDS. In addition, a 1987 survey revealed that at least 25% of all AIDS deaths went in prison undiagnosed until autopsies were performed.[2]

All in all, the AIDS picture in prison reflects the AIDS picture as a whole. Women inmates are more likely to contract HIV than their male counterpart. The difference was greatest among prisoners under the age 25, with 5.2% of women in that age group testing positive for HIV antibodies compared with 2.3% of men. And overall, people of color were significantly more likely to be infected with HIV than whites, with infection rates running 4% and 2.5% respectively.[3]

CRIMINALIZATION OF HIV SEROPOSITIVITY

Ronald Reagan issued an executive order in the Summer of 1987 requiring testing of all federal prisoners. If the result is positive, then the local Department of Health is notified. And 17 states[4] have

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[1]Sentencing Project, *The Young Black Men and the Criminal Justice System*, 1991.
[2]Sue Rochman, *AIDS Behind Bars*, The Ithaca Times, 1991.
[3]Rebecca Kolberg, *AIDS Infection Rate Highest Among Female Prisoners*, Daily Challenge, March 7, 1991.
[4]Alabama, Arkansas, Colorado, Georgia, Idaho, Iowa, Michigan, Mississippi, Missouri, Nebraska, Nevada, New Hampshire, North Dakota, Oklahoma, Rhode Island, Utah, and Wyoming.are the 17 states that require mandatory testing of their state prisoners.

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instituted a mandatory testing policy; five states[1] followed up testing with segregation of all HIV positive inmates.[2]

Because sex in prison is considered a felony, many states deny condoms to inmates. The Commissioner of the New York State Department of Correctional Service (DOCS), Thomas Coughlin III, refuses to allow condom distribution in state prisons. Activists argue that his Catholic background may dictate his decision.

Similarly, it is illegal to possess needles in jail, but like sexual activity, drug use does occur. In fact, 60 to 70% of New York State' s more than 52,000 prisoners have a history of drug abuse. No correctional system provide bleach to inmates to clean their works, although IV drug use does occur within the system. Inmates with AIDS and a history of IV drug use survive an average of half as long as IV drug users with AIDS in New York City.

Prisoners are offered minimal health care. New York State currently spends $1500 per year per inmate on health care. That is half the amount allocated by California and Illinois for prisoner medical services. But in many cases, inmates are denied medical care.[3] The death rate for AIDS among New York State' s general population is 20 per 100,000. The AIDS death rate for parolees in New York is 331/100,000.

Of at least 7,000 inmates in City and State correctional facilities who are likely to need treatment at any given time, fewer than 1,500

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[1]Alabama, California, Colorado, Mississippi and Nevada segregate their AIDS prisoners.
[2]Sue Rochman, *The Final Lockup*, Advocate, February 26, 1991.
[3]Hilary Stout, *Prisoners With AIDS Virus Often Face Discrimination, U.S. Commission Finds*, The Wall Street Journal, March 29, 1991.

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are receiving care for AIDS-related illnesses. About 140,000 people pass through city jails each year. Nationally, two to six percent of all inmates are infected as against one-tenth of one percent for the national population as whole,that is a large number if the total prison population amounts to approximately one million and half people.[1]

Prisoners with HIV may be mistreated by the staff and segregated in special wards. In addition, security, medical and civilian staff have no respect for confidentiality laws.

Prisoners with HIV are also mistreated by other prisoners ignorant of the facts of AIDS. Some prisoners with HIV have had their belongings or their mattress burned out. In Alabama, in response to a class suit filed by the American Civil Liberties Union (ACLU)[2], 7,000 inmates signed a petition to keep Dorm 7, where AIDS prisoners were segregated. Yet it was shown that AIDS has not raced through the prison system. Contrary to popular expectations, prisons to date have not proved to be breeding grounds for AIDS. An annual survey funded by the National Institute of Justice (NIJ) shows that since 1985, AIDS has spread at a slightly slower rate within prisons than outside of them. While inmates are still more likely than the average citizen to have AIDS, the NIJ survey indicates that since the start of the AIDS epidemic, fewer than one percent of the nation's 700,000 State and Federal inmates have developed AIDS.[3]

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[1]Philip J. Hilts, *Prisons Faulted on Combating AIDS*, The New York Times, March 29, 1991.
[2]Peter Applebome, *For AIDS Inmates, a Prison in Prison*, The New York Times, March 3, 1989.
[3]David Whitman, *Inside an AIDS Colony*, U.S. News, January 29, 1990.

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Yet, those who are segregated are often denied recreational library, visitation, and religious privileges. Judge John B. Mariano sentenced Gregory Smith to 25 years in prison for allegedly biting a prison guard. Mr. Smith, a young black, gay prisoner with HIV was convicted for attempted murder despite the court's acknowledgement that HIV is not transmitted through biting. The Judge stated in court that he wanted to send the message that: "criminal conduct of this nature will be met with swift and severe punishment."

Over the past three years, approximately 10 cases have been brought to court in which people with AIDS have been indicted for attempted murder or assault with attempt to commit murder for biting and spitting on police or corrections officers. In almost every case, the defendant with HIV has been convicted and sentenced to a long prison term.

Curtis Weeks, a Texas prisoner serving a two-year term was sentenced to life in prison for allegedly spitting on a prison guard.

Gregory Scroggins, a Georgia resident with HIV, was convicted of aggravated assault with intent to commit murder for allegedly biting a policemen during an arrest after police had been called to his residence to break up a domestic dispute. The jury deliberated for three hours; Mr. Scroggins was sentenced to 10 years in prisons.

Donald Haines was in the midst of a suicide attempt when police and paramedics burst into his home. A struggle ensued between the distraught Mr. Haines, who was bleeding and the emergency personnel. Mr. Haines, accused of "intentionally" spraying the paramedics with his blood and biting a policeman, was convicted of

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attempted murder. Mr. Haines was sentenced to 30 years in an Indiana prison.

In 1990, the CDC delivered the result of study concerning the transmission of HIV through biting. Researchers interviewed 89 household members living with 25 children with HIV. Although many of the children with HIV had bitten non-infected siblings and other members of the households, there was no transmission of the virus.

According to the 1989 study of the National Institute of Justice on AIDS and Correctional Facilities, no police or correctional officers have contracted HIV infection through on-the -job exposure.

COMMUNALIZATION OF AIDS PRISONERS

Although New York has provided mandatory education since 1984 for prisoners, the information they would receive was far from being comprehensive. In order to make up for this lack of information, inmates organized the AIDS Counseling and Education (ACE) program in 1988, at Bedfort Hills Correctional Facility, New York' s only maximum security prison for women. While incarcerated, some women were allowed to educate other women about AIDS. Still, the situation was far from perfect at Bedfort Hills, and care was substandard. Since then other prisoners have followed suit. The COPE programs at Staten Island and Fishkill are similar programs set up by prisoners for prisoners. The NAACP also organized an AIDS education group at Sing-Sing

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It was also in 1988, out of the Nine Days of Action organized by ACT UP and ACT NOW that the first version of the Prison Committee was created. Activists went to Harlem to voice their anger fueled by the mistreatment inflicted upon inmates with AIDS. The Prison Committee went through three versions. In 1989, new members worked on prison issues, but the volume of activity was still pretty low. It was in 1991 that the Prison Committee, in which one out four members was a former prisoner, was reactivated for the third time.

In May 1991, ACT UP/Ithaca with ACT UP/N.Y organized a demonstration in front the New York State Commissioner for Corrections' office in Albany. "Prisoners with HIV and AIDS should not be punished for an offense they did not commit. AIDS is a disease to be treated and prevented, not a crime to be punished," "Commissioner Thomas A. Coughlin III, Chief Medical Officer Robert Greifinger and Mario Cuomo are clearly the ones in need of correction," "Make the DOCS Remove the Locks," read the slogans.

A couple of hundred of activists participated in the action, staging a mock murder trial of the Commissioner. Their demands included improving access to treatment, the provision of anonymous testing, pre and post counseling and culturally sensitive HIV/AIDS education support for peer education programs run by prisoners. They also demanded the distribution of condoms, dental dams and bleach to all prisoners, representation in the committees designing clinical trials and access to the Family Reunion Program (FRP) for HIV positive prisoners. FRP allowed some prisoners to spend 48 hours with family members in a housing unit on prison grounds, yet outside the main

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prison buildings. All these demands were endorsed by the National Commission on AIDS. As a result, prisoners with AIDS are now allowed to benefit from the Family Reunion Program.

A second demonstration was organized by the Prison Committee in collaboration with Harlem/Stand Up on July 9th, 1991 at the State Office Building of the Department of Correctional Services (DOCS), in Harlem. PRISONERS WITH AIDS ARE NO THREAT TO SOCIETY, OUR SOCIETY IS DANGEROUS TO THEM, GIVE PRISONERS CHOICES: FREEDOM OF TREATMENT, FREEDOM OF INFORMATION, THE FREEDOM TO SURVIVE, shouted the activists. The DOCS was responsible for the largest prisoner population in the United States, and the largest AIDS treatment practice in the world under one administration. The only readily available AIDS treatment behind bars is AZT, a highly toxic drug that has never proven useful for African American patients.

Activists wrote letters to and phone zapped the State Legislature to press for the medical parole Bill, which would allow the release of prisoners with AIDS. The Bill is still being negotiated. In the meantime, the Governor of the State of New York gave in 1991 clemency to a female and a male prisoner with AIDS.

In addition ACT UP is now part of a coalition-the Alliance for Inmates with AIDS. The priority objective is the creation of a directory of people and organizations currently providing services to prisoners and parolees with HIV/AIDS, towards the goal of establishing, among other things an AIDS education curriculum, AIDS information clearinghouse, political strategies, and recommendations to New York

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City and State officials for improvement and change. The only missing actors will be the prisoners themselves.

MOST HOMELESS ARE PEOPLE OF COLOR

Many prisoners just released immediately become homeless. Although homelessness is unquestionably a pervasive phenomenon, there are hardly any statistics at the Federal level. Statistics are frequently based on shelter censuses, then doubled to include homeless people living outside the system (people living in the streets, abandoned buildings or public places.) None of these figures include people living doubled or tripled up. These people, living in crowded and generally substandard housing, are at high risk of becoming homeless (50 to 60% of homeless people reported living doubled just prior to becoming homeless.)

According to the National Coalition for the Homeless, there are approximately three million homeless persons in the U.S.. A study by the federal government's Department of Housing and Urban Development (HUD) found that the number of people in shelters alone had grown by 155% between 1984 and 1988. Families with children appear to be the fastest growing component; they now comprise 39% of the homeless population. The U.S. Conference of Mayors found that demands for emergency shelter increased by 23% from families with children in one year (1989). African Americans and Latinos represent 90% of the people living in shelters.

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A 1988 National Survey of Shelters for the Homeless, conducted by HUD, reveals the following rough portrait of the homeless population:

Unaccompanied men 45%

Unaccompanied women 14%

Families 40%

Under 18 years old 26%

Mentally ill 34%

Physically disabled 11%

Domestic violence victims 21%[1]

A third of the nation's homeless are veterans in Boston, many are being helped at a shelter run by Vietnam Vets who declare: Your brothers are here.[2]

Since 1970 there has been an increase in households headed by women, one half of whom live below the poverty line. Women are among the fastest growing segments of the homeless.

The federal Housing Act of 1949 established the national goal of "a decent home and a suitable living environment for every American family." In 1968, additional housing legislation aimed to create six million units of federally assisted low-income housing. But these goals have not been met.

In spite of half a century of federal low income housing programs, there are fewer than 5 million subsidized rental housing units in this country. A recent Census Bureau report found that in

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[1]The National Coalition for the Homeless Report, 1991.
[2]Parade, Your Brothers are Here, October 13, 1991.

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1989 only 2.2 million of the 11.4 million households with incomes below the poverty level were living in subsidized housing.

Finally, drastic cuts in federal housing programs during the 1980's have worsened homelessness in this country. Poverty increased from 26 million people in 1979 to 32 million in 1988. And the income of the average poor family fell $4,851 below poverty line in 1988. The U.S.A is actually experiencing the widest gap between its poor and its rich since the end of World War II. A 1990 study by the Ways and Means Committee estimated that almost half (49%) of the increase in poverty between 1979 and 1988 was caused by cuts in federal low-income and social insurance programs. During the first term of the Reagan Administration, appropriations for federal low-income programs averaged $22 billion per year less than they had under the Carter Administration, a cut of 18%. In 1988, 66% of the population living in poverty received food stamps; by 1988 that number had fallen to 59%. More families are forced to resort to soup kitchen and emergency food banks when they do not have any more food stamps.

Benefit levels for recipients of AIDS to Families with Dependent Children (AFDC), the major federal assistance program for poor families have also been substantially reduced. From 1970 to 1989, the median value of AFDC benefits dropped by 39%. In 1989, the combined AFDC and Food Stamp benefit was less than the poverty line in all but 3 states.

In 1981, the Social Security Administration undertook an aggressive review of the records of Americans who were receiving Social security Disability Benefits. By 1985, out of approximately 4 million receiving disability benefits, almost 500,000 recipients had been

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dropped from the rolls. The reviewing process was later ruled illegal by the Supreme Court, and by 1987 an estimated 63% had been reinstated.

One third of the homeless population is mentally disabled. In the mid 1960's, research began to show that chronically mentally ill individuals could be treated more humanely in community than in large state mental hospitals. As a result, thousands of mentally disabled persons were released from or never admitted to institutions for treatment. However fewer than 800 of the 2,500 community mental health centers which were to replace hospitals were established.

Unemployment is obviously a major reason for homelessness but sometimes even two people earning the minimum wage cannot afford a reasonably priced apartment. Also, not having an address deters many people from obtaining a job. Homelessness also impacts on the children's ability to attend school. Estimates of the numbers of homeless children that do not regularly attend school range from 28% to 43%.[1] Every year two million children live the pain of homelessness for days, weeks or months.[2] Second, many families are barely getting through each day. They are victims of an expensive housing market and most often decreasing incomes. There are now more than 10 million low income households competing for the more than six million housing units they might possibly afford.

Yet the constitution includes an amendment (XXVII)

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[1]National Coalition for the Homeless; *Homelessness in America: Summary,1991.*
[2]Marian Wright Edelman, *Home is Where the Child Should Be,* New York Amsterdam News, Saturday, July 13, 1991.

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> No person being a citizen of the United States of America regardless of their religion, national origin, race, color, sex age, marital status, military service, disability or income shall be deprived or denied adequate affordable housing. Such an adequate affordable housing shall be such so as not to deprive or deny any citizen of any rights written in the United States Constitution.
>
> Any circumstance or housing that leads to housing arrangements other than adequate affordable housing that shall result in a citizen being deprived of any constitutional rights shall be unconstitutional
>
> Congress shall have power to enforce this article by appropriate legislation.

In 1986, the National Coalition for the Homeless and ten other organizations drafted an omnibus bill, "The Homeless Persons' Survival Act," to create a responsible federal role in ending homelessness. The Act had over 60 co-sponsors and received endorsements from over 60 national and regional organizations.

In the Spring of 1987, Congress passed the Stewart B. McKinney Homeless Assistance Act, the first comprehensive federal response to homelessness. In its first few years the McKinney Act was grossly underfunded; roughly 50% of authorized funds were actually appropriated. In October of 1989, more than a quarter of a million people from across the country came to Washington to demand that

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the political leaders make the creation of affordable housing a top priority. As a result of the march, legislation (HR 4621) has been introduced in the House of Representatives.

On any given day, there are about 5,200 families, 12,000 children, and 7,000 adults in the City's Emergency Housing System. The average family consists of 2 or three children with an average age of six years and a female family head of about 27 years. Finally, 40% of drug users are homeless.

children: an estimated 100,000 children are homeless each day.

HOMELESSNESS AND AIDS: DOUBLE MORALIZATION, DOUBLE PUNISHMENT

Congressional hearings estimate there are now almost 32,000 homeless seropositive nationally, with 102,000 projected by 1993. Yet, there are fewer than 1,500 supportive units available. Also, the ratio of HIV seropositivity among homeless people nationwide is 3 to 4 times that of people who are not homeless. In addition 30% of children and babies with AIDS are homeless and spend most of their time in hospitals.[1]

In New York City alone there are 90,000 homeless individuals, of whom 30,000 are people with HIV and 13,000 have full blown AIDS.

The ability to pay for housing, argue the activists, is directly related to the Protestant work ethic which isolates and condemns those who do not work and by extension cannot afford housing. Reagan

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[1]The National Coalition for the Homeless Report, 1991.

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commented: "The homeless want to be homeless" is reflective of this thinking.[1]

As a result, in 1988, there was no Federal funding available to provide housing for people with AIDS and HIV. Moreover, Housing and Urban Development decided that people with AIDS do not qualify for subsidized housing for the handicapped. The reason given was that their illness was not expected to be of long continued and indefinite duration.

The response of activists was that HIV-related conditions are chronic and manageable diseases. They also argued that housing should afford maximum independence and freedom from paternalistic intrusions, while providing access to adequate social services and medical care.

While the City was denying PWAs housing in the Spring of 1988, it granted Donald Trump a tax abatement for $6,208, 774.00 to build the Trump Tower. That money could have rehabilitated approximately 1,200 city owned apartments. Instead, only 44 beds at Bailey House, and fewer than 250 units of supportive housing for people with AIDS were made available.

In July 1988 the Coalition for the Homeless filed a class-action suit charging the city for not fulfilling its mandate to find emergency housing appropriate to the medical needs of all homeless people with AIDS. In January 1989, State Supreme Court Justice Edward Lehner granted a preliminary injunction agreeing with the Coalition's complain and urging the City and State to take immediate actions.

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[1]Ibid.

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Two years later, homelessness has worsened. A 1990 survey conducted by the National Coalition for the Homeless-Fighting to Live- reports that the enormous need for decent housing for people living with HIV is experienced nationwide. Los Angeles has only three shelters, with a total of twenty-five beds, for homeless with AIDS. The San Francisco Health Care for the Homeless Project has set up one city-funded residential program for homeless intravenous drug users with AIDS, which serves between five and seventeen clients.

ONCE AGAIN, THE CDC DEFINITION IN THE WAY OF PWAS' SURVIVAL

The only way a homeless person has access to medical care or housing assistance is through the shelter system. Once within the shelter system, the broader State definition of AIDS is used, but to qualify for the Division of AIDS Services everyone must have CDC-defined AIDS.

So while New York City's Division of AIDS Services provides rent support and placement assistance to 20% of the AIDS homeless, it refuses to help the vast majority who have ARC or are HIV positive and tuberculosis or chronic diarrhea for example.

In addition, Dr Ernest Drucker, executive director of Montefiore Medical center's drug use treatment program estimate that on any given day at least 250 AIDS patients are in the city's public hospitals because they have no other place to go. According to Dr Jerome Ernst, chief of respiratory and infectious diseases at Bronx Lebanon Hospital, more than one third of these patients die before housing is found.

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Because hospitals cannot discharge persons with AIDS until they are provided with an apartment, doctors are very reluctant to give an official diagnosis.

At present there are thousands of people with suppressed immune systems living covertly in shelters (otherwise they would not be admitted) or on the streets and receiving no medical attention or special services. New York City shelters house as many as a thousand people in a single large space. These warehouses are noisy, dirty, and are often either brutally hot or underheated. Flu, pneumonia and tuberculosis are rampant and adequate rest and nutrition are impossible. Because shelters are closed during the day, people with symptoms such as chronic diarrhea are forced out onto the street.

In addition no safe sex information is provided. A survey done by the Reverend Julio Torres, director of community support services at the Franklin Avenue Shelter in the Bronx, found that while only 5% of the residents said they were exclusively homosexual, 50% reported having had homosexual sex. The impact of this finding can be appreciated when the largest population of homeless are single men. As Sarah Shulman says: "Thus, while a few in the homeless population may have a gay identity, many have a gay reality."[1]

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[1]Sarah Shulman, The Nation, 1990.

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ALTHOUGH NEW YORK CITY IS THE LARGEST LANDLORD IN THE NATION, IT HAS THE LARGEST NUMBER OF HOMELESS

New York City has thousands of empty apartments while real estate prices continue to guarantee mass homelessness. Comptroller Harrison J. Goldin admitted that out of the more than 200,000 city-owned apartments, 3,540 were empty. He claimed that 1,700 need only minor repairs and could be rehabilitated for $15 million. Repairing all the city-owned housing would cost $63 million. And, according to Goldin, this could be completed in a little over a year.

There is currently no Federal funding program to develop supportive housing for homeless with HIV/AIDS. In the last ten years, only $50 million have been appropriated by Congress to care for the 30,000 homeless persons living with AIDS, out of $156 million authorized by the 1990 National Affordable Housing Act. And the president requested nothing for his 1992 budget.

Activists are still demanding that the AIDS Housing Opportunities Act be fully funded, that programs authorized by the National Affordable Housing Act be fully funded to create housing opportunities for PWAs; that the housing and social-service needs of all Americans living with AIDS be met by committing the necessary federal resources; that federal disability benefits be increased to enable disabled persons to live independently for as long as possible; that AIDS and HIV related illness be recognized as disabilities in regulations for HUD-sponsored housing.

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COMMUNALIZATION OF HOMELESS ISSUES

Activists argue that AIDS and homelessness have become deadly cofactors. The course of HIV illness is critically affected by a lack of safe housing, an essential baseline for meeting the health care and psychosocial needs of persons with AIDS and HIV-related illness.

For persons living with HIV, progression to serious illness and death is hastened by malnutrition, exposure to the elements, chronic stress and the rampant infectious illness and crowded living condition in public and private shelters. Homeless people are largely unable to obtain either emergency or ongoing medical treatments for such serious HIV-related condition as pneumonia, meningitis and wasting syndrome. Many find it impossible to maintain antiviral drug therapies and prophylaxis against opportunistic infections. Since the creation of ACT UP, the demands of housing activists for PWAs have been the same: access to medically appropriate housing.

The 1988 legal case Mixon v. Grinker raised the issue of AIDS and homelessness for the first time. It was a class action lawsuit that demanded that medically appropriate housing--a private sleeping accommodation and private sanitary conditions--be provided for people with AIDS. The suit makes the obvious point that conditions in the City shelters and streets endanger people with AIDS, people with other HIV-related illnesses and those who are HIV positive asymptomatic. Mixon and the other two plaintiffs were provided rooms at a YMCA, far from medically appropriate housing but still within the guidelines of what the suit asked for.

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New York City's AIDS Case Management Unit (ACMU) of the Department of AIDS Services (DAS) of the Human Resources Administration (HRA) was required to locate housing for people with AIDS. Most often it is a single room occupancy (SRO) in YMCA or similar site. As of June 1989, the ACMU had already placed more than 500 persons with AIDS in such ill-suited rooms. People who did not have CDC defined AIDS were not eligible.

In response to Mixon vs. Grinker, the Mayor announced a new policy to include persons who are incapable of toiletting or bathing themselves even if they do not have CDC-defined AIDS. Yet information about this expansion of services had not been made public for fear the CMU would be overwhelmed by new clients

In December 23, 1988, the Housing Caucus had its first demonstration and took its demands to Mayor Koch at Gracie Mansion, the Mayor's home.

On June 23, ACT UP met with homeless at City Hall Park to organize a "Talk-In." whereby homeless people shared their experience of living in the street and in the shelters. ACT UP exchanged information with homeless people in a tent in City Hall Park, protesting the City's policies on the homeless. At this rally activists gave information AIDS and distributed condoms.

Finally, on November 25 ACT UP protested the lack of housing for PWA's while city would give tax breaks to developers such as Donald Trump. Numerous affinity group actions were involved, numerous arrests occurred, and the press coverage was quite impressive.

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In April 21, 1989 an action was organized at the Cardinal Cooke Health Care Center, where Mayor Edward Koch showed up at the dedication to take credit for this facility when he had nothing to do with its development. The Housing Caucus showed up with a list of demands:

1) that the City stop using CDC defined AIDS in determining eligibility for housing an services.

2) that the City set aside 100 apartments per month to house homeless PWAs. The first to be made available by 15, 1989.

3) that the City and State provide medically appropriate housing (inducing Scatter-site housing) to all people with HIV-related illnesses.

4) That the City and State develop better funding streams or HIV housing.

Sixty legal pickets were organized and three people at the dedication disrupted speeches by Koch and Cardinal O' Connor. There were no arrest.

In June 28, 1989 the Housing Caucus set up house at Housing Preservation and Development (HPD) to protest policies discriminating against homeless HIV-positive people

1) HPD controls over 100,000 units city wide. Almost 4,000 of these are available for immediate occupancy, yet none of these are scheduled for HIV-related housing.

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> 2) HPD says there is no money for HIV-related housing yet $25 million was allocated in 1988 and almost two years later none of it has been spent.
>
> 3) The City's ten-year housing plan allocates $5.1 billion to provide 250,000 new and rehabilitated apartments, but none of these have been especially set aside for people with HIV-related illnesses.

Sixty legal pickets were organized, and 8 people were arrested for acts of non-violent civil disobedience.

On the 13th of June, 1989, the Caucus to House Homeless People With AIDS of ACT UP was created. It was an advocacy group for homeless people who were HIV positive regardless of the stage of their HIV illness. The newly formed Caucus criticized Covenent House-a private facility to house adolescents without a home and sponsored by the Roman catholic Church-for refusing to provide safer sex information or condoms, despite a 7.5% HIV seropositivity rate among 16 to 20 years old youth.

On the 26 of January, 1989 twelve ACT UPers occupied the floor of the Human Resources Administration (HRA), where the office of Grinkers, then Housing Commissioner, was located, and demanded to see him. They posted their demands on the walls.

> Minimum appropriate housing applies to all HIV positive people, symptomatic or symptomatic, with

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or without ARC or CDC defined AIDS. We demand:

1) A private room for one person (unless two people wish to share the room. This is necessary because all HIV antibody positive people symptomatic or not , may be at increased risk for opportunistic infections. Sharing sleeping space with people with contagious diseases increases the risk of infection for the HIV ill person.

2) A private bathroom with a full bath (not just a shower).
This is due to the disabling effect of HIV illness and the common problem of diarrhea.

3) A refrigerator, for storage of drugs and food.

4)Convenient access to a shared kitchen.

5) Reasonable handicapped accessibility. Housing units for people with HIV illnesses should be elevator accessible though they need not comply with the full requirements of local law 58. Requiring housing for PWA's to comply would severely hamper some programs, especially scattered-site programs.

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6) Free access for health, social and support workers, at all times. Such services are not strictly required at every stage of HIV illness, but are clearly needed at some stages. It is both economically sensible and necessary for the dignity of people with HIV illness that they remain as long as possible in their own apartments.

7) All buildings which house people with HIV related illness must be clean, safe, and kept in good repair. No violations of state or city building, building maintenance, fire or health codes will be acceptable. In addition, the location of the buildings should be in a residential community, with easy access to health care facilities, laundry, grocery stores, etc., as well as public transportation.

8)No more than 50 people with HIV related illness should be housed in any one residential building or facility. At present and foreseeable future death rates for homeless people with AIDS, facility with 50 beds will have an average of one death a week. This causes a high level of burnout in support staff; a facility with more beds would have to deal with acceptable high turnover. Because a group of people housed together becomes a community, this

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is also extremely stressful for the occupants. Larger facility would be inhumane.

Some people with HIV illness may need, and have a right to, more specialized housing than described here. These people include, but are not limited to, families, IV drug users, the mentally disabled, the physically disabled, and adolescents. When dealing with these special populations, the following guidelines must be considered.

1) Drug use must not be prohibited or be used as a criterion for eligibility. Clean work information must be available. Not every persons will house or will be able to stop drug used. The fact that it is a chemical dependence and not a character fault must be recognized.

2) Freedom of association, right to healthy relationships, and safe sex activities must be respected. Many religious organizations promote abstinence instead of safe sex in their housing facilities. This is denial that has been proven deadly--especially when dealing with homeless adolescents, many of whom engage in sex for money as the means for survival. Distributing condoms will save lives.

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> 3) Individuals must be able to make their own decisions about medical care. With consideration given to illiteracy and language barriers, all efforts must be made so that each person be able to practice informed consent.[1]

After boisterous negotiations, activists were granted an appointment with the Commissioner.

That same month, the New York Supreme Court ruled in Phillips v. Grinker- a case brought by the Coalition for the Homeless, that the City of New York had to provide appropriate housing for Wayne Phillips, a man with AIDS Related Complex (ARC). Judge Lehner stated in his decision that "there is no reason for a distinction between CDC-defined AIDS and other illness without ever meeting the criteria for CDC-defined AIDS." He denied class action status, however, and as a result people with HIV-related illness, but not CDC-defined AIDS, would have to be considered on a case by case basis.

Unfortunately, while the courts may order the City to provide shelter, they do not always specify the terms of that shelter. Homeless people usually end up in the Washington Armory and the Third Street Men's Shelter, two horrible places to sleep, let alone live. The case of Phillips illustrates the lack of willingness of the courts to involve themselves in social service issues. The court did not consider the issue of appropriate health care for Wayne Phillips, indicating only that

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[1]ACT UP Hou: ng Caucus, *Handbook on Homelessness and AIDS*, August 30, 1989.

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"he be provided shelter by the City with a facility where he will not be in close proximity to those who may have infectious diseases." This meant that the City could still house Wayne in a shelter if such accommodations complied with the letter of the court's ruling. It did not fail. The City attempted to house Wayne in the Third Street Men's shelter infirmary until ACT UP and other groups pressured the Human Resources Administration out of it.

The class action status in Phillips v. Grinker was denied. Justice Lehner stated that "no matter how difficult the solution [it is hoped that] the government will act [to fulfill the obligations of this decision ad expand it to include other similarly situated individuals] without being further prodded by the courts." This whole decision was based on the judge's appraisal of the City's "good will" to treat this particular case as a class action case. As expected, the City never treats the Phillips case as a class action case, the practice effect of this case is almost nil.

Already in 1989, Mayor Koch acknowledged that all individuals with HIV-related illness , not just those with CDC-defined AIDS were eligible to receive City housing and social services. Yet the major effort resulted in Koch's release of a plan to create segregated units for people with HIV, a total of 255 beds within the existing shelter system. In the meantime 44 beds at bailey house 44, 20 Scattered-site Units, 52 chronic beds, 300 single room occupancies, and 900 rent subsidies represented the total picture of housing assistance of the city for the 10,000 homeless with AIDS.

While campaigning for Mayor, Dinkins promised in his mayoral campaign that he would not use shelters for PWAs:

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> I am strongly opposed to any notion of providing services to HIV ill or people with AIDS in shelters. Given the nature of the disease, we place this vulnerable population at greater risk of contracting other infections and illnesses, like tuberculosis, by placing them in shelters.[1]

In 1989 two actions were organized against the special fiscal treatment wealthy developers were being granted, especially Donald Trump. In February 1989, a Soup Kitchen rally was organized against the perks afforded Donald Trump. Food and entertainment were provided and a member of Housing Committee spoke. In October 31, ACT UP organized the Trick or Treat action at Trump Tower. The Housing Committee passed out candy with condoms and literature about AIDS and homelessness in front of the Tower.

Several demonstration were organized against the Human Resource Administration. In August 8 ACT UP phone zapped Human Resource Administration (HRA) for not providing service at the Division of AIDS Services Case. Another demonstration was organized against HRA, which was followed by a march toward City Hall.Management Unit. A third demonstration was organized in October 18, 1991 against Division of AIDS Services (DAS) for not having desks or phones for its newly caseworkers. The activists attempted to deliver office furniture to their offices. When the police tried to stop them they found they were handcuffed to the desks and

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[1]David Dinkins, *Letter to Mayor Edward I. Koch*, June 5, 1989.

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chairs. In support of the protest, the caseworkers' union held a picket at the same time.

ACT UP joined the National March on Washington in October 7, 1989: Housing Now! The Housing Committee tied together the Quilt and led the Housing Now! March to walk around the Quilt, while distributing flyers. The Committee provided the only homeless people with AIDS to speak at the rally. In fact the committee forced the March organizers to agree to have a non-gay PWA, who was allowed to speak last.

Housing Committee joined in a WHAM! (Women's Health Action Mobilization) action in October 26 against Covenant House. They protested the lack of condoms, safe sex and contraceptive and homophobia in this Catholic-run shelter of homeless teenagers.

In November 4, members of the Housing Committee zapped HUD Commissioner Jack Kemp as he spoke at a conference in Arlington, VA on supported and SRO housing. The protest was against the Department of Housing and Urban Development (HUD)'s refusal to fund housing programs specifically for PWAs. Their main argument was that HUD's funding for the disabled could not be targeted toward any particular disability as this would be discrimination (this despite their funding of projects for the blind, for example). Also, they argued that AIDS was not a disability per se. The result of this zap was a meeting with Assistant Commissioner Anna Kondratas. This action occurred in connection with a lawsuit brought against HUD by a housing provider in San Jose, CA.

Activists met again with Anna Kondratas who surrounded herself with lawyers. She was surprised at the knowledge activists

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displayed concerning internal HUD documents. Ultimately the issue of funding for particular disability was resolved through Congress, which passed new law attuned to the activists' demands.

Yet, when in office, Dinkins forgot his promise and enacted a Human Resources Administration Plan-the Comprehensive Care Plan, a rehashed version of Koch's plan-to dump very sick people, including people with HIV-related illnesses, in its "Special Needs Unit" at the Bellevue Men's shelter. The City went out of its way to find a doctor who would testify that shelters were a healthy environment for PWAs. They found one in New Jersey.

ACT UP demonstrated against the plan at Gracie Mansion on three occasions. At the first demonstration several ACT UP members were arrested for chanting "Housing, not shelter!" a gesture forbidden in the mayor's neighborhood. At the second action, leafletting at a mayoral cocktail party, Housing Committee members were arrested and handcuffed for 10 hours. They spent 30 hours being put through the system. An ACT UP member recalled that they had just done a subway sweep. So the Housing Committee was in company of many homeless people. At the last demonstration, the 100 or so ACT UP members were surrounded by an estimated 80 policemen and 40 horses. Special needs programs are not cost effective and are economically short-sighted, argued the activists. It costs $71 per bed per day; supportive scatter site housing costs $58 per bed per day. The absence of services to forestall onset of illness implies higher acute care costs and more frequent hospitalization. In those Special Needs Units, residents are provided a cot and a locker, crowding as many as s 10 to a room, 3 feet apart. Chronic diarrhea is a common condition of HIV-

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related illness, yet toilets must be shared by 10 or more people. Harassment and violence by shelter staff and residents against those perceived to have AIDS or to be HIV positive are rampant.

There is currently an increase in tuberculosis and other communicable diseases in the shelter population. Those diseases are life-threatening to HIV positive people who have a weakened immune system. In addition, without housing, PWAs cannot receive medicaid and health benefits.

ACT UP proposed a scatter-housing plan which Dinkins supported before he was elected mayor. Besides being the most humane and swiftest to create, it is also the least expensive. Scatter-site housing programs would be run by community service providers who would coordinate services such as medical care, drug treatment, and counseling.

This plan would cost $15 less than placing a person in the shelter. At first paying more for disastrous living conditions look like illogical reasoning. But a closer look at the situation, activists argue, reveals that this way PWAs die much faster than they would in scatter-site housing. This is ultimately greater savings for the City. A class action suit had been brought against the City to force it to provide a safe environment for homeless people with AIDS.

Until January 1990, a homeless person with HIV-related illness who demonstrated a need for assistance with "instrumental needs of daily living, such as shopping, cooking, laundry and household chores, was entitled to non shelter housing, enhanced home relief, and case management through the Division of AIDS Services Case Management Unit. Though this standard was arbitrary and excluded

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large numbers of persons who were immune suppressed or ill as a result of HIV infection, it did provide many homeless persons with HIV illness access to housing and AIDS Division Services.

In January 1990, Gail Gordon, Human Resources Administration Deputy commissioner for AIDS ordered that the criteria be restricted to require that homeless persons with AIDS demonstrate a need for assistance with the personal activities of daily living. Homeless PWAs needed now to demonstrate a need for assistance in bathing and toileting. With this new regulation a man was discharged from Bellevue Hospital, recovering from bouts with pneumonia whose T-4 cell count was only eighteen and was not given housing; a woman with cervical cancer was discharged from the hospital two weeks after giving birth by caesarian section and was not given housing; neither was a man with a T-cell count of only four.

In 1990, Governor Mario Cuomo proposed cuts on Home Relief by $9 million. Yet, in June of 1989, there were 238,000 Home Relief (HR) recipients in new York State. Nearly half of all HR recipients report major health problems including AIDS and HIV-related illness. Many are person with HIV-related illness who are not sick enough to quality for disability or DAS.

About 45% of single Home Relief recipients are women, and 39% of the heads of HR households are also women. About 2/3 are first generation Public Assistance recipients. Nearly 1/3 or 69,700 of the HR recipients for this month were families. Of the HRA's Home Relief recipients 185 are 18 years or or younger. Less than half of HR recipients have a high school education, 21% cannot read or write and

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20% are not fluent in English, and 70% of the HR population have never received training of any kind

In February 1990, June 27 and September 28, Housing Committee members protested the Public Health Councils' attempt to approve the Archdiocese of New York for money for health-related facilities (nursing homes) for people with AIDS. The Archdiocese refused to provide safe sex and clean works information, condoms, contraceptive and abortion counseling, and gynecological care, among other things, citing "institutional ethics." The Public Health Council was more than willing to re-write the State Health law. On May 16 the Housing Committee demonstrated at the AIDS Institute for the same reason.

In June, 13 activists zapped the Housing Authority, which discriminated against gay and lesbian tenants because they did not fit into the traditional family concept.

Finally, for the first time, in October 7, the Housing Committee organized the Camp LaGuardia Outreach Action, which resulted in the director's permission to provide on an experimental basis AIDS education, condom and bleach kit distribution for homeless men at an upstate shelter.

In January 23, the Day of Desperation was organized by ACT UP. For that occasion, the Housing Committee joined Stand Up/Harlem, Emmaus House and various Harlem religious leaders in protesting the lack of housing and services for people with HIV. They marched down Martin Luther King Boulevard to the State Office Building, carrying coffins. The activists staged a die-in in the street , with some handcuffed to the coffins. Several arrests occurred

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In May 9, 1991 Dinkins attempted to evict all the homeless people from Thompkins Square. He closed the park on June 3, a week after a disturbance erupted during a rock concert when the police tried to prevent a group of people carrying open beer bottles from entering the park. A drug store was looted, and bottles were thrown, in a reminder of a melee in 1988 that left 500 people hurt, 31 arrested and led to 121 complaints of police brutality.

At that point some activists on the Housing Committee decided that advocacy for housing for PWA homeless was not enough. They created Housing Works in December of 1990 and incorporated it in June 1991. Housing Works is officially a service organization, which was financially helped by ACT UP, and provides housing for PWAs. The recent victory of Housing Works were 3 scattered housing contracts, including medically appropriate housing plus case management for 20 people.

The Housing policy of the city deteriorating, Nancy Wackstein, Mayor David N. Dinkins' chief policy adviser on the homeless, resigned in September 1991 to become president of a Manhattan social service agency. She had no authority.

Finally two anti-Bush demonstration were organized by ACT UP to protest his lack of AIDS policy for PWA homeless. In September 25, 1991 about 50 ACT UP members protested Bush Administration's continued negligence toward the over 20,000 people living with AIDS.

On Tuesday, January 7, 1992, the Commission on the Homeless held a public hearing. Twelve death masked activists appeared in the back of the City Hall hearing room, to protest the absence of homeless people on the commission. No arrests occurred and what is more,

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Larry Thodes was appointed to the commission evidence that the housing activists are making progress.

RACISM IN ACT UP?

The common thread between the communalization processes of all the ethnic caucuses of ACT UP is that, although each is in many ways unique, all involve a two-layered communalization process. People of color have to communalize their concerns with regard to the non-response of the government, but also with regard to ACT UP's racism.

There is not one interview with activists of color which does not make any reference to ACT UP's racism. "When we speak, the floor starts mumbling;" complains an activist of color. "We are very rarely called on for the preparation of the action. Oh! when the action is ready to go, then they need their token black, Latino/a or API. But we are not made to feel that we are part of the brain of ACT UP." These were the typical remarks made by a lot of activists of color.

Another type of criticism from activists of color includes the white members' tendency to see people of color as sexual objects only. "Many times, white members approach me to have sex. But they are the ones who ignored me the day before when I tried to take part in the logistics of an action."

This was a major reason for the creation of the Latino caucus, argue some Latinos activists. "We were very tired to see those white rich boys hang around us. It was obvious that they were not interested

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only, in fact not at all for some of them, in the actions that we were organizing."

Yet feelings collected in the interview showed that for many racism in ACT UP should not be a reason for activists of color not to do their work. "ACT UP is not my social movement, but I use it as a cultural space to do my work."

Yet, it seems racism was too much for others. ACT UP does count hardly any black members any more.

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THE SOCIOLOGY OF AIDS ACTIVISM, THE CASE OF ACT UP/NEW YORK, 1987-1992

BY

GILBERT ELBAZ

VOLUME II

A dissertation submitted to the Graduate Faculty in Sociology in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York

1992

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DRUG AND AIDS: A DECIMATED COMMUNITY[1]

When ACT UP started to talk about giving clean needles to addicts, unsafe injection drug use represented the second main behavior through which HIV transmission could occur.

Although, it is very difficult to determine the extent of illicit drug injection, the US Public Health Service estimates that there are 750,000 "regular" injection drug users (IDU's) and another 750,000 "occasional " IDU's in the United States. A "regular" drug user is defined as a person who injects at a frequency of at least once per week. "Occasional" IDU's are persons who use drugs intravenously but have never injected more than once per week. Heroin is the drug most used by addicts, then comes cocaine. Noteworthy is the fact that those statistics do not capture middle and upper class individuals who can afford clean needles, and escape the attention of federal health or justice agencies.

In Europe the greatest concentration is found in Northern Italy, southern France and Spain. Italy and Spain are the only two countries in the world in which heterosexual IDU's constitute the majority of CDC-defined AIDS cases.

In 1988, over 20% of the CDC-defined AIDS cases nationwide were attributed to dirty needle sharing during injection drug use. And over 50% of female CDC-defined AIDS cases were attributed to unsafe drug use. Black women, in particular, represented almost four times

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[1]This chapter relies heavily on the article written by Samuel Friedman, R., Des Jarlais D.C., Sterk CE, Sotheran J.L., Tross S., Woods J., Sulfian M., Abdaul-Qader A.S. *AIDS and Social Relations among Intravenous Drug Users.* The Milbank Quarterly; 68: Supplement 1: pp.85-110, 1990.

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the number of white or Hispanic women with CDC-defined AIDS. The number of births to women who use narcotics continues to increase sometimes dramatically, for example in Northern Brooklyn, an increase of 75% of such births occurred in just one year. In New York City, 80% of pediatric AIDS cases were (and still are) attributed to a present or former drug-using parent. The NYC Department of Health estimates that by 1993, 50% of NYC AIDS cases will be among IDU's.[1]

In New York State, there were (and still are) approximately 260,000 IDU's , the largest concentration being in New York City. About 60% of them were HIV positive. That same year, for the first time, the drug using population in New York City was outnumbering gay men in terms of reported AIDS cases. Compared to the rest of the U.S., New York State's PWA's are at least three times as likely to be IDU's.

The three States of New York, New Jersey, and Connecticut account for almost three-quarters of CDC-defined AIDS cases involving heterosexual IDU's.

Even when low seroprevalence rates among IDU's in certain geographic areas are found, they should not be considered stable situations. Studies of historically collected blood samples from IDU's indicate the potential for very rapid spread of the virus within the group. HIV infection among IDU's in Manhattan, Edinburgh, Scotland, and Italy had increased to 40% just 3 to 4 years after the virus was first introduced in the group.

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[1]Frank Blanchy and William Hopkins, *Current Drug Use Trends in New York City,* New York: New York State Division of Substance Abuse Services, p 11-155, June 1989.

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To make matters worse, the Centers for Disease Control has not included pulmonary tuberculosis in its AIDS definition. Pulmonary tuberculosis is about the most common opportunistic infection contracted by IDU's, because of their socio-economic environment and the pollution that they inhale everyday. As in the case of women, the CDC does not take the socio-cultural and environmental context in which the syndrome can develop in the IV drug population, whose economic world is quite different from that of white middle class gay men. This does mean that gay men do use drug. They do, in large enough numbers to create a category of its own.

There are certain malignancies that are not AIDS-defining, yet life-threatening, that are occurring in mostly male IDUs. They include lung cancer and cancers of the GI tract, bacterial infections, tuberculosis, sexually transmitted diseases, HTLVI and II, endocarditis/septis, pulmonary TB and herpes zoster. In addition, there are almost no cases of Kaposi's Sarcoma in male IDU's who are also HIV infected. When IDU's develop pneumonia, it is bacterial pneumonia and TB, not PCP. And bacterial pneumonia cannot be treated with bactrim or pentamidine. CD4 counts are probably not the best way to determine whether or not these diseases will occur in this population. Using Beta 2 levels as a marker is also not useful in HIV positive drug users because Beta 2 levels are high in all drug users.

Unsafe sex is a factor in the entire drug user population. For example, cocaine and alcohol have a disinhibiting effect on people' s risk-taking behavior as well as people's threshold for engaging in unsafe sex.

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The allegation by biomedical researchers that IDU's are not a "reliable subject population" allows them to restrict their enrollment in drug trials, and therefore access to much needed health care. When users are women, then they are officially banned from many drug trials. Yet even without HIV, the immune system of users is already quite weakened. Many contract infections such as hepatitis, endocarditis, syphilis, and septicemia, as well as injection-related injuries such as cellulitis and abscesses. A way to strengthen the likelihood of return of those subject would be to include comprehensive care, not limited to HIV infection.

DRUG INJECTION AND VIRAL TRANSMISSION: SPECIFIC HIV TRANSMISSION RELATED TO SPECIFIC BEHAVIOR PATTERNS

HIV is transmitted among IDU's primarily through the exchange of blood which takes place while sharing hypodermic needles, syringes, cotton (or other material used as a filter), and "cookers," or containers in which the drug is heated and/or dissolved. Blood of the previous users lodges most often in the tip of the hypodermic needle or in the syringe, but may also be found in other parts of the apparatus.

During injection, the user may draw his/her own blood into the syringe to mix with the dissolved drug and then inject the blood/drug mixture, a procedure known as "booting".

Sterilization equipment may not always be readily available. And addicts may also be fearful of damaging precious equipment through sterilization procedures such as boiling.

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SHOOTING GALLERIES: ADDICTS' HOME

The spread of HIV among IDU's has been consistently linked to frequency of unsafe drug injection and the use of "shooting galleries". Users of heroin inject about three times, whereas users of the cocaine shoot up to 10 times a day. Unsafe intravenous use of cocaine therefore increases the users' risk of infection.

Shooting galleries rent drug injection equipment to multiple users. After one person uses the equipment, it is returned to the proprietor for renting to the next person. Studies have shown that 90-100 % of known IDU's report sharing needles and almost three-quarters frequent shooting galleries.

In smaller cities, shooting galleries are not as prevalent, but "house works" which can serve the same function of rapid spread of the virus among IDU's, are likely to be available. A dealer who is selling illicit drugs for injection will often keep a set of "house works" injection equipment that is lent to a purchaser so the drugs can be used immediately. These works are then returned to the dealer for lending to the next customer.

IDU'S, TOO, HAVE A CULTURE

Needle sharing also often occurs as part of initiation into drug use and as part of important social behavior with other users. Even in areas where shooting galleries are not common, a large percentage of users report that they share injection equipment daily.

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New users are unlikely to purchase their own injection equipment at first. Intravenous injection or "skin popping" is often done with and by an associate or friend who is experienced in the technique and who supplies the equipment. Initiation is not likely to be a planned event.

Sharing "works " with a partner, friend or lover on a regular basis is also a common part of the drug world. Those who share are often "running partners." They steal together, buy and use drugs together. Only one of the pair may carry "works" and share it with the other, as both a convenience and a token of friendship. Injecting together may also be a way of splitting an amount of drugs or a mutual protection mechanism, partners watching out for signs of overdose. Sharing equipment in this fashion is an important social bond in the addict world, and refusal to share may be seen as a serious sign of mistrust or disloyalty among partners. Some studies, however, have discounted this cultural argument, arguing that sharing is strictly an economic response to needle scarcity. Others argue that "contrary to popular notion, addicts did not share needles as part of some ritual of the drug culture but predominantly due to fear of arrest for possessing needles/syringes and the scarcity. The difficulty of obtaining sterile needles forced many to borrow equipment from drug dealers or to rent equipment in shooting galleries or share with friends/partners."[1]

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[1]Elaine O'keefe, Edward Kaplan, and Kaveh Khoshnood, *Preliminary Report: City of New Haven Needle Exchange Program*, July 31, 1991.

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FAILINGS OF THE CURRENT PROGRAMS

To no avail, the Reagan Administration has attempted for eight years to "just say no to drugs." The big money-making international drug trafficking market is booming more than ever. And it seems to be more and more difficult to indict the profiteers, although they openly engage in their commerce. That is, if there is real hunt.

At the State level, the situation is abysmal. There are currently about 43,000 treatment slots in New York State, 35,000 of which are for heroin addicts. The State Department of Substance Abuse Services says it plans to add 5,000 more slots, although such an increase would clearly be insufficient. In addition, there is no centralized referral service for monitoring treatment program capacities. Treatment slots sometimes remain empty for weeks because no one knows they are open.

Only 30 residential treatment slots exist in the entire state for women with dependent children: 5 in Rochester, 25 in New York City's Odyssey House and none for pregnant women. This model of residential treatment is faulty in that a woman's child/ren cannot stay with her, while she is in treatment.

Methadone maintenance programs in the state continue to operate at 105% utilization. The waiting lists are long, and it is impossible to get into treatment if one cannot pay for private services.

No new treatment programs have opened since 1974, and New York State's drug treatment system is almost wholly Methadone-based (30.1% of DSAD's budget.) Crack and cocaine are stimulants and Methadone works only on opiates such as heroin. In addition,

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methadone maintenance programs are often reluctant to deal with the issue of polydrug and alcohol use among their clients, much less AIDS.

Because of the low success rate of Methadone treatment (the Washington Post cites the figure of 82% recidivism, 2/20/89), and because needles, aside from drugs are in themselves physically addictive, many addicts shoot up, while in treatment.

Yet alternatives do exist. Drug-free treatments like acupuncture have been shown to be effective in the treatment of various addictions. Residential programs, which have a much higher treatment success rate, comprise only 20.2% of DSAD's budget.

Too, the Drug Reform Coalition (DRF) advocates heroin therapy. DRF activists argue that heroin is more benign than drinking or cigarette smoking. It does not cause teeth to rot, appetite to decrease stomach, intestines and liver to cease functioning. In fact doctors have found few ill effects associated with heroin addiction besides those accruing from criminalization. In Britain, heroin maintenance programs have been standard medical procedure since 1926. John Morgan, professor of pharmacology at CUNY Medical School announced: "Heroin is a medically superior to the widely used Demero, an artificial opiate whose only advantage lied in its legality. They, of course, advocate decriminalization of drug.

The City emulates the State. More than 25,000 of the 100,000 prisoners passing through City jails are heroin-addicted, according to the New York City Correction Commissioner. There is no system in place to help addicts, who recover while in prison, to continue recovery once they are out.

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Further, although blacks are over represented in drug statistics, whites hold a disproportionate number of spaces in Methadone clinics.

New York City gives no money to drug treatments programs at all. As a result of a deal cut between the city ad the State, New York City accepted the responsibility of paying for the police, the State for drug treatment. Further, in 1987, New York City promised the State 10 buildings for drug treatment programs. Only one has opened so far.

Injection drug use is a factor in at least 80% of NYC's pediatric AIDS cases. Neither the State Department of Substance Abuse Services nor the NYC Department of Health could provide a figure regarding the number of babies born with traces of heroin or cocaine in their blood.

Soon after he took office, Mayor Dinkins ended the politically-compromised Needle Distribution Program in New York City, arguing that any program that will bring more needles into the inner cities is an act of "genocide" against the minority community. Yet, Don Desjarlais: an AIDS researcher at Beth Israel medical Center in Manhattan says that study of 40 needle exchange programs throughout the world have the same conclusion: needle exchange does not lead to increased drug use.

AS THERE IS HOMOPHOBIA, THERE IS ADDICTAPHOBIA
THE MAKING OF A CULTURAL TABOO AND THE VICTIMIZATION OF THE STREET ADDICT

From a cultural analysis standpoint, the similarities between the way sex and drug are conceptualized are striking. Both are thought to

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be harmful. The indulgence in each cannot be talked openly in public. Both take place in a coercive environment. And the arsenal of control and coercion used tend to victimize the most vulnerable targets: street sex workers and street drug addicts.

Interestingly enough, as in the case of sexual matters, drugs were medicalized in the 19th century. Up until the turn of the century drugs were not regulated and certainly not prohibited. In fact healers praised the pain relieving qualities of opiates. Many physicians viewed them as something of a wonder drug. With them, they could treat menstrual cramps and diarrhea. Opium derivatives such as morphine were also used to cure alcoholism. Opiates produce a peaceful, calming effect and do not interfere with physical coordination nor do they lead to violent outbursts of temper, as does alcohol.

Cocaine was used to ease certain ailments. After its introduction in this country in the 1870's, coke emerged as popular home remedy. Rolled into small cigars, it seemed to alleviate depression.

In 1914, the Harrisson Narcotics Act was adopted limiting the distribution of all opiates including morphine and heroin to licensed physicians. By the mid-twenties opiates were essentially banned. And in 1937, Congress made marijuana on the list of proscribed substances. Upping the ante in 1966, Nelson Rockefeller proposed from 15 years to life imprisonment for possession of two ounces or more of any narcotic substance, plus stiff penalties for marijuana.

The criminalization of drugs gave birth to one of--if not the most--profitable and exploitative market in the world. Many politicians, organized crime, and members of almost all known communities are involved in the drug market. And drugs come from

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all over the world. Marijuana and cocaine are imported from Latin America, in particular Colombia, Peru and Bolivia. Heroin is imported from South East Asia, China and the Mideast. But drugs are also produced in the United States. Individual may produce or even invent their own drug. This was the case of crack, designed in a Los Angeles kitchen.

Furthermore, drugs support a huge market. For example, 10% of the Colombian economy is sustained by the drug trade. Since the criminalization of the possession of drugs, the motive for profit has not ceased to increase. Thus, drugs are not sold pure anymore, they are cut usually with some synthetic component which increases their immune suppressing effect.

Nixon started the War on Drugs in the 70's with his Operation Intercept, which supposedly would step up boarder control with Mexico. The consequence was a shift in the mode of transportation for the smugglers who learned to fly airplanes.

In the 70s, there was tentative support within the democratic party for drug law liberalization. A marijuana decriminalization bill was sponsored by Jacob Javit and Edward Koch. Eleven states decriminalized simple possession, while one -Alaska-legalized cultivation for personal use. But then came Ronald Reagan.

In 1989, Reagan appointed vice president George Bush to be the director of the South Florida Task Force, a super agency aimed at controlling the flood of hot money and drugs in and around Miami. And Operation Delta-9 was completed with troops and military helicopter against domestic marijuana growers in all 50 states. Drug traffic and terrorism were conflated as Lazare points out:

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> The Reagan administration accused Moscow not only of fostering terrorism, but, by way of Cuba and Nicaragua, fostering the drug trade as well. A new word, narco-terrorism, an '80s update of the old image of heroin-pushing Commies, was born.[1]

William J. Bennett, appointed by Ronald Reagan to deal with the drug problem declared in a speech in Washington:

> The drug crisis is a crisis of authority-in every sense of the term 'authority'... What those of us in Washington, in the localities can do is exert the political authority necessary to make a sustained commitment to the drug war. We must build more prisons. There must be more jails. We must have more judges to hear drug cases and more prosecutors to bring them to trial, including military judges and prosecutors to supplement what we already have.[2]

Reverend Jesse Jackson illustrates in his own way what addictaphobia is:

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[1]Daniel Lazare, *How the Drug War created Crack,* Village Voice, January 23, Vol. 35, No 4, 1990

[2]Quoted in Daniel Lazare, *How the Drug War created Crack,* Village Voice, January 23, Vol. 35, No 4, 1990.

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> Drugs are poison. Taking drugs is a sin. A drug user is morally debased and sick... Since the sale of drugs into the U.S. is an act of terrorism, antiterrorist policies must be applied.... If someone is caught transmitting the death agent to Americans, that person should face wartime consequences. The line must be drawn.[1]

But as Lazare notes:

> Terrorism..death agent...wartime consequences-this was the language of a political culture that had detached itself from reality and was spinning wildly out of control. Jackson and Rangel notwithstanding, minorities are the greatest victims of the drug war. Military courts such as those sought by Bennett would not be set up in the suburbs, where brokers snort and occasional line of coke and teenagers sneak off to smoke joints. Rather, they'd preside over battle zones like Washington Heights and the South Bronx. That's where the drug trade is concentrated, that's where the cops concentrate their forces, and that's where civil liberties are first to come under assault. It's also where the indirect effects of the drug war-

[1]Daniel Lazare, *How the Drug War created Crack*, Village Voice, January 23, Vol. 35, No 4, 1990.

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> crime, corruption, the displacement of background business and needle-borne disease such as AIDS-are most intense.[1]

One consequence of this war on street drug users is that addicts risk their lives and others' to obtain drugs. Drugs have displaced first degree robbery as the number one cause of incarceration. Drug use accounts for more than half of all felony indictments. Many Cubans or Haitians, for example are killed every year, trying to ship drugs to Miami.

As Thomas Jefferson had predicted:

> No nation is drunken where wine is cheap, and none sober where the dearness of wine substitutes ardent spirits as the common beverage.[2]

As in the case of homosexuals, the neglect that governments have shown with regard to their drug using communities has a punitive component to it. Society's disapproval of drug users has prevented the latter from obtaining adequate medical attention. Even the New York City Department of Health estimated that drug users are being undercounted by 130%. Hateful attitudes against drug users have been best exemplified by the debate around the "blood" issues. Drug users were denounced by the media for giving their "contaminated"

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[1]Ibid.
[2]Ibid.

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blood. Symbolically and historically "blood" has been frequently used to define the purity of a race.

As a divider of "us" against "them," the image of blood could not have been more timely. Yet many more drug users live in their upper or middle class houses than in the street. What makes a drug addict distasteful to the eyes of many is not so much his/her addiction as his/her disclosure of it. As in the case of closeted homosexuals, many drug addicts live "respectable lives," because no one suspects their addiction. In addition, upper and middle class users are educated about the different effects of drugs, and have easy access to clean needles.

When one addresses the issue of street drug addiction, one looks at a community that is disenfranchised as a result of its addiction and its socioeconomic status.

Two recent studies--the Lower East Side Health Project (LESHP)[1] and the Risk Factors Study[2] --broke away from the stereotype of the IDU. They included respectively 1,541 and 1,056 subjects and concluded that the typical profile of the IDU's was black, white or Hispanic, 37 years of age with 11 years of formal education. The studies showed that drug users were aware of their personal risk status. They were also informed of the modes of transmission for HIV and harm reduction.

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[1]Samuel Friedman. R., Des Jarlais D.C., Sterk CE, Sotheran J.L., Tross S., Woods J., Sulfian M., Abdaul-Qader A.S. *AIDS and Social Relations among Intravenous Drug Users.* The Milbank Quarterly; 68: Supplement 1: pp.85-110, 1990.

[2]O'Keefe, Elaine, Kaplan E., Khoshnood K. Preliminary Report City of New Haven Needle Exchange Program, 1991.

William Rathje,*The Garbage Decade,* American Behavioral Scientist; 28:1 pp9-29, 1984.

Susan Tross, Abdul-Quader A.S., Silvert H.M., Rapkin B., Des Jarlais D.C., Friedman S.R, *Determinants of Needle Sharing Change in Street Recruited New York City IV Drug Users.* Paper Presented at the Seventh International Conference on AIDS, 1991.

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About 80% of the sampled IDU's had taken steps to lower their own risk of HIV infection. Generally, these risk reduction behavior changes have been either reduction of needle sharing, bleaching of shared needles or condom use. Still 33% continued to share needles on a regular basis. The rate of seropositivity was 43% in the Risk Factors sample and 51% in the LESHP.

NOT ONLY IS CRIMINALIZATION OF NEEDLE POSSESSION AT THE ROOT OF THE HIV/AIDS EPIDEMIC AMONG IDU'S, BUT SO IS CRIMINALIZATION OF DRUG USE

Because needle possession is a crime in New York City, a subculture with its own economy has evolved. Fear of AIDS, as spurred a market for new syringes, often supplied by diabetics that sell for $3 apiece, though many addicts still buy used ones for half price.

A $5 vial of cocaine can be bought with a case of Sustacal, a nutrient drink prescribed to prevent weight loss. The 12-can case which costs about $30 in pharmacies can be bought $15 in the street, but the price has dropped as more individuals with AIDS sell the cans they get free through Medicaid.

As Daniel Lazare puts it:

> Although the feds have succeeded in pushing marijuana prices up-from $20 an ounce in the 1960s to $200 and up today-coke has plummeted from $50,000 per kilo in the late 1970s to under $10,000 early last year. As a result of this interdiction-

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> driven price structure, marijuana-once a "poor man's drug"-is now a gourmet item; cocaine, once reserved for the media elite, is now the lumpen proletariat's drug of choice.[1],[2]

The price of sex also has dropped because of increased supply. As more women and men have become addicted to crack, they have turned to prostitution often with infected drug users as clients. Don Desjarlais estimates that the number of regular crack smokers in New York could be anywhere from 50,000 to 400,000. After IDU's, crack users are probably the next generation of HIV infected. A few years ago a women would charge at least $40. Now some of them would go as far down as $5, says Linzt Richardson, one of the many welfare recipients living at the Lincoln Motel in Downtown Newark.

Decriminalization of drug use would undercut the drug lords. By introducing free and open competition it would keep profits and prices down to normal business level. Instead of expending vast sums for police, prosecutors, prison guards, the city would be able to finance non-coercive drug treatment. An alternative to a war on drug is a policy based on peaceful persuasion. Instead of ostracizing drug users, the new approach would educate people not to use dangerous drugs, much as a broad based anti-tobacco campaign has educated millions of Americans. As Thomas S. Szasz argues: "the verminization of those

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[1]Daniel Lazare, *How the Drug War created Crack,* Village Voice, January 23, Vol. 35, No 4, 1990.

[2]The last statement about cocaine is of course a reference to crack.

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who choose to get high outside the officially approved triad of nicotine, caffeine and alcohol would cease."

A rational policy would recognize that all drugs are not necessarily dangerous and that drug use does not necessarily constitute abuse. On the other hand, it would recognized that just as some people persist in smoking some will persist in doing hard drugs. Rather than punishing those who do, legalization would promote moderation while seeking to minimize the risk to users and the disruption of communities.

Moderation has already asserted itself with regard to legal drugs. Since the health revolution of the 1970's, consumption of alcohol has declined as distilled spirits, gave way to wine coolers and light beers. Alcohol has undergone a process of demystification. Americans drink more decaffeinated coffee and smoke fewer cigarettes.

The decriminalization of marijuana is long over due. The Chief Administrative Judge of the DEA observed that "pot is one of the safest therapeutically active substances known to man." According to John Morgan "There has never been a confirmed overdose due to marijuana alone, while hundreds die each year from internal bleeding brought on by aspirin. In Holland, where marijuana has been decriminalized since the 70's per capita consumption has declined well below U.S. levels.

AS THERE IS SAFER SEX, THERE IS SAFER INJECTION DRUG USE

It will take a relatively long time to open enough new treatment programs to accommodate those IDU's who want to enter treatment.

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Treatment may also not be successful for all who enter, and there will still be a significant number of IDU's who do not want to enter treatment. Therefore, activists suggest that if the spread of HIV is to be controlled, those IDU's who continue injecting must adopt "safer" drug injection practices. Promoting safer injection practices is a controversial measure. Critics contend it may encourage continuation of an illegal activity rather than stopping it. Those who advocate it, however, see it as necessary to reduce HIV transmission among users unwilling or unable to stop Injection drug use regardless of the threat of AIDS.

Some European countries have provided for legal access to sterile injection equipment as part of their programs for preventing AIDS among IDU's. IDU's may either purchase sterile needles and syringes at pharmacies or may participate in "needle exchange" programs. In the needle exchange programs, the IDU's return their used injection equipment and it is replaced with new, sterile equipment. These needle exchanges provide for potential therapeutic contact between health officials and the drug users as well as for the safe disposal of potentially contaminated equipment.

A needle exchange program in Holland has been in operation for several years, and has increased its distribution of sterile needles and syringes from 25,000 per year to over 600,000 per year. Despite this great expansion there appears to be no increase in the number of IDU's and no decline in the number of drug users entering treatment. Early reports from Holland show that drug users are both utilizing the needle exchange system and reducing their frequency of injecting drugs as a result of concerns about AIDS. Thus, while the data are still

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preliminary, it appears that the AIDS prevention strategies of providing treatment for IDU's and providing for "safer" injection procedures may be complementary rather than contradictory. The concept of Needle Exchange Program originated as a disease intervention strategy in the Netherlands in the early 1980s to reduce the spread of Hepatitis B among users. Similarly, in Canada, Australia and England, where a needle exchange program is implemented, only 4% of IDU'S are seropositive.

Only 12 states in the country require prescriptions for the sale of needles and syringes, but these include almost all of the states with large numbers of IDU's. In many of the other states, drug paraphernalia laws make it difficult for needle users to obtain sterile equipment.

Some of the outreach programs discussed in previous section provide information to IDU's on how to sterilize drug injection equipment. In addition to this information, some of these programs are now providing small bottles of bleach or alcohol to be used for sterilizing equipment. During the late 1980s, several needle exchange programs were begun in the United States. Presently, there are publicly-funded Needles Exchange Programs in Tacoma, Spokane, Seattle, Portland, Boulder, Santa Cruz, Oakland, Philadelphia, and some smaller towns in Western Massachusetts, and activists in a half dozen other U.S. cities are planning to establish Needles Exchange Programs. More recently, Needle Exchange Programs were established in Honolulu, and New Haven. A bleach distribution program has been in operation in San Francisco and has led many IDU's to start using bleach to sterilize their equipment. The weekly needle trade-in

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has grown into what is believed to be the largest needle exchange in the nation in 1991, distributing more than 16,000 clean needles in exchange for dirty ones. These programs exist despite state laws criminalizing the possession of drug paraphernalia.

Outreach workers in these programs report that encouraging "safer" injection actually leads many IDU's to seek treatment in order to reduce their drug use. Many of the drug users realize that they are unlikely to be able to follow safer injection procedures if their drug use (and lives in general) are out of control.

THE COMMUNALIZATION OF DRUG ISSUES

THE NEEDLE EXCHANGE PROGRAM OF ACT UP/NY: ACT UP/NY'S LONGEST CIVIL DISOBEDIENCE ACTION

The decimation of and discrimination against the drug using community caused the creation of the Needle Exchange Program of ACT UP in February, 1990.

The Needle Exchange Program of ACT UP/NY did not come out of the blue. Jon Parker, from the National AIDS Brigade, was already doing needle exchange in Boston and sporadically in the lower East Side.

Twenty volunteers are regularly involved in the Needle Exchange Program of ACT UP/NY, with a budget of about $17,000 every six month. About a third of them identify themselves as ex- or recovering drug injectors and bring their experience to the street. Some live in the neighborhoods or have bought drugs on the street

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where the sites are located. There are Spanish speakers; men and women of color; HIV+ individuals; and gay men and lesbians.

Illegal in New York, needles have to be ordered from another state. Considered a felony by Federal regulation, activists risk three years in federal prison for illegally distributing needles. They operate in the West Bronx, East Harlem, Lower East Side and Brooklyn. They had helped start one site in South Bronx, but a local activist took it over.

Although each borough is a fixed site, activists have "roving" teams to outreach to the shantytown. Also, while the sites work together in a coalition that is the ACT UP Needle Exchange Program, each outreach team operates its needle exchange site autonomously from the others, because, to be effective, outreach sites must adapt themselves to the unique street scenes in which they are located. Reportedly, activists would never go where they would not have any contact.

In the Exchange site, they set up a table and provide individuals with bleach kits, alcohol and extra condoms. Bleach, in particular, has proven a vericide against HIV, and so has been incorporated into U.S. AIDS prevention programs as an easy way for drug users to clean their needles. The kit contains Spanish and English instructions and diagrams on how to clean needles and use condoms. It is noteworthy that the majority of those who request the services of the the Needle Exchanger Program are poor, some of them may be economically independent and already be in treatment programs.

Sometimes the police harasses the activists. In May of 1990, for example, the police confiscated the works the activists were

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distributing. However, after negotiation with the precinct, it was agreed that they would move, and keep a low profile. In addition, Tompkins Square Park, a central meeting place for drug users, was closed.

More vocal than the police's opposition was the opposition of certain Black leaders who called the needle exchange "genocidal." The Black Leadership on AIDS declared that:

> It is gravely concerned that the distribution of bleach or drug paraphernalia represents a Trojan Horse for the African American community in that it is superficially attractive but contains an element of grave risk. The risk is that such methods fail to address the long term problems of continued drug use and the current inadequacies of drug treatment and rehabilitation programs within the African American community.[1,2]

Yet one of the top authorities on drug research issues, Don Desjarlais, Director of Research, from the Chemical Dependency Institute at Beth Israel Center retorted:

> As a researcher in the AIDS and intravenous drug use field, I have been monitoring the results of the syringe exchange programs being conducted in

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[1]Black Leadership On AIDS' Official Corporate Policy Statement, June 1990.
[2]Not all Black officials were against the needle exchange, such as state senators Patterson from the Bronx and Montgomery, Bedfort stuyvesant.

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> Europe, Australia and in a limited number of cities in the United States. While these studies will be continued for many years, it is possible to draw some conclusions from the current findings: 1- There is yet no data to support the belief that syringe exchange programs lead to increases in drug infection 2- syringe exchange programs should be conducted in conjunction with treatment programs to reduce abuse. Syringe exchanges can serve as excellent recruitment sites for drug treatment programs. 3- Participation in syringe exchanges is associated with large reductions in HIV transmission behavior.

As the research argument did not go along with the City's disapproval, officials decided to use their coercive power to deter exchange programs from flourishing in New York City.

In May 22, 1990, Woodrow Myers decided to cut funding to the Association for Drug Abuse Prevention and Treatment, which pioneered safe drug use education in the streets of New York. ADAPT would continue to receive funds for safe sex programs, but city money could no longer be used to teach addicts how to clean their needles.

What really angered AIDS activists was Myers' statement on CBS radio that "fighting drug use was a higher goal than preventing AIDS." In response, ACT UP/NY zapped the Department of Health.

David Rogers and Don Des Jarlais of the National AIDS Commission met with Myers to try to change his mind. Likewise,

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Mathilde Krim of the American Foundation of AIDS Research laid out the results from several studies in the U.S. and abroad demonstrating that teaching users how to clean needles reduces high risk behavior and correlates to reductions in HIV infection rates.

Myers discounted the studies that showed the effectiveness of needle exchange, but Krim responded "I had the impression that he hadn't actually read the studies."[1]

This time, The Minority Task Force on AIDS joined ACT UP in the streets in front of the DOH.

More than ever, the activists realized that they would not obtain the support of the City. In that, the plight of drug users resembled that of the gay community very closely.

> The gay community didn't wait until researchers could demonstrate the actual leveling off of HIV transmission through safe sex practices. They knew they couldn't afford to wait. Drug addicts, their sexual partners and their children can't wait either.[2]

At one point, the Department of Health would not even accept dirty needles returned by ACT UP. A demonstration was held to force the DOH to take charge of those lethal needles. The DOH finally gave in to the activists' demands. Each month the DOH accepts and disposes

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[1]Mala Szalavitz in Voice*DOH Waffles on Needle Hygiene*, May 22, 1990.
[2]An AIDS Activist, 1990.

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of the 20,000 needles returned monthly by the activists without even the threat of arresting them.

When the DOH said it would no longer supply community based organization, including ACT UP's Needle Exchange Program, with condoms, ACT UP organized three sit-ins and demonstrations. Activists met three times with DOH officials before they agreed to provide condoms.

DOH officials now have capitulated to the activists' demands, and in doing so have recognized the Needle Exchange Program of ACT UP/NY.

DEAD ADDICTS CANNOT BE TREATED

Unquestionably, ACT UP does not want to encourage drug use, but addicts dead, activists argue, cannot be treated. Activists understand that Needle Exchange is not a solution for either drug addiction or AIDS. It is just an emergency strategy to keep people alive, while they wait for treatment. In fact, an abstract sent to the San Francisco Conference showed that HIV positivity among diabetic addicts was minimal because they had to use clean needles. The Study was done by a John Hopkins University epidemiologist, Konrad E. Nelson, who concluded that is research "lends support to calls for needle exchange programs and the repeal of drug paraphernalia laws."

The Needle Exchange Program of ACT UP refers people to health, housing and legal services. Activists provide users with AIDS information and answer their questions. Provided needles are marked with a specific color indicating the site of the Exchange, and a tally of

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the returned needles is kept. Stunningly, the return rate is about 60%. If the users return untagged needles, they only receive one needle for two untagged needles. This decision was made to discourage the users from selling the tagged needles.

The ACT UP/NY Needles Exchange Program has created an outreach model and service that no other organization in New York has been able to offer. Activists have shown that needle exchange can work in New York City. Over the past year and half, numerous individuals from social service organizations have come to observe and participate in the exchange. About a quarter of the people involved in the ACT UP New York Exchange Program are from other organizations or are individuals who were not previously associated with ACT UP.

The Needle Exchange Program currently services about 1,000 injectors per week. Activists realize that their program is a drop in the bucket compared to the need that exists, but their program is important, besides providing the services it does, for several reasons. Operating a needle exchange program has given the activists an incredible amount of knowledge that they otherwise would not have had about how people are using drugs in 1991, what people are using, with whom they are using, the social networks injectors are part of and how these networks can facilitate safer drug use, specific inadequacies of the drug treatment system, and some of the issues facing injectors who are HIV or who have AIDS. All of this information is vital if governments are to understand how intervention programs for injectors should be designed and if activists and users are to have a voice in designing them.

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The success of the program is due to the fact that some of the activists involved are themselves former addicts. They have an intimate sense of what it is to be "hooked" to a drug. They know the culture, the language, the habits, the dangers and the pleasures of drug addicts. And most of all, as one activist says:

> In time of blizzard, rain and storm we are there. We have been there for 23 months. They know we do something illegal for them. That, the addicts do not forget.[1]

Furthermore, activists recognize the intelligence and the rationality of the addicts as opposed to deviance or psychologizing theories which conceptualize the user as irrational and self-destructive. The contention that users are rational and care for their lives is a particularly important one, because it goes against the allegation by researchers that users are an unreliable subject population. In contrast, programs like needle exchange give the drug users a measure of control, however small, over his or her health and well-being.

> They are politicized and have an analysis of society, sometimes more radical than many ACT UP members.[2]

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[1]Personal Interview, 1991.
[2]Personal Interview, 1991.

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In fact, users play an active role in the Program. Most of the newcomers to the needle exchange program are brought by people who already use it. They alert the activists when not enough Spanish speakers on the team;. they pass out cards that advertise the Exchange. They explain to their how to use a bleach kit. They also encourage others to join and help the team. Many ACT UP members have retorted that giving out clean needles goes beyond the political purview of ACT UP. Activists retort that as long as needle possession is illegal, they will advocate, and risk arrest when distributing clean needles. In fact, they never distribute needles without carrying their ID with them. Ideologically and practically, the Needle Exchange Program is enforced in a context of a well thought out civil disobedience action.

Activists demand the legalization of needle possession, treatment on demand with community-controlled drug treatment and a central referral service.

ACTIVISTS, WHO DELIBERATELY ARRESTED, TURNED THEIR TRIAL INTO THE TRIAL OF THEIR OWN CITY FOR LACK OF AIDS POLICY WITH REGARD TO INJECTION DRUG ISSUES

Four public and deliberate arrests were at the origin of the now quasi-legalized Needle Exchange Program. First, National AIDS Brigade activists were arrested in Boston in August 1988 and were acquitted. One of them, John Parker from the National AIDS Brigade, had been already arrested 12 times.

Second, eight activists, from both ACT UP and the National AIDS Brigade were arrested while distributing clean needles between

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Essex and Delancey streets in New York City, on June 25, 1991. Activists announced publicly, in a March 2, 1991 Newsday article, that they would be distributing clean needles. A demonstration was organized by other ACT UP members, but a counter-demonstration was also organized by the Guardian Angels, calling the AIDS activists "murderers."

Supported by the testimonies of experts such as Dr. Don Desjarlais, Research Director on Chemical Dependency at Beth Israel Hospital and Dr. Ernest Drucher, Director of Community Health at Montefiore Health Center and Professor of Epidemiology at Albert Einstein Medical School, activists were acquitted.

Even Stephen Joseph, former City Health officials despised by the AIDS community testified in favor of the activists:

> Clearly the availability of clean infection equipment is a way of stopping the transmission of the virus from person to person. That availability of clean infection equipment is also a way to bring people, whether they are infected or not, into a stream of health care and public health preventative efforts that are equally important in this epidemic.[1]

Joseph went on to say that while he was the Health Commissioner of New York City, he instituted a small scale pilot needle exchange program in November 1988. He had hoped to locate the program at

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[1]Stephen Joseph, Criminal Court of the City of New York, July 5, 1991.

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four neighborhood sites. Vehement community opposition prevented this plan and ultimately the Department of Health ran the program out of its main office at 125 Worth Street in Manhattan. Only 300 people entered the program. Each participant had to have sought but been denied drug treatment elsewhere. Moreover, each participant had to be willing and responsible enough to travel to 125 Worth Street on a regular basis. The program counselors provided each addict education on risk reduction behavior and access to health care. Condoms and hypodermic instrument cleaning instructions were provided. In addition, each addict was given clean, tagged hypodermic needles.

Although very constrained, Dr. Joseph believed the program demonstrated that a needle exchange program could be effective and avoid most dangers of concern to the publicly. Interviews with the addicts suggested they did not continue sharing their needles. The program did not create or promote drug use. In addition, 78% of the participants ultimately entered drug treatment programs with 60% still in treatment after one month. But the program ended effectively January 1, 1990 with change of administration in City Hall.

Third, four activists from ACT UP/New Jersey and New York were arrested in Jersey City in April 19, 1990 and were defended by the ACLU/New Jersey for distributing syringes in front of the Spectrum Health Care Methadone Maintenance Program. They had chosen this site to demonstrate their disapproval of methadone as a way to cure drug addiction. Some activists argued that "on methadone, addicts remain addicts, but they are controlled by the system."

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The defense, based on ACT UP fact sheets, was so eloquent that not only were the four activists acquitted, but one of the jurors himself became a Needle Exchange activist.

Fourth, ACT UP activists were arrested in June 1990 in Delaware with 3 felony charges because they gave needles to undercover officers. But the charges were dismissed for fear of embarrassment. Delaware is one of the States which has no AIDS policy and which never allowed condom distribution.

In each of the three trials, the judge's verdict agreed with the activists' use of the "necessity" justification defense to explain their breaking the law in order to "save lives."

Penal Law Section 35.05(2) reads as follows:

> ... conduct which would otherwise constitute an offense is justifiable and not criminal when:
>
> (2) Such conduct is necessary as an emergency measure to avoid an imminent public or private injury which is about to occur by reason of a situation occasioned or developed through no fault of the actor, and which is of such gravity that, according to ordinary standards of intelligence and morality, the desirability and urgency of avoiding such injury clearly outweigh the desirability of avoiding the injury sought to be prevented by the statute defining the offense in issue. The necessity and justifiability of such conduct may not rest upon considerations pertaining only to the morality and

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> advisability of the statute, either in its general application or with respect to its application to a particular class of cases arising thereunder.

Evolved at common law, the necessity defense recognizes that extraordinary circumstances may justify violation of the law.

> The law ought to promote the achievement of higher values at the expense of lesser values and sometimes the greater good for society will be accomplished by the criminal law.... The matter is often expressed in terms of choice of evils. When the pressure of circumstances presents one with a choice of evils, the law prefers evil by bringing about the lesser evil. LaFave and Scott, Substantive Criminal Law (1986) § 5.4, p. 629.

In the case of the New York City trial, the judge ruled that

> Turning to the facts in this case, this court finds it was reasonable for the defendants to believe their action necessary as an emergency measure to avert an imminent public injury. Without doubt, AIDS has created an imminent crisis in New York City. There is no dispute that use of clean needles by addicts prevents the spread of HIV infection. The defendants presented significant expert medical and

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> public health witnesses who testified that needle exchange programs have proven successful as a means of providing addicts with clean needles which addicts will use.

Interestingly, the judge did use the term "crisis." She also noted that unlawfulness of needle possession had been the result of the "War on Drugs," which had very limited success. And she added that eleven states have statutes similar to New York's law, and despite these statutes, these states have among the highest rates of addiction.

Her ruling could have been inspired by an ACT UP teaching. Her judgement, however, did not have force of law.

ALTHOUGH UNAPOLOGETIC, OPPONENTS OF THE NEEDLE EXCHANGE PROGRAM PROGRESSIVELY CHANGE THEIR MIND

The National Commission on AIDS, in its "Report: the Twin Epidemics of Substance Use and HIV, July 12, 1991, also recommended the removal of legal barriers to the purchase and possession of injection equipment. The Report states, "Such legal barriers do not reduce illicit drug injection. They do, however, limit the availability of new/clean injection equipment and therefore encourage the sharing of injection equipment, and the increase in HIV transmission."

Similarly, the Black Leadership on AIDS is preparing a statement about Needle Exchange Program. Activist expect a more open position to the program than has been expressed thus by the Black Leadership on AIDS.

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Thirdly, in January, 1991, State Senator Velmanette Montgomery (D-Brooklyn) introduced legislation to decriminalize needle possession, use, and sale. The legislation was introduced into the House of assembly by Deborah Glick (D-Manhattan). The bill was not voted out of committee during the legislative session in which it was introduced, but gained strong support

But the success of the Needle Exchange Program reached its apex when David Dinkins, Mayor of New York, changed its position vis a vis the Program in November 1991. Although his attitude was still very resistant, he declared that he would now allow the activists to pursue their illegal activities and he would issue a legal waiver for them. Still, he announced that he would not finance this type of program. As a consequence of this decision, the American Foundation for AIDS Research (AmFAR) made grant money available to implement similar programs.

In the Spring of 1991, the Lower East Side AIDS Strategy Group--a consortium of medical and social service providers serving people with HIV/AIDS in the area (LESASG) joined forces with the Needle Exchange Lower East Side Committee of ACT UP. In fact ACT UP became a member of LESASG. The Lower East Side and Tompkins Park/East Village sites submitted a grant proposal to AmFAR as part of the LESASG. The Lower East Side and Tompkins Square Park/East Village sites, if funded by AmFAR, will use the one-year grant to maintain these sites and to train providers from the lower East Side AIDS Strategy Group to eventually take over the program.

The West Bronx and East Harlem sites submitted a grant proposal to AmFAR in conjunction with the Minority Task Force on

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AIDS (MTFA). If funded, the ACT UP West Bronx and East Harlem sites will in essence become part of the Task Force. The Bronx and Harlem street based needle exchange sites as they now exist will be maintained, and the ACT UP Bronx Harlem outreach team will help MTFA develop an in-house needle exchange model. Clients who use the street based component will be able to readily access the many services MTFA provides.

Finally, the Brooklyn sites (Williamsburg and Bushwick) are working with community-based organizations to have them start a needle exchange.

If those different community-based groups are funded, then ACT UP will remove itself from the needle exchange program, its mission being accomplished. The communalization process of drug issues, although not expressly articulated, is at the center of the activists' approach:

> The ACT UP/NY Needle Exchange program has been essential in putting treatment issues for injecting drug users on the New York agenda. We have made the phrase "needle exchange" a household word among local AIDS service providers and policy makers. We have proved, in newspaper articles after newspaper articles, one of the founding "principles" of ACT UP: that WE are the experts.[1]

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[1]The ACT UP Needle Exchange Program, Fact Sheet, Unpublished Document, 1990.

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ADOLESCENTS ARE NOT AT RISK, SO THEY SAY

Although the AIDS rate among adolescents in 1987 was less than 3% of the total number of AIDS cases, the number of teens with AIDS was doubling every 14 months. In addition, 20% of U.S. AIDS cases were found among the 20-29 years olds. With an average incubation period approaching eleven years (time from infection with HIV to diagnosis with full blown AIDS), virtually all of this age group were infected as teenagers.

HIV infection among teenagers indicated a trend toward the heterosexualization of the epidemic. Among New York City adolescents aged 13 to 21 years, the ratio male/female who was HIV-positive was 3 males for 1 female.

One of the major reasons for the skyrocketing spread of the epidemic among adolescents was the lack of governmental attention to this particular population. And one city particularly affected was New York. Only 3% of the nation's teens lived in New York City, yet more than 20% of adolescent cases (occurring in young people between the ages of thirteen and twenty one) in the United States had been reported in New York City, making it the city with most adolescent AIDS cases.

KIDS DON'T HAVE SEX, SO THEY SAY

A false assumption often upheld was that adolescents did not (or should not) have sex. Statistics, however, proved this assumption wrong: 57% of teens nationwide had engaged in sexual intercourse by age 17. The figure was in fact considerably higher for urban teens,

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whose first intercourse occurred 11-12 years of age on average in some neighborhoods. In New York City, 50% of females ages 15 to 19 and 60% of males ages 15 to 19 had engaged in sexual intercourse.[1]

Teenaged women were particularly hit by the epidemic. AIDS was the number one killer of women 25-34 in New York City. Again, the majority of these women--most of whom were Black and Hispanic--had been infected as teenagers. Like their teenaged male counterparts, female teenagers engaged in sex fairly early. One in six female high school students had had at least 4 different sexual partners. And one out of every 10 women ages 15 to 19 years would become pregnant each year in the United States. This rate amounted to over one million teenaged pregnancies annually.[2] Lack of knowledge and use of contraceptive explained this high pregnancy rate. Equally terrifying was the fact that although more than 80% of the city's teens were sexually active by age nineteen, only one-third used any form of protection. This meant that each year roughly thirty thousand teenagers in New York City would become pregnant. Likewise, sexually active teens had the highest rate of venereal diseases of any group--mainly due to their ignorance of sexually transmitted diseases (STD) and lack of skills in using preventive measures. 1 in 7 teens would (and still) contract an STD each year.

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[1]Sonnenstein, FL et al. Sexual Activity, *Condom use and AIDS Awareness Among Adolescent Males.* Family Planning Perspectives, 21 (152), July/August, 1989.
[2]Henshaw, SK & Van Vort, J. *Teenage Abortion, Birth and Pregnancy Statistics: An Update.* Family Planning Perspectives, 21 (85), March/April, 1989.

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ADOLESCENTS, SEX, DRUG AND VIOLENCE

Most psychologists agree that adolescence is one of the most complex periods of life. Period of confusion and deep questioning, adolescence is also a period of experimentation. Sex marks the beginning of adolescence, and holds a special place for most youth, although a silenced one. Indeed all this experimenting has to operate in hiding. No questions around issues of sex can be asked from parents, who would generally be hard pressed to answer anyhow. Friends turn sex into a hilarious topic, to further avoid it. Silence is the context in which sexual experimentation takes place for most adolescents. And silence around sex is reinforced by the tenets of the Church.

At the same time, adolescents are bombarded with sexual images. Television, radio, outside advertisements are all filled with sexually explicit or implicit messages. Adolescents are then confronted with contradictory societal attitudes toward sex. Some social forces turn the youth away from sex, whereas others draw them to it. The problem is that neither force leaves the youth with enough educative information to empower them in order to make decisions for themselves. Sex guilt or consumerist sexual indulgence are the only two options offered to teens.

Yet, already in the late 80's money for AIDS education was made available by the Centers for Disease Control (CDC), exactly $815,000 for 980,000 students. The problem is that nobody seemed to agree on the particulars of the instruction. How explicit should sex education be, how early should students be taught, to what extent safer sex should be

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stressed, and whether or not condoms should be made available to students in high-schools.

In September 1987, the New York State's Board of Regents mandated that all public school students receive AIDS eduction. Children in the lower grades (K-6) were to be taught that AIDS is a blood-borne disease that affects some people, and that since it is hard to catch they should not be frightened. In the upper grades (7-12), students would be taught how the virus is transmitted (unsafe sex, IV drug use), and the various preventive methods, such as abstinence and condom use.

Although the intention was well meant, the New York City's Board of Education HIV/AIDS curriculum was only echoing the general silence around sex. The position was "Just Say No," avoiding any real discussion around sex. The assumption shared by many families and the Church was that this type of exposure would entice students to engage in behaviors, from which they otherwise would "naturally" keep away.

In contrast, the activists' position was based on the experience of adolescents and not a morality dictated by other institutional forces.
As they put it:

> If we want to raise our children as adults, we have to teach them to be responsible for their own decision and not act as if there is no problem.

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> Parents need training to talk to their children about sex and AIDS.[3]

Yet outside its Board of Education, New York City had been a site for piloting innovative risk reduction and education efforts geared specifically to adolescents. A few examples included the Star Teen Theater group at Mount Sinai hospital, the ARREST (AIDS Risk Reduction/Education Skills Training) Program at Montefiore's Adolescent AIDS Program, the street outreach programs of the New York City Department of Health, the Victim Services Agency ("Street work Project" in Manhattan, Planned Parenthood's Project" in the Bronx, the Hetrick-Martin Institute projects, and the special care unit for HIV-positive adolescents at Covenant House.

Many of those projects would use theater as a way to bring home issues that statistics and abstract concepts could not achieve. Adolescents themselves, the actors would ease the process of the information to their equally young audience.

With or without the consent of the parents, activists knew that the youth would get their information from the TV, movies, or their peers. Yet, most of the messages were riddled with biases and misinformation.

And, the lack of sexual information often translated (and still do) into violence for many adolescents. Youth were the most frequent victims of violent crimes including sexual assault and sexual abuse.

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[3]The Youth Education Life Line, Unpublished Document of ACT UP, 1990.

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Half of all rapes were perpetrated against teenagers. Gay and lesbian teenagers in particular were one of the main targets of street violence.

RUNAWAYS AND THROWAWAYS ARE MOST AT RISK FOR HIV INFECTION

Runaway and homeless youth using the services of Covenant House were shown to be infected with HIV at the rate of 10%. The figure was much higher among street youth, at least 40% of whom were homosexually oriented. The Hetrick-Martin Institute was taking care of those gay and lesbian youth, most of whom were not runaways, but throwaways.

Lesbian and gay youth were particularly susceptible to HIV infection, because safe sex was not taught in high school specifically for them.

A large percentage of them became (and still do) seropositive by way of prostitution, their main means of survival. A large percentage of them also used crack. In 1987, the crack epidemic among teens was directly related to the spread of HIV since the use of this drug would distort judgment and lead to risky behavior such as engaging in unprotected sexual intercourse as a payment for crack itself.

Adolescents seeking treatment realized quickly that rehabilitation facilities are almost nonexistent for them. Methadone maintenance programs are not usually open to adolescents younger than 18 years of age in this country, although a few accept people 16 years of age.

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Faced with societal hypocrisy, different and contradictory messages about sex, and epidemic of drug and violence, many youth found themselves with shattered self-esteem, putting themselves further at risk for HIV infection. Indeed, public health research demonstrated that people with low self-esteem resist being told to change their behavior.

Skyrocketing AIDS statistics among adolescents led to growing pressure for mandatory testing from conservative groups. This pressure was sporadically successful. Adolescents were (and still are) mandatorily tested for certain jobs such as Job Corps or Peace Corps. Upon the announcement of their seropositivity, the youth were (and still are) left on their own with no post-counselling session, and no treatment available. Clinical trials for adolescents with HIV/AIDS were (and still are) very scarce, a consequence of which is our current scant knowledge about the progression of the disease among teenagers. To make matters worse, if the youth did not wish to reveal their status to their parents, they could not use their coverage and could not have access to minimal treatment.

Providing adolescents with information about safe sex and safe injection drug use, AIDS activists argue, was as much a source of information about AIDS as it was a source of empowerment for expressing the adolescents' sexuality and assertiveness.

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THE BUSH ADMINISTRATION'S RESPONSE TO AIDS AND THE YOUTH

Although, it tended to view youth with HIV/AIDS as *innocent victims,* the position of the Bush administration fell short of real compassion. Exemplifying this contradiction was the recent removal of a chapter on contraception from a best selling book guide on child rearing--*Taking Care of Your Child*-- before distributing the book to 275,000 Federal workers. It was authored by Donald Vickery and James F. Fires who already sold one million copies.

The six-page discussion of contraception and adolescent sexuality was deleted from the Special Federal Employees Edition by Constance Bernewman, director of the Office of Personnel Management, the Federal Government's central personnel agency. His reason:

> I thought as a Federal bureaucrat and someone in charge of making this decision, am I going to cause some people to be offended? he said. Yes. Sending this out to hundreds of thousands of people, it probably would. It was a judgment I was making. You know, there are issues that alarm people very quickly.
>
> I felt silence would be best. I felt silence would have the best chance of avoiding controversy.[4]

[4]New York Times, April, 1992.

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He further added that Catholics would be offended. One of the passages, considered too offensive to be included in the Government sanctioned edition reads:

> While a variety of techniques prevent pregnancy, the seriousness of sexual disease serves as a reminder that other than abstinence only condoms used in combination with specific information can prevent infection. Your adolescent should discuss with his or her doctor the full range of contraceptive/disease prevention options[5]

The deleted section emphasizes dialogue between with their children about sexuality:

> Discussions about sexuality between children and their parents is unusual in our society. However we are at a crossroads in our history when frankness between parents and children about sexual behavior can mean the difference between continued maturation into adulthood or a life prematurely encumbered with a child or prematurely terminated with AIDS.
> Adolescents need someone to talk to about these issues. You can be sure they are talking with their

[5]Ibid.

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> friends and some are talking with health care providers. It would be better if they could talk comfortably with their parents about the issue of sexuality as well. Just saying no is not a conversation.
>
> Until very recently our reluctance to openly discuss sexual behavior in school rooms and living rooms has resulted in teen agers who are far less informed and reliable than Canadian and many European teenagers in their use of contraception and practices of safe sex. American teen agers have higher rates of pregnancy and sexually transmitted diseases.[6]

The deleted section also lists various contraceptives and describes the effectiveness of each.

This deletion adds to a series of acts of censorship by the White House. Among the targets of this censorship policy was the study of teen age behavior and attitudes because it included questions about contraception and sexual behavior. A similar survey of adult sexual attitudes and behavior was also censored.

A brochure on condoms and how to use them was held up for three years and later distributed. Recently, the Administration's AIDS education literature has been widely criticized for censorship of television and radio advertisements in which Hollywood stars mention condoms.

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[6]Ibid.

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The House Select Committee on Children, Youth and Families, concluded in a report recently issued that the number of teenagers with AIDS increased by more than 70% in the past two years and that AIDS is the sixth leading cause of death among people 15 to 24.

COMMUNALIZATION THROUGH CONDOMS

Panicked by the 40% increase in HIV infection among teens between 1987 and 1989, several gay teachers, members of ACT UP, decided to gather information about the spread of the disease among adolescents in New York.

As teachers, they unquestionably knew that many students were sexually active. They first formed a caucus called Youth Brigade, but quickly became a committee in October of 1989 with the flamboyant name of Youth Education Life Line (Y.E.L.L.).

Y.E.L.L's goal was to deal with the growing problem of AIDS and HIV among New York City adolescents by ensuring their right to complete AIDS education and providing them with information on HIV prevention, safer sex, and safer drug injection.

They also created flyers with large pictures and fewer words to distribute with condoms. They pressured for more high-schools to receive this information, and outreach to other youth communities, such as homeless youth, runaways, and prostitutes.

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ACT UP'S SECOND LONGEST CIVIL DISOBEDIENCE: CONDOM DISTRIBUTION

Even before Y.E.L.L. initiated the controversial notion of condom distribution, a class of Cambridge High School, Mass., students were trained in 1989 as peer educators to distribute condoms to fellow students. After a series of well publicized hearings (in themselves an education for the community), the Cambridge School Committee ruled that condoms could be distributed through the Teen Clinics at the school. Subsequently, the Cambridge City Council enacted an ordinance requiring most public establishments to provide condoms in vending machines along with AIDS education brochures. The Massachusetts Department of Public Health has now taken a leading role with public advertisements and condom distribution.

If Y.E.L.L.'s initiative was not a first in the country--the oldest condom availability program was started in Commerce City, Colorado.[7]--it was certainly a first in New York City. The group started to distribute condoms, as an emergency measure to save youth's lives. Handing out condoms was (and still is) the opportunity for the activists to provide information about safer sex and safer drug injection, as well as respond to long unanswered questions. Condom distribution usually would take place in the morning so that students could bring the information directly to their school and disseminate it to their peers. Schools' administrations were thus forced to confront the issue.

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[7] Flax, E. *Condom Policies Move Up School Board's Agendas.* Education Week, December 11, 1991.

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The first result was that, within six months, they had reached over 25,000 students, handing out a safe sex, safer drug injection pamphlet, in which was inserted a condom.

The second result of condom distribution was direct contact with the students, as professionals and as activists. This direct contact gave Y.E.L.L. members an edge that people who set public school policy often lack.

The third result was media attention on adolescence and HIV/AIDS, which otherwise would have hardly reached people's consciousness.

While some administrators have been adverse to Y.E.L.L.'s direct action strategy, others have welcomed it. It allowed them to introduce a topic they did not know how to approach. As in the case of needle exchange, the attitude of the police has been unusually and cooperatively lax.

Despite the effort of Y.E.L.L., no national study of HIV prevalence among the nation's youth has been conducted. Several sporadic studies however indicated that HIV was and is still spreading among teens. A national study of Job Corps applicants, ages 16 to 21 during 1987-1991, indicated that 3.6 per 1,000 were HIV-positive upon testing, a rate 210 times that of military applicants of the same ages. One in 40 Black and Hispanic 21-years old applicants were HIV positive. Another study of 19 college campuses found that one in 500 college students was found to be infected with HIV.[8]

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[8]Gayle, HD, et al. *Prevalence of the HIV Among University Students,* New England Journal of Medicine, 323 (22), November 29, 1990.

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In addition, recent high school surveys demonstrated that more than 80% of students had full knowledge of the means of AIDS transmission, but only one-quarter to one third were actually practicing safer sex, because many did not perceive themselves at risk or did not have a sense of their own mortality.[9]

Some ACT UP members criticized condom distribution as service oriented and not pertaining to ACT UP's political work. This argument was reminiscent of the criticisms leveled against the concept of needle exchange. But like the Needle Exchange Program of ACT UP, as long as the action is illegal and involves saving lives, condom distribution operates in the context of a well thought out civil disobedience. When condom distribution becomes legal, then Y.E.L.L. will have to concentrate its political work in other areas.

Y.E.L.L., A CENTRAL FORCE IN THE CHANCELLOR'S PLAN

ACT UP's representation in the AIDS Advisory Council did not happen by way of an invitation. Y.E.L.L. had to zap the office of the newly appointed Hispanic and Catholic Chancellor Fernandez, who finally agreed to appoint Y.E.L.L. members in the Council. Along with the Hetrick-Martin Institute, which caters to gay and lesbian runaways and throwaways, Y.E.L.L. was a major force in shaping the Chancellor's plan mandating sex and HIV/AIDS education from kindergarten through high-school. The expanded curriculum included a proposal for better AIDS education and for making condoms available in the

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[9]Paul Epstein, *Condoms in Schools: The Right Lesson*, The New York Times, Saturday, January 19, 1991.

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schools. The proposal, introduced in October, 1991 by School Chancellor Joseph A. Fernandez was one part of an in depth revision of the board of Education AIDS/HIV curriculum that was being upgraded to include discussion of bad viruses as early as kindergarten along with lessons in the upper grades on proper condom use for safe sex to help prevent transmission of HIV.

Provision of Condom Distribution Plan:

> For grades 7-12, there will be emphasis on abstinence as the most effective way to avoid sexual transmission of HIV, the virus that causes AIDS and explicit discussions of infection through intravenous drug abuse. Classes will include instruction on the appropriate use of latex condoms as a barrier against the transmission of HIV.
>
> For grades K-6, lessons on HIV/AIDS will be mandated. Currently, such lessons are mandated only for grades 7-12.
>
> HIV/AIDS education teams that already exist in 120 high schools and include teachers, parents and students will develop specific plans for expanding HIV/AIDS education including how to make condoms available.[10]

[10]Chancellor Joseph A. Fernandez's AIDS/HIV Curriculum Plan, 1991.

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Since the Fall of 1991, Y.E.L.L garnered all its energies to ensure that the plan would be passed by the Board of Education. During the first public hearing, Y.E.L.L and other organizations managed to motivate enough people to speak so that a cross-section of concerned individuals would be represented.

Among others were testimonies from high schools students, parents, and ACT UP members. Three hundred people had signed up to speak.

Giving in to the pressure of conservative groups such as the Catholic Church, the Board of Education postponed the vote, but this time ACT UP planned a major demonstration. About 300 people turned up to demonstrate, producing Y.E.L.L's largest action. "Rally for Your Life" was one of the slogans chanted by the activists, while others were staging a die-in in front of the Board of Education.

The final hearing was scheduled on Wednesday, February 27 to last 10 hours. An 11-year old boy with AIDS, Joe Depaulo, testified with his mother. A statement by Madonna was read by a Y.E.L.L. member, and Dinkins came out in favor of the plan in the last minute. The room was filled with emotions as the following testimony suggests:

> I am a person living with AIDS. Chances are I contracted the virus in the early 80's. Those were the days when we were liberated. Though many hated us, at least we could enjoy uninhibited sex without fear of pregnancy like heterosexuals had to worry about. Little did we know then that by not using condoms that we were infecting each other

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with a deadly virus. We didn't know then what we do know now--condoms save lives! While gay men were contracting AIDS in America, half way around the world AIDS reached epidemic proportion in Africa through heterosexual transmission. There is no reason to believe the same thing could not happen here. Why take the risk?

Condoms save lives even though nobody likes condoms. They make sex a lot less enjoyable and alot less worth the risk of pregnancy and or disease. To the extent you as educators are effective in indoctrinating students as to the necessity of using condoms during sex-to that extent you will be responsible for discouraging sex and saving lives. Giving out condoms signals to our youth how serious we believe the consequences of unprotected sex can be--as if the prospect of having to get an abortion, or becoming a premature parent weren't bad enough--it's gotten worse--now you can die!

My bet is that rather than engaging in direct intercourse with a condom, we will enter a period reminiscent of the 50's when necking and playing with bra straps was usually about as far as it went. Unfortunately for me--I won't be around to see that return to a more romantic era. It's too late for me but not for the kids in school today. When I die of

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> AIDS it will be because of ignorance--we just didn't know. If these kids die of AIDS--you do know and it will be your fault!
> Please don't be responsible for their death. Approve the Chancellor's plan and help bring to an end this terrible crisis.[11]

Inspired by the testimony of the 11-year old with AIDS, Wayne Fisher, a member of Y.E.L.L, and a school teacher in the public schools system, caused a media sensation and drew greatly needed public attention to the issue when he revealed himself to be gay and HIV-positive:

> As I make these statements, it is important that you know the following facts about me:
>
> 1) I am a teacher and grade advisor at Martin Luther King High School.
>
> 2) I am a member of ACT UP
>
> 3) I am HIV-positive.
>
> 4) I am gay.
>
> As an educator, I am appalled by the AIDS curriculum distributed by the New York City Board of Ed. It is at best incomplete; at worst it is deadly. The question is: how can the curriculum meet the needs of the students. Here are some suggestions:

[11]Testimony by Robert Rygor Before the Board of Education in Support of the Chancellor's AIDS Education Plan, January 16, 1990.

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1) Have condoms and dental dams available for distribution in all junior and senior high schools. Notices of where they are available should be posted in places such as cafeterias and gymnasiums so that all students are aware of their availability. In case you are concerned about parental resistance, a 1987 NBC poll found that 91% of adults approved of teaching AIDS-prevention to children in public schools. Almost 80% favored television advertising that promoted the use of condoms. (NBC news poll results, New York, January 16, 1987).

Let's all be realistic: a condom in one' s pocket does not encourage one to have sex. What it does do, however, is help to insure the life of the person who makes the decision to have sex.

2) Include extensive discussion and teaching of safer sex practices in a manner that is sex-positive. Many of the students today still lack basic information about what constitutes safe sex as well as how to be responsible for their bodies. When I teach about AIDS, I talk about safer sex, and do so in a way that is sex-positive. I attempt to meet the needs of all the students in front of me.

Therefore, I include not only a discussion of heterosexuality, but homosexuality as well. I believe that:

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a) We must make all students feel that their desire for sex, whatever the orientation, is natural.
b) We must make them aware that condoms and dental dams are beautiful because they save lives.
c) We must encourage them to make responsible decisions about their lives.
3) AIDS should be included throughout the curricula. AIDS is in fact political, historical, biological, chemical, physical, social cultural and unbearably mathematical. I have taught about AIDS in elementary, junior high school, high school, and adult education programs. I included AIDS in my course, whether I was teaching Science, Math, English, Social Studies, or Spanish. I have not used the curriculum distributed by the Board of Education because I wanted to be just to all of the students in my classes.

As a person who has personally experienced the devastating effects of AIDS in the lives of those close to me, I implore you to act now. I myself, as a person who is HIV-positive, know the fear of AIDS because it exists in each cell of my being. However, along with that fear is great hope that working together we can all conquer this disease. I do not talk to you from a mountain top; I plead with you from my heart: Don't follow the path of the United States' government with their deadly silence about

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AIDS. Walk with me side by side on the road to a better future.

There are at least "one million good reasons" for implementing a more conclusive and fair curriculum on AIDS. They are the one million children in our New York City public schools system. It is out of love and concern for them that I deliver this statement.

Martin Luther King, Jr. asked "Why we can't wait". In the case of AIDS, the answer is clear. If we wait, many of our students will continue to be at risk for being infected with the human immuno virus. If we act now, we can save lives. I thank you for your time and look forward to working with you to end the AIDS crisis. ACT UP--Fight back--Fight AIDS!! 9/6/90. [12]

Later on Wayne Fisher was on the front page of the major newspapers such as New York Times and Newsday and was invited on TV shows, such as Phil Donahue's. He received a great deal of support and encouragement from his students and colleagues, even the Chancellor himself. The students too demanded that he give a workshop on AIDS.

The Board of Education finally approved Chancellor Fernandez's revised AIDS curriculum for New York City public

[12]Courtesy by Wayne Fisher, 1990.

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schools, which includes condom availability, after five months of public comments. The plan was approved 4 to 3 without a parental "opt out" amendment that many feared would make the plan ineffective. The central vote was that of an African-American woman, Dr. Western Matthews'. She gave a lengthy speech, which did not help predict what her vote would be. But eventually she voted in favor of the plan, saying that she "had to think about the children's lives rather than abstract morality."
She nonetheless expressed her intention to introduce an "opt out" clause in the near future.

On July 16, 1991, the Board of Education voted 5 to 2 to consider an "opt-out" provision--also supported by the Catholic Archdiocese in Brooklyn--which would allow parents to deny their adolescents access and required parental consent for students wishing to obtain condoms in the high schools. The opt out provision, according to the activists, contradicts the intent of the condom availability program to reduce the risk of HIV infection. For activists: "The opt out provision is an expensive, logistical nightmare and would set up yet another barrier for adolescents."[13]

Parental Optout would also compromise the confidentiality of all students by requiring them to identify themselves to Resource Room staff before obtaining condoms Faced with such a prospect, many students would be likely to risk HIV infection rather than give their names. The opt-out provision was voted down on September 4, 1991.

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[13]Y.E.L.L. fact sheet, Unpublished Documents, ACT UP, 1992.

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ALTHOUGH THE CONDOM AVAILABILITY PROGRAM PASSED, IT STILL MAKES MANY PEOPLE UNHAPPY

The passage of the Chancellor's AIDS/HIV curriculum was followed by a lawsuit on September 17, 1991. It was filed by a member of the Board of Education and four parents against the Chancellor and the Board for violating parental rights. One of the main charges was that the Chancellor's plan spent too much time in lesson talking about condoms to avoid AIDS and other sexually transmitted diseases than about avoiding sexual activity.

Opponents to the AIDS/HIV curriculum believed that the plan would entice adolescents to engage in sex more frequently. Thus, Bush Administration's Public Health Service Director Dr. James Mason told SPIN that condom distribution

> is perceived as promoting sexual activity among teenagers. And since they are at such high risk for the disease, we do not want to support such programs. Abstinence is the only safe approach for teens to day. They have to remember that every boy or girl they have sex with is like having sex with every other person that boy or girl had sex with. How can we reasonably promote that?

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Yet study after study showed that school-based condom distribution programs had no measurable impact on teenage pregnancy.[14]

Opponents to the AIDS/HIV curriculum were also concerned about condom unreliability. A March 1989 Consumer Report found that only 1 in 165 condoms broke during vaginal intercourse and 1 in 105 during anal intercourse. Other surveys had reported higher breakage rates, which suggested that a thorough review was needed by Federal health authorities, followed by a strict regulatory process.[15]

Currently, latex condom with Nonoxynol-9, which account for 95% of the commercially available condoms, provide, according to activists, a true barrier against HIV. Additionally, condoms provide protection against other sexually transmitted diseases.

Most of all, activists pointed out that this opposition to condom availability would go against the will of the majority. Almost two-thirds of adults support condom availability programs in high-schools and almost half support such programs at the junior high-school level.[16]

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[14]Douglas Ksoy, *Effectiveness of School-Based Clinics,* Transcript of Report to the 16th Annual Meeting of the National Family Planning and Reproductive Health Association, Washington, D.C., March, 1986.
[15]Ibid.
[16]The Roper Organization, Inc. *AIDS: Public Attitudes and Education Needs.* Gay Men's Health Crisis, New York, 1991.

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SEPARATION OF STATE AND CHURCH?

Under the State's mandatory AIDS Education Program, local school boards are required to establish advisory councils to make recommendations on the content and representation of AIDS awareness and prevention courses. State Education Department regulation required local schools to include on the councils, parents school board members, appropriate school personnel, and community representatives, including representation from religious organizations. The presence of a religious representative was passed through a 5-2 vote. The majority found no endorsement of religion in the regulation, which it said was meant to reach out to the broadest possible network of input and viewpoints and encourage community acceptance of AIDS education.

Judge Fritz W. Alexander II, complained that the regulation went too far:

> When the government mandates the participation of religious leaders as a class, the message is clear that what the government is seeking is specifically religious perspective. That message represents a forbidden endorsement of religion and is inimical to the First Amendment's goal of preventing, as far as possible, the intrusion of either into the precinct of the other.[17]

[17]New York Times, April 1991.

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Rejecting a constitutional challenge by the School Boards Association, the Court of Appeals upheld state regulations directing local educators to appoint religious representatives to advisory councils on AIDS education in all public schools.

The Court of Appeals asserted that the role of religion in citizens' lives and it said the primary purpose of the regulation is to advance rational, legitimate, education and sexual goals. Judge Bellacose wrote:

> Including the views of religious groups insures that the AIDS instruction that is eventually adopted will more likely enjoy greater societal consensus and therefore, greater secular effectiveness. By thus neutralizing or reducing possible objections from parents and subsequent opt-outs by schoolchildren, a more universal education program is likely to result.[18]

Dissenting, Judge Titone said the regulation are a direct endorsement of religion.

> The unmistakable message is that the views of religious leaders enjoy a favored status and that relevant secular viewpoints, such as those of

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[18]Ibid.

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> psychologists, social workers and business leaders are of substantially less significance. The endorsement of religion could not be clearer.[19]

John Cardinal O' Connor opened a new front in the battle over distributing condoms in New York City schools by encouraging parents to challenge the new Board of Education policy in the courts and offering free legal services for such fights. The Cardinal's position toward condom availability is quite well known when preaching from his pulpit: "the truth is not in condoms and clean needles. These are lies. Good morality is good medicine." The Catholic Church has consistently lobbied against the condom plan. The Cardinal will use the service of a prestigious law firm.

In his column in Catholic New York, the Archdiocese's newspaper, the Cardinal wrote of the firms' lawyers: they have offered to help any Catholic parent with a youngster in a public school to bring suit if condoms are forced on such a youngster without parental consent. The suit would argue that condom availability violates the civil rights of the parents.

It is important to understand however that the Church, through the mandate of Cardinal O' Connor represent a major influence, by which not all Catholics abide. Chancellor Fernandez, for example, himself a Catholic, is a fervent defender of the condom availability program. As a Catholic Y.E.L.L. member puts it:

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[19]Ibid.

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> Although the Cardinal can be quite influential, the program is now being implemented in 60 schools. It is too late to back up.[20]

THE IMPACT OF COMMUNALIZATION OF AIDS AND ADOLESCENCE AROUND CONDOM AVAILABILITY

High-schools were given technical assistance in developing their condom availability plans. A training committee of outside experts was established to design the training of high-schools in HIV information and condom availability. A K-6 curriculum was written and shared with national readers, and is about to be submitted to the Board for adoption. Private foundations and corporations donated $195,000 to establish a small grant program for high-school students to develop HIV/AIDS education projects. Further, over half a million dollars were privately donated to hire staff to assist with the implementation of condoms availability in the high schools. Finally, half a million condoms were donated by the Carter Wallace and London International, leading condom manufacturers.

Sixteen high-schools began their training in June 1991. On November 26, two of those 16 schools began condom availability. More than 100 of the City's high-schools are in the process of completing or have completed their training. As of January 10, 1992, 15 of the 16 high-schools were making condoms available, reaching more than 35,000 students in communities across the city. And programs for

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[20]Personal Interview, 1992.

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condom availability are beginning in several areas of the United States. Many school systems with school-based clinics make condoms available to students as part of their services. Schools in Los Angeles, Main, Baltimore, Houston and Chicago have made condoms available to students at clinic sites. The Governor's Advisory Council on HIV/AIDS in Washington State has recommended condom availability programs for junior and senior high schools, including access to lubricants and dental dams.

Even after the passage of the Chancellor's plan, Y.E.L.L has to ensure that the new policy is being implemented. As the plan is only implemented in 16 high-schools, activists will continue their direct action of distributing condoms and safe-sex information to others.

In ACT UP, the communalization of youth and AIDS issues has now reached its apex at two levels:

Firstly, It helped break the myth of the homosexual as child molester. As an activist explains:

> Not only are the majority of homosexuals not child molesters, but with group like Y.E.L.L, we' ve proven that we care about the lives of the youth, and I can say that we' ve saved the lives of hundreds of thousands of kids.[21]

Secondly, as of now, only high-school students comprise the committee of Y.E.L.L. As a high-school member of Y.E.L.L puts it:

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[21]Personal Interview, 1992.

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> I believe strongly in peer education. The silence has been so heavy about who we are, about our sexuality. It's about time we take our fate in our hand and help one another. And this team work can be done at the high-school level, but also junior-high school.
>
> In my school, Stuyvesant High-School, the administration allowed me to form an HIV/AIDS club. Peer education is fundamental and really life-saving because few kids will feel secure enough in their sexual identity to go to their counselors to ask for information about sex. Now the administration is amazed to see how much work we have accomplished. May be they know they would not have been able to accomplish as much.[22]

The communalization of AIDS and youth shakes many assumptions about adolescents that adults, some of them professionals, have entertained about adolescents. Adolescents can understand AIDS as it affects themselves, and can take care of themselves if given the structural opportunity to be responsible for themselves.

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[22]Personal Interview, 1992.

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TESTING: THE CONSTRUCTION OF THE "OTHER"

Years before the creation of ACT UP, discrimination through testing was haunting PWAs. Between 1981 and 1984, discrimination was rampant against those who harbored the symptoms of the disease. With the discovery HIV and the HIV-antibody test in 1984, the construction of the "other" was made possible. Contact tracing also became possible.

Although neither cure nor treatment existed at the time, the push for testing was growing, as if being able to point at the "infected" could cleanse society from the disease. As any public health policy would have predicted, the coercive use of testing without counselling or treatment led to discrimination and drove people away from testing sites. For instance, after South Carolina began recording the names of individuals testing HIV-positive in 1986, the number of gay men coming forth for testing fell by 51% at the state' s largest testing site. Without therapeutic follow up, people knew that discrimination would be the price of testing positive.[1]

When the HIV-antibody test became widely available, the Gay Men's Health Crisis (GMHC) had serious qualms about it. People who tested positive were not assured that the result was correct. They were threatened with discrimination, and struck by devastating anxiety. Indeed since its establishment in 1983- a year before the HIV-antibody test was made available- the AIDS discrimination Unit at the New York City Commission on Human Rights had, in 1988, documented

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[1]Elizabeth Ehrlich, *A Weapon that could Backfire in the War on AIDS*, Social Issues, Business Week November 7, 1988.

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well over 1,500 incidents of discrimination.[2]

As expected, conservative groups jump on the opportunity that the test offered to separate those who were infected from those who were not. In 1986, William F. Buckley originated the idea that those who tested positive should be tatooed on their buttocks. The same year, Lyndon LaRouche introduced Proposition 64, which called for the testing and quarantining of the estimated quarter of a million Californians with the virus. The proposition was eventually defeated.

ACT UP's first Gay Pride Action, in June 1987, was a concentration camp float, criticizing mandatory testing and quarantining of seropositive individuals. In July of 1987-four months after the creation of ACT UP-North Carolina Senator Jesse Helms attached an Amendment to an appropriation bill, which required the President to add AIDS to the list of communicable diseases and prevented health agencies from intervening. The hysteria was pervasive: the Amendment passed unanimously.

On August 28, 1987, the Department of Health and Human Services substituted HIV infection for AIDS on the list of contagious diseases that rendered an alien inadmissible for immigration under the U.S. Immigration and Nationality Act. Testing was the arm to be used to implement this new policy.

In the Fall of 1988, the campaign for testing was mounting as illustrated by Representative William E. Danemeyer's sponsorship of proposition 102, which included mandatory testing. It was introduced by Paul Gann, the anti-taxation crusader who contracted AIDS after

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[2]Jim Whelan, *The Human Rights Commission AIDS Discrimination Unit*, New York Native, November 14th, 1988.

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receiving a blood transfusion.

Pushing for generalized testing, a prenuptial testing law in Illinois was voted in January of 1988. It required prospective spouses to take the HIV-antibody test before marriage.

Testing was not advocated by conservative politicians only, but by medical professionals as well. Groups that petitioned for mandatory testing and reporting included the State Societies of Surgeons, Orthopedic Surgeons, Obstetricians and Gynecologists, as well as the Medical Society of the State of New York.[3] In June 30 of 1988, the American Medical Association, breaking with the Hyppocratic tradition of confidentiality, strongly urged physicians to warn the sexual partners of patients found to carry HIV.[4]

In June of 1989, at the 5th International Conference on AIDS, Stephen Joseph, the-then City Health Commissioner, announced that he would promote mandatory testing and contract tracing.

AIDS was officially a reportable disease in all 50 states, HIV seropositivity was only reportable in 15 states including the District of Columbia. Of this latter group only four states required names to be reported. As well, to date only four states allow partner notification. Denver, in the state of Colorado, was one of the cities requiring that names of anyone testing positive on the HIV-antibody test be reported to the state. Health authorities discovered in August of 1989 that many gay men were edgy about their names being on a master list of the HIV-infected. To turn around the regulation, they simply wrote down the

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[3]Tamar Lewin, *Judge Refuses to Declare AIDS a Sexual Disease*, New York Times, 11/16/88.
[4]Isabel Wilkerson, *A.M.A. Asks Doctors to Warn AIDS Carriers' Sex Partners*, New York Times, 7/01/88.

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name of Nancy Reagan when they were tested.. Thus, hundreds of Nancy Reagans were reported to the state to be HIV-positive.

In 1989, the Department of Health (DOH) was pressing pregnant women to be tested. Since, there was no treatment for women, the DOH pressured seropositive pregnant women to be aborted.

Finally, that same year Mayor Dinkins appointed Woodrow Myers as City Health Commissioner, despite the staunch opposition from activists. Myers had been State Health Commissioner in Indiana and had conducted a mandatory testing and partner notification program.

In the Fall of 1990, unable to implement mandatory testing and name reporting, the City decided to minimize the number of anonymous testing sites. They were reduced to 5, while confidential testing sites increased to 40.

In addition, ACT UP was questioning the validity of the test, when false positive and negative could occur so frequently.

COMMUNALIZATION OF TESTING ISSUES: A BILL OF RIGHTS FOR HIV-ANTIBODY TESTING

During its inceptive years, ACT UP was categorically against testing, as this slogan reflected: "Test Drugs, not People". At the 1989 International AIDS Conference in Montreal, City Health Commissioner was booed for devising a partner notification plan. Throughout New York City, posters of Joseph's picture read: "Deadlier than the Virus" and were placed in the subway stations. Stephen Joseph eventually resigned.

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When David N.Dinkins appointed Woodrow Myers activists went to his demonstrate in front of his mansion. Woodrow Myers eventually resigned.

ACT UP even demonstrated even against GMHC for promoting testing in 1990. Yet progressively, ACT UP started to differentiate between voluntary and mandatory testing. Especially with the advent of new therapies for opportunistic infections, some activists argued that testing was made necessary to start early intervention therapies. Testing changed meaning. Once viewed as a coercive measure, testing could now be viewed as part of the therapeutic process, if counselling and treatment were provided. Yet activists realized that the City did not seem to share activists' view of "therapeutic testing" and would rather enforce "coercive testing."

In March, 28, 1990, despite the opposition of the Department of Health, ACT UP with a coalition of 36 groups issued the nation's first Bill of Rights for HIV-Antibody Testing to inform people of their legal rights. It progressively changed its position, distinguishing between mandatory and voluntary testing. From then on, no one could be forced to be tested without a written consent. By law, the test had to be explained in the language understandable by lay people. All questions had to be answered in an easy fashion. In case of discrimination resulting from taking the test a complaint could now be filed at the City's Human Rights Commissioner. The test could be taken free of charge and without any obligation to provide name or any other type of information.

Activists knew that a Bill of Rights would not be enough. Mandatory testing programs had already been started throughout the

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country. For example, the military, the Peace Corps or the Job Corps would test applicants without their consent.

CONSTRUCTING THE ALIEN AS THE OTHER

Discrimination against foreigners on the basis on health criteria was not new in the annals of the Immigration and Naturalization Service (INS). In 1891, the first immigration law excluding persons for public health reasons excluded those with a "loathsome or contagious diseases." In 1961, the law changed language of exclusion to dangerous and contagious disease and gave the U.S. Public Health Service (PHS) authority to establish the exclusion list. In 1970, PHS deleted 14 diseases from the list leaving tuberculosis, leprosy and several sexually-transmitted diseases on the exclusion list.

As already mentioned, the Department of Health and Human Services, under the aegis of Jesse Helms, added on August 28, 1987, HIV-infection on the list of contagious diseases that barred seropositive aliens from immigration under the U.S. Immigration and Nationality Act.

In December 1987, the largest mandatory testing program of civilians in the world was launched by the U.S. government with over 4 million persons seeking to adjust to permanent residency or seeking entrance as refugees.

The designated civil surgeons, doctors authorized by the INS to administer INS medical examination including the HIV antibody test, were not required to have any experience or knowledge regarding HIV-testing or infection. They had not received any training from the CDC

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or the INS in providing pre and post-test counselling with the HIV test. In many areas, there was a shortage of bilingual civil surgeons. Therefore many non-native individuals did not know how to interpret the results. Civil surgeons concluded that applicants were HIV seropositive without conducting the required confirmatory Western blot test.

Because of problem,with inadequate counselling, lack of confidentiality, and misinformation, disseminated throughout the country by the INS, large numbers of seropositive persons did not apply for legalization.. Many believed they were ineligible when in fact they were eligible to apply for waivers, even if they tested HIV-positive.

There have been breaches of confidentiality by civil surgeons and INS officials announcing HIV-test results in public offices. And it was the consensus of many public officials at the World Health Organization and the United Nations that mandatory testing and quarantining were useless from a public health standpoint. Scores of organizations have now expressed their opposition to the policies of the United States government, the International AIDS Society, the European AIDS Service Organizations, the National AIDS Commission, the Presidential Commission on the HIV Epidemic and the California Department of Public Heath. In fact, at the 5th International Conference on AIDS in Montreal, in June 1988, two ACT UP members joined the International AIDS organization to introduce a proposal not to hold conferences in countries which deployed immigration and/or travel restrictions against seropositive foreigners.

The Verhoef case brought discrimination experienced by persons with HIV/AIDS, when coming to the U.S to media attention. In the

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Summer of 1989, during a brief stopover at the Minneapolis Airport , Hans Paul Verhoef told a custom inspector he was heading for the National Lesbian and Gay Health Conference and the AIDS forum in San Francisco. Verhoef's luggage contained a letter he had written about the stress of traveling with AIDS, a gay guidebook, sextoys, and a personal supply of AZT. Because of his presumed seropositivity, he was arrested and spent five days in jail, detained by the Immigration and Naturalization Services (INS) as a danger to the public

A gay activist, Verhoef was the first to raise a legal challenge, arguing that the virus could not be stopped at the border. After much media attention, Minnesota's regional INS director recommended a waiver for Verhoef, but Washington said no. The INS argued that Verhoef's sexual paraphernalia could be used in sexual activities involving single or multiple partners. Yet, Verhoef noted that it could also be used in safe sex education.

Finally, a federal immigration judge in St Paul overruled the INS and ordered Verhoef released on a $10,000 bond, which was posted by the Minnesota AIDS Project. Verhoef also had to promise that he would refrain from high risk behavior while in the country.

Another category of people-the Haitians-came to the attention of the state, yet many of them were already U.S. citizens or legal residents. In 1990, the Food and Drug Administration announced that Haitian blood be banned from donation. A couple of months later, the FDA proposed that the ban be expanded to the originators of the Subsaharan region of Africa. This was a clever strategy to include not only individuals who were visitors, but also those who were legal residents born in the Subsaharan region of Africa.

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COMMUNALIZATION OF ISSUES AFFECTING ALIENS

In April of 1990, a huge demonstration was organized in New York City. Over 100,000 Haitians and others of African origin clogged lower Broadway. As a result, the FDA announced that within a short period of time it would follow the the recommendations of its advisory board and reverse its policy of singling out Haitian and African blood for rejection.

Aliens from Mars, a caucus made up of foreigners, was created in January of 1990. Beside the Immigration policy, aliens in ACT UP did not know their rights in case of arrest. They found out that if they led a riot or committed a crime of "moral turpitude" such as rape or murder, they could be deported.

The celebration of the reopening of Ellis Island was thought to be a major media stage for a well publicized action around immigration issues. The goal was to publicize nationwide the INS' discriminatory policy against seropositive foreigners. Although the president himself was heckled, no one was arrested.

Aliens from Mars boycotted the 1990 San Francisco AIDS Conference, while ACT UP as a whole voted to go. They brought an amendment to the floor forbidding merchandizing on what they qualified "soiled ground." Some of the activists ferociously disagreed. Like in other marginalized groups in ACT UP, Aliens from Mars realized that it would be hard for them to have their vision appreciated by the rest of the membership. As one activist says:

> ACT UP is racist against Latinos/as, against Blacks,

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why should it be any different with aliens?[5]

Or another:

> We are marginalized because we are such a small minority, even by other racial groups. We're so scared, we're such a small minority.[6]

Aliens from Mars organized a massive demonstration against the Helms' Amendment in New York City at Federal Plaza where the building of the Immigration and Naturalization Service is located, while the AIDS Conference was unfolding in San Francisco. As they had advertised the action in main newspapers, 400 individuals participated. "Take Your Stupid Law and Stick It, the Virus Has no Airline Ticket" chanted the activists.

The ACT UP members who went to the 1990 San Francisco Conference had also planned an action. When Health and Human Services Louis Sullivan approached the microphone to read his speech, the activists shut him down using whistles throughout his speech.

Other countries were concerned about this ban as well and had planned actions. In Sidney, Australia, activists went over the wall of the U.S. consulate and had been arrested.

That same year, several Democratic members of Congress, including Roy Ronwal of Georgia and Henry A. Waxman of California introduced legislation to give the Health and Human Services

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[5]Personal Interview, 1991.
[6]Personal Interview, 1991.

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Department sole authority to decide what disease threatens public health and required exclusion from entry into the United States.

Even the Centers for Disease Control recommended in January 1991 that AIDS and all other contagious diseases, except tuberculosis, be removed from a list of communicable illnesses. The agency's decision followed protests of the immigration regulations by numerous organization, including the National Commission on AIDS, the World Health Organization and International Societies of Red Cross.

The Bush Administration, realizing the growing opposition to HIV-testing and the Helms' Amendment, decided to ease the restrictions on seropositive foreigners. The seropositive foreigners who wanted to attended conferences in the U.S. could apply for a visa and seek a 30 day waiver of restrictions barring entry of people with communicable disease. Obviously, the new policy fell short of the activists' demands, which included the elimination of any restriction against seropositive foreigners.

Finally, in November of 1990, after vociferous protests by AIDS activists, Congress gave the Secretary of HHS the unilateral power to designate which disease were dangerous and contagious. Sullivan acceded to 1989 recommendations of the Centers of Disease Control and sent letters to the State and Justice Department stating that, effective June 1, 1991, screening for HIV and syphilis, gonorrhea, leprosy, chancroid and two rarer venereal disease should cease.

However, bowing to pressure from conservatives, the Government halted a plan to allow people infected with HIV to enter the United States. Conservatives voiced a strong opposition and the Government received 40,000 letters opposing the proposal leading the

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health department to table it for the foreseeable future. Representative William E. Dannemeyer relished the HHS Secretary's decision:

> I'm very pleased that HHS woke up to the absurdity of this proposal and I hope it stays buried in the bottom of a circular file in the deepest inwards of the bureaucracy. It was ludicrous what they were saying . On the one had they said AIDS is a major problem; on the other hand they say that we should take in HIV carriers with impunity."[7]

Whereupon Massachusetts openly gay Democratic representative Barney Frank responded:

> This is a perfect example of political cowardice. This is just some raw meat that the George Bush administration can throw to Republican primitives so he can get on with what he's really interested in: foreign policy."[8]

In June of 1991, at the plenary session of the 7th International Conference on AIDS in Florence, Italy, the activists convinced Max Essex, chair of the next conference scheduled to be organized by Harvard University in Boston, to address the issue of U.S.

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[7]Karen De Witt, *U.S., In Switch, Plans to Keep Out People Infected With AIDS Virus,* New York Times, 5/27/91.
[8]Karen De Witt, *U.S. Reverses Plan to Drop bar for AIDS-Infected,* New York Times, 5/26/92.

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immigration. He finally declared that if the Immigration Act was not changed, the conference would be moved to another country. In 1991, the International AIDS Society announced that the 7th International Conference on AIDS is to take place, not in the U.S., but in Amsterdam, Holland, were no such restrictions exist.

As of this writing, an alien activist is planned to speak at opening of the 8th Conference.

TESTING FOR HOMOSEXUALITY?

In June 1990, a dormant law to bar homosexuals from the U.S. started to reemerge close to the time of the San Francisco AIDS Conference. The law was amended in 1965 to describe people who should be barred from entry to the United States as those with psychopathic personality, sexual deviation, or mental defect. The Supreme Court ruled in 1967 that homosexuals could be barred from the country as sexual deviants.

The Immigration and Naturalization Service (INS) policy was to detain "professed homosexuals" at the airport. Then, Public Health Service doctors would issue a certificate attesting that "professed homosexuals" were indeed homosexual. Eventually, the INS would turn them over to a judge to decide whether or not they should be excluded from the United States.

On July 31, 1990 openly gay Democratic Representative Barney Frank of Massachusetts revived efforts to remove the U.S. prohibition on lesbian and gay immigration by attaching an amendment striking the ban to a broad based immigration reform bill.

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CONSTRUCTING HEALTH PROFESSIONALS AS THE OTHER

The testing campaign against homosexuals, Haitians and Subsaharan descents was unsuccessful. Only the 1987 Helms Amendment was in effect. This did not seem to be enough for conservative groups, who turned to health care professionals as their next target. It was easy to understand that by testing health care professionals, spreading HIV-antibody to the rest of the population was only one step away.

Yet, until 1991 there had been only five alleged cases of HIV transmission from dentists to patients. At the 1991 International Conference on AIDS in Florence, Italy, Dr. Alert Lowenfels of New York Medical College calculated that the risk of transmission from an HIV-infected surgeon to a patient was about one in 48,000. Dr Lowenfels argued that the risk of HIV transmission from doctor to patient closely resembled the risk of vehicular fatality during transportation to and from the hospital.

Finally, the CDC had recorded only 40 cases of health care workers around the country who contracted HIV from patients. Most of those cases came from accidental needle sticks or cuts.

Since the introduction of testing for Hepatitis B (HBV) infection in the early 1970's, there had been published reports that 300 patients were infected with HBV after treatment by HBV infected health care workers. Most of those cases were due to lack of observance of universal precautions. When doctors modified their procedures no

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further transmission was observed.[9]

Yet, the media compiled and inflated AIDS cases involving health care professionals. A prominent breast surgeon at John Hopkins hospital Dr. Rudolph Almaraz died of AIDS in November of 1990. He had performed surgery until March, 1990. A long investigation had been conducted by Johns Hopkins to decide whether his 1,600 patients had been infected.

Another case involved a family doctor who practiced in the Minneapolis area and sent letters to 328 of his patients telling them he had AIDS and urging them to be tested by the state. The doctor, Philip Beson, 39 years old, continued to perform invasive procedures, including delivering babies and conducting oral, rectal and gynecological examinations, after the virus was diagnosed in September of 1991. Dr. Beson was suffering from a skin condition that caused open sores on his hands. Further investigation revealed that those doctors did not practice universal precautions.

But the case, which stirred most media attention was Kimberly Bergalis'. She was one of five patients who allegedly became infected while being treated by their HIV-positive dentist, David Acer of Suart, Florida, who died in September of 1990. The reason the case so much attention is that Bergalis decided to sue the Dentist's estate for malpractice. In that endeavor, she garnered the support of the media, the government and politicians such as William F. Dannemeyer and Jesse Helms.

In the New York Post, Ray Kerrison wrote:

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[9]Centers for Disease Control, Surveillance Report, p.3, 1991.

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> She is dying because the political and public health systems are more interested in protecting the wayward, the deviant and the promiscuous than the upright. She was like a lamb led to the slaughter. Why is AIDS, the deadliest of all such diseases, the lone exception? Because New York's politicians, especially Cuomo and Dinkins, and their governmental departments are prisoners of the radical homosexual lobby. They place the public' s health at risk rather than offend the militants of ACT UP.[10]

This article echoed the tone the Bergalis' case would take. Instead of understanding the problem as a public health issue, it was constructed as a moral issue leading to punishment of those thought to be culprit. Bergalis saw herself as a "victim" and condemned those she thought put her in this predicament:

> Whom do I blame? Do I blame myself? I sure don't. I never used IV drugs, never slept with anyone and never had a blood transfusion. I blame Dr. Acer and every single one of you bastards. Anyone who knew Dr. Acer was infected and had full blown AIDS and stood by not doing a dam

[10]Ray Kerrison, *Innocent's Blood is on Politicians' Hands,* New York Post, Monday June 24, 1991.

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thing about it. You are all just as guilty as he was.[11]

Before she became bedridden, Bergalis lobbied tirelessly for full disclosure of AIDS status between doctors and patients, and mandatory AIDS testing of health care workers.

> I did not do anything wrong, yet I am being made to suffer like this. My life has been taken away. Please enact this legislation so that no other patient or healthcare provider will have to go through the hell that I have.[12]

Another dying woman with AIDS, Belinda Mason, a member of the National Commission on AIDS, had a quite different attitude, yet never was granted as much media attention:

> There is not time for me to do much more about any of this. but there is time for you Mr.President. Doctors don't give people AIDS--they care for people with it. The blanket screening of health care workers will create the false illusion that people with AIDS are a threat to others.
>
> After more than ten years of the AIDS crisis, it is disheartening to realize that some people are

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[11]Bruce lambert, *Kimberly Bergalis is Dead at 23; Symbol of Debate Over AIDS Tests,*
New York Times, 12/9/91.
[12]Ibid.

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> still pointing fingers and looking for a place to lay blame. Only our effort as a united people has any hope of slowing the epidemic and avoiding the further human tragedy that statistics tell us we will all surely face one day.
> Mr. President, those who come after me are counting on you.[13]

Belinda Mason contracted the disease from a contaminated blood transfusion. Ms. Mason was infected during the birth of her second child, in 1987. The birth required an emergency Caesarean. She hemorrhaged, and had her uterus removed. Struck by a cardiac arrest, she lapsed into a coma for days. Because the initial emergency occurred on a weekend, the staff members at the hospital in Eastern Kentucky who would have tested the blood to be sure it was not contaminated with HIV were off duty. Fearing that she would die if she did not have a transfusion at once, the doctors gave her one.

Because of the way she contracted HIV, Belinda Mason knew that she had been spared the stigma which typified the plight of persons with AIDS. She was against testing of health care workers as well as aliens.

> Because of the way I contracted AIDS, the audiences of businessmen, church leaders and college students I speak to are spared a

[13]ACT UP Testing File, Unpublished Document, 1991.

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> confrontation with the muddy realities of sex and drugs. That's the innocent victim syndrome and I don't like it. In my bio, put out by the commission, it says I got AIDS from a transfusion but I've asked them to take that out. I don't want to be considered different.[14]

Although dying, Mason was aware of her privileged condition as a person with AIDS.

> If I was a young woman of color in the Bronx, I wouldn't be standing up and talking about AIDS. I'd be home worrying about how to pay the rent.[15]

She will be remembered by many activists as one of the most grandiose and humbling heroes in this epidemic:

> But the bitterness puzzles me. It seems to me that it's based on an assumption that things are supposed to be easy in life; that what happened is not fair and shouldn't have happened to me. This occurs to people, particularly people like me who got AIDS from a blood transfusion and Kimberly Bergalis who got it from an unfortunate contact with her dentist.

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[14]Ibid.
[15]Philip J. Hilts, *Dying Member of Panel on AIDS Wants her Illness to Lift Stigma,* New York Times, August 4, 1991.

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> But the question is, why should it happen to anybody? I never felt I was a member of an exclusive club that should go through life unscathed. I suppose if I say this it sounds hokey, like 'Pllyana gets AIDS, but I have always had wonderful things in life.[16]

In sharp contrast to the philosophical position of Belinda Mason, figures who supported Kimberly Bergalis was surrounded by hateful politicians such as William F. Dannemeyer and Jesse Helms. Thus, Dannemeyer, using the CDC guidelines, sought to co-sponsor the Kimberly Bergalis Patient and Health Providers' Protection Act of 1991. This bill required that health care providers be tested and tell their patients the results. It also gave doctors permission to test patients without obtaining informed consent. Using the emotion of the situation Dannemeyer added:

> Kimberly and her family have reviewed this legislation and support it fully. By co-sponsoring it, you can help respond to her dying plea.[17]

THE BERGALIS CASE STIRRED HYSTERIA AMONG LAY

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[16]Ibid.
[17]Congressional Record, June 26, 1991, p. 2376.

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INDIVIDUALS AS WELL AS SCIENTISTS

Logically, Senator Jesse Helms introduced a similar bill criminalizing the performance of "invasive procedures" by HIV-positive health care workers, who do not divulge their serostatus. The penalty for breaking this law included a minimum of ten years imprisonment and a fine of up to $10,000. Strategically, "the bastard letter" by Bergalis was inserted into the Congressional Record by the Senator. The Helms Bill passed in the Senate by 81 to 18 on July 18,1991. This legislation was coupled with another bill, the Leadership Bill passed in July 18- 99 to 0- which mandated that states not complying with the CDC guidelines not receive certain federal medical funding.

Finally, a third piece of legislation , the Patients Testing Bill passed July 30, 1991. It allowed patients within the health care setting , to be HIV-antibody tested for any reason, without their knowledge or consent.

In January of 1991, the American Medical Association (AMA) and the American Dentist Association (ADA) declared that medical doctors and dentists be tested for HIV-antibodies, and that those infected warn their patients about their condition or give up surgery. Additionally, the House of Delegates of the AMA passed a resolution saying that physicians had an ethical obligation to turn in "impaired" colleagues who refuse to voluntarily seek treatment, and Dr. Nancy Dickey, an AMA board member, added that HIV infection might be

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viewed as a form of impairment.[18]

Reversing its stand that universal precautions-gloves, sterilization of equipment-are sufficient, the CDC released guidelines recommending that:

> HIV+ doctors who perform "exposure-prone" procedures know their antibody status and seek counsel from an expert review panel that will decide under what circumstances they may continue to practice these procedures.[19]

This declaration did not change the position of the ADA. On April 5th of 1991, the Association announced that it would not relax its strict guidelines for HIV-infected dentists.

Despite the emphasis on voluntary testing in the CDC guidelines, activists knew that they would result in mandatory testing. With legal and financial stakes so high, medical institutions and insurance agencies would be forced to require that participating providers test and divulge their results.

The CDC guidelines were not binding, but they could become the basis of malpractice suit if a patient became infected through a procedure performed by a doctor, who did not follow them. Insurance companies were conscious of this type of legal ramifications. For example, an AIDS litigation involved a doctor who contracted AIDS

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[18]Colen, D.D., *MDs Spurn AIDS Tests*, New York Newsday, July 27th, 1991.
[19]Centers For Disease Control, *Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B virus to Patients During Exposure-Prone Invasive Procedures.*, MMWR 1991, 40, No. RR-81.

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when she pricked a finger on a contaminated hypodermic needle. She filed $175 million lawsuit against the hospital where she worked, the city's Health and Hospital Corporation and two physicians.

Another case involved a doctor at Kings County hospital, who won a $1.3 million settlement from the city, after contracting AIDS when she was pricked by a contaminated needle, that another doctor had carelessly discarded. Finally, Kimberly Bergalis won a one-million-dollar settlement.

COMMUNALIZATION OF TESTING ISSUES AFFECTING HEALTH CARE PROFESSIONALS

ACT UP was against restricting HIV-infected health care workers from their jobs. All available research indicated that universal precaution to prevent transmission of HIV and their bloodborne pathogens kept the risk of infection very low. The Association of Sea and Territorial Health Officers, the American Public Health Association, and public officials all over the country shared this position.

The Centers for Disease Control's own statistics revealed that the chances that an HIV-infected health-care worker will infect a patient during an invasive procedure such as surgery or a tooth extraction are much lower than the risk of more infectious disease. The risks of hepatitis B infection from an infected surgeon was 2400 in 1 million; death from anesthesia 100 in 1 million; death from penicillin 10 to 20 in 1 million; HIV infection from an infected surgeon 1.4 to 24 in 1 million.

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In February 26, 1991, at the opening of a two day conference in Atlanta sponsored by the federal Centers for Disease Control, 1,000 medical experts representing more than 50 organizations agreed that the risk of HIV transmission from doctor to patients had been greatly overstated by federal health officials and that mandatory testing and restrictions would place a tremendous and unnecessary economic burden on the health care system.[20]

Yet, hysteria around testing reached new heights when two doctors advertised in a newspaper that their HIV-antibody test was negative. Furious, AIDS activists protested in front of their offices, chanting "Fill Teeth, not Pockets."

Restricting workers from practices would, according to activists, reduce the quality of care that all people receive. Already, fear of infection caused many health care workers to refuse to treat people with AIDS. Of the 5,000 calls the GMHC Hotline received each month, 300 came from HIV positive people seeking medical and/or dental referrals. Yet GMHC had only five dentists on its referral list, a number unchanged since 1988.

As a result of testing, activists argued, the shortage of health care providers would extend the waiting period in infectious disease clinics, the average of which was already between three to six weeks.

The implementation of those restrictions was also illogical, according to the activists. As HIV-antibodies took between six weeks and six months to develop, testing would have to be continually repeated although public discourse put forth the idea that, once tested,

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[20] Malcolm Gladwell, *Groups Oppose HIV Tests for Medical Professionals,* Washington Post, Friday, February 22, 1991.

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an HIV negative health care provider would never transmit the virus. The costliness of testing as often as necessary would make such program ineffectual and would use huge sums of dollars that should be available for research and healthcare. In addition, Activists realized soon through their research that transmission from patient to patient was more likely to occur.

Education-which was the primary function of the CDC-and not testing, was for the activists a better way to deal with this very rare type of transmission. Sexually explicit education was required, because, as in the case of the CDC epidemiology, activists were asking to focus on procedures, not practitioners. Yet, the same law makers, who were pushing to criminalize HIV were, noted the activists, slashing funding for the programs that actually might stem the epidemic.

In May of 1990, representative William F. Dannemayer strong armed the Public Health Service into cutting three quarters of the federal research scheduled to attend the Florence AIDS conference. In June, the CDC came under fire for funding AIDS education at a Gay and Lesbian Health Conference. In 1991, the Public Health Service stopped a study of sexual practices among teenagers. And most of all, at the 6th International Conference on AIDS in San Francisco, everyone expected Georges Bush to make an appearance to show concern for the hundreds of thousands of PWAs and respect for the AIDS researchers who came from all over the world to share their findings. Not only did he not appear, but he was in North Carolina, supporting a fundraiser for Senator Jesse Helms, who originated the Amendment to the appropriation bill for the National Endowment for the Arts, according to which sexually explicit, and more precisely homoerotic art

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could not be funded.

ACT UP organized a boycott against Miller Beer, a subsidiary of Philip Morris, one of the supporters of Jesse Helms' campaign for reelection at the Senate. The boycott was not a response specific to Jesse Helms' Amendment, but the latter was certainly in the list of grievances ACT UP had amassed against the Senator. Most of the gay bars throughout the country observed the boycott.

Unexpectedly, the American Medical Association together with 40 other organizations refused on August 29, 1991 to help draw up the list of "exposure prone procedures" as requested by the CDC. Former Surgeon General C. Everett Koop said at a AMA press conference:

> Let me assure the American public that their chances of getting AIDS from a health care worker are essentially nil, unless they are having a sexual relationship or shooting drugs and sharing needles with him or her.[21]

Most of the 40 medical nursing and other health care groups invited to a meeting on in Chicago declined to help develop these lists as well. They contended that new data showed there was no significant risk of infecting patients.[22]

In the meantime, Vice President Dan Quayle told a press conference:

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[21]Lawrence K. Altman, *Health Units defy U.S. on AIDS Rules,* New York Times, Friday, August 30, 1991.
[22]Lawrence K. Altman, *Health Units defy U.S. on AIDS Rules,* New York Times, Friday, August 30, 1991.

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> Mandatory AIDS testing of doctors and patients is a good idea. I believe that every body would like to know whether their doctor is infected with the HIV. It is a good idea to have that knowledge and information as I think doctors would want to know whether their patients are infected.[23]

Quayle's speech at the Chicago Hilton and Towers was interrupted by an activist from ACT UP, who shouted: "People with AIDS Need National Health Care. The Elderly Need National Health Care."[24] Outside a demonstration was organized against the position of the AMA vis à vis AIDS. The demonstration resulted in 27 arrests.

ACT UP joined a coalition of health worker unions, seeking safer working conditions for hospital employees, demanding that the Occupational Safety and Health Administration (OSHA)-a branch of the federal government-use its authority to enforce safety regulation. Yet, OSHA had not released standards for this regulation drafted five years ago.

The Coalition called for immediate implementation of Occupational Safety and Health Administration (OSHA). Bloodborne Disease Standards as the ONLY proven measure necessary to protect both patients and health care workers from HIV or any other infection.

ACT UP forced the CDC to release documentation on the Kimberly Bergalis case. Activists found out that the CDC's own reports

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[23]Howard Wolinsky, Quayle: *Test MDs for AIDS*, Chicago Sun Times.
[24]Ibid.

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indicated that Dr. Acer and his assistants took a stunningly listless attitude toward infection control. Needles and other reusable equipments were improperly sterilized. Disposable items were reused. Gloves were washed with regular soap, which is known to cause tiny holes in latex. According to Dr. Acer's medical records he treated his own Kaposi's sarcoma lesions with the same instruments used on his patients. These were blatant violations of the safety precautions issued by the the CDC in 1985 to prevent HIV transmission. In addition, activists found out that Kimberly Bergalis had genital warts. This, some activists argued, might have been caused by sexual activity, that Bergalis had always denied.

Endowed with this new information, ACT UP along with NYC DOH, NYC Commission of Human Rights, DC 37 pressured the Mayor of New York City, David N. Dinkins, to cosponsor two days of public hearings. He did not want those hearings to happen because of Governor Cuomo's pending presidential campaign.

September 11, 1991, day of the New York City hearings coincided with a National Day of Protest against legislation passed in the U.S. Senate designed to identify and segregate and/or eliminate doctors, dentists and other heatlh care workers who are HIV-positive.

ACT UP gathered at Bekman Hospital at 3:30 PM and marched together with New York Physicians for Human Rights (NYPHR) to a mass rally at City Hall. The speak out was sponsored by the Coalition for Safe Health Care representative labor union, civil liberties groups, community organizations, medical professionals and people with HIV and AIDS. The Coalition drafted a consensus statement recommending the immediate implementation of OSHA Bloodborne

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Disease Standards, designed to protect both health care workers and patients.

John J. Seeney, President of the Service Employees International Union (SEIU), said:

> Speaking on behalf of the 375,000 health care members of SEIU, we are outraged that such legislation could even be seriously considered, much less actually passed, by the highest legislative body in our country...The hysterical reaction of the U.S. Senate to the unproven HIV transmission in a single Florida dental office... is a grim reminder of what happened in our country when the institutions charged with protecting the public shirk their obligation....and create vacuums for master demagogues like Jesse Helms.[25]

AIDS activists also organized protests in Seattle, San Francisco, Washington, DC , Columbus, OH, Portland, ME and in other cities.

ACT UP charged the Centers for Disease Control (CDC) with deceiving the public into believing that the Florida dentist who died of AIDS infected five patients in a mysterious and unexplainable manner.

> These bills will protect no one. CDC director Dr. William L. Roper has treacherously promoted

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[25]Ibid.

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> public hysteria and legislative panic, instead of focusing on Universal Precautions.. Witch-hunt will not end the AIDS crisis. Only education, health care and research will stop AIDS.[26]

The National Day of Protest coincided with the reopening of Congress which was to take up three bills inspired by Senator Jesse Helms.

Tony Davis of ACT UPs CDC Working Group said:

> For ten years the Reagan and Bush administrations have pursued an AIDS policy of neglect. By default, our national policy has been directed by right wing demagogues. Today, the policy of neglect has become a campaign of active persecution.[27]

Steve Ault said:

> We deserve a CDC driven by science -not right wing politics. Unfortunately, since the beginning of the AIDS crisis, the CDC has been obsessed with "risk groups" and not with providing education to prevent the spread of infection. The new CDC guidelines have created a new "risk group"-doctors and dentists. The CDC has done little to control

[26] ACT UP Testing File, Unpublished Document, 1991.
[27] Ibid.

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> AIDS, the CDC merely controls the public perception of the epidemic and these new guidelines sanction fear!"[28]

In September of 1991, ACT UP went to the state and showed that the Kimberly Bergalis case was flawed. Activists did a cost factor analysis and demonstrated that testing health care workers would not only lower quality of care but would be outrageously exorbitant. They also submitted a consensus statement signed by 150 organizations, including the Presidential Commission on AIDS.

Dr. David Axelrod, the State Health Commissioner, issued new guidelines based on a conclusion that

> doctors and other health care workers infected with HIV, the virus that causes AIDS, posed only a "remote" risk of infecting patients during surgery. "Workers with HIV infection should be dealt with as any other employee with medical condition. If their functional status enables them to work and to adhere to basic infection control practices, there should be no restrictions on job duties.
> The probability of transmission from an infected health care worker to a patient during an invasive procedure has been estimated to be between one per 100,000 and one per 1 million procedure.[29]

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[28]ACT UP Testing File, Unpublished Document, 1991.
[29]Dr. David Axelrod, State Health Commissioner's Report, 1991.

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The department defined an invasive procedure as one in which there is significant risk of a patient coming in contact with a health care workers' blood or other body fluids. Hysterectomies, pelvic surgery and oral survey are invasive procedures.

ACT UP demonstrated at the American Medical Association and the American Dental Association branding banners that showed a handcuffed health care provider and that read:"Free HealthCare."

Realizing through research information the real risk of dentist-to-patient transmission, and realizing that no dentist had been appointed to the team that investigated the Kimberly case, the ADA changed its position.

ACT UP contacted the different subspecialty association, including gynecologists, obstetricians, neurophysiologists, orthopedists and all agreed to say no to testing of health care professionals.

During hearings organized by CDC in November of 1991, ACT UP brought the consensus statement, the report from the City and State hearings and plus their public education flyers. ACT UP members showed the effect that testing health care professionals would have on access to care for people. Community based physicians gave concrete example of this impact in Brooklyn and Bronx. ACT UP literally forced the CDC to create a record of documentation that harm would be created if that bill passed.

Although the CDC did not change its guidelines, the legislation was annihilated. Guidelines were relegated to each state.

Culture is a tangled web. The intertwining between science and politics has never been clearer than in the debate around testing.

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Whereas one battle is won by the activists, who have successfully curbed the rigid positions of the CDC, the AMA and ADA, a registry of HIV positive individuals has begun in New Jersey, right after the eloquent testimony of former Surgeon General, Everett Koop at the Hearings on CDC Guidelines on Prevention of AIDS Transmission in September 19, 1991:

> The virus of AIDS is difficult to transmit.
> Our scientific understanding of HIV and AIDS has not been changed b the report of apparent dentist-to-patient transfer of the virus. We still know that an HIV negative test is worthless because a positive serology does not turn positive for three to six months.
>
> But time and attention directed to the HIV-infected health care worker is time and attention away from the real issues of patient care and patient protection. All who seek to improve patient protection--be they in or out of the medial community--should be concentrating on better infection control.
>
> Education in how to avoid exposure to HIV through sexual activity and needle sharing will protect tens of thousands for infection and death. It takes time and effort that should not be squandered on a theoretical danger that threatens few if any patients. Indeed the risk of a patient being infected

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through medical care from an HIV-infected physician is so remote that it may never be measured.

A concentrated effort to identify a case of physician-transmission to a patient of HIV infection has produced no such case. More than 50 ongoing programs to study patients of HIV infected health care workers has not documented a single case of physician to patient transmission.

The emotional response to the HIV-infected health care worker ignores experience, science, medical history , a well as the best interest of the patient and the health care worker. The emotional outcry is fed by the ignorance of some and the personal interest of others.

It is time to separate statesman-like behavior from political behavior; to separate those who serve the patient from those who use the patient, those who those who throw water on a fire from those who throw gasoline.

Because there is no scientific basis for the proposed restrictions on HIV-infected health care workers, there is disagreement in the medical community on how to proceed.

I am troubled because some are trying to manipulate us back into the dark era of this epidemic when a Ryan White could be shunned

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and kept out of school for a non-existent threat. Or when the three Florida hemophilia boys had their house burned down because of unnatural and unfounded fear in the community. The day will come when those who support such a witch hunt will be ashamed they did.

I am a physician,but I appear before you as a patient advocate which I have always been.

So I say there is need for immediate action to improve patient protection.

1) There is a need for vigorous effort to assure adherence to infection control by heath care workers.

2) There is a need to improve infection control procedures.

3) There is a need to review medical and dental equipment design to seek ways to improve infection control.

4) There is a need to educate the public about risk and benefits inherent in medical and dental care so they can be wise consumers.

5) There is a need to educate all health care workers on the importance of infection control.

Then there is a need for more science on which to base decisions.

1) For example there is a need for scientifically conducted look back programs with regular

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reporting to the public of the number of patients tested for HIV and any documented case of transmission--if one ever occurs.

2) It would also be important to report on numbers of cases where HIV is transmitted from patient to health care worker--to emphasize the relative risk.

3) there is also a need for studies of the frequency of non-HIV transmission from healthcare worker to patient and patient to healthcare worker.

4) There is a need for an independent re-appraisal of the Florida in-dental office transmission to learn more about infection control and the investigation of such cases.

If the Congress whishes to get into this matter, I would suggest

1) A public education campaign on the risks of HIV transmission to patients form health care workers.

2) A professional education campaign on proper infection control procedures, possibly with a certification process through states of physicians and dentists and appropriate co-workers.

3) A local committee to review and define the practice of each HIV positive physician with a monitoring function.

4) Revelation of the HIV positive status of a physician or dentist only when an HIV positive worker poses a significant risk to the patient.

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These suggestions, Mr. Chairman, are based upon knowledge of the science of transmission, not on window dressing of unreliable information feeding the already unreasonable fear of the public.

I might add that last night I answered questions from the listening audience of radio talk show. Every question on AIDS revealed a lack of understanding of the most basic science of HIV transmission. Some segments of the public are poorly informed.

People would be more concerned about heir own risky behavior than in the HIV status of their doctor, dentist, or nurses.

Enforced testing will give people a false sense of security. They will relax their guard against the one thing they can control their behavior.

Who would do the testing of health care workers-- a federal bureaucracy like the Post Office or Amtrak? And who would supervise them?

A certificate of HIV negativity is worthless unless you know the sexual behavior and drug abusing activity of the individual six months before they take the test until the present.

Many people who are carrying the virus now test negative --and it is believed that they are most infectious before their test becomes positive.

One very plausible explanation of the Florida

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> dental episode is transmission of the HIV from patient to patient because of unacceptable technique with contaminate instruments. That means that an HIV negative dentist could pass AIDS form patient to patient, just by unsterile procedures.
>
> If we have mandatory testing of health care workers we will eventually have mandatory testing of everyone--after all 40 health care workers have contracted HIV trough some misadventure in the course of treating an HIV positive patients .
>
> Let's turn from this infinitesimally small risk and pay attention
>
> 1) to unsafe sexual behavior,
>
> 2) to contaminated needles among drug abusers,
>
> 3) to guarantying a safe blood supply of transfusion, and scrupulous technique in health care.[30]

Although read by a physician member of Jerry Falwell's Moral Majority, this testimony could have been written by ACT UP.

ACT UP members know that the war against testing is not over. The sate of New Jersey has just started an AIDS registry.

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[30]Prepared Statement of Dr. C. Everett Koop At Hearings on CDC Guidelines On Prevention of AIDS Transmission, September 19, 1991.

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EVEN IF A CURE WAS FOUND TODAY, MANY PEOPLE WITH AIDS COULD NOT AFFORD IT

From the time the AIDS epidemic was identified, many, if not most insurance companies, tried to avoid paying AIDS-related claims and/or insuring PWAs or people fitting insurers' stereotypes of what a person with HIV should look like. In that regard, AIDS activism made a larger issue more visible. Almost 40 million people do not have any coverage whatsoever. Of those 40 million, 20 million are children. Their uninsured status is not due to lack of employment, since 80% of those 40 million uninsured are fully employed or the dependent of an employed person. As in other areas of poverty, African-American, Latinos and Asians are less likely to be insured than Euro-Americans.[1]

In addition to the 40 million uninsured are 55 million individuals, who are not adequately insured. They are called the underinsured, because their insurance does not cover for such basic needs as routine check up or sometimes hospitalization.

MEDICARE, MEDICAID, FEDERAL BANDAIDS

People who are underinsured are often recipients of Medicare or Medicaid. Medicare is a federal program that benefits the elderly over 65, and Social Security Disability Income recipients. Medicare hospital insurance helps pay for inpatient hospital care and, with limitations, for inpatient care in a skilled nursing facility, home health care and

[1]National Center for Health Statistics, 1991.

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hospice care. Eligible individuals may also choose to buy supplementary medical insurance under Medicare.

LIMITATIONS OF MEDICARE

Medicare only pays 55% of the medical costs of the elderly. One third of the elderly lack any private insurance coverage to pay the rest, called Medigap. Those lucky enough to obtain Medigap saw their premiums rise an average of 19% in 1990. A provision in the Medicare statute requires Social Security Disability Income (SSDI) beneficiaries to wait 24 months after the beginning of disability benefits before becoming eligible for Medicare. For people who seek to obtain Medicare through SSDI eligibility, this amounts to a 29-month waiting period, since SSDI itself has a five-month lag between the onset of disability and the beginning of benefits. And since many PWAs cannot wait this long period, Medicare reimburses only one to two percent of the cost of AIDS care in the United States. Until the recent past, most people with full-blown AIDS did not survive more than 29 months after diagnosis and thus failed to qualify for Medicare.

In the fall of 1990, the Treatment and Data Committee of ACT UP formed the Management and Budget Working Group, which, later, became the Medicaid/Medicare Working Group. One of its first demands was the elimination of the 29-month period.

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40% OF PWAS HAVE RECOURSE TO MEDICAID

Medicaid is the most important medical entitlement program for people with HIV. In fact, it is the largest single payer of direct medical care services in the country for people with AIDS. Indeed 40% of PWAs have recourse to Medicaid. Whereas Medicaid reimburses roughly 11% of non AIDS-related medical expenses, the program pays about 25% of the aggregate costs of AIDS care in the United States.[2]

Medicaid is a cooperative federal/state program designed to provide medical care for poor people. The federal government funds 50% of Medicaid costs for the most affluent states, such as New York or New Jersey, but will fund up to 82% for poorer states in the South.

Although Medicaid is expressly designed to aid poor people who need medical attention, one does not obtain Medicaid merely by demonstrating a need for medical care. The following are the primary routes by which persons become eligible: 1) AID to Families with Dependent Children (AFDC) or General Assistance (GA);

2) the aged, blind and disabled recipients of Supplemental Security Income (SSI);

3) at the discretion of the state, persons who meet the general characteristics for eligibility for AFDC, GA, or SSI, yet whose income is too high. In such circumstances, these persons are required to "spend down" a portion of their monthly income before the government will assist with their medical expenses. These recipients are referred to as "medically needed" recipients. Medicaid

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[2]Health Care Financing Administration, 1991.

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cover the 10 million people below the official poverty level, ($13,360 per year for a family of four). In many states, the family income limits for Medicaid are far below the poverty level. In Alabama, for example, state officials said a family of four was ineligible for welfare if it had a net income exceeding $155 a month, or $1,860 a year.

States are not obliged to participate in Medicaid programs. But in general they do. Those which participate must offer "mandatory services," which include doctor visits, hospital visits, x-rays and laboratory services.

They may offer approved "optional services." Prescription drugs are technically an optional service; in practice, however, virtually every state reimburses for prescription drugs. The most severe limitations occur in Washington State (two prescriptions per month, with the possibility of an additional two), Texas (three), Oklahoma (three), and South Carolina (four).

States are not required to offer services to the medically needy and they may discriminate between the categorically needy (i.e. those on AFDC or SSI) and the medically needy. They set reimbursement levels for doctors who accept Medicaid and they have their lists or prescription drugs for which Medicaid will pay. Most states refuse to pay for unapproved treatments.

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MEDICAID'S ELIGIBILITY RULES VIRTUALLY PRECLUDE THE DELIVERY OF EARLY INTERVENTION TO POOR PERSON WITH HIV INFECTION

The primary route to Medicaid for HIV-positive adults is through Social Security Income (SSI), which requires proof of disability before benefits begin. Although some HIV-positive applicants receive SSI, most can only obtain SSI when they receive a full-blown AIDS diagnosis. Obviously this defeats the purpose of early intervention. For both Social Security Disability Income (SSDI) and Supplemental Security Income, disability is defined as "the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months."

A full-blown AIDS diagnosis under the Centers for Disease Control's standard definition makes the applicant presumptively eligible for benefits. Applicants who are HIV-positive but have not been diagnosed with AIDS must provide sufficient medical evidence to demonstrate existence of a medical disability.

Yet the CDC's AIDS definition was derived primarily from research performed on men. (See Chapter on Women and AIDS) Female specific conditions are not listed by the CDC. Either women end up without benefits or have to endure an excruciatingly difficult procedure of documenting their illness. S.P. vs. Sullivan, which challenges the federal government's reliance on this inadequate AIDS definition, is a class action lawsuit in federal district court in

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Manhattan. An ACT UP member lawyer for a a legal services AIDS project began the suit and invited Lambda Legal Defense to be a co-counsel.[3]

Medicaid's failure to promote case management also precludes early intervention. Early intervention involves a package of coordinated services, including drug therapies, social services, and regular diagnostic testing.

Moreover, early intervention cannot be effective without the oversight of primary care providers. In some states-New York, for example-reimbursement rates are so low that few private physicians accept Medicaid. For a single doctor visit, New York pays less than 50% of what Alabama pays. As a result, less than 25% of the state's doctors have agreed to participate in Medicaid.

In addition, Medicaid rules make it difficult for poor people to participate in clinical trials. Such participation requires regular laboratory tests, the costs of which are beyond the means of poor people.

The shortage of doctors willing to accept Medicaid leads poor New Yorkers to seek care in overcrowded clinics and emergency rooms. The many Kings County Hospital's scandals dramatized by the media are illustrative of the type of substandard care individuals receive in city or state hospital's emergency rooms. Another example is Chicago's Cook County hospital.

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[3]This was necessary because her project is the only project serving poor people with HIV in New York. In fact, there are only six such projects in the U.S. In addition to filing the suit, she sees 150 clients per week. She invited Lambda in order to make the work less taxing since they see very few clients and have much greater resources.

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CHICAGO'S COOK COUNTY HOSPITAL, EPITOME OF PUBLIC HEALTH CARE

In Chicago most of the people who must rely on Cook County Hospital for their healthcare are Black and Latino, a disproportionate number of whom are women and their children. The waiting period for outpatient appointments can be up to 8 months, forcing more and more people to use the emergency room for their primary health care. Meanwhile emergency rooms have waiting periods of 6-8hrs. Therefore, people who must rely on Cook County Hospital for their primary care often wait until they are very sick.

The hospital is short 200 nurses, and those working at the hospital are overworked. One of the consequences of this situation is described in the conclusion of the Health Care Financing Administration (HCFA) investigations of the Hospital in 1988 and 1989. The Administration found evidence of more than 500 cases of mismanagement involving unsanitary conditions and questionable medical practices in Cook County Hospital.

At present, 800-1,000 County residents at various stages of HIV infection are being treated by the Hospital. More specifically, 150 patients are treated each week. Yet, there are only 30 beds on the AIDS ward, and 50% of those beds lie empty due to understaffing.

In light of the severe underfunding of AIDS services at Cook County Hospital, it is paradoxical to find out that in fiscal year 1989, $21.7 million of Hospital allocations went unspent; this money could have funded all of Cook County's AIDS services. Finally, a 100%

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cigarette tax was supposed to go to Cook County Hospital, but only half this amount was appropriated.

An action was organized by ACT UP in 1990? (find detail). A demonstration was also staged in front of the AMA and several insurance companies (MONY and Prudential), which were discriminating against PWAs or perceived as such, or perceived to be "at risk."

Finally another action was organized at Circle, a food company which refused to reimbursed AIDS-related claims. ACT UP/UCLA send letter. They zapped their phone, tying up the ligns for retailers or wholesales. The company finally rescinded its discriminatory policy.

THE EMERGENCE OF INSURANCE ACTIVISTS, A FIRST IN THE MEDICAL HISTORY OF THE UNITED STATES

Worsening recipients' situations, numerous state practices threaten the efficacy of Medicaid for people with HIV. In any given year, Medicaid in Lousiana will cover the cost of only 12 hospital days. Oregon has adopted a controversial "rationing" system which places treatment of terminal HIV disease-- defined as presenting less than a 10% survival rate in five years--in the category of conditions receiving the lowest priority for Medicaid funds.

Finally, Medicaid has been reducing its coverage by increasing co-payments and deductibles. In 1978, Medicaid covered 65% of the poor in the U.S., but by 1988, it covered only 38% of the poor. The demands of the Medicaid/Medicare working group of ACT UP included:

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1) The expansion of eligibility to all person who meet the income criteria and who face imminent disability.

2) Requirement of case management to facilitate better care (and to save costs).

3) Adhesion of Health Care Financing Administration (HCFA) to its obligation to police state programs to ensure that necessary drugs are provided.

4) Abolition of monthly prescription limit.

5) Coverage of unapproved treatments, diagnostic tests, and commonly used alternative treatments by HCFA.

The issue of insurance coverage was becoming a first priority in ACT UP, and in August of 1989, the Insurance and Health Care Access Committee was created. The committee endorsed direct action and mobilization in favor of legislation and reform of the insurance marketplace. After five teach-ins offered by two insurance policy professionals, activists were able to slowly school themselves into the field.

Their first action took place in October of 1989. A demonstration was staged at Blue Cross/Blue Shield (BC/BS), because it did not offer a stop loss clause. As a result now, after $10,000 open enrollment claims have been submitted, BC/BS reimburses at 100% rather than 80% as was previously true.

When activists started researching the insurance system, their first finding was that health was considered a commodity or a mere consumer good by commercial insurance companies. "If you want to have it, buy it" was the assumption. Commercial health insurance

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companies were part of a larger puzzle that Barbara Ehrenreich[4] called the medical industrial complex, where each piece-doctors, drug companies, insurance companies and holdings-was profit-driven.

EXPERIENCE RATING OR THE CREATION OF THE HIGH RISK CUSTOMER

Commercial insurers use what is called experience rating. The rate of premium that a prospective customer must pay to obtain health coverage is based on probability theory or actuarial calculation, to use the insurance terminology. Insurers, and more specifically actuaries, calculate the probability of the person falling sick, either based on the person's medical history or on that of the group, with which the person is believed to be identified. Much of their information comes from the Medical Information Bureau (MIB), in Cambridge, Massachusetts. The rationale behind experience rating is to totally avoid high-volume consumers or to have them pay for their sickliness. As far as AIDS is concerned, commercial insurers argue that AIDS patients would ruin them, if they kept them. In reality, AIDS claims represent only 2% of all claims among insurance companies.

The use of mathematics usually indicates concern for accuracy and rigor. A closer look at the insurers' assumptions, based on which those probabilities are calculated, reveals a host of myths filling the objective-looking risk assessment procedure. Still commercial insurance companies use this flawed procedure to develop and justify

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[4]Barbara Ehrenreich, *The Medical Industrial Empire*, New York: Vintage, 1971.

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an endless list of strategies to circumvent their responsibility to cover prospective clients, or even clients who have already paid their premium. Some of those strategies triggered actions from the Health Insurance and Access Committee of ACT UP.

Thus in the Spring of 1991, the National Air Traffic Controllers Association offered for sale a disability insurance policy that was underwritten by Lloyds of London. This policy contained an exclusion against insureds who became disabled from AIDS contracted through sexual contact or drug use. The Insurance and Healthcare Access Committee of ACT UP/N.Y. discovered that such an exclusion was illegal in a number of states where it was offered for sale, including both Illinois and Kentucky. ACT UP zapped the phone of the company that administered the policy, and their business was shut down for a day, but to no avail. The Insurance Committee wrote letters, but did not obtain any answer either. Finally, the Committee filed a complaint in 50 states, as well as in Guam, Samoa, the District of Columbia and Puerto Rico. This time Lloyds rewrote the policy, taking out its AIDS discriminating clause.

Sometimes insurers' discriminatory practices are more subtle. Redlining is a subtle loophole insurers use to exclude PWAs. It refers to the denial of health coverage on the basis of occupation, zip code and residence. A New York Times' article revealed that 40 industries were being listed by insurance companies as ineligible for group plans. According to an August 22, 1989 Village Voice article, insurers such as U.S. Life, Harford Life and New England National Life have deemed ineligible for coverage, people in the following occupations: artists, authors, art galleries, waiters, hairdressers, theater and dance

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companies that are deemed to have a high incidence of HIV infected people.

This type of discrimination is called redlining in reference to the Anti-Discrimination Act, prohibiting discrimination against persons of color with regard to City housing. To maintain racial segregation, City housing authorities would impose criteria they full well knew would not be met by blacks. Although redlining is condemned by the National Association of Insurance Commissioner, it is very common practice.

Lab tests to detect pre-existing conditions are another way commercial insurers use to either deny or dramatically restrict health care coverage.[5] Insurance companies are allowed, although not everywhere, to request HIV testing and discriminate on the basis of serostatus. A few of them may decide that HIV infection or AIDS are pre-existing conditions and start covering those illnesses only 12 months after the customer has purchased his/er policy. Persons with AIDS left untreated for 12 months see their chance of survival tragically diminished.

Skyhigh premium increases are another strategy commercial insurers can use to keep away high-volume users. Some of them have imposed increases as high as 400%. They may also decide to exceedingly increase their co-payment and deductibles.

Since there is very little in the way of national insurance law, insurance regulations greatly vary from one state to another. Some insurance companies may take advantage of this legal variability to

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[5]Sarah Henry, *Redlining People With AIDS*, The Nation, November 11, 1991.

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circumvent the regulation of the state in which they operate by adopting a MET structure. MET stands for Multiple Employer Trust. By creating a MET structure, insurers place a number of small employer group plans (some of these groups are as small as one policy holder) under a single trust contract. This trust is often legally domiciled in a state with lax insurance regulations. The policies are then subject to the regulations of the state in which the trust is domiciled, not the state in which the policies are sold.

The DUAL-Plus company of Long Beach, California, managed METS. Dual-Plus had a blanket exclusion for HIV related-claims, even though California law prohibits blanket exclusions. Companies such as Prudential, Aetna and Lincoln National/ Employers Health have a tendency to market METs to small and medium sized companies, which have only limited funds to spend on their employees' health plan. These smaller firms are willing to accept policy language that creates discriminatory caps and exclusions in order to save money. Noteworthy is that small and medium sized businesses employ the vast majority of workers in the United States.

SELF-INSURANCE, LEGALIZED DISCRIMINATION

The Federal Employee Retirement Income Security Act of 1974 (ERISA), was created to protect employees' benefit plans, especially pensions. ERISA does not, however, require employers to provide specific benefits. Many businesses self-insure under this federal act. A 1990 survey, by the employee benefits consulting firm Foster Higgins, indicates that 73% of large companies are self-insured, as are 44% of

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businesses with fewer than 1,000 employees. Many businesses self-insure because the federal regulation is much more lax than the state's. Thus employers, under this act, can lawfully discriminate against people with AIDS. According to a recent study cited by the Employee Benefit Research Institute, more than half the companies that converted to self-insurance say they did so to avoid state mandates for certain types of coverage

Thus, in March of 1990 Galaxy Carpet Mills, a self-insurer, placed a limit of $10,000 to their lifetime reimbursement for PWAs. Other diseases were not subject to any such cap. Galaxy did make an exception: full coverage was provided for those who would prove that HIV was "involuntarily acquired." According to that formulation, only individuals who contracted HIV through a way other than unsafe sex and unsafe drug injection, were eligible for the coverage.

In May of 1990, ACT UP coordinated a nationwide phone zap of Galaxy, disrupting the order desk during the busiest week of the year. After nearly five hundred phone calls, and within a week, the company rescinded the policy, giving the same coverage to AIDS as to other diseases.

Likewise, in July 1990, Preston Trucking, a self-insurer, which represents 3,000 lifters had no AIDS-related coverage. This time ACT UP sent the company a press release giving them 50 days to rescind their discriminatory policy. Also mentioned in the press release were the victories of ACT UP in curbing the discriminatory policies of Galaxy and Circle K. Preston Trucking complied right away.

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MONEY FOR AIDS, NOT FOR WAR

The Ryan White AIDS Care bill was passed by Congress to aid an overburdened public health care system. Although Congress originally authorized $880 million for such aid, it actually appropriated only $351 million. Less than $145 million of the amount appropriated went to new or expanded programs. In September of 1990, ACT UP demonstrated at the Army Recruiting station in Times Square to protest severe cuts in appropriations for the Ryan White CARE bill by Congress. As an activist eloquently demonstrates, the effort deployed by the government was beyond limit. A comparison with its effort to dealing with AIDS is quite educating:

> The first eight hours of the war cost more than was spent for the first ten years of the AIDS crisis. The Bush Administration sent 2 million people to the middle of a desert virtually overnight. Each federal tax dollar was spent as follows in Fiscal 1991: 52cts to the military-29cts to current military, and 23 cts to past military endeavors (i.e., WWII, Korea, Vietnam, Grenada, Panama)-9cts was spent on the Savings and Loan Crisis and Bailout. 10cts of each tax dollar goes to general government. This leaves 29cts of every dollar for everything else: education, homelessness, AIDS research, prenatal care,

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> infrastructure, medicaid, health care, energy research, mass transit, hospitals, the arts, etc. Specifically, 23cts of that 29cts goes to human resources, the other 6cts to physical resources. This means 0.17 of 1ct of each dollar goes to AIDS, according to 1991 spending levels.[6]

Along the same anti-militaristic lines, two other actions were organized by ACT UP. During the war AIDS coverage was practically eliminated. In January 1991, ACT UP members invaded CBS and PBS studios dressed up as security or carrying ID cards. The ACT UP members waited and as Dan Rather's CBS News Program and the MacNeil Lehrer's PBS News went on the air, they interrupted the live broadcasts, chanting: "Fight AIDS, not Arabs."

In the McNeil/Lehrer studios, activists, chained to desks, were able to speak for several minutes on television about the AIDS crisis.

Finally, on January 26, 1991 a rally in Washington D.C. against the war attracted tens of thousands of people including scores of ACT UP members.

COMMUNALIZATION OF HEALTH INSURANCE ISSUES THROUGH COMMUNITY RATING

The Blue Cross/Blue Shield (BC/BS) insurance network began to develop during the New Deal of the 1930's. Already conventional

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[6]George M. Carter, *ACT UP the AIDS War and Activism*, Open Magazine Pamphlet Series, P.O. Box 2726, Westfield, New Jersey, 007091 USA.

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commercial insurance options were felt to exclude too many people from coverage. BC/BS was designed to function as non profit, quasi-public corporation. It would make coverage more accessible, and in exchange they would be granted tax breaks on their premiums. Over the years, BC/BS was granted a price break for in-patient hospitalization vis à vis commercial insurers. The price break was known as the differential and was set at 13%. If an in-patient hospitalization costs $1,000, the commercial insurer will pay $1,000 plus 13% of that amount, whereas BC/BS would only pay $1,000. These two benefits were granted to give Blue Cross a competitive edge over commercial insurers. The reason BC/BS was granted this differential was to reward it for its "social responsibility."

Unlike experience rating, community rating often implies Open Enrollment, whereby no one is excluded from the policy and the risks are shared by all the pool of policy holders.

Community rating was the long term tradition of BC/BS. In fact this is upon this principle of community rating that insurance companies were created in the nineteenth century. The history of insurance companies in the United States began with the mutual assurance societies, which were set up in ethnic communities during the flood of immigration that began in the last half of the nineteenth century. These societies were money pools which required dues from their members and were indented to cover unforeseen large expenses its members could not individually cover, such as funeral expenses.

In 1896, the Supreme Court ruled in Paul vs. Virginia that insurance was not commerce and not subject to federal law. Not until 1944 did the court reverse this decision, subjecting insurance to federal

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regulation when conducted over state lines. However, in 1945 Congress passed the Mc Coran-Ferguson Act permitting the states to retain primary regulation of insurance, as long as they did so to the satisfaction of Congress.

At this time, the concern for the community prevailed over profit considerations. Decision makers saw a direct connection between healthy individuals and a healthy economy. The term in vogue was community health rather than health industry.

COMMUNITY RATING ENDANGERED, COMMUNALIZATION ENDANGERED

Because BC/BS does not discriminate based upon health status and because commercial insurers do, it ends up providing coverage for all the high-volume consumers of health care. Conversely, commercial insurers end up with a pool of policy holders comprised mainly of so-called "healthy " people and low-volume consumers. They are then able to offer much lower premiums to those they will take. BC/BS is left with an ever-increasing, higher percentage of high volume consumers. This practice is commonly referred to as "cherry-picking." The only way BC/BS claims they can continue to pay for all the coverage used by this group is by raising its premiums, driving even more people away.

In July 1991, Empire Blue Cross Blue Shield (the Blue Cross Association which covers the 28 Eastern and Southern counties of New York State, including New York City and Long Island) applied to the New York State Insurance Department for approval to:

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1) raise premiums of 50% for the individual market;

2) end "community rating" of the small group market;

3) create a "high risk pool" for the small group market, with a corresponding 50% rate increase.

BC/BS is the insurer of last resort for the majority of the otherwise uninsurable. It insures 100 million people, nationwide. Upon the rate restructuring request filed by Empire Blue Cross Blue Shield, which would do away with community rating, ACT UP with other organization formed a coalition of voluntary health organizations in the Summer of 1991. They called it New Yorkers for Accessible Health Coverage. (NYFAHC) It included 30 different organizations, among which People With AIDS Coalition, Body Positive, Long Island Association for AIDS Care and Gay Men's Health Crisis, but also Cancer Care, Disabled in Action, Chronic Fatigue Syndrome Coalition, Hemophilia Association, Leukemia Society, Multiple Sclerosis Society, and National Transplant Support Network.

On January 16, BC/BS, citing "massive losses" withdrew their July proposal and requested approval for the following:

1) increasing premium by 42% for small groups and individual policies;

2) increasing premium by 25% for medicare supplemental policies;

3) stopping the sales of major medical "wraparound" policies to individuals;

4) offering two "bare bones" policies with extremely high deductibles up to $3,000, high annual stop loss up to $20,000, which will

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not cover outpatient lab work, diagnostic X-rays, prescriptions, chiropractic, and no mental or physical therapy.

On Tuesday, February 4, 1992, 16 representatives of this coalition held 14 separate meetings in Albany with State Legislative Leaders and other State Government officials. ACT UP and NYFHAC managed to temporarily halt these rate increases. The superintendent postponed the increase until April 1, 1992 and requested that fundamental reforms of the health care financing system be implemented.

The purpose of those meetings was to press for fundamental reforms in the health care system in the State of New York as it applies specifically to small groups and individuals. Large groups are less affected by high-volume users because the risk is spread over a large enough base.

Insurance activists who attended those 14 meetings wanted to preserve open enrollment, community rating. They also wanted to stop uncontrolled premium increases and facilitate access to insurance coverage for those presently uninsured or underinsured.

At the same time, several bills were introduced by the legislature. Governor Cuomo's Community Rating Bill ("Program Bill #42R) mandated that all insurance offered in the small group and individual market by any insurer be community rated and not be medically underwritten, that is based on the person's medical history. As expected, the commercial insurance industry is vehemently opposed to this bill and is aggressively lobbying against it. They really see community rating as the precursor of a national health care system in this country.

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The Small Group Insurance Reform Bill (S6641) of Senator Valella, Chair of the Senate Insurance Committee was a direct response to the Governor's Bill. This bill was in fact the creation of the "life Insurance Companies of New York" (LICONY)-the commercial industry trade group. It only provides, according to the activists, a few cosmetic changes, since it does not provide community rating and open enrollment.

Similarly, the Schimminger/McHugh Bill (A3719) known as the Small Business Insurance Act was introduced by the Small Business Committee of the Assembly and Senate. This Bill only offers "bare bones" i.e. minimum benefits to the small group market. Like the Vallella's Bill, this bill does not offer real coverage to the employees in those businesses.

The last initiative of the Republicans is to create a high risk pool, meaning that those who are sick, including persons with HIV, would have to pay very high premium due to their condition. Nationally, most pools charge participants between 125% and 150% of a standard average premium rate, but in some states such as Florida the premiums may go as high as 300% of standard average premium for high-risk individuals. In addition, the high risk proposal of the commercial industry does not make any provision for the large group of people who are too rich for Medicaid, but too poor to afford the premiums of a high risk pool. According to a study, the 25 states with risk pool legislation have 13.8% of uninsured versus 9.1% in the 11 states with BC/BS.[7] Yet already in 1988, the General Accounting Office

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[7]Communicating for Agriculture, Inc. *Comprehensive Health Insurance for high Risk Individuals; A State by State Analysis*, 5th Edition, 1991.

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examined high risk pools and determined that they paid out $1.60 for every $1.00 received in premiums. That loss trend has intensified. In addition, administrative costs are over 12% of premiums, as opposed to approximately 7% of premiums which Empire Blue Cross Blue Shield currently reports. Finally, high risk pools do not improve care.

ACT UP in conjunction with NYFHAC voiced its objections to all Republican initiatives, and pressured the Legislature to enact NYFHAC's reforms by April 1st, 1992.

GENERALIZED COMMUNITY RATING OR NATIONAL HEALTH CARE

The existence of BC/BS is in jeopardy and activists want to preserve Open Enrollment and Community Rating. Insurance activists are aware that even if BC/BS is saved, many million of people will still not be able to access health care. In the meantime, medical costs keep rising. The total health care costs were up by 42% over the last five years. One out of every eight dollars spent in the U.S. is spent on health care, close to 12% of the Gross National Product (GNP). And it is expected to climb to a record of 14% of the nation's output of goods and services in 1992 according to a Commerce Department's report titled *U.S. Industrial Outlook 1992*.[8] In addition, the Commerce Department predicts it will be 17% in the year 2000. No other industrialized nation spends as much. Canada spends between 8 and

[8]Walt Bogdanich Health Expenditures Expected to Climb to Record 14% of U.S. Output in 1992,Wall Street Journal January 30th,1991.

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9% of its GNP for health care, and most European countries spend much less.

IF SO MUCH MONEY IS SPENT ON HEALTH CARE, AND SO MANY PEOPLE DO NOT HAVE ACCESS TO HEALTH CARE, HOW IS THE MONEY WASTED?

ADMINISTRATIVE WASTE

Of every health care dollar, 15 to 50% goes just to pay for administrative overhead. Private insurance companies spend between 15 to 35% of every dollar paid as premiums on administrating their plans. Thirteen percent of every individual policy premium dollar goes to support the sales agents.

CLINICAL WASTE

Clinical waste is the massive amount of inappropriate, ineffective or unnecessary procedures and care performed by the U.S medical industry. Even Secretary of Health Louis Sullivan, the New England Journal of Medicine, as well as an array of medical researchers and experts agree that at least 25% of all things done by the American physicians today do more harm than good.

Various surveys reveal that 44% of coronary bypasses, 56% of pacemakers, 16% of angiograms, 25% of cataract surgeries, 21% of hospital admissions for children, 40% of medications prescribed to

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senior (resulting in 15% of all seniors' hospital admissions) and 50% of all Caesarean sections are either unnecessary or inappropriate.

These are not random mistakes made by doctors. The victims of these unneeded procedures are selected based on who is paying the bill, their income level, where they live, or even the occupancy rate of the hospital to which they happen to be admitted. The Rand Foundation found patients are two to four times more likely to receive a certain heart procedure based solely on where in California they live. Caesarean section rates are highest in private hospitals, and lowest in public hospitals.

SYSTEMIC WASTE

Systemic waste is due to the fact that the health care system in the U.S. is not organized to meet the needs of people in the most clinically or cost effective way. Rather it is based on a lucrative partnership of fee for service medicine and private insurance. California is building more hospital rooms despite the fact that the occupancy rate is 60%; at the same time, over crowded emergency rooms are being closed.

Very expensive diagnostic equipment are bought and costs must be recouped as soon as possible. For example a Magnetic Resonance Imaging Machine costs 2 million dollars. (It allows instantaneous scanning of bodies). Doctors are then pressured to prescribe this type of procedure at the expense of the patient.

More generally, we have a system which spends huge sums of money on heroic measures (organ transplants etc..) but ignores basic

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health maintenance. The death rate for some black women, caused by diseases today's medicine can treat is way too high. Likewise, the average life span of a male in Harlem is shorter than for a male in Bangladesh.[9]

Even Health Maintenance Organizations, (HMO), originally created to emphasize preventive medicine, are more and more concerned about profit considerations. They were designed to address the skyrocketing health care costs. They have enrolled millions in programs that, for a set monthly fee provide routine primary care. Instead of receiving fees for specific services, physicians are paid a set salary. The problem is that HMOs, while originally non profit organizations, have become profit-making corporations which are aggressively competing for healthy, young, white patients and avoiding the poor, people of color, the elderly and people with a predisposition to illness, including people with HIV infection. The more patients an HMO sees the greater the profit margin. HMO doctors and hospitals are therefore driven to treat as many patients as possible creating a factory mentality for health care delivery.

NATIONAL HEALTH CARE, AN ACTIVIST DEMAND

Three out of four Americans would like fundamental reforms in the health care system in the U.S. Up to 60% would like to trade our system for the Canadian system. Only 4% of Canadians want the American system.

9Neil McGhee, *Insurers Upbraided On Rise In Health Care Costs*, National Underwriter, February 4, 1991.

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Even some of the nation's largest corporations, including Marriott Corporation, Ford Motor Co, American Telephone and Telegraph Co.,
Dupont Co. and Eastman Kodak Co, have joined with a number of the nation's largest labor unions in an effort aimed at enacting some form of national health insurance.[10]

In October 1, 1991, following a month of actions and ending with a demonstration at the White House, ACT UP continued its assault with a massive civil disobedience at the U.S. Capitol to demand National Health Care.

Over 450 demonstrators, representing 23 national ACT UP chapters, affiliate organizations, and the 3000-member group "Physicians for a National Health Care Program," stormed Capitol Hill demanding a National Health Care Program and an end to the AIDS crisis. Activists closed Independence Avenue in front of the Rayburn Office Building and stung congressional leaders with biting "Political Guerrilla Theater" on the Capitol steps, while the fountains at the Supreme Court ran blood-red, an indictment of government ineptitude and inaction in the face of the AIDS epidemic.

In the U.S. Capitol Building itself, 37 demonstrators were arrested in the rotunda as AIDS activist Brad Lengyel stormed the Senate floor, disrupting the session to demand universal health care and an end to the AIDS crisis. Said ACT UP member Scott Robbie:

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[10]Frank Swoboda, *Major Firms, Unions Join in National Health Insurance Bid,* The Washington Post, , Wednesday, March 14, 1990.

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"We indict the members of Congress for crimes of greed in their collusion with the American Medical Association, insurance, and pharmaceutical industries in denying U.S. citizens adequate health care."

ALONG WITH OTHER ORGANIZATIONS, ACT UP MADE HEALTH CARE, A PRIMARY ISSUES, DURING THE 1992 PRESIDENTIAL PRIMARIES

Never before AIDS was health care such a political issue. All candidates have had to come up with some form of health care plan. Bush is proposing tax credits ranging from about $1,000 to $3,000 for the poorest families. Bush's program is estimated to cost up to $100 billion over the next five years, but no funding method was offered. The program includes essentially vouchers or tax credits for the purchase of health care by the government, up to $1,250 a year for individuals, $2,500 for couples and up to $3,750 for families of three or more. There is an $80,000 annual income limit for the benefits. Health care tax deductions would be allowed for Americans with incomes up to $50,000 for individuals, $65,000 for couples and $80,000 for families of three or more. Self-employed persons would be allowed to deduct 100% of their monthly health care premiums. Small businesses could pool purchases of health insurance plan for employees. Insurers would be required to cover people with pre-existing diseases, with no waiting period when changing jobs. The use of managed care plan for Medicaid and Medicare would be expanded and states would be

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encouraged to use such plan for tax credit recipients. States would be urged to cap malpractice awards for pain and suffering and other non medical damages. The use of dispute resolution to avoid lawsuits would be promoted and medical practice standards and guidelines offered.

On the democratic side, Bill Clinton espouses the "play or pay" approach adopted by the Democratic leadership in Congress, which would require all employers to either provide health care coverage or contribute to a national fund to cover all uninsured workers.

Paul Tsongas would use a form of "managed competition," in which conglomerates of health-care providers (employer groups, unions would pool their bargaining powers in single payer units to bid for health care at the minimum cost for full time workers, while the federal government picks up the tab for the jobless and part timers.) It would be financed through a payroll tax on business to cover the uninsured.

Bob Kerrey would adopt a Canadian-style universal system of national health care with the federal government taking charge of all coverage. Although there is no consensus in ACT UP around the issue of what type of national health care system the activists would like, the Canadian system seems to be the predilection of many of them.

The modern Canadian system began in Saskatchewan in 1962. Within a decade, it was available in each of the provinces. Some differences among provinces persist, but generally coverage is universal and comprehensive. Private insurance is, for the most part, outlawed. Fees are standardized, and health care providers are prohibited from adding to the established fees. Ninety-five percent of

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Canadian physicians are self-employed (more than in the United States) and patients can choose among them. Most of the funding for the Canadian system is raised through taxes on income, although Alberta and British Columbia impose a premium of about $425 per year per family. There is some cost sharing with the federal government so that poorer provinces are not penalized.

The United States spends 38% more on health care per capita than does Canada. Eighty one percent believed the health care system needs fundamental change. Physician fees in the United States are nearly two and one-half times those of Canadian physicians.[11] The plan would be financed entirely through payroll taxes on employers and employees.

While the concern for health care has become a national priority thanks to the pressure of groups like ACT UP and others, the concern for communities' control over access to the type of care that they need and want has not crossed the mind of one single politician running for presidency.

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[11]Judy Haiven, *MediScare*, Mother Jones, April 1991.

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ACT UP'S STRATEGY: SELF-EMPOWERMENT AND DIRECT ACTION

ACT UP's strategy is based on two concepts: self-empowerment and direct action. Self-empowerment is enhanced by the unwillingness of ACT UP to be affiliated to any party. This is what the group means by being a non partisan group. Self-empowerment is also enhanced by the very structure of the group. As the Structure Section described only the floor can make decisions about vital policies and financial matters. The Coordinating Committee can only make financial decisions up to $1,000 amount. Even those decisions can be overridden by the floor, that is by the activists themselves. Elected positions in ACT UP are rotated often so that individuals do not build up untouchable power turfs.

ACT UP does not have any paid staff, nor does it have a president. The role of the administrators is reduced to strictly administrative tasks such as ordering supplies for the workspace and making sure that the machines--fax, copiers, computers etc.--are working.

Although there is structural room for self-empowerment for everybody, the expression of self-empowerment is different from one individual to another, depending on the area the individual is working as those different responses suggest:

> Self-empowerment is at the heart of ACT UP's philosophy. The very name of ACT UP, AIDS Coalition to Unleash Power, includes the word

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> power and describes very well the main goal of the organization. We have to organize to become powerful, not only as a group, but also as individuals.[1]
>
> Self-empowerment for me is being able to affect change in a real way and quickly. Time is our enemy. And self-empowerment is not just a personal thing, to help myself. It is helping find a cure. And that's more complex.[2]

The following letter, however, best embodies the expression of self-empowerment:

> As some of you know, I'm leaving the city on May 18th (I'll be back for visits, I hope) and driving to that conservative pie-in-the-sky town of Colorado Springs, Colorado (home of Fort Carson Army Base, the Air Force Academy, Neil Bush's Silverafo Savings, the John Birch Society, and that wonderful group Colorado from Family Values who're in the process of bringing the already passed gay rights anti-bias bill to a vote in November to recall it). But before I leave I want to take the opportunity to thank you all for making me an AIDS activist.

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[1]Personal Interview, 1992.
[2]Personal Interview, 1992.

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I sat out the civil rights movement (I was in college and afraid), and I sat out the peace movement (I was a music teacher in a small town in Kansas). And I sat on my butts for 10 years of the AIDS crisis and did nothing but hold hands, attend funerals, and cry. After seeing the Wall Street action on TV, activism began to make sense. Over the last summer I began to move from sorrow to anger and I knew I couldn't sit any longer... You had me. Last July I joined ACT UP.

Sorry if this seems trite and you already know it, but let me remind you of it. You can create activists--you did it for me! I could no longer stay in my gay closet and let my queer, straight, black, white, Asian and Hispanic brothers and sisters and children die. Not now--not ever again. You did this--by putting your lives on the line.

Never forget this--YOU ARE VERY IMPORTANT PEOPLE--ALL OF YOU! Never forget it. Any one sitting in Cooper Union listening to us squabble would not know how powerful collectively we are.

Thank you for empowering me and teaching me how to use it.

Special thanks go to the Needle Exchange Committee (Where I got to do minor C.D. every Saturday in Brooklyn) and to all those people (ACT

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UP or not) who faithfully make bleach kits, and who paint and distribute clean syringes every week rain, snow or heat. I joined N.E. after my 2d ACT UP meeting. Hopefully soon we can do other things with that money if New York State will "grow up."

Also thanks to those who helped me through my first CD at the American Dental Association and the subsequent court appearances.

I owe so much to so many of you, please let me say publicly a final thanks to: Amy Bauer for her strength, her CD training and her "Pipes"; to Donald Grove for his anger and my first male to male kiss; to Joe Chiplock for his great enthusiasm even in the rain and cold; to Steven Barker, Steven Schiff and Rod Sorge for their patience with a beginner; to Peter Ennis for his calm; to Nora Ghibbons for her joy; To Lon Harvey for his grace; to Bob Rafsky for his wisdom and fierce words when needed; to Sharon, my wife of 25 years; and to all of you who work and work and work to end this crisis.

It's nice to be trained by the best!

I hope in the future to be able to report that you didn't waste your time on me. I want to start an ACT UP/Colorado Springs. There are many issues there that need to "ACT UP touch."

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> You're all invited to stay with us as you pass through Colorado, home of beautiful Pike's Peak.[3]

Much of the work of ACT UP has been to challenge the word "expert." As the later sections will show ACT UP has succeeded not only in questioning the "experts' position," but convincing those experts that the perspective of the persons affected by the disease is a scientifically valuable one. Some people in ACT UP are professionals. In fact, over fifty percent of the members surveyed in 1989 had graduated from college. Many teach-ins were organized to share the knowledge to lay individuals who want to work in a specific area. For example, before the 1989 FDA actions, several 3-hour FDA teach-ins were organized. Participants could ask any question that came to their mind without feeling discomfort.

> At first in T&D (Treatment and Data Committee) we had teach-ins organized by people who in were professionals in the field. Then we were able to do the readings ourselves. The drug-buddy system was also helpful for people who wanted to get acquainted with the pharmaceutical terminology.
>
> I personally use the AmFAR guide a lot. I do not have the time to go to the library, but I can use different publications such as John James'. Articles

[3]Farewell Letter of ACT UP activist, May 1992.

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> are distributed during the meetings and I use them a lot too. We also receive professional publications, that I can use too.
>
> Now we are reaping the fruit of the old T&D, who was helped by a few professionals, and had to work much harder than we do.[4]

As in the Women' s Health movement, biomedical research was used for obvious political reasons. As in the Women's Health movement, biomedical research was used by many lay individuals. As in the Women's Health movement, biomedical medical science had become part of the every day's culture of lay people.

DIRECT ACTION

Direct action is the second pivot of ACT UP's strategy. In the midst of an epidemic, that activists would rather call "crisis," standard lobbying strategies cannot work. They have not worked with cancer, they will work even less in the case of AIDS. Activists argue that lobbying around cancer has done nothing, but bureaucratized the disease, preventing any overall appraisal of research on cancer.

In turn, direct action is the main tool of ACT UP's strategy:

> Direct action allows you to go right to the source of your oppression. As opposed to letter writing, you

[4]Personal Interview, 1992.

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> show your oppression right in the face of your oppressor.[5]

The number of ACT UP's direct actions is so impressive that only a few examples can be selected. Activists took over the AIDS conference in Montreal in 1989 and declared the Bill of Rights for Persons with HIV in front of a worldwide audience. In 1989, they shut down the Food and Drug Administration. In 1990 and 1991, they "stormed" the Centers for Disease Control for failing to expand the definition of AIDS to include all populations affected by HIV. They "stormed" the National Institutes of Health, in May 1990, to expose the inadequacies of its drug trial system. In June of that same year, they shouted down Health and Human Services Secretary Louis Sullivan for upholding restrictions against foreigners with HIV. One of the latest sensationalist direct actions was organized by affinity group called Treatment AIDS Guerilla (TAG), which later on separated from ACT UP. To protest Jesse Helms' discriminatory AIDS politics, they planted a huge condom over his house in Virginia in September of 1991.

CIVIL DISOBEDIENCE

Almost inevitably, direct action calls for some form of civil disobedience. Because the political system allows only rarely for direct confrontation between concerned parties, the activists were forced to elect civil disobedience as a way to attract attention, as a way to force

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[5]Personal Interview, 1992.

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politicians or scientists to deal with the issues. Critics of civil disobedience have condemned ACT UP for disrupting conference or stopping the New York Stock Exchange, yet not until then did so many meetings including activists take place in the history of medicine of this country, even the world.

Civil disobedience has also been used to literally save lives. Needle Exchange Program and Y.E.L.L's Condom Distribution Program of ACT UP, before they were legalized by the City, have both saved thousands of lives. "Storming" the FDA and the NIH both resulted in the creation of a Women's Committee and the quicker release of drugs not only for Persons with AIDS, but also other diseases.

Civil disobedience has also been used for personal purposes. As one activist explains:

> Up until now I could not violate laws that were oppressing me. With ACT UP, I can violate them for what I stand, for what I think is right, without worrying about the consequences. It's so empowering to see that you were part of a civil disobedience, which helped further a life-saving cause.[6]

Before each action and civil disobedience, activists go to a special training and learn basic logistical and legalistic recommendations. Actions are thus well supervised legally and have never led to serious

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[6]Personal Interview, 1992.

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sentencing. Not even the propriety trespass sentence in the case of holding former New York City Health Commissioner Stephen Joseph in his office translated to community service, which activists performed for diverse AIDS organizations.

ZAP

In addition to those very costly dramaturgical actions, ACT UP is also known for its smaller zap actions. A zap is a quickly organized action by a small number of activists. It is quickly organized because the occurrence of the event does not allow for more preparation. An activist would usually look into the *Sunday Times' Charity Events*,. This is how they found out during the 1989 Mayoral campaign that Rudolph Giuliani, opponent of David N. Dinkins, would be the guest of honor of the Liberal Party's annual dinner. This was, for the activists, "the" opportunity for a zap.

The activists had checked out the Hilton Hotel, where the event was scheduled to happen. They realized that one back door gave access to the ballroom, where the dinner was planned. Dressed up as businessmen they walked through this door, totally unnoticed. They started to distribute leaflet explaining that Rudolph Giuliani have neither AIDS policy, nor gay and lesbian agenda. Disrupting Rudolph Giuliani's speech, the activists started to chant: "Giuliani, Where Is Your AIDS Plan." They were evicted to the sounds of "Die Faggots" and the threat of violence from certain "liberals." The Hotel security rushed to the ball room to protect the demonstrators, who finally left

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with the satisfaction that, if not well received, at least the message had been sent.

YOU MUST FUND THE FUN

Right after the first large demonstration, ACT UP realized that money would be necessary, and therefore a problem. Because of the nature of the epidemic, people from all walks of life were drawn to ACT UP. The survey showed that a third of ACT UP was quite well off, a third lower middle class, and a third very poor, some of them with no money whatsoever. Thus the first Wall Street demonstration was funded by Larry Kramer who lay down the first $1,000.

Unexpectedly, a symbol--*Silence=Death*--created out of passion and rage, became one of the greatest profit makers of ACT UP. The *Silence=Death* project gave ACT UP the right to use their logo on a T-shirt. Thousands of them were bought at the March, 1987 gay pride. Another thousand T-shirts were bought by heterosexuals who did not have the slightest idea that the *Silence=Death* Logo would become the emblem of the AIDS community. Around the same time an activist expressed the idea that since other political organizations had their buttons, there was no reason that ACT UP should not have its own. A button was then created using the same *Silence=Death* logo, and another international market opened to ACT UP, as well. One thousand buttons were sold during the 1987 gay pride march, and another thousand were sold at the 5th International Conference on AIDS in 1988. Then, at the next AIDS Walk, activists sold all their button supply in 25 minutes.

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Gran Fury, a collective working with ACT UP, although separate from the group, worked on several posters, such as the*AIDSgate.* Likewise, those posters quickly became motives for T-shirts. And during the National march on Washington in 1987, people rushed to buy the 2,000 T-shirts.

ACT UP also turned to the bars to organize fundraisers. Although some did not wish to be associated with ACT UP, the majority of the bars agreed to hold fundraisers for the group. ACT UP had a policy to approach only bars that did not have a discriminatory admission policy. The first fundraiser took place at the Saint in August 1987, at the end of which a couple of thousand dollars were collected. Others followed at the World, the Palladium, Lick It, Limelight, to name just a few.

Fundraising had to become ongoing and generalized. A brochure was put out and sent to the couple of hundred of people who attended the ACT UP meetings. A group of activists formed the Fundraising Committee and decided to contact other fundraising organizations to propose to them a judicious exchange. The product of this exchange became the ACT UP' s larger donors list.

The use of "big names" became a popular fundraising tactic. In the Spring of 1988, Harvey Firestein was asked if he would sign a fundraising letter. Since then, the entry of money kept on increasing.

The year of 1988 marked the professionalization of the Fundraising Committee. A former Wall Street stock broker joined the committee with his computer, fundraising letter knowledge, balance book, and mailing list. A PO box was rented and since then money has

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not stopped pouring in, as it was pouring out to fund the increasingly expensive actions of ACT UP, as well.

In 1989, the internationally known Keith Haring generously helped the Fundraising Committee by donating several posters, among which the *Dance for Life*, *Silence =Fear, Hear no Evil, Speak no Evil* posters.

Keith Haring, along with Peter Max, also participated in the 1990 Auction for Action, which became the greatest money maker in ACT UP's history: close to half a million dollars were collected in one night!

The Fundraising Committee decided to touchbase with a mass mailing company and was able to send 100,000 letters, the result of which was the collection another half a million dollars.

The use of celebrities was now a key components of ACT UP's fundraising strategies. Showbusiness stars, including Grace Jones, Jimmy Sommerville, Billy Bragg and others donated the proceeds of their benefit to ACT UP.

MEDIA, NECESSARY NARCISSISM

The role of the media has been considerable in reinforcing this sense of self-empowerment. ACT UP realized from day of its creation that the media played the role of a microscope, magnifying small events into worldwide phenomena. . Already in the Fall of 1987, the Media Committee was formed. At first, the Committee worked around the gay press, but as time went on and as new professionals joined the group, the Committee expanded its attention to other media, including mainstream newspapers, radio and television shows.

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Some of the first members of the Media Committee were already well established in the media circle. One members would relay information to Liz Smith for her "*gossip,s*," while another was working for *Good Morning America.* Soon enough, the vice president of Public Relations --one of the most powerful public relations firms-- and the person who, later on was to become Interview's editor, joined the Media Committee.

Already in 1988, the Media Committee had identified a possible ally in the New York Times, an openly black gay male journalist. That same year, a major feature about ACT UP appeared in the New York Times. As one member argued:

> This helped us be on the map. During the Anniversary Action at Wall Street, there were more journalists than demonstrators.[7]

If the media can inflate an event, they also need to be informed. ACT UP devised the press kit, which is a folder including the description of the issue and the action, a historical capsule of ACT UP and a glossary of terms that the media must understand before broadcasting AIDS-related news. For example it took a long time for the media to understand that ACT UP did not wish to be presented as a gay and lesbian group but as an AIDS group. Also, it took a long time for the media to understand that PWAs did not wish to be called *AIDS victims.*. Most of them have adopted the terminology, including the

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[7]Personal Interview, 1992.

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New York Times. Finally, the press kits were full of soundbites that the media could easily pick for their articles.

As the Media Committee evolved, its role became more and more vital to AIDS activists. Media became important for three reasons:

1) Media allowed events to be covered. For example, in November, 1991 Board of Education member Irene Impellizeri did not have a position on condom availability. Y.E.L.L, the youth committee, decided to double the pressure against the Board member. They organized a civil disobedience at Borough Hall against Howard Golden, the Brooklyn Borough President, to whom Impellizeri reports.

In order to attraction media's attention, the Media Committee chose to use words such as "youth," and "condoms." Media members knew that certain words would lure the media more easily than others. For that event, the journalists were at the demonstration site before the activists themselves. Media Committee members have steadfastly become savvy at dealing with the media:

> The AIDS market is saturated. So I know what to say, and what not to say. It's about packaging the issue. Both meet the purpose of the activists and the media.[8]

2) Media protected against violence by the police. Indeed the rare incidents of violence that activists encountered occurred when the

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[8]Personal Interview, 1992.

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media was absent. In February 1991, 3 ACT UP members were arrested and beaten for spray painting. The following week, ACT UP decided to have a demonstration to protest police violence. The police were able to relapse, because no media were present. Chris Hennely, a demonstrator, was beaten, hospitalized. Immobilized for three months in a wheel chair, he is left with permanent brain damage.

3) Media could be used to further the goals of an action. For example, In April of 1989, four activists decided to organize an action to pressure Burroughs Wellcome to lower the price of AZT. They went down to North Carolina--Senator Jesse Helms' State--to lock themselves up to an office in the company's headquarter. The media had already been called in advance, but remained silent about the upcoming event, because ACT UP members had promised them a good piece of news.

Although the media covered the event, Burroughs Wellcome did not change the price of AZT. In September of 1989, dressed up as businessmen, activists introduced themselves in the Wall Street New York Exchange and shut down the international market for five minutes. Still, Burroughs Wellcome refused to change its price.

AIDS groups throughout the country sent a consensus letter to Burroughs Wellcome, which still refused to decrease its price. One of the media members decided to talk to the New York Times about it. The paper decided to cover the event, and Burroughs Wellcome, deluged with criticisms, was forced to lower its price.

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> We were trying to affect the corporate culture, which I knew very well, since I had been in it for so long.[9]

The Wall Street Journal, too, decided to write a story about ACT UP. It led the story with the Burroughs Wellcome action, shaping or changing the perception that many people had about the group. In the Fall of 1989, the price of AZT was lowered by 20%.

This was the ultimate use of the media by the activists: to have them unconsciously partake of the action. Many activists were stunned by the power of the media, and how it could be used through diplomacy and astuteness. As an activist put it: "We played with the media, and beat them at their own game."[10]

The power of ACT UP over the media was certainly not limitless. One of the most controversial ACT UP 's actions--St Patrick's Cathedral demonstration--was controversial because of the media's representation of the action. The media totally discarded the activists' analysis, although press kits were sent to them, explaining in detail the reasons ACT UP was demonstrating in front St Patrick's Cathedral. The kit made it clear that the church hierarchy--and not religion--was questioned, and most particularly the Cardinal O'Connor, whose position, was according to the activists, killing so many people.

During the demonstration a group of activists walked into the church, and posed as worshippers. As the Cardinal was extending the

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[9]Personal Interview, 1992.
[10]Personal Interview, 1992.

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wafers, one activist crushed the wafer, while others started to scream at the Cardinal that his position towards AIDS was a murderous one.

Although Media Committee representatives explained that the inside action had been organized by individuals, without consulting with the floor of ACT UP, the media went on to present this punctual event as the main event and purpose of the action.

A press conference was organized the following week. Unapologetic, ACT UP Media Committee representatives re-explained the reasons and the target of the demonstration, but to no avail. The media still refused to present this new version.

EXPERTIZATION VERSUS COMMUNALIZATION

Between 1990 and 1992, committees became more and more specialized--expert--whereas the rest of the membership did not keep up with the level of knowledge required to fully understand the issues. Teach-ins became rarer as well as hand-outs and handbooks. At the same time, the gap between the committees and the floor became wider and wider.

The result of this uncontrolled spiral was a drastic change in the dynamic between the floor and the committees. Committees would come to the floor with their own analysis of an issue, without consulting with the floor. Whereas the floor would expect the committees to come with the issues, presented and analyzed. The action was expected by the floor to have been thought out by the committees and ready for vote.

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T & D provided a good example of this development. Although people attending the meeting were of quite diverse origins, the discussions were tightly controlled by a group people who had become--many of them highly credentialed already, i.e. Harvard graduates, physicians, lawyers among others--expert in the field.

Less concern was paid on trickling down the information to the "lay lay" individuals. In fact, many activists were complaining that it was harder to ask genuine questions in the meetings for fear of disrupting the flow of conversation and feeling embarrassment for displaying ignorance. Although most of the veterans have gone from T&D to join a new organization--TAG--the new group of T&D members has not yet set up any teach-in mechanism to involve more activists in treatment issues.

The floor has become a passive consumer of the committee's work leaving way to a long time avoided structure: hierarchy by knowledge status. Thus, ACT UP counts several "czars" on different issues, forging their own coalition outside ACT UP, and reporting to the floor only when the action is ready for a vote: the Insurance, and Treatment and Data Committees offer good examples of the expertization process that ACT UP is going through. The last Treatment Agenda was geared toward the scientist community and not the activist community. An activist qualifies this development with much pessimism: "We are being eaten by the monster we created."[11]

The highest form of expertization is the creation of outside structures. Because of the the lack of real formal power structure in

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[11]Personal Interview, 1992.

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ACT UP, some activists have found a way to establish a external power structure of their own, yet staying in ACT UP and benefitting from the advantages of dual membership.

So instead of being at the service of the larger community, ACT UP is becoming more and more the refuge of experts, who organize their action outside ACT UP, and come to ACT UP to ask for funds and mobilization.

This disconnectedness led to some unexpected and contradictory actions. In 1991 during the "storming" of the first Conference on Women and HIV, which had been voted upon by the floor, T&D activists had dinner with some NIH officials.

INSTITUTIONALIZATION AND BUREAUCRATIZATION

Indicative of the progressive institutionalization of ACT UP is the presence of activists in the International Conferences on AIDS. Not one single conference is planned without the official invitation of activists by the organizers. Panels are pre-arranged between activists and organizers.

As there are fewer actions, ACT UP relies more on its popularity. ACT UP does not need to call the media to draw their attention as used to be the case before. Now, journalists call ACT UP to know its opinion on many AIDS or gay and lesbian-related issues. For example when Presidential candidate H Ross Perot announced that he would not hire a gay person, ACT UP was called right away to make a position statement. An activist summarizes the situation: "we've gone from

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'challenging the experts' to 'we are the experts' to 'we have the experts'."[12]

Although the bureaucratization process of ACT UP is far from completion, like any organization, it gradually follows its institutionalization process. Progressively, some activists find comfort in ACT UP, and tend to be more interested in renewing their prestige position in ACT UP than fighting the issues. As an activist suggested: "ACT UP is seen as a home, rather than a tool, by a growing number of members."[13]

Institutionalization and bureaucratization are the flip side to communalization, which requires flexibility and creativity.

PROFESSIONALIZATION VERSUS COMMUNALIZATION

Professionalization can be defined as obtainment of money for one's expertise, a relationship that ACT UP had fought since its creation. The Weberian corollary to professionalization is that professionals have a delineated area of power, which they usually intend to protect.

The professionalization process in ACT UP started in 1989, when many activists--most of them male--started to obtain paid employment in the AIDS industry. T&D again provides a good example of this new trend among AIDS activists. In this committee alone the majority of active members were professionally involved in some AIDS

[12]Personal Interview, 1992.
[13]Personal Interview, 1992.

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organizations, whether it be AmFAR, GMHC, CRIA, ST Vincent Hospital, or the PWA Health Group, to name just a few.

As early as 1989, AIDS Treatment Registry, an ACT UP spin off, became the AIDS Treatment Resources in 1990, with a board of director and paid staff. Most ATR staff were ACT UP members, and in that capacity could come back to the floor to ask for money for their own organization. ATR obtained in this fashion $25,000 from the floor. Eventually, ATR was taken over by AIDS Treatment Data Network in 1991.

Housing Works, is a non-for-profit organization came out of the Housing Committee of ACT UP, which granted seed money for the new organization to take off. Some of the Housing Works staff are also ACT UP members, who, too, shuffle back and forth between ACT UP and Housing Works.

Using a special waiver from the City, and pending legalization of needle possession, the Needle Exchange was awarded a grant from AmFAR and the State for its Lower East Side Needle Exchange program. The project director, a member of ACT UP, is a salaried employee.

VOCAL--Voices of Color Against AIDS and for Life Inc--a Latino organization, spin off of ACT UP, was formed by a member of ACT UP. Although the organization is not part of ACT UP, members of the organization use their dual membership and can thus use both organization. VOCAL has a board of directors, and pursues funds from public and private institutions. VOCAL staff are working on developing a relationship with BAM, Black AIDS Mobilization, a former ACT UP caucus, now independent organization.

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As of April 1992, an Alternative Treatment activist is in the process of creating its own organization: Treatment Alternative Project, Research and Empowerment Inc. The organization would have two purposes: to obtain treatment with no pharmaceutical sponsorship to be researched. The second involves community education to allow lay individuals to evaluate information presented to them. The office is located in the PWA Health Group and funds are being pursued to pay prospective staff.

TAG is probably the spin off of ACT UP which caused most stirring among activists, leading them to think that a schism may soon happen. No such thing happened. But TAG epitomizes the extreme form of expertization and professionalization coming out of the ACT UP culture.

Born as an ACT UP affinity group, TAG--Treatment AIDS Guerilla--engaged in some extravagant actions. Planting a gigantic condom up the roof of Jesse Helms' house in Virginia during was their response to the senator's anti-gay, anti-HIV positive, and anti-AIDS legislation in the fall of 1992. The inflated condom displayed: "A Condom to Stop Unsafe Politics. Helms is Deadlier than a Virus."

TAG organized a coalition of 16 groups AIDS groups to ask Astra Pharmaceuticals Inc. in Massachusetts to lower the price of Foscavir. Astra's drug--Foscavir--costs $21,000 annually. The drug combats an eye infection that often causes blindness in the final stage of AIDS. Patients typically need to take the drug for the rest of their lives.

Greenpeace provided technical advice for a second demonstration on October against Daiichi Pharmaceutical in Fort Leo, N.J. TAG activists blockaded the company's reception area by

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handcuffing themselves together inside plastic tubing. They were protesting the slow development of a cancer drug that may work against a skin cancer common in AIDS. TAG didn't secure any promises from the company, but they did happen to find a confidential memorandum in a fax machine that indicated that the company will pursue federal approval to market the drug this year. There were no arrests in the action.

Back in November the group considered blocking the driveways into the White House to protest the AIDS policies of the Bush Administration Greenpeace taught them how to chain people underneath trucks in such a way that the trucks must be dismantled to safely remove the activists.

Divorcing itself from ACT UP, TAG--Treatment AIDS Group--formed in January of 1992. TAG is formed of two committee. A policy committee which functions very closely to T&D, and also nominates other people to join the group. The vote has to be unanimous. The Administrative Committee has total leeway with regard to administrative tasks and needs no approval from TAG's floor. TAG membership is by invitation only. TAG plans to finance its work through national direct mail solicitation . They expect to spend $200,000 in 1992. Members said they raised $5,500- for the first two actions with a few phone calls.

Defying all paradoxes, Treatment AIDS Guerilla (TAG) TAG was awarded a grant from Burroughs Wellcome in April, 1992 and pays its members. TAG represents the highest form of professionalized activism.

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POLITICAL CORRECTNESS AND THE LEGITIMATION OF EXPERTIZATION AND PROFESSIONALIZATION

As the floor's influence weakened, cliquishness intensified, and so would personality issues. Whereas personality issues always existed before, a much stronger floor was able to contain them. Yet as the floor's participation lessened, those personality issues would take on much greater significance.

In the context of a weakened floor, recriminations of representational and political incorrectness would ultimately be detrimental to ACT UP.

Communalization of an issue meant that although a consensus was not always reached, communal conscience mandated that activists had to be consistent with and respectful of the floor's decision. Cliquish politics would not only destroy communalization, but would also paralyze the strength of the floor.

REPRESENTATIONAL INCORRECTNESS

The issue of representation was not a new one in ACT UP. Should the group be identified as a Gay and Lesbian group? Should it be identified as an AIDS-specific group? And in either case: was the group representative of the whole spectrum of the communities affected?

This question had always been central to ACT UP, yet never been divisive or destructive to the group. Activists realized that universal representation would be too ambitious or ambiguous a goal. So like

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any other group, ACT UP would be representative of itself, and through outreaching would attempt to diversify itself as much as possible.

Representational concerns peaked during the formation of the Community Constituency Groups (CCG), which were intended to represent the AIDS communities at the AIDS Clinical Trial Groups (ACTG's). Some activists in ACT UP thought that the appointees were not representative of the communities because they had not been chosen by the communities themselves, but by the ACTG's. Yet other activists thought that communal representation in ACTG's was an achievement never reached before and criticisms should be moderated, because the few gains made could be as easily lost. Division started started to mount.

One clinical trial in particular--trial 076--caused a major split in ACT UP reflecting the growing alienation among the diverse groups. The purpose of 076 was to study the effect of AZT on perinatal transmission. Some ACT UP members, men and women, disagreed with the fact that 076, the first trial on women, should focus on the fetus and not the woman, when a study had already revealed that AZT could be carcinogenic to women.

In March 1991, the dissenting activists went down to Washington to attend the 076 investigators' meeting. There, they had to face attacks of racism for allowing themselves to speak about a community, of which they were not part. Back to New York City, they were faced with the same attacks.

Not only was race used against those activists' action, but their serostatus as well.

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> Seronegative ACT UP women were presuming to tell HIV infected women of color what to do. While the CCG thereupon took up the issues around 076 and tried to change the trial, the factional disruption impaired ACT UP's credibility and destroyed the morale of many treatment activists for a long time to come.[14]

The letter ignores the presence of a significant number of activists, male, female and of color who were seropositive and participated in the 076 action. The statement also obscures the fact that all seropositive individuals did not necessarily share the same opinion about 076. Some were in favor, others were against. This point is well articulated by a response to Harrington's letter:

> The point is that not all people with HIV agree on these or other issues. That's why ACT UP was called a coalition when it was formed by people from several different AIDS and lesbian and gay organizations who could only agree on working together to end the AIDS crisis. A coalition can't work if we don't admit that in every category the work uses to describe us and we use to describe ourselves (HIV+, HIV-, women, men, Afro-

[14]Mark Harrington, Fifth Anniversary Letter to ACT UP, Unpublished Document, March 1992.

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> American, Latino/a, Native American, Asian Pacific Islander, white, gay, lesbian, straight and so on) people within those categories do not always agree with each other. To infer that one particular committee or working group in ACT UP takes its direction from people with HIV while all others don't is simply untrue. And, we have to find a way to have discussions about issues precisely because it's untrue, rather than to reify any one point of view as representative (or unrepresentative) of all HIV+ people, all HIV+ AIDS activists, or all HIV- AIDS activists in ACT UP NY or other ACT UPs.[15]

The letter also ignores the positive results of the action, as the Response to the 5th Anniversary Letter points out:

> As a result of the action, the NIH was forced to put out a public statement about the trial, and women around the country got information about it through the action, through newspaper articles on the pros and cons and so on. Despite being told that women were "knocking down the doors" to get into this trial, only 10 women are being accrued per month from 30 sites. And, contrary to the protocol, 2/3 of the women have over 500 t cells. When

[15]Maxine Wolfe, *Response to a "Letter to ACT UP on its Fifth Anniversary,"* , Unpublished Document, April 21, 1992.

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> asked whether women would be informed that taking AZT during this trial with this T cell count might affect their ability to use it for themselves later on, we never got a straight answer. And, though the ACTG still has an abysmally low enrollment of women in any trials and few trials for children with HIV, they now have two more iterations of 076 in the offing in addition to the Women and Infants Transmission Study (WITS) which is also an 076 in disguise (and a better one).[16]

The division rose further when a proposal for a six-month moratorium on meetings with any government official about women's issues was presented to the floor. The main attack against this moratorium was that monopolization of women's issues was its real intention:

> Just as seronegative activists had presumed to tell advocates of seropositive women of color how to think and act on 076, so they now presumed to tell ACT UP treatment activists -many of whom are actually living with HIV-how to work to save own lives.[17]

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[16]Ibid. p.4.
[17]Mark Harrington, Fifth Anniversary Letter to ACT UP, Unpublished Document, March 1992.

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The issue was framed as a heated exchange between T&D and the Women's Action Committee, and not presented to the floor. This cross interaction ignored that the floor had voted for the dissenting activists to go down to Washington to zap the 076 meeting. The floor, and not the activists who went to Washington, should have been addressed. The fact that the floor was ignored was already indicative of the lessened influence of the major voting body in ACT UP. This experience was felt as disempowering by many activists.

POLITICAL INCORRECTNESS

As in the case of representational incorrectness, the debate around political correctness was always present since the creation of ACT UP. It became generalized when an activist argued that "social activists" were hindering AIDS activism. According to the activist, "social activists" were engaged in battles that went beyond the purview of ACT UP. Because of its nature, the AIDS crisis could not be resolved via Marxist Revolution and therefore discussions involving class struggles, although relevant to the AIDS epidemic, were only of remote interest to ACT UP members.

> Yet no crisis has ever been like the AIDS crisis. Thus, while we can and have learned much from previous movements, there is much we have had to invent for ourselves.
> Our tactics, new methods, lacked the ideological "purity:" demanded of "the movement."

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> ....I thought the movement I joined four years ago was devoted to lengthening and ultimately saving the lives of people with HIV or AIDS. Had I known that some in ACT UP felt it was rather merely vague aspirations towards impossible Utopias, I might have devoted my energies elsewhere. I was not then, nor am I now, interested in leaving a noble, frustrated legacy erected over a pile of our corpses so that lifelong movement parasites can move on to the next issues.[18]

Likewise, the tension between those, who wanted the battle to be specific, and those, who wanted to link AIDS issues to the general oppressive nature, which characterized a capitalist and patriarchal society, was always present in ACT UP.

Yet, as the involvement of the floor became more scattered and less consistent, this tension became destructive especially around the clinical trial 175. This trial was a combination involving AZT, ddI, and ddC. Many activists agreed that pharmaceutical companies, and not the government, should pay for this trial. A number of activists decided to zap a cocktail organized in December of 1991 to acknowledge the accomplishments of the ACTG's. Although the zap was voted upon by the floor, it caused a major conflict in ACT UP. Some T&D members had already developed a "professional relationship" with

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[18]Ibid.

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ACTG's researchers and pharmaceuticals as well and deplored the lack of tactics by the zappers.

The most recent effect of ACT UP's expertization was caused by an attempt, from a TAG member, using his ACT UP membership, to obtain funding from pharmaceuticals to help community based research centers. This attempt raised a major objection, because, if it had not been for its swift mention in one T&D Digest, the idea would never have been presented to the floor. Opponents argued that this personal initiative--using for its completion the name of ACT UP--violated the democratic principle by which ACT UP functioned.

Still, some activists framed the issue as a battle for or against inside/outside strategy. This tactics, however, as this activist shows, had always been used by ACT UP.

> The inside/outside strategy allowed us to learn, become the experts, know what is going on, know your adversaries, respect some people from the inside. For example, ddI was approved, and made available through Expanded Access because people such as Mark Harrington sat in those meetings. It was made cheaper without a single demonstration.[19]

[19]Personal Interview, 1992.

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Although no one disagreed with the instrumentality of inside/outside strategy, the issue was still presented as if its instrumentality needed to be defended.

> The inside/outside strategy has always existed: for example, in 1988, several of us were arrested several times seeking a "necessary, unscheduled meeting" with them -NYC Commissioner of Health Stephen C. Joseph.
>
> In 1988, several of us representing a broad range of ACT UP committees sought and obtained a meeting with FDA leadership just days before ACT UP and ACT NOW "Seize Control" of that agency on October 11.
>
> Within months, we were regularly meeting with FDA and NIH (and testifying before their advisory committee) at the same times as we targeted them for demonstrations when appropriate, which has been used so often, and sometimes so well, by Treatment and Data, the Housing Committee and Housing Works, the Needle Exchange, the Youth Education Life Line (YELL) among others.[20]
>
> The advances made with the FDA and the NIH stand in stark contrast to the repeated failure to budge the CDC. The CDC working group's main

[20]Mark Harrington, Fifth Anniversary Letter to ACT UP, Unpublished Document, March 1992.

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> tactics was street demonstration. ACT UP spent hundreds of thousands of dollars sending people down in airplanes usually generating only local media coverage, and which in any case failed to dent the CDC's policy apparatus.
>
> Yet street demonstrations are useless unless they are accompanied by extensive efforts to mobilize other forces to generate allies and forge coalitions, so that demonstration become milestones within more extended campaign.[21]

The end of this statement was indicative, not only of the alienation of the floor from the discussion, but the alienation between committees, as well. In no way did the CDC working group work from the outside only. The group met, in 1991 and 1992, with both James Mason and William Roper, directors of the CDC. In 1991, they met with the CDC definition working and many professional health workers. In the summer of 1991, they testified at hearings organized by the CDC on the definition. Lastly, they send hundreds of cards calling for the change of the CDC definition to professionals and organizations, producing one the largest coalitions ever formed by ACT UP. More generally women in ACT UP have used the inside/outside strategy a lot. This strategy was used by the Women's Action Committee and the ACT UP Network's Women's Issues Committee who have worked on issues concerning the NIH and women with

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[21]Ibid.

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HIV. This strategy resulted in the first National Women and HIV conference held by the government (10 years into the pandemic), the formation of the ACTG Women's Health Committee and the new NIAID epidemiology study focusing on women. The response to the 5th Anniversary Letter pointed to its inaccuracies.

> The inside/outside strategy is good on. I AGREE. In fact, I have never argued solely for an outside strategy. I have also been among the people in ACT UPs who have met with people in the NIH, NIAID, CDC and so on, as well as being among the people on the outside. The inside/outside strategy has been used in ACT UP from its inception (and even before, members of the Lavender Hill Mob were doing both direct action and meeting with people from the CDC and FDA and other agencies).[22]

Inside strategy is viewed very differently by female and male activists in ACT UP. As the latter sees it as a way to create more professional ties with the establishment, the former tend to be more openly suspicious:

> Activists working on women and HIV issues take the same position towards the Women's Health Committee that ACT UP took toward

[22]Maxine Wolfe, *Response to a "Letter to ACT UP on its Fifth Anniversary,"* , Unpublished Document, April 21, 1992.

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NIAID when we did the NIH Action and talked about the "Gang of 5"--the researchers controlling the content and focus of research. While we have argued and fought for a Women's Health Committee we also have to make sure that they do what will help women with HIV and we also have to make sure that a male-dominated research establishment takes their work and issues about women seriously (a point they--members of the committee--frequently mention). At the last ACTG meetings, women AIDS activists from all over the country pressured the Women's Health Committee by being assertive in their meetings. In addition, as our report to the floor described, we handed out 20 different fact sheets to them and others about women in clinical trials (both those specifically concerned with women's OI's and others) and a criticism of the Women's Health Commmittee decided to send a letter to the CDC in support of adding cervical cancer to the CDC definition and criticizing the use of T-Cells. Originally, all they wanted to write was that "women would be upset if they suddenly found out they had AIDS". The members of the committee may not be our "enemies" but they are also not our "friends". Unless we stay on top of what they are doing and

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> keep being assertive about what we want they will move at a snail's pace while women die.[23]

The letter went on to say that the inside/outside strategy is one among other strategies, to be discussed and then chosen by ACT UP. Yet the discussion between the different committees is not there anymore. Committees are becoming totally disconnected from one another. They are more concerned to compete for the right strategy, money, than communalize the issue, and strengthen the floor.

LEGITIMATION OF EXPERTIZATION AND PROFESSIONALIZATION

Not only is communalization under jeopardy, but activist are well aware of it and instead of redressing this situation deploy efforts to legitimize it.

> Ever since ACT UP's work became so specialized that it was mainly done within committees, the Floor has not been the prime policy maker, but rather a sometimes ratifier of existing and new campaigns. Things tended to be brought to the floor either by disgruntled committee members who lost a policy vote (e.g. Campbell bill within T&D or members of another faction who opposes a

[23]Ibid. p.4.

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> committee's policy (mainly used in the past to thwart T&D). The floor never voted an any of ACT UP's annual Treatment Agendas for the International AIDS Conferences.[24]

Precisely, a great number of activists complained about the fact that the Treatment Agenda was geared towards the scientific community, and not the activist community. The Response to the Anniversary letter underlined the treatment activist work was done by individuals and groups other than Treatment and Data, thus resisting the expertization of issues:

> There are many people and groups in ACT UP who have done work on treatment issues. The latino/a caucus did work on those issues in Puerto Rico and in Bilingual community Forums; the Alternative and Holistics Committee has put out a newsletter, held forums and actions about government restrictions on use of different types of therapies while others have worked on getting clinical trials for alternative treatments. The ACT UP Women's Handbook Group produced a book, Women, AIDS and Activism which not only documents the clinical and treatment issues for women with HIV but also has articles by HIV+ women about their

[24]Mark Harrington, *Fifth Anniversary Letter to ACT UP*, Unpublished Document, March 1992.

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> experiences medically and personally and a section on how to do actions; the ACT UP Network's Issues Committee produced the Women's Treatment and Research Agenda, first handed out at the Women and HIV Conference in December 1990, at the ACTG's that spring and revised and handed out at the Florence International Conference.[25]

Unable to recognize the constant weakening of the floor, the problem is construed as a personality battle:

> If ACT UP has any further contribution to make to the AIDS movement, it must cease persecuting its own members and its allies in other organizations and communities.
>
> ...AIDS activist ....finds itself involved in vicious cycles of self recrimination, periodic orgies of attacking its closest allies, leaving the real antagonists unscathed. ACT UP is now so bitterly factionalized it rarely raises to the occasion to mount a decent demo, let alone longer-term, more ambitious campaigns. To make matters worse,those of us who actually continue to focus on AIDS work, rather than on infighting and

[25]Maxine Wolfe, *Response to a "Letter to ACT UP on its Fifth Anniversary,"* Unpublished Document, April 21, 1992.

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> posturing,are regularly vilified and held up to collective abuse.[26]

The extreme consequence of the expertization, professionalization, and bureaucratization was embodied by the creation of TAG

> We want a family atmosphere, and a team effort. No personality, political war. Everybody must feel part of a team. We do not allow saboteurs or hot heads. We had people attack us from behind, or impose their "social activism," with their formula. We have abandoned the politically correct form of activism. We just want to get things done.[27]

[26]Mark Harrington, *Fifth Anniversary Letter to ACT UP*, Unpublished Document, March 1992.
[27]Personal Interview, 1992.

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EXPANDING SOCIOLOGICAL THEORY ON SOCIAL MOVEMENTS

Classical theorists on social movements were heavily under the influence of Durkheim's and Parsons' modernist project. Sociology then was a sociology of modernity, a sociology of reason, a sociology of normalcy. It is no wonder that at the time the very concept of social movement was not even enunciated. Sociologists talked about riot, social disruption, pointing to some pathological disturbance caused by maladjusted individuals.

The following excerpt exemplifies the psychologistic dimension of those theories:

> The frustration-aggression is... analogous to the law of gravity: men who are frustrated have an innate disposition to do violence to its source in proportion to the intensity of their frustration, just a objects are attracted to one another in direct proportion to their relative masses and inverse proportion to their distance.[1]

Those individuals were described as emotional, frustrated and ignorant of the assumed "all beneficent" institutions. In addition, their behavior was characterized as contagious, needing strengthened social control.[2][3]

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[1]Ted Gurr, *Why Men Rebel.* Princeton: Princeton University, p. 37, 1970.
[2]Gustave LeBon, *The Crowd.* New York: Viking, 1966.
[3]Neil Smelser, *Theory of Collective Behavior,* New York: The Free Press, 1963.

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NORMAL, NOT NORMAL

Studies on social movements pointed to the central concept of unity, equilibrium, rationality and normalcy: in one word the modernist project, with its universalistic aspirations. Talcott Parsons, major sociological referent of the time, posited in his patterned variables model that values translated into norms, themselves into institutions. The consistency between each level was alleged to be smooth and unproblematic.[4] Little did sociologists know that activists would shatter this model perceived by them as coercively normalizing.

With an ironic twist of the fate, those social movements, allegedly penetrated with epidemiological emotionality, started to include members credentialled in the sociological profession. All of a sudden, those collective behaviors became social movements, that is large scale activities, now moved by well calculated rationality. Using Mancur Olson's free rider model, social movement theory in the United States became a sociology of cost and benefit. And the most challenging question was: " What do we do with individuals, who do not partake of the movement and benefit from its gains?"[5]

Sociology of social movements became then a sociology of motivations: "Why do some individuals take the risk and others don't?" Unable to answer this question--the Olson's challenge--the sociology of social movements became the sociology of marketing: "What do social movement organizations do to attract as many members as possible?" One answer that North American sociology

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[4]Talcott Parsons, *The Social System*. New York: The Free Press, 1951.
[5]Olson Mancur Jr., *The Logic Of Collective Action*, Cambridge, MA: Harvard, 1971.

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found was that social movements had to act like an industry, the aim of which was to expand their market. Sociology of social movements shifted from the individual to the organizational level--forgetting the individual. It looked at social movements as a free market, the way any liberal economist would look at capitalism. The organizational approach assumed that individuals were totally rational and would embark in the most offering organizations.[6,7]

SOCIAL MOVEMENT AS BUSINESSMAN

Sociologists set out to study the different resources organizations would mobilize to attract more members.[8] With time, some variants were brought to the this perspective, which came to be called the resource mobilization perspective. Thus, a Marxian version of resource mobilization was introduced in the United States, but the emphasis remained resource mobilization.[9,10,11,12] Discussing Tilly's perspective, Larkin and Foss note:

> The confusion found in *From Mobilization to Revolution* seems to stem from an internal

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[6]Michael Useem, *Protest Movements in America.* Indianapolis, IN: Bobbs-Merill, 1975.
[7]Charles Tilly, *The Vendee.* Cambridge, MA: Harvard, 1964.
[8]John McCarthy and Zald Meyer, *Resource Mobilization and Social Movements: A Partial Theory,* American Journal of Sociology 82: 1212-41, 1977.
[9]William Gamson. *The Strategy of Social Protest.* Homewooe, IL: Dorsey, 1975.
[10]Charles Tilly and Edward Shorter, *Strikes in France: 1830-1968.* New York: Cambridge, 1974.
[11]Charles Tilly and Louise Tilly and Richard Tilly. *The Rebellious Century: 1830-1930,* Cambridge, MA: Harvard, 1975.
[12] Frances Fox Piven, and Richard A. Cloward, *Poor Peoples' Movements, Why they succeed, How They Fail,* Vintage Books,1979.

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> contradiction in Tilly's theorizing. He tends to waffle from positivistic to historical explanations of collective action. (The term "collective action" itself has a positivistic tinge to it, since it can be considered a variable that can be easily enumerated and subjected to multivariate analysis. It is also devoid of historical context.)[13]

While resource mobilization is an important aspect of a social movement, it cannot alone explain social movement construction. To be sure, a major difference between ACT UP and the feminist-health movement is the ability of the former to garner resources historically denied to women. Yet, ACT UP's material aspect alone does not explain that it is a social movement. The feminist-health movement, poor as it was, is a social movement as well. The feminist-health movement had laid the theoretical work for the AIDS movement. As will become clearer later on, the ideological dimension of the culture of a social movement is constituent of its being a movement. ACT UP made possible the vision that the feminist health movement had painfully entertained--because of lack of resources--and yet had originally created. This is not to discard the many accomplishments of the feminist-health movement, but they would have been more numerous, had it not been for the limited resources that women

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[13]Foss, A. Daniel and Ralph Larkin, Introduction by Stanley Aronowitz, *Beyond Revolution, A New Theory of Social Movements*, Borgin and Garvey Publishers Inc.: 22-23, 1986.

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activists faced, reflecting the socio-economic situation of women in general.

Resource mobilization theory does not even account totally for the "how" of social movements, as some critics have argued. There are many types of resources that ACT UP would not, and has not, used to benefit the movement for which it fights. Buying arms is an example. Theoretically, one might think that one way to further the goals of the AIDS movement would be to physically eliminate those--individuals, bureaucrats, doctors, researchers--who would come in its way. Yet historically, ACT UP has always opposed the use of violence--and the paraphernalia that goes with it--which could be considered a potential resource. This exemplifies how ideology explains both the "why" and the "how" of a social movement.

However, demonstrations and other actions can be very costly, and it is important to know how social movements garner resources to organize those events. Resource mobilization may add to the strength of a movement, but does not define a social movement. Because of this conflation between social movement and their ability to garner resources, resource mobilization theorists tend to conflate lobby organizations with social movements. Although some of its strategies may include lobbying, ACT UP cannot be typified as a lobby organization. In fact, the lobbying activities of ACT UP is very much colored by its activist thrust. When Insurance activists now go to Albany to lobby some Congress(wo)men, the latter know very well who ACT UP is and responds to them more as ACT UP--the activist group--than the traditional lobbying group.

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Likewise, resource mobilization theory would not establish a major difference between ACT UP and other disease organizations, such as the American Cancer Society, or Diabetic Society. The latter have a major aim of raising funds and although they do not challenge the dominant allopathic model, they would still be considered social movements by resource mobilization theorists.

Touraine explains the difference between merely mobilizing resources and a social movement:

> The formation of anti-nuclear movements does not depend on its capacity to mobilize a population, as was sometimes said, but on its capacity to transform a non-social problem into a social analysis.[14]

One of the rare resource mobilization studies in medical sociology involved several cancer controversies. The study compared four conflicts: Fluorouracil, Ascorbic Acid, estrogen replacement therapy, saccharin and Laetrile, and concluded that knowledge claims should be considered by resource mobilization theorists a form of resource.[15] Yet there is no discussion about the reason the Laetrile controversy in particular became so politicized. This significant lack is due to the author's failure to see the direct opposition between the ideology of the movement and that of the dominant culture. There is no analysis of the culture of biomedicine in particular, and science in

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[14]Alain Touraine, *Ecologie Sociale et Mouvements Ecologiques*, Presse de l' Université de Montréal, Volume XIII, no. 1, Avril 1981.
[15]C Petersendab, and Gerald E. Markel, in Research in Social Movements, Conflict and Change, vo. 4, Press in 1981.

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general. In fact disputes among scientists are not considered political, and the main concern of the movement, according to the author, is to garner as many adherents as possible.

Thus, resource mobilization is generally not interested in the historical and cultural location of the movement. Yet, this cultural location is what European thinkers consider major determinants in the emergence of social movements.

ACT UP AN IDENTITY MOVEMENT?

As the aforementioned criticisms suggest a redefinition of social movements was urgently needed. Alain Touraine set out to do just that. Definitions of social movements were inadequate, according to Touraine, because they-classical and resource mobilization theories--shared the assumption of the modernist project, one of its many forms being pluralism:

> For Weber, Durkheim and Parsons, sociology is above all characterized by a movement toward modernity, that is a process of rationalization and secularization.[16]

Classical and resource mobilization theories argue that modern society provides institutional channels for people to express their disagreement. Even in the resource mobilization perspective, protest is

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[16]Alain Touraine, *Redefining Modernity, The Challenge to Sociology*, Thesis Eleven, 23, 1989.

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viewed as a rational--notwithstanding extra-parliamentary-- extension of the political process.

Touraine, along with the European School, disagrees with this normative assumption. It is normative because it obscures the many power relations that riddle society. In this regard, Touraine does not deny his debt to Michel Foucault, who argued that power is everywhere. The main project of the sociologist is then to unravel the multilayered forms of power, thus rejecting the very premise of societal balance upon which classical sociology was built.

Sociology for Touraine is not the analysis of society, because there is not such a thing as society. But it is the analysis of social relations of power, echoing a major Foucaultean concern:

> Today we can no longer rely on principles of order of images of the society; we can only think in terms of action, change and social relations, and theorize in terms of strategy, politics or, as I prefer, the conflictual self production of society.[17]

Touraine's second cultural heritage is Jean Paul Sartre, whose philosophy allowed people--as actors--to reemerge from the stifling confines of Marxism.[18] The author of the *Return of the Actor* intends to do just the same in sociology.

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[17]Alain Touraine, *The Return of the Actor*, Minneapolis: The University of Minnesota Press, 1988.
[18]Alain Touraine, *Une Sociologie sans Société*, Revue Francaise de Sociologie, Janvier-Mars 1981.

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> We do not have, then a general crisis of modernity but a limited one. This crisis is deep enough, however, to indicate that something important is happening, namely we are seeing the disappearance of social evolutionism, that is, of the idea that there exists a "natural" process of modernization, governed by "laws" of historical development capable of accounting for all aspects of social life and its transformation. We observe the decline of materialist social thought, which had been dominant since the nineteenth century and is attested to by the "geological" representations of social life, for which the economic and technological resources of a society are its deepest "strata" whereas the forms of political organizations and ideological manifestations are surface ones.[19]

He wants to free individuals from the ever tightening grips of Parsonian model as well:

> But in contemporary industrial societies, situations do not determine actions, it is, rather, actions that bring to light relations of domination and subordination, which lack a visible juridical or

[19] Alain Touraine, *The Return of the Actor*, Minneapolis: The University of Minnesota Press, p. 31, 1988.

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> political expression. The concept of class must therefore be replaced, as a central category of sociological analysis, by the concept of the social movements[20]

Anticipating the criticism that the social system does have patterned constrains, [21] Touraine emphatically demonstrates that cultural reproduction is a core concerns of the new social movements.

This criticism comes out of a misreading of the concept of identity. Identity for Touraine is not just the activists' claim that they are "gay," or "AIDS activists," or even "neo-nazi," for example, but it is the product of a conflictual relationships of power and domination. In this sense, the concept of identity is inseparably intertwined with the concept of cultural reproduction of power as explained by Larkin and Foss:

> As identity cannot be separated from social structure when society evidences the appearance of the forcible assertion of antistructure, the identities of those involved in the struggle are necessarily changed as they are now members of self-acting collectivities. It is in this sense that the limits of human consciousness are the products of history.[22]

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[20]Ibid. p.19.
[21]Jean Cohen et al., *Social Movements*, Social Research, 1985.
[22]Foss, A. Daniel and Ralph Larkin, Introduction by Stanley Aronowitz, *Beyond Revolution, A New Theory of Social Movements*, Borgin and Garvey Publishers Inc., p.105, 1986.

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Not only does this concept reveal that activists are aware of the relation of domination that they fight, but the social analyst is forced to conduct a twin analysis of the activist political process and their impact on cultural reproduction of power. Identity, in the case of AIDS activism, is a response to institutionalized homophobia, sexism, racism, stratified inequities, bureaucratized--that is domination-laden--science and health care.

SOCIAL MOVEMENT, UNIT OF ANALYSIS

Rid of those overly structural categories, Touraine is now able to account for the centrality of social movements. Sociology is the analysis of social movements, which are its unit of analysis. And this is how he defines social movement:

> Finally, when conflictual actions seek to transform the relations of social domination that are applied to the principal cultural resources (production, knowledge, ethical rules) they will be called social movements.[23]

Yet after collapsing traditional sociology's boundaries, Touraine decides to institute his. While class retains a central position in his perspective, he does not want to define this concept in terms of

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[23]Alain Touraine, *The Return of the Actor*, The University of Minnesota Press, p.64., 1988.

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contradictions between productive forces and social relations of production. Instead class is constituted by:

> groups that are opposed to each other in a central conflict for the appropriation of the historicity toward which they are oriented and which constitutes the stake of their conflict. For example, in industrial society, the conflict does not pit capitalists against proletarians (that is , worker deprived of all forms of property) but industrialists against workers. The two groups have the same cultural orientations: both believe in progress, in deferred gratification, in a repressive control of sexuality, but at the same time they fight each other for the social control of this industrial culture in order to give different social forms to the same cultural orientations.[24]

and more specifically:

> The idea of the social movement is thus new; it forms a recognition of the fact that actors do not limit themselves to reacting to situations but actually produce situations. They define themselves both by their cultural orientations and

[24]Ibid.

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> by the social conflicts in which they are engaged. And by cultural orientation, I do not mean values contrary to those of one's opponents, but on the contrary those held in common with them and defining the stakes of the conflict.[25]

LIMITS TO THE TOURAINIAN PERSPECTIVE

Two criticisms can be leveled at this definition. The first one is that it is arbitrary to define social movements as conflicts between groups which *share the same cultural orientation.* This arbitrariness leads Touraine to hastily conclude that the women's movement is not a social movement, but more a cultural movement. The confusion is exacerbated by his assertion that historicity is at the core of relations of domination:

> I call historicity precisely the set of cultural models that rule social practice only through social relations that are always relations of power. Such a conception does not admit of an analysis still centered on the idea of a society; like organization theories, it grants the social aggregate or anyone of its subjects a very low level of stability or even coherence. It does not, however, look upon social reality as a pure system of disorderly flows. Quite

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[25]Ibid.

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> the contrary, it upholds the idea of a central locus around which everything orders itself, but this locus is not constituted by a will or a power; it is a Stake.[26]

This distinction is not just semantic finesse. Touraine misses an important mission of the movement, which can be characterized by its epistemological project and cultural vision. Indeed, feminists, social ecologists, holistic activists, and ACT UP following their footsteps, have, through their corrosive critique of modernity, proposed new ways of knowing and new cultural models. In fact, what keeps those movements moving is precisely those epistemological and visionary projects.

At the highest level of achievement, a social movement can successfully--even if silently--produce a paradigmatic shift. This is what ACT UP has--if not produced--at least been part of. AIDS activists have broken the long epistemological tradition of untouchability of biomedical science. Not only are activists part of the scientific committee with real power to vote, but they made scientists accountable for their act, realizing quickly that the latter could be subjects to the same political weakness as any full-blown politicians.

Why does Touraine place such a restriction in his definition? His answer is quite unconvincing:

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[26]Ibid. p.26.

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> Cultural innovation, and resistance to it, cannot constitute by themselves a social movement, for the latter combines by definition a reference to the field of culture with the consciousness of a social relation of domination.[27]

Paradoxically in the same page of the *Return of the Actor,* Touraine shows the connection between social movements and cultural models.

Ineluctably, Touraine's classification results in alienating women from the centrality of social relations. In those terms too, ACT UP would simply be considered a cultural movement and not a social movement. May-be Touraine's focus on industrial conflicts blinds him to the significance and efficacy of cultural movements. That Touraine's classification calls some movements social, and others cultural would not be as problematic if he did not give a higher status to the first one; the status of unit of analysis.

But Touraine's argument becomes clearer when he argues that the new social movements are less sociopolitical and more sociocultural. According to him, the distance between civil society and State is increasing while public and private are becoming conflated. He concludes that new social movements (understand cultural movements) can easily become segmented, and transform themselves into defense of minorities or search for identity.[28]

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[27]Ibid. p.68.
[28]Alain Touraine et al., *An Introduction to the Study of Social Movements,* Social Research, Volume 52, Number 4, Winter 1985.

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Yet, ACT UP and the feminist-health movement have emphatically shown--what Touraine seems to be missing--the pervasiveness of the presence of the state in everyday life, or what was conceived in the precises of political science as civil society. Both movements have shown that the most disenfranchized individuals in society never had a civil space. Confirming Foucault's scholarly work, those movements popularized the idea that sexuality is not--in fact--had never been a private matter. The state has always rigidly codified people's sexual desire. So where is the civil society that Touraine is now discovering?

Those movements have also shown the influence of the state on science, scientific research and the scientific community in order to further control social relations. All AIDS-related issues dealt with by the activists involve sooner or later some confrontation with the state. So that when social movement theorists argue that new social movements are not interested in politics, but just in the cultural area, they discount the intertwining between the cultural and the political. Like abortion, AIDS has been very politicized by activists and they have indicted the Presidents for spreading the disease. Activists also forced AIDS into the political agenda of Mayoral or Presidential candidates.

The new social movements are not driving away from the political arena as Touraine and others argue, they are showing the politicality of everyday life. More than just showing the politicality of everyday events, activists are mandating politicians to take up their issues. The campaign around testing issues is again a good example. A matter which would customarily have remained within the confines of experts became object of public debate. The large number of lay

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individuals, who testified in front of federal institutions, and affected final decisions probably made AIDS one of the most politicized diseases in the medical history of this country.

Although the new social movements tend to use political institutions less, they definitely expand the political arena.

The second criticism levelled at this definition concerns the drive for control of cultural patterns, that Touraine systematically impugns to social movements. Indeed he argues that:

> ....as I do myself, a basic role to the notion of social movements, defined as an agent of conflict for the social control of the main cultural patterns.[29]

Some movements vie for power, such as the Nazi movement, and some don't. The analysis of ACT UP shows that they are in no way interested in the control of cultural patterns whether it be industry or science. They are more interested in representative democracy, which is a revolutionary concept if one considers the centuries old unquestioned sovereignty of the scientific community.

ACT UP in general has never argued for the elimination of scientists, but for the inclusion of activists at all levels of the research process. It has argued for a different type of research, for example research on alternative treatment. Both inclusion of activists in the research process, as well as research on alternative treatment represent major encroachments upon Western cultural tradition. The most

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[29]Alain Touraine et al., *An Introduction to the Study of Social Movements*, Social Research, Volume 52, Number 4, Winter 1985.

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revolutionary demands of activists is one that shattered that core of Western science. It rest on the idea of "situated science," a postmodern concept by itself. Activists do not reject the tools of science, but want to adapt them to their needs. They desacralize the modernist concept of science with its universalistic pretense.

EXPANDING THE TOURAINIAN DEFINITION

A more accurate definition would be the one proposed by Daniel Foss and Ralph Larkin:

> A social movement is the developing collective action of a significant portion of the members of a major social category, involving at some point the use of physical force or violence against members of other social categories, their possessions or their institutionalized instrumentalities, and interfering at least temporarily--whether by design or by unintended consequence--with the political and cultural reproduction of society.[30]

Still, this definition sounds very much like a resource mobilization definition, although it connects this mobilization with the disruption of cultural reproduction. Somewhere else, Foss and

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[30] Daniel. A. Foss, and Ralph Larkin, Introduction by Stanley Aronowitz, *Beyond Revolution, A New Theory of Social Movements*, Borgin and Garvey Publishers Inc., p.2, 1986.

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Larkin argues that resource mobilization occurs before activists start re-interpreting reality. In the case of ACT UP, however, some members--women in particular--were very well aware of the functioning of the biomedical establishment, and the cultural reproduction of its domination, before they joined ACT UP. With time, they shared their knowledge with other activists, increasing the general consciousness of the group.

Rather than placing a priority between resource mobilization and the construction of reality, the concept of dialectics would be more appropriate. Thus, activists come to the movement with different degrees of political and cultural consciousness, which increases as they mature in the movement through political action and interaction

Secondly, the use of violence is really not a requirement, although it may be part of the repertoire of the movement. As ACT UP, the women's movement, the social ecology movement demonstrate that a social movement can be dedicated to non-violence.

A social movement is therefore the ever increasing awareness of a challenge to the cultural reproduction of domination--including all levels of society, i.e. political, economic, scientific etc.--accompanied by the mobilization of human and material resources consistent with the ideology of the movement. This definition is very close to Foss and Larkin's:

> We assume that the basic etiology of social movements resides in the process of the reproduction of social privileges and that social movements, regardless of the subjective awareness

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> of the participants, as to their purpose, are attacks on the maintenance of social privilege.[31]

The progressive self-awareness element should be more emphasized by social theorists. Social movements are in many ways schools, where members learn to act and react vis a vis the dominant culture. Long standing activists know, if not expressly, at least intuitively, the basic principles of cultural reproduction.

Culture has to be understood broadly. It can be defined as an ensemble of relationships made possible by both shared and imposed meanings and practices, as well as the social, economic, political, ideological and epistemological process by which those relationships are reproduced. Equally involved in cultural reproduction are religion, science, politics and economics, each intwined with the other, yet keeping some measure of autonomy from one another.

As in Touraine's definition of society, this definition of culture implies no specific privileged location from each level of society. Gender and economics are equally important in the reproduction , or change thereof, of culture. Social movement in the Tourainian sense as well as those he called cultural, such as the women's movement, should fall in the category of social movement. Stanley Aronowitz had already critiqued dialectical materialism:

> Even if capital-logic is an adequate explanation of the origin of the ubiquity of cultural domination in

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[31]Ibid. p.29.

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> general and mass culture in particular, it cannot account for their autonomy. For having been produced as an aspect of capital's new conditions of reproduction, mass culture reproduces itself on the basis of its own logic, whose economic dimension, while not insignificant cannot encapsulate its influence, which exceeds its intended function.[32]

In keeping with Touraine's perspective, social movements are at the core of social change. Yet in contrast with Touraine, cultural movements should be viewed as central to social change. Thus, the women's movement is a cultural movement, therefore a social movement. The pro-life movement is not a cultural movement, because it does not challenge cultural reproduction. Neither is the labor movement in the United States. The latter would be more classified as social conflicts. The neo-nazi movement on the other hand would be considered a cultural movement. With the women's movement, the neo-nazi movement proposes new models of cultural development. The former is interested in cultural representation and self-determination, the latter in domination of one race over the others.

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[32] Stanley Aronowitz, *Crisis in Dialectical Materialism*, Class, Culture and Politics in Marxist Theory, New York: Praeger, 1981.

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ACT UP IS A CULTURAL MOVEMENT, THEREFORE A SOCIAL MOVEMENT

The present dissertation has shown some of the aspects of the dominant culture that ACT UP challenges. Chief among them is the biomedical establishment. ACT UP does not view it as an institution, in the Durkheimian sense, that an institution has the magnanimous purpose to fulfill a social need.

Activists view the biomedical establishment as a location of power, where knowledge is centralized, often kept within the limits of a few credentialled individuals.

This aspect of culture is maintained and reproduced, not because of its inherent sacrality, but because of its socially ascribed sect-like nature. Throughout a specific socialization process, mainly through the credentialling process of the university, biomedical scientists have been erected to a position of power where they have access to information and financial resources. They can almost unquestionably use people as subjects.

ACT UP is a social movement, because it shakes the cultural pillar that science represents. Max Weber had already shown that rationalization, science being its supreme tool, is what characterized society. Yet Weber did failed to see the unscientific part of science.

ACT UP reveals through its handbooks on the FDA, NIH, CDC that, like any other institution, biomedical institutions are riddled with magic, that is cultural bias. ACT UP looks at those institutions the way it would look at any other institution to understand how the culture of science or even the magic of science is reproduced.

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ACT UP questions the word of federal scientists. It argues that they, like any official bureaucrat, have deep seated beliefs ingrained in their own culture. And like any true believer, they use all the means at their disposal, including state coercion, to impose their ideas, although many alternative interpretations are offered to them.

Activists showed that principle investigators (PI's) maintain their power because of their socio-political and economic location, but also their intrinsic culture. In other words scientific production has as much to do with science as it has to do with extra-scientific factors. Thomas Kuhn had already shown that.[33]

Thus, ACT UP challenged the magic bullet ideology of the principle investigators with their insistence on virology.

Activists challenged the conflict of interest, of which PI's were guilty. Like many bureaucrats, PI's are often guilty of conflict of interest. The difference between scientists and bureaucrats is that the former believe that they are entitled to this dual membership. They think that it can benefit science, therefore society at large.

ACT UP challenged science's golden principles, one major example of which is placebo-controlled experiments. ACT UP forced the FDA to release drugs before the traditional procedure was completed, showing the need to bring back science to the reality of people affected by the disease.

ACT UP challenged the scientific position, according to which people have to be subjects, and forced scientists to be responsive to Persons With AIDS' needs.

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[33]Thomas Kuhn, *the Structure of Scientific Revolutions*, Chicago: University of Chicago Press: 1962, 1969.

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ACT UP challenged the scientists' attitude, according to which they are beyond reproach and forced them to be accountable to the culture at large.

ACT UP challenged the sacralized separation object/subject, according to which the subject cannot study itself. Not only did it challenge the subject/object separation principle, but it gained representation in the main federal scientific committees.

ACT UP challenged the claimed objectivity of scientists by pointing to their cultural biases. Scientific production is embedded in a culture, and in many ways reflect its biases. Activists challenged homophobia, sexism, racism and classism in the design of clinical trials.

All those challenges form the crux of the radical AIDS movement, because they reveal how the cultural patterns of scientific production are maintained and reproduced. Stanley Aronowitz echoes this idea:

> The power of science consists, in the first place, in its conflation of knowledge and truth. Devising a method of proving the validity of propositions about objects taken as external to the knower has become identical with what we mean by truth.[34]

The self-determining ideology of ACT UP is drastically at odds with the tenets of the dominant culture about what science should be.

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[34] Stanley Aronowitz, *Science as Power*, Minneapolis: The University of Minnesota Press, 1988.

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In fact, self determination represents a major challenge in an area--biomedicine--which claims total expertise, and therefore control over people it studies and treats. What makes ACT UP a social movement, of great cultural significance, is precisely the alternative cultural model of science it proposes. ACT UP represents an intervention, a disruption in the heart of one of the fundamental processes of cultural reproduction. Analyzing the Students for a Democratic Society (SDS), Stanley Aronowitz developed a definition of social movement:

> SDS became part of a social movement when it no longer defined itself in terms of "issues," but demanded nothing less than social transformation.[35]

Then, there is no doubt that ACT UP is a social movement.

ACT UP, A MULTIDIMENSIONAL MOVEMENT

ACT UP is a multilayered movement. Science is one aspect of the dominant culture that activists have fought. State bureaucracies, politicians, the church hierarchy, as well as the private sector have been indiscriminate targets of ACT UP's.

For example, through its educational campaign, and condom distribution ACT UP has shown how the state, with the joint force of

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[35]Daniel A. Foss,. Daniel and Ralph Larkin, Introduction by Stanley Aronowitz, *Beyond Revolution, A New Theory of Social Movements*, Borgin and Garvey Publishers Inc., p.XV, 1986.

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the Catholic Church hierarchy and conservative politicians, control people's sexuality. Sexual control is one of the main sources of cultural reproduction of the dominant culture. Thus, the response of the prevailing culture (or lack thereof) to the AIDS epidemic in many ways echoes the tabooization of sex in general and homosexuality in particular.

The abundant feminist literature eloquently shows how society is gendered, and how ongoing socialization concurs to produce a gendered society, where women and gay men and lesbians are disempowered. Indeed AIDS has been seen as a gay disease, as a self-induced disease, as a deserved disease.

ACT UP has persistently condemned homophobia which not only biases social policy on AIDS, but also research. Scientists did not know anything about the sexual behavior of gay men. Yet, the problem was that they were not willing to know.

On the political scene, although the arguments were those of public health, the real fight was about sexual control. Senator Jesse Helms and William Danemeyer rushed to push for mandatory testing while being consistently opposed to any public health measure which would call for an open debate about sexuality. Condom distribution was an egregious example of the dominant culture's refusal to even admit that adolescents in general were having sex. As for homosexual youth, if it was not for the effort of the community, they would still be waiting for a national policy on sex education and condom distribution.

The fight over clean needle distribution unraveled stunning similarities with the way dominant culture views sex. Drug use and

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sex have the commonality of evoking forms of pleasure. The tenets of the dominant culture is that drug and sex are forbidden pleasures, although most people engage in them in hiding. The cultural condemnation of pleasure leads to a medical apartheid where the good sick (babies, hemophiliacs) are well treated and the bad sick (gays and drug users) are not. The view on pleasure is also another important pillar of society. ACT UP has challenged this interdiction by confronting the authority trusted with public education and research to deal with AIDS sensitively to the communities affected.

The irony is that the state--federal and local-- has probably never dealt openly with so many openly gay representatives. In both cases, the cultural interventions of ACT UP were successful, condom availability and clean needle distribution have been legalized. In both cases, a slow change in new cultural consciousness vis à vis homosexuality, sex, drug, and more generally pleasure and desire is emerging.

A MOVEMENT MAY BE PART OF A LARGER MOVEMENT

Too much, social movement theorists have focused on specific movements, and failed to see their connection either with the dominant culture or with other movements as Touraine's statement shows:

> Couldn't it be said that this American experience is being generalized today and that various social conflicts are becoming more autonomous in

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> relation to each others? this hypothesis seems reinforced by the failure of the new left, the chief theory of which is that all types of conflict are nothing but a particular form of a general anti-capitalist struggle, itself identified with anti-imperialist action.[36]

One would have a very microscopic view of ACT UP if its connections with the gay and lesbian movement, the feminist-health movement, the holistic movement, the social ecology movement and others were not established.

Thus, well before ACT UP and the AIDS movement, the entire women's health movement used not only scientific research as lay people, but provided 10,000 abortions to women without any doctors involved. Women's Health Centers did all of the research on the use of cervical caps and were using them for years before they were legal. *Our Bodies, Ourselves* sold hundreds of thousands of copies and Women's Self Help Health groups and Feminist and Women's Health Centers, employing lay people in them, sprang up all over the country, where women do their own self-examinations. Barbara Ehrenreich shows that the Women's Health movement, before ACT UP, had already questioned the position of authority of the medical establishment, shifting the movement from a state of mere social conflict to that of social movement:

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[36]Ibid. p.33.

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> Beyond those concrete gains, the women's health movement is increasing the prospect of a wholly new form of medicine, one which could integrate objective findings with the subjective experience of the health or illness, that is integrating curing function with the caring.[37]

Too, well before ACT UP, social ecology and radical feminism had formulated a radical critique of the neutrality of science and technology and their taken-for-granted separateness from the cultural context from which they are produced. In particular, social ecologists argue that by subordinating nature, the powers-that-be are subordinating other human beings. This principle could apply to the logic of pre-AIDS activism clinical trials, and to a certain extent, to many trials, still today.

All those new social movements are united by what Foucault would call an epistémé[38]: self-determination; self-determination with regard to one's body; self-determination with regard to individuals' relationship to the environment; and self-determination with regard to the treatment that one wishes to receive.

All those movements work from different locations, although there is much overlap. Many ACT UP members, for example, are part of the social ecology movement or the feminist movement, or again

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[37]Helen I. Marieskind and Barbara Ehrenreich, *Toward Socialist Medicine; The Women's health Movement*, Social Policy, 1975, p.41.
[38]Michel Foucault, *Order of Things: An Archeology of the Human Sciences*, London: Tavistock Publications, 1970.

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the holistic and alternative movement. In turn, Greenpeace has been the model for certain ACT UP's actions.

When abortion rights are being jeopardized, women know that some ACT UP members will be at their march. For example, on Saturday 27, 1992, when Operation Rescue announced that it would organize a rally in New York City in front of an abortion clinic, ACT UP was called right away by WHAM! to join a counter-demonstration. Conversely, ACT UP members know that some women will be at their demonstrations as well.

Therefore, a larger cultural movement based on self-determination is now emerging. Slowly. Homophobia still present in many movements weakens the general strength that this large cultural movement could deploy. Conversely, sexism, racism and classism in ACT UP weakens this general thrust equally. Although movements fight the dominant culture, they, in many ways are still embedded in it.

THE DEMISE OF AN ORGANIZATION MAY NOT SIGNAL THE END OF A SOCIAL MOVEMENT

Too often, social movements analysts have looked at break ups in an organization, usually accompanied by its institutionalization, as the demise of the movement itself. This is quite a narrow-minded view.

Break ups in organizations may be viewed in two ways, negatively and positively. Break ups in organizations may be viewed negatively, because indeed, movements are in constant struggle with the state and have to keep up their energy. They also have to maintain

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their level of resource mobilization. Some members may become coopted by the bureaucracy, or by the dominant ideology. If this is the case of the majority, then indeed the movement is dying, because it is not leaving any cultural legacy behind itself. In the case of ACT UP, the dissertation showed that many off-shoots have been created. Yet some members use their dual status to benefit from both organizations. This attitude is at odds with the communalizing goal of the movement.

Break-ups in organizations may be viewed positively, because its explosion may also mean dissemination of the new cultural tradition of the movement. Thus out of ACT UP, Queer Nation was created to provide a space for those concerned with gay and lesbian issues. Likewise, WHAM! (Women Health Action Mobilization!) WAC (Women's Action Coalition), and the Breast Cancer movement, as well as Can Act, another cancer movement owe their cultural debt to ACT UP.

As ACT UP is becoming more bureaucratized, other grass-roots, non-hierarchical, direct-action oriented groups are being formed to carry the ACT UP tradition to different places to fulfill different missions.

The success of a movement should be assessed not only in terms of the concrete changes it was able to produce, but also in terms of the dissemination of the cultural model that it has produced. If this is the case, then the women's movement and the AIDS movement should be considered very successful.

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ACT UP IS A MATERIALIST-POST MATERIALIST, INDUSTRIAL POST-INDUSTRIAL, MODERN-POSTMODERNIST MOVEMENT

ACT UP is a materialist movement because it is concerned with survival, biological survival, as much as the women's movement is also a materialist movement, because one of its many concerns is the protection of women from the violence to which they are subjected every day. ACT UP is post-materialist because it does not take materiality or biology for granted. Biological survival is not a linear concept, and can be conceived very differently depending on the location of the subject. At the core of post-materiality is the concept of choice.

ACT UP is industrial, in the sense that activists argue that profit, rather than need, dictates primarily the policy of drug companies. ACT UP had to fight companies a lot to have them produce drugs other than antivirals, thought to be most profitable by the companies. But ACT UP is also post-industrial, because much of its work deals with health care provision, and services provided for PWAs.

It is a modern movement, because most activists in ACT UP believe in scientific knowledge. Their reading, their alertness to up-to-date research attest to that assertion. Biomedical research is taken very seriously, and although many activists are not medically credentialled, they schooled themselves into the language of biomedicine. Yet, ACT UP is postmodernist, in the sense that it deprives the scientific community of its royal mantle. ACT UP wants a science that is culturally relevant to the communities affected.

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Science, for ACT UP, can only be valid if used from a specific place. There is no overarching discourse, or master discourse any more. Science is no longer viewed as a dogmatic paradigm, but as a tool at the disposal of the communities. Science cannot be absolute, it must be culturally situated.

ACT UP wants to own the issue--be it scientific or not-- through the process of communalization

COMMUNALIZATION

Communalization starts with redefining reality from the community's perspective and ends with finding solutions--not for some abstract truth--but for the very same community. Communalization is not necessarily a smooth process. Because many individuals belong to the same movement, they do not necessarily interpret reality similarly. The clinical trials 076 and 175 glaringly exemplify that difficulty. Not only socio-economic factors can explain that activists' interpretation may differ, but also their intersubjective relationships. Here, hermeneutics and ethnomethodology can be instrumental in understanding how individuals communalize issues.

This concept of communalization is close to Larkin and Foss's concept of "communitas:"

> The new praxis, whatever form it may take--and it does take new forms during social movement periods--is fundamentally in opposition to the set of social relations that pervade the social order.

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> Thus, as dissidents struggle to alter those social relations, to which prior to the social movement, most had acquiesced, the conception of reality is changed as a consequence of entry into the struggle. It is one thing to be a passive recipient of one's social subordination and quite another to struggle against it as part of a collectivity. Therefore, the "communitas" that is experienced by dissidents during social movement periods provides a context in which not only new social realities can be constructed, but also offer a therapeutic function in that it becomes a means where by dissidents are able to retrieve aspects of human consciousness that were alienated from them as part of their socialization to positions of social subordination.[39]

Conflicts can have a positive effect in that they can facilitate the process of communalization. Members can vent their opposition, sometimes anger, and the group may find some common grounds of understanding.

Yet, conflict can also hamper or even destroy the communalization process of a movement. Activism is a struggle against the established power, but it can be, to certain extent, also a struggle for power acquisition, as well, from within the group. If the ideology of a group mistakes individual power over the group with the

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[39]Ibid. p. 90.

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empowerment of individuals within the group, some members will drop out of the group because they cannot have power, and others because they cannot be empowered. The organization may die, but its initial cultural model can be carried over by another group, keeping the movement going. However, when certain members start believing in the values of the dominant culture, such as expertise or professionalization, they hamper the communalization of a movement. When professionalization takes over, the organization dies. When it takes over a movement, the movement is dead.

In many ways a social movement is like a psychoanalytical tool. It reveals the actors' as well as the culture's boundaries.

This is the story of this dissertation.

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ACT-UP SURVEY

Dear ACT-UP member:

Hi! my name is Gilbert Elbaz and I too am an ACT-UP member. I am also a student at the City University of New York, and I am doing research on -you gessed it- ACT-UP.

What prompted me to do this work was my concern to represent the group accurately. I think that it is essential that the history of ACT-UP be recorded properly by individuals from inside the group. As much as we must be responsible for our health and our community, we must be responsible for the writing of our history.

Yet, being from inside the group does not allow me to write anything I want about it. I know some of you but not all of you, and thus cannot make any assumptions about who you are. Therefore I need your help to fill out this socio-demographic questionnaire. It is pretty detailed for I want my source of information to be as accurate as possible.

THIS QUESTIONNAIRE IS TOTALLY ANONYMOUS. So you can answer the questions in total safety. Of course you do not have to participate, but I cannot empasize enough the importance of your input in this study. This is the first time that research is being done on AIDS activists by an AIDS activist himself. Despite much resistance within academia (where the idea of a group studying itself is not a popular one), I managed to get this project accepted. Beyond its academic impact, the questionnaire could be of immediate use by and for the organization. For example, it could help ascertain and even anticipate the decline of involvement of certain members in the organization. Instead of dismissing the issue by simply telling the discouraged members to "take a break", the questionnaire could help in the establishment of support programs and groups more appropriate to the needs of those members.

You do not have to answer all the questions and can withdraw at any time. If you decide to answer the questions, however, do not think that there are "correct" or "wrong" answers. The only answers are the ones that correspond to your personal situation. You are therefore the only one to know them. This is the reason why the questionnaire should be completed individually.

Should you have any comments (and you will) please feel free to insert them in the questionnaire for there is no such thing as "a perfect questionnaire".

I would like to add that the questionnaire is only one among other methods (such as in-depth interviewing) that will be used to conduct this study. Once the study is completed, the findings will be made available to any respondent requesting them.

Remember, the success of this research will partly depend on the number of returns I will get. I cannot and will not manufacture information about you. So, please help me achieve this arduous and costly task.

If you wish to get in touch with me or wish to be interviewed, my phone number is (212) 237 8694

see you at the Monday meeting.

Gilbert

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We'd like to know the reasons that brought you to ACT-UP.

Please circle the numbers that correspond to your answers. The available responses are:
1=Extremely Unimportant
2=Moderately Unimportant
3=Slightly Unimportant
4=Doesn't matter one way or the other
5=Slightly Important
6=Moderately Important
7=Extremely Important

1. What was your initial motivation to join ACT-UP?

1. To channel your anger about AIDS into constructive action	1	2	3	4	5	6	(7)
2. To make some response to the AIDS crisis	1	2	3	4	5	6	(7)
3. To become more active in the community	1	2	3	4	(5)	6	7
4. To feel you are supporting a cause you believe in	1	2	3	4	5	6	(7)
5. To learn to cope with your own problems by helping others	1	2	3	4	(5)	6	7
6. To do something to protest the mistreatment of PWAs	1	2	3	(4)	5	6	7
7. To help gay friends do something about AIDS, because others were not doing enough to help persons with AIDS	1	2	3	4	(5)	6	7
8. To show gay pride	(1)	2	3	4	5	6	7
9. To offer a skill you have to people in need	1	2	(3)	4	5	6	7
10. To help members of minority groups	1	2	3	4	5	6	(7)
11. To learn more about AIDS	1	2	3	4	5	6	(7)
12. To make new friends	(1)	2	3	4	5	6	7
13. To learn more about the health care delivery system	1	2	3	4	5	(6)	7
14. To learn more about drug experiments	1	2	3	4	5	(6)	7

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1=Extremely Unimportant. 4=Doesn't matter one way or the other
2=Moderately Unimportant 5=Slightly. Important
3=Slightly Unimportant. 6=Moderately Important. 7=Extremely Important

15.	To learn more about the way women are facing the AIDS crisis	1	2	3	4	5	(6)	7
16.	To learn more about the way the Black and Hispanic communities are addressing the AIDS crisis	1	2	3	4	5	6	(7)
17.	To address in a practical manner your health status	1	2	3	4	5	6	(7)
18.	To address in a practical manner the health of your friends	1	2	3	4	(5)	6	7
19.	To address in a practical manner the health of your lover	(1)	2	3	4	5	6	7
20.	To learn more about politics	(1)	2	3	4	5	6	7
21.	To learn more about drug companies	1	2	3	4	(5)	6	7
22.	To learn more about the way our economic system works	1	(2)	3	4	5	6	7
23.	To work with other oppressed people such as people of color, women and the poor	1	2	3	4	5	(6)	7
24.	To learn more about the US government	(1)	2	3	4	5	6	7
25.	To learn more about the other major institutions of society such as the Supreme Court	(1)	2	3	4	5	6	7
26.	To feel empowered by a knowledge which otherwise you feel would not be given to you	1	2	3	4	5	6	(7)
27.	To learn more about scientific research	1	2	3	4	5	(6)	7
28.	To learn more about sexuality	1	2	3	(4)	5	6	7
29.	To learn more about safe-sex	1	2	3	4	(5)	6	7
30.	To meet sexual mates	(1)	2	3	4	5	6	7
31.	To learn more about science	1	2	(3)	4	5	6	7
32.	To learn more about medicine	1	2	(3)	4	5	6	7
33.	To be more responsible with your health	1	2	3	4	(5)	6	7

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1=Extremely Unimportant. 4=Doesn't matter one way or the other
2=Moderately Unimportant 5=Slightly Important
3=Slightly Unimportant 6=Moderately Important. 7=Extremely Important

34. To learn more about law..... (1) 2 3 4 5 6 7

35. To understand better how homosexuality is perceived in our society..... (1) 2 3 4 5 6 7

36. To understand better how drug-users are perceived in our society..... (1) 2 3 4 5 6 7

37. To fight homophobia..... 1 2 3 (4) 5 6 7

38. To fight for the civil rights of PWA's..... 1 2 3 4 5 (6) 7

39. To fight for the civil rights of lesbians and gay men..... 1 2 (3) 4 5 6 7

40. Other (please, specify)_____

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SOME GENERAL INFORMATION

PLEASE CIRCLE A NUMBER

2. In what range does your age fall?

1. less than 18
2. 18-20 years old
3. 21-25
4. 26-30
5. 31-35
6. 36-40
7. 41-45
8. 46-50
9. more than 50

3. What is your gender? 1. Female (2) Male

4. What is the job from which you draw the main source of your income? Specify the field in which you work. For example, Health Service, Education, Commerce... Please answer the same questions for your mother, father or those who are or were your legal guardians. If retired, mention the last job title.

	JOB	FIELD
4.1. YOURS	ART DIRECTOR	PUBLISHING
4.2. FATHER'S	POSTAL CLERK	US GOVERNMENT
4.3. MOTHER'S	TEACHER	EDUCATION

4.4. If you had the choice, would there be a job that you would rather be doing? yes (2) no

4.5. If yes, which one? _____(please, specify field)_____

4.6. Are you legally married? 1. yes (2) no

4.7. Do you have children? yes (2) no 4.8. If yes, how many? _____

5. In which of the following groups does the total income of your household fall? (i.e include the income of the people you live and share the expenses with) Please circle the number that corresponds to your answer.

1. 0.000-5.000
2. 5.001-10.000
3. 10.001-15.000
4. 15.001-20.000
5. 20.001-25.000
6. 25.001-30.000
7. 30.001-35.000
8. 35.001-40.000
9. 40.001-45.000
10. 45.001-50.000
11. 50.001-60.000
12. 60.001-80.000
13. 80.001-100.000
14. 100.001 and up

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6. Which of the following best describes your work situation now? (Please, circle ALL that apply)

1. Work full-time for pay
2. Work part-time for pay: number of hours per week_____
3. Self-employed or free-lance
4. Retired
5. Full-time student
6. Part-time student
7. Unemployed looking for a job
8. Unemployed not looking for a job
9. Never worked

6-1 Does your job offer: (Please circle ALL that apply)

1. Seniority ?
2. Tenure?
3. Union support?
4. a non-discriminatory sexual orientation clause?
5. None of the above?

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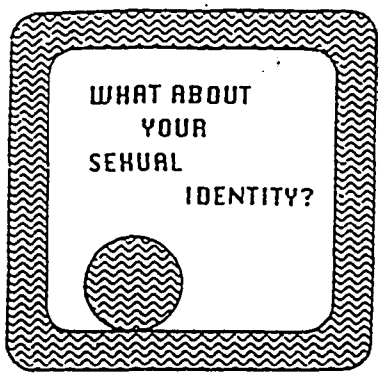

PLEASE CIRCLE THE LETTERS OR NUMBERS THAT CORRESPOND TO YOUR ANSWERS

7. Do you define yourself sexually as a:

1. Lesbian?
2. gay?
3. heterosexual?
4. homosexual?
5. bisexual, primarily homosexual/lesbian/gay?
6. bisexual, primarily heterosexual?
7. Other (please specify)?_____

7-1. How would you describe your sexual thoughts and feelings over the past year?.Please, circle one number

Exclusively heterosexual 1 2 3 4 5 6 7 Exclusively homosexual

7-2. How would you describe your sexual actions and behavior over the past year?

Exclusively heterosexual 1 2 3 4 5 6 7 Exclusively homosexual

If you are lesbian, gay or bisexual to what extent :

7-3. were you open about your sexual identity,

before joining ACT-UP? Not at all Out 1 2 3 4 5 6 7 Completely Out

7-4. have you been open about your sexuality

since you joined ACT-UP? Not at all Out 1 2 3 4 5 6 7 Completely Out

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7-5. If you are not out completely now, are you out to:
(please, circle the number that corresponds to your answer)

1. Your mother?
2. Your father?
3. Your sister?
4. Your close friends?
5. Your boss ?
None of the above?

8. What is the highest level of education you have completed?
(please, circle the number that corresponds to your answer).

1. Less than high school degree
2. High school degree or its equicalent
3. Some college or technical school
4. Associate's degree
5. Some graduate work
6. Master's degree (please specify field and school) _____
7. Doctoral degree (please specify field and school) _____

9. In what religion were you raised? **Please specify the denomination, for example: Protestant: Baptist, Jewish: reform...**

1. Catholic: _____
2. Hindu: _____
3. Jewish: _____
4. Moslem: _____
5. Protestant: Baptist
6. None: _____
7. Other (please, specify) _____

9-1 What is your religious preference? (PLease, specify)

1. Catholic: _____
2. Hindu: _____
3. Jewish: _____
4. Moslem: _____
5. Protestant: _____
6. None: _____
7. Other(Please specify) _____

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10. What is your "race" or ethnic background, as well as your parents'. After circling the number that corresponds to your answer, please write in your specific ethnic background. For example: Black not of Hispanic origin: Afro-American, Hispanic : Jamaican.

Your ethnic background	Your mother's	Your father's
1. ~~Black~~, not of Hispanic origin: Afro-American (1)	2. Afro-American (1)	3. Afro-American (1)
4. White, not of Hispanic origin	5.	6.
7. Hispanic:	8.	9.
10. Other (please, specify)	11.	12.

11. Approximately, how long have you been a member of ACT-UP?

1. 2 weeks or less
2. 1 month or less
3. 2-3 months
4. 4-5 months
5. 6-7 months
6. 8-9 months
7. 10-12 months
8. 13-16 months
9. 17-20 months
10. 21-24 months
11. 24-26 months

11-1. As far as you can remember, could you specify the date you joined ACT-UP?

DAY 1 MONTH MARCH YEAR 88

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Now we'd like to know about your involvement in ACT-UP.

Please, circle the numbers that correspond to your answers.

12.

	never	rarely	sometimes	many times
1. How regularly do you attend the ACT-UP Monday meeting?	1	2	3	(4)
2. Do you attend other ACT-UP meetings during the week	1	2	3	(4)

3. If your answer is positive which one(s): Majority Actions, Coordinating Comm. (11) (22)

4. Are/have you been chair of a committee 1. yes 2. no

5. If your answer is yes, which ones: Majority Actions (11)

PRIOR TO ACT-UP WERE YOU INVOLVED IN OTHER ORGANIZATIONS?

13.

1. Before joining ACT-UP, did you belong to an organization(s)?
   1. yes 2. no

2. If yes, which one(s) most impacted on you? Please indicate the name of the organization(s) and whether the organization(s) was gay-identified, political and/or social Please circle ALL that apply.

	Gay-identified	political	social
_____	1	2	3
_____	1	2	3
_____	1	2	3

3. If you belonged to an organization(s) prior to joining ACT-UP, did you leave this organization(s) when you joined ACT-UP?
   1 yes 2. no

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4. If yes, why (please, specify) _____

5. In the 1988 US presidential election, did you vote? (1) yes 2. no

6. If yes, who did you vote for? Micheal Dukakis

7. Do you perceive yourself as:
(Please, circle the number that coresponds to your answer)

1. Republican?
2. Democrat?
(3). Independent?
4. Socialist?
5. Communist?
6. Anarchist?
7. Other (please, specify)? _____

14. **Please circle your answer. If your answer is positive, please specify it in the appropriate space.**

Before joining ACT-UP, did you:	never	rarely	sometimes	many times	if you did, which one(s) most impacted on you?
1. vote in the local elections	1	2	3	(4)	minor
2. ever feel strongly about any causes, even if you did not participate in any substantial way?	1	2	3	(4)	(4) abortion
3. contribute money to any other causes?	1	2	(3)	4	(4) greenpeace
4. lobby for any causes?	(1)	2	3	4	
5. participate in demonstrations	1	(2)	3	4	(3) anti-gay
6. participate in civil disobedience	(1)	2	3	4	
7. deliberately take part in a collective arrest	(1)	2	3	4	

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15. Since you joined ACT-UP, did you:	never	rarely	sometimes	many times	If yes, which one(s) most impacted on you?
1. vote in the local elections	1	2	3	(4)	Mayor
2. read the literature distributed by ACT-UP?	1	2	3	(4)	?
3. participate in the workshops, such as the FDA or the women and AIDS teach-ins?	1	2	3	(4)	(5) FDA-Teach In
4. participate in demonstrations?	1	2	3	(4)	(5) ~~FDA~~
5. participate in the actions that took place outside New York, such as the FDA action in Washington DC?	1	2	3	(4)	(5) FDA
6. participate in zaps?	1	2	3	(4)	(12) Housing zap
7. deliberately take part in a collective arrest?	1	2	3	(4)	(7) City Hall 89

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16. Below is a list of professional groups or bureaucracies which have been said to be directly or indirectly involved in the AIDS crisis. Please circle the numbers that correspond to the extent you think that each of them impacted positively or negatively on the way the national response to the AIDS crisis has been mounted (the Gay organizations have been omitted on purpose).

Please, circle the number that corresponds to your answer.

	strong negative impact	some negative impact	positive and negative impact	some positive impact	strong positive impact	don't know (dk)
1. Department of Health	(1)	2	3	4	5	8(dk)
2. US Congress	1	2	(3)	4	5	8(dk)
3. Drug Companies	1	2	(3)	4	5	8(dk)
5. The scientific research community	1	2	(3)	4	5	8(dk)
6. The Reagan/Bush administration	(1)	2	3	4	5	8(dk)
7. The Federal government as a whole	(1)	2	3	4	5	8(dk)
8. The administrations of the different states	1	(2)	3	4	5	8(dk)
9. The administrations of the different cities	1	(2)	3	4	5	8(dk)
10. The state bureaucracies in general	1	(2)	3	4	5	8(dk)
11. The major national newspapers, such as The New York Times, New Post or Daily News	1	(2)	3	4	5	8(dk)
12. The major television networks such as CBS, NBC or ABC	1	2	(3)	4	5	8(dk)
13. The diverse religious institutions such as the Church	(1)	2	3	4	5	8(dk)

14. Other: (please specify)_____

16-1 In order of priority, which first two do you think have had the greatest impact on the way the national response to AIDS has been mounted. Please, just write in the numbers with a plus or minus sign to indicate whether the impact was positive or negative -6- ,7-

17. In your judgment, should ACT-UP share in joint activities with other groups in order to further those groups' goals? (1.)yes 2. no

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17-1. If yes, among the following how often should ACT-UP join in political activities with the:
(please, circle the number that corresponds to your answer)

		never	sometimes	very often	don't know (dk)
1.	Republican Party	1	2	3	8(dk)
2.	Democratic party	1	2	3	8(dk)
3.	Liberal party	1	2	3	8(dk)
4.	Anarchist groups	1	2	3	8(dk)
5.	Right-to-life groups	1	2	3	8(dk)
6.	Socialist groups	1	2	3	8(dk)
7.	Communist groups	1	2	3	8(dk)
8.	The Rainbow Coalition	1	2	3	8(dk)
9.	The Homeless Coalition	1	2	3	8(dk)
10.	Groups against US intervention in Latin America	1	2	3	8(dk)
11.	Anti-nuclear movement	1	2	3	8(dk)
12.	Pro-choice organizations	1	2	3	8(dk)
13.	American Medical Association	1	2	3	8(dk)
14.	American Society of officials	1	2	3	8(dk)
15.	Feminist groups	1	2	3	8(dk)
16.	Green Party	1	2	3	8(dk)
17.	Peace movement	1	2	3	8(dk)
18.	Unions	1	2	3	8(dk)
19.	Anti-racist organizations	1	2	3	8(dk)
20	ADAPT	1	2	3	8(dk)
21.	Alcoholic Anonymous	1	2	3	8(dk)
22.	DAYTOP	1	2	3	8(dk)
23.	COYOTE	1	2	3	8(dk)
24.	Other(s) (please, specify) _____				

17-2. In order of priority, which first two do you think ACT-UP should join in activities with? Please, just write in the numbers that correspond to your answers 9 , 19

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17-3. Among the already existing AIDS organizations, which ones do you think ACT-UP should join in activities with, in order to further the goals of those organizations.

Please circle the numbers that correspond to your answers

	never	sometimes	very often	don't know (dk)
1. The Gay Men's Health Crisis	1	(2)	3	8(dk)
2. The People With Aids Coalition	1	(2)	3	8(dk)
3. The National Aids Task Force	1	(2)	3	8(dk)
4. The Minority Aids Task Force	1	(2)	3	8(dk)
5. HEAL	1	(2)	3	8(dk)
6. Body Positive	1	(2)	3	8(dk)
7. ACT-UPS in other cities	1	2	(3)	8(dk)

8. Others **(please, specify)** _____

17-4. Among the gay organizations that do not specifically focus on the AIDS crisis, which one(s) do you think ACT-UP should join in activities with, in order to further the goals of those organizations?

	never	sometimes	very often	don't know (dk)
1. The National Gay Task Force	1	(2)	3	8(dk)
2. The Lesbian and Gay Community Services Center	1	(2)	3	8(dk)
3. GLAAD	1	(2)	3	8(dk)
4. Dignity	1	(2)	3	8(dk)

5. Other **(please, specify)** _____

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WE WOULD LIKE TO KNOW IF YOU ARE INVOLVED IN ORGANIZATIONS WHOSE PRIMARY GOALS ARE NOT THE RESOLUTION OF THE AIDS CRISIS.

please, circle the number that corresponds to your answer

18. SINCE YOU JOINED ACT-UP, DID YOU:

	never	rarely	sometimes	many times	If you did, please, specify the one(s) which most impacted on you:
1. Support the struggle of people who were not engaged in AIDS activism?	1	2	(3)	4	(11) pro-choice,
2. contribute money for causes other than the ones fought for by AIDS activists?	1	2	(3)	4	(14) central-amer.
3. lobby for causes other than the ones fought for by AIDS activists?	(1)	2	3	4	_____
4. participate in demonstrations or marches for causes other than the ones fought for by AIDS activists ?	1	2	(3)	4	(8) anti-nuke
5. participate in civil disobedience, the primary goal of which was not the end of the AIDS crisis?	(1)	2	3	4	_____
6. deliberately participate in a collective arrest, the goal of which was not the end of the AIDS crisis?	(1)	2	3	4	_____

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DOES BEING LESBIAN OR GAY MAKE A DIFFERENCE ?

PLEASE CIRCLE YOUR ANSWERS. THE AVAILABLE ANSWERS ARE
1=STRONGLY DISAGREE
2=MODERATELY DISAGREE
3=SLIGHTLY DISAGREE
4=NEITHER AGREE NOR DISAGREE
5=SLIGHTLY AGREE
6=MODERATELY AGREE
7=STRONGLY AGREE
8=DON'T KNOW

19.

1	Being openly Lesbian/Gay is a political act.	1	2	3	(4)	5	6	7	8
2.	Lesbian/Gay issues and AIDS issues are closely related.	1	2	3	4	5	6	(7)	8
3.	My involvement in ACT-UP has reaffirmed my Lesbian/Gay identity.	1	2	3	4	(5)	6	7	8
4.	ACT-UP is the organization where I can best express my lesbian/gay identity.	1	2	(3)	4	5	6	7	8
5.	If an injustice was committed to a Lesbian/Gay person, I would always help her/him right away.	1	2	3	4	5	6	(7)	8

20. We would like to know your feelings about society in general. Please circle your answers.

To what extent do you think that the political institutions, as they currently exist, can meet the needs of:

		They cannot meet any of their needs						They can meet all their needs
20-1	seropositive people or people with AIDS?	1	2	(3)	4	5	6	7
20-2	lesbians and gay men?	1	2	3	4	(5)	6	7

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To what extent do you think that the economic institutions (e.g. insurance companies, banks) as they currently exist can meet the needs of:

20-3. seropositive people or people with AIDS

	They cannot meet any of their needs						They can meet all their needs
	1	(2)	3	4	5	6	7
20-4. lesbians and gay men?	1	2	3	(4)	5	6	7

PLEASE CIRCLE YOUR ANSWER	never	sometimes	many times
20-5. Over the last eight years have you personally experienced:			
a. any anti-gay insult ?	1	(2)	3
b. any anti-gay act of violence?	1	(2)	3
20-6. Over the last eight years have you witnessed:			
1. any anti-gay insult?	1	(2)	3
2. any anti-gay act of violence	1	(2)	3

20-7. How satisfactory is your your relationship with your:

	Totally Unsatisfactory							totally Satisfactory
1. family?	1	2	3	4	(5)	6	7	
2. friends?	1	2	3	4	(5)	6	7	
3. coworkers?	1	2	3	4	(5)	6	7	
4. partner/lover?	1	2	3	4	(5)	6	7	
5. husband/wife?	1	2	3	4	(5)	6	7	
6. Boyfriend/girlfriend?	1	2	3	4	(5)	6	7	

20-8. How satisfactory is your life:

	Totally Unsatisfactory							totally Satisfactory
1. intellectually?	1	2	3	4	(5)	6	7	
2. romantically?	1	2	(3)	4	(5)	6	7	
3. sexually?	1	2	3	4	(5)	6	7	
4. professionally?	1	2	3	4	5	(6)	7	

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Now we'd like to know about your views on the testing issue and your health status. We remind you that your responses will remain totally anonymous.

please circle your answer.

21. Have you been tested for HIV antibodies? 1. yes (2) no (8)

21-1. if no, why not?(please specify) presume ~~me~~ to be HIV+ and felt hzd no need for the verification if no treatment was available. Now reconsidering finding out my T-cell count because of the drug available ~~for~~ for the prevention of PCP.

21-2. Are you seropositive? 1. yes 2. no
if no, please go to question 22

21-3 If yes, please circle the answer that best characterizes your health status

1. HIV asymptomatic
2. ARC
3. AIDS
4. Other (please specify)

21-4. If you are seropositive, did you know it before joining ACT-UP? 1. yes 2. no

21-5 If you are seropositive, to what extent did you disclose your health status to:

	Not disclosed at all						Totally Disclosed
1 family?	1	2	3	4	5	6	7
2 siblings?	1	2	3	4	5	6	7
3 friends?	1	2	3	4	5	6	7
4 coworkers?	1	2	3	4	5	6	7
5 ACT-UP members?	1	2	3	4	5	6	7

22 Did you lose a person(s) dear to you to AIDS? (1) yes 2. no

22-1 if yes, how many 1

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PLEASE CIRCLE YOUR ANSWER. THE AVAILABLE ANSWERS ARE:
1=STRONGLY DISAGREE 4=SLIGHTLY AGREE
2=MODERATELY DISAGREE 5=MODERATELY AGREE
3=SLIGHTLY DISAGREE 6=STRONGLY AGREE
8=DONT'KNOW

23. AS A MEMBER OF ACT-UP:

1.	I understand better the legal system of this country	1	2	3	4	(5)	6	8(dk)
2.	I understand better the way scientific research is conducted	1	2	3	4	5	(6)	8(dk)
3.	I understand how to practice safer sex	1	2	3	4	5	(6)	8(dk)
4.	I have learned to educate other people about AIDS	1	2	3	4	5	(6)	8(dk)
5.	I understand better my sexuality	1	2	3	(4)	5	6	8(dk)
6.	I am sometimes disappointed because the focus is not always on AIDS	1	2	3	4	5	(6)	8(dk)
7.	I have a better understanding of the way the media function	1	2	3	4	5	(6)	8(dk)
8	I feel proud to be gay	1	2	3	(4)	5	6	8(dk)
9.	I have learned about holistic medicine	1	2	3	4	(5)	6	8(dk)
10.	I have come to realize that being open about one's seropositive status is a political act	1	(2)	3	4	5	6	8(dk)
11.	I see the need to increase our efforts to outreach to other communities	1	2	3	4	5	(6)	8(dk)
12.	I understand better the power structure of the United States	1	(2)	3	4	5	6	8(dk)

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1=Strongly Disagree
2=Moderately Disagree
3=Slightly Disagree
4=Slightly Agree
5=Moderately Agree
6=Strongly Agree
8=Don't know

13.	I understand better how other minorities are oppressed	(1)	2	3	4	5	6	8(dk)
14.	I realize how women are oppressed	1	(2)	3	4	5	6	8(dk)
15.	I think that issues of class should be more addressed during the meetings	1	2	3	4	(5)	6	8(dk)
16.	I have a good handle on the way the drug protocols are conducted	1	2	3	4	(5)	6	8(dk)
17.	I see the connection of the AIDS crisis to other social problems	1	2	3	4	5	(6)	8(dk)
18.	I realize that the group is too radical	(1)	2	3	4	5	6	8(dk)
19.	I have made a lot of friends	1	2	3	4	(5)	6	8(dk)
20.	I feel intimidated to speak in public	(1)	2	3	4	5	6	8(dk)
21.	I have learned to take control over my body	1	2	3	4	(5)	6	8(dk)
22.	I have become more critical of science	1	2	3	4	(5)	6	8(dk)
23.	I think that we often loose sight of our focus during the meetings	(1)	2	3	4	5	6	8(dk)
24.	I realize that I still find myself pretty much isolated	(1)	2	3	4	5	6	8(dk)
25.	I have learned to understand better how lesbians and gay men are oppressed	1	2	(3)	4	5	6	8(dk)
26.	I am convinced that we should address more frequently the international aspects of the epidemic	1	2	3	(4)	5	6	8(dk)
27.	I have become more critical of the scientific community	1	2	3	4	(5)	6	8(dk)
28.	I understand better the position of religious institutions such as the church with regard to the gay community	1	(2)	3	4	5	6	8(dk)
29.	I understand better the political differences within the gay population	1	2	(3)	4	5	6	8(dk)

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1=Strongly Agree
2=Moderately Disagree
3=Slightly Disagree
4=Slightly Agree
5=Moderately Agree
6=Strongly Agree
8=Don't Know

30	I keep myself informed of the drug trials currently underway	1	2	3	(4)	5	6	8(dk)
31.	I admit that it is hard to be admitted in certain circles of friends that are already established in the organization	(1)	2	3	4	5	6	8(dk)
32.	I am sometimes disappointed because the discussion are too technical and difficult to understand	(1)	2	3	4	5	6	8(dk)
33.	I often feel uncomfortable because there are no support groups when I am "burned out"	(1)	2	3	4	5	6	8(dk)
34.	I am sometimes discouraged because the group is not radical enough	1	2	(3)	4	5	6	8(dk)
35.	I am convinced that the group should spend more time on minority issues	1	2	3	4	5	(6)	8(dk)
36.	I have learned to fight homophobia	1	2	(3)	4	5	6	8(dk)
37.	I have learned to fight for the rights of seropositive individuals	1	2	3	4	(5)	6	8(dk)
38.	I wish there were more social events planned by the group	1	2	3	(4)	5	6	8(dk)
39.	I am convinced that the group should spend more time addressing women's issues	1	2	3	4	(5)	6	8(dk)
40.	I am convinced that sexuality should discussed publicly	1	2	3	4	(5)	6	8(dk)
41	I realize that I learned a great deal about lesbian and gay history	1	(2)	3	4	5	6	8(dk)

23-1. Is there anything in ACT-UP that you don't like? (1.yes) 2. no

1. If yes, please explain briefly what you most dislike about the organization.
The problem of wanting to be an AIDS activist group and a gay-lesbian activist group at the same time. I feel that both struggle need lots of attention. However, I join the AIDS Coalition To Unleash Power. (1)
2. Would you say that what you don't like about ACT-UP caused you to be significantly less involved in the organization? 1. yes (2. no)

23-2. Did ACT-UP change your life in any dramatic way? (1.yes) 2. no

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1. If yes, please explain briefly how. the feeling of being in total control of my life, body, etc. 567

WHAT IF TOMORROW THERE WAS A CURE FOR ALL THE SEROPOSITIVE INDIVIDUALS REGARDLESS OF THE DEGREE TO WHICH THEY ARE AFFECTED BY THE DISEASE ?...

24. According to you, would there still be a reason for ACT-UP to exist? (1.) yes 2. no

24-1. If yes, please briefly explain why? It could be a gay/lesbain activist group.

THANK YOU FOR SPENDING THE TIME...

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From: The AIDS Knowledge Base
1990 Medical Pub. Group : Waltham, Mass.
Author : Cohen, P.T., Sande, M.A. & Volberding;

1.1.1

Definitions and Codes for HIV Infection and AIDS

Dennis Ormond

Persons infected with the human immunodeficiency virus (HIV)[1-4] may have a variety of manifestations, ranging from asymptomatic infection to severe immunodeficiency and life-threatening secondary infectious diseases or cancers. Various means are now used to describe and assess patients with these manifestations and to describe their signs, symptoms, and laboratory findings. The Centers for Disease Control (CDC) surveillance definition of AIDS has proved to be extremely valuable and reliable for some epidemiologic studies and clinical assessment of patients with the more severe manifestations of disease. However, more inclusive definitions and classifications of HIV infection are needed for optimum patient care, health planning, and public health control strategies, as well as for epidemiologic studies and special surveys. A broadly applicable, easily understood classification system should also facilitate and clarify communication about this disease.

The classification system described in this chapter has been proposed by the CDC.[5] The system is meant to provide a means of grouping patients according to the clinical presentation of disease. It does not imply any change in the definition of AIDS used by the CDC for national reporting.

■ DEFINITION OF HIV INFECTION

The most specific diagnosis of HIV infection is by direct identification of the virus in host tissues by virus isolation. However, the techniques for isolating HIV currently lack sensitivity for detecting infection and are not readily available. For public health purposes, patients with repeatedly reactive screening tests for HIV antibody (e.g., enzyme-linked immunosorbent assay) in whom antibody is also identified by the use of supplemental tests (e.g., Western blot, immunofluorescence assay) should be considered both infected and infective.[6-8]

Although HIV infection is identified by isolation of the virus or, indirectly, by the presence of antibody to the virus, a presumptive clinical diagnosis of HIV infection has been made in some situations in the absence of positive virologic or serologic test results. There is a very strong correlation between the clinical manifestations of AIDS as defined by the CDC and the presence of HIV antibody.[9-12] Most persons whose clinical illness fulfills the CDC surveillance definition for AIDS will have been infected with the virus.[10-12]

■ CLASSIFICATION SYSTEM

This system classifies the manifestations of HIV infection into four mutually exclusive groups, designated by Roman numerals I through IV (Table 1). The classification system applies only to patients diagnosed as having HIV infection. Classification in a particular group is not explicitly intended to have prognostic significance, nor to designate severity of illness. However, classification in the

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Group I. Acute HIV Infection. Defined as a mononucleosis-like syndrome, with or without aseptic meningitis, associated with seroconversion for HIV antibody.[12,14] Antibody seroconversion is required as evidence of initial infection; current viral isolation procedures are not adequately sensitive to be reliable for demonstrating the onset of infection.

Group II. Asymptomatic HIV Infection. Defined as the absence of signs or symptoms of HIV infection. To be classified in Group II, patients must have had no previous signs or symptoms that would have led to classification in Groups III or IV. Patients whose clinical findings caused them to be classified in Groups III or IV should not be reclassified in Group II if those clinical findings resolve.

Patients in this group may be subclassified on the basis of a laboratory evaluation. Laboratory studies commonly indicated for patients with HIV infection include, but are not limited to, a complete blood count (including differential white blood cell count) and a platelet count. Immunologic tests, especially T lymphocyte helper and suppressor cell counts, are also an important part of the overall evaluation. Patients whose test results are within normal limits, as well as those for whom a laboratory evaluation has not yet been completed, should be differentiated from patients whose test results are consistent with defects associated with HIV infection (e.g., lymphopenia, thrombocytopenia, or decreased number of helper T lymphocytes).

Group III. Persistent Generalized Lymphadenopathy (PGL). Defined as palpable lymphadenopathy (lymph node enlargement of 1 cm or greater) at two or more extrainguinal sites persisting for more than three months in the absence of a concurrent illness or condition other than HIV infection to explain the findings. Patients in this group may also be subclassified on the basis of a laboratory evaluation, as is done for asymptomatic patients in Group II. Patients with PGL whose clinical findings caused them to be classified in Group IV should not be reclassified in Group III if those other clinical findings resolve.

Group IV. Other HIV Disease. The clinical manifestations of patients in this group may be designated by assignment to one or more subgroups (A through E) listed below. Within Group IV, subgroup classification is independent of the presence or absence of lymphadenopathy. Each subgroup may include patients who are minimally symptomatic, as well as patients who are severely ill. Increased specificity for manifestations of HIV infection, if needed for clinical purposes or research purposes or for disability determinations, may be achieved by creating additional divisions within each subgroup.

Subgroup A. Constitutional disease. Defined as one or more of the following: fever persisting more than one month, involuntary weight loss of greater than 10 percent of baseline, or diarrhea persisting more than one month; and the absence of a concurrent illness or condition other than HIV infection to explain the findings.

Subgroup B. Neurologic disease. Defined as one or more of the following: dementia, myelopathy, or peripheral neuropathy; and the absence of a concurrent illness or condition other than HIV infection to explain the findings.

Subgroup C. Secondary infectious diseases. Defined as the diagnosis of an infectious disease associated with HIV infection or at least moderately indic-

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four principal groups, I through IV, is hierarchical in that persons classified in a particular group should not be reclassified in a preceding group if clinical findings resolve, since clinical improvement may not accurately reflect changes in the severity of the underlying disease.

TABLE 1. SUMMARY OF CLASSIFICATION SYSTEM FOR HIV INFECTION

GROUP I.	Acute infection
GROUP II.	Asymptomatic infection*
GROUP III.	Persistent generalized lymphadenopathy*
GROUP IV.	Other disease
Subgroup A.	Constitutional disease
Subgroup B.	Neurologic disease
Subgroup C.	Secondary infectious diseases
Category C-1.	Specified secondary infectious diseases listed in the CDC surveillance definition for AIDS†
Category C-2.	Other specified secondary infectious diseases
Subgroup D.	Secondary cancers**
Subgroup E.	Other conditions

* *Patients in Groups II and III may be subclassified on the basis of a laboratory evaluation.*

† *Includes those patients whose clinical presentation fulfills the definition of AIDS used by the CDC for national reporting.*

Group I includes patients with transient signs and symptoms that appear at the time of, or shortly after, initial infection with HIV as identified by laboratory studies. All patients in Group I should be reclassified in another group after resolution of this acute syndrome.

Group II includes patients who have no signs or symptoms of HIV infection. Patients in this category may be subclassified based on whether hematologic or immunologic laboratory studies have been done and whether results are abnormal in a manner consistent with the effects of HIV infection.

Group III includes patients with persistent generalized lymphadenopathy, but without findings that would lead to classification in Group IV. Patients in this category may be subclassified based on the results of laboratory studies in the same manner as patients in Group II.

Group IV includes patients with clinical symptoms and signs of HIV infection other than or in addition to lymphadenopathy. Patients in this group are assigned to one or more subgroups based on clinical findings. These subgroups are:

A. constitutional disease

B. neurologic disease

C. secondary infectious diseases

D. secondary cancers

E. other conditions resulting from HIV infection.

There is no a priori hierarchy of severity among subgroups A through E, and these subgroups are not mutually exclusive.

Definitions of the groups and subgroups are as follows.

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underwent minor revisions.[18,19] A more substantive revision took place in June 1985, when additional diseases were added to the case definition. At the same time, results from HIV antibody tests and viral cultures began to be employed, thereby increasing the specificity with which AIDS-related diseases could be identified.[20] Even so, the CDC has estimated that its 1985 revisions resulted in reclassification of less than one percent of previously reported cases.[20]

1987 CHANGES IN CDC DEFINITION

In August 1987, the CDC published a major revision of the adult case definition for surveillance, broadening the definition in three ways:[21]

Changes in Adult Case Definition

1. Inclusion of HIV encephalopathy and HIV wasting syndrome.
2. Inclusion of diagnoses made presumptively with laboratory evidence for HIV infection.
3. Elimination of exclusions due to other causes of immunodeficiency with laboratory evidence for HIV infection.

Changes in Pediatric Case Definition

1. Inclusion of multiple or recurrent serious bacterial infections.
2. Inclusion of lymphoid interstitial pneumonia or pulmonary lymphoid hyperplasia in children under 13 years old.

1987 CDC ADULT AND PEDIATRIC CASE DEFINITION FOR SURVEILLANCE PURPOSES

Based on this latest revision, the following are the CDC criteria for defining AIDS in adult and pediatric cases.

For national reporting, a case of AIDS is defined as an illness characterized by one or more of the following "indicator" diseases, depending on the status of laboratory evidence of HIV infection, as shown below.

I. Without Laboratory Evidence of HIV Infection

If laboratory tests for HIV were not performed or gave inconclusive results and the patient had no other cause of immunodeficiency as listed in Section I.A. below, then any disease listed in Section I.B. indicates AIDS if it was diagnosed by a definitive method.

A. Causes of immunodeficiency that disqualify diseases as indicators of AIDS in the absence of laboratory evidence for HIV infection:

1. High-dose or long-term systemic corticosteroid therapy or other immunosuppressive or cytotoxic therapy <3 months before the onset of the indicator disease.
2. Any of the following diseases diagnosed <3 months after diagnosis of the indicator disease: Hodgkin's disease, non-Hodgkin's lymphoma (other than primary brain lymphoma), lymphocytic leukemia, multiple myeloma, any other cancer of lymphoreticular or histiocytic tissue, or angioimmunoblastic lymphadenopathy.

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ative of a defect in cell-mediated immunity. Patients in this subgroup are divided further into two categories.

Category C-1. Includes patients with symptomatic or invasive disease due to 1 of 12 specified secondary infectious diseases listed in the surveillance definition of AIDS: *Pneumocystis carinii* pneumonia, chronic cryptosporidiosis, toxoplasmosis, extraintestinal strongyloidiasis, isosporiasis, candidiasis (esophageal, bronchial, or pulmonary), cryptococcosis, histoplasmosis, mycobacterial infection with *Mycobacterium avium* complex or *M. kansasii*, cytomegalovirus infection, chronic mucocutaneous or disseminated herpes simplex virus infection, or progressive multifocal leukoencephalopathy.

Category C-2. Includes patients with symptomatic or invasive disease due to one of six other specified secondary infectious diseases: oral hairy leukoplakia, multidermatomal herpes zoster, recurrent salmonella bacteremia, nocardiosis, tuberculosis, or oral candidiasis (thrush).

Subgroup D. Secondary cancers. Defined as the diagnosis of one or more kinds of cancer known to be associated with HIV infection as listed in the surveillance definition of AIDS and at least moderately indicative of a defect in cell-mediated immunity: Kaposi's sarcoma, non-Hodgkin's lymphoma (small, noncleaved lymphoma or immunoblastic sarcoma), or primary lymphoma of the brain.

Category C-1 and Subgroup D, it should be noted, include those patients with one or more of the infectious diseases or specified cancers fulfilling the definition of AIDS as used by the CDC for national reporting.

Subgroup E. Other conditions in HIV infection. Defined as the presence of other clinical findings or diseases, not classifiable above, that may be attributed to HIV infection or may be indicative of a defect in cell-mediated immunity. Included are patients with chronic lymphoid interstitial pneumonitis. Also included are those patients whose signs or symptoms could be attributed either to HIV infection or to another coexisting disease not classified elsewhere, and patients with other clinical illnesses, the course or management of which may be complicated or altered by HIV infection. Examples include patients with constitutional symptoms not meeting the criteria for subgroup IV-A, patients with infectious diseases not listed in subgroup IV-C, and patients with neoplasms not listed in subgroup IV-D.

■ CDC AIDS CASE DEFINITION FOR SURVEILLANCE: 1987 REVISION

As opposed to the CDC's definition of HIV infection, we now explore its definition for cases of AIDS, the syndrome occupying the far end of the spectrum of problems caused by HIV. The first surveillance definition of an AIDS case used by the CDC was published in *Morbidity and Mortality Weekly Report* in September 1982[13]:

> *A case of a disease at least moderately predictive of a defect in cell-mediated immunity occurring in a person with no known cause for diminished resistance to that disease.*

This general definition of AIDS included a list of specific diseases and qualifications as well as a list of disqualifying conditions that were considered possible causes of non-AIDS-related diminished resistance. After 1982, the definition

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5. Isosporiasis with diarrhea persisting > 1 month.
6. Kaposi's sarcoma at any age.
7. Lymphoma of the brain (primary) at any age.
8. Other non-Hodgkin's lymphoma of B-cell or unknown immunologic phenotype and the following histologic types:
   a. Small noncleaved lymphoma (either Burkitt or non-Burkitt type).
   b. Immunoblastic sarcoma (equivalent to any of the following, although not necessarily all in combination: immunoblastic lymphoma, large-cell lymphoma, diffuse histiocytic lymphoma, diffuse undifferentiated lymphoma, or high-grade lymphoma.

   [Note: Lymphomas are not included here if they are of T-cell immunologic phenotype or their histologic type is not described, or is described as "lymphocytic," "lymphoblastic," "small cleaved," or "plasmacytoid lymphocytic."]
9. Any mycobacterial disease caused by mycobacteria other than *M. tuberculosis*, disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes).
10. Disease caused by *M. tuberculosis*, extrapulmonary (involving at least one site outside the lungs, regardless of whether there is concurrent pulmonary involvement).
11. Salmonella (nontyphoid) septicemia, recurrent.
12. HIV wasting syndrome (emaciation, "slim disease").

B. Indicator diseases diagnosed presumptively:

[Note: Given the seriousness of diseases indicative of AIDS, it is generally important to diagnose them definitively, especially when therapy that would be used may have serious side effects or when definitive diagnosis is needed for eligibility for antiretroviral therapy. Nonetheless, in some situations, a patient's condition will not permit performance of definitive tests. In other situations, accepted clinical practice may be to diagnose presumptively based on the presence of characteristic clinical and laboratory abnormalities.]

1. Candidiasis of the esophagus.
2. Cytomegalovirus retinitis with loss of vision.
3. Kaposi's sarcoma.
4. Lymphoid interstitial pneumonia or pulmonary lymphoid hyperplasia (LIP/PLH complex) affecting a child < 13 years of age.
5. Mycobacterial disease (acid-fast bacilli with species not identified by culture), disseminated (involving at least one site other than or in addition to lungs, skin, or cervical or hilar lymph nodes).
6. *Pneumocystis carinii* pneumonia.
7. Toxoplasmosis of the brain affecting a patient > 1 month of age.

III. With Laboratory Evidence against HIV Infection

With laboratory test results negative for HIV infection, a diagnosis of AIDS for surveillance purposes is ruled out unless:

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INCONCLUSIVE EVIDENCE (NEITHER FOR NOR AGAINST INFECTION)

a. a repeatedly reactive screening test for serum antibody to HTV (e.g., ELISA) followed by a negative or inconclusive supplemental test (e.g., Western blot, immunofluorescence assay) without a positive HTV culture or serum antigen test, if done; OR

b. a serum specimen from a child <15 months of age, whose mother is thought to have had HTV infection during the child's perinatal period, that is repeatedly reactive for HTV antibody by a screening test, even if positive by a supplemental test, without additional evidence for immunodeficiency as described above (in I.b.) and without a positive HTV culture or serum antigen test, if done.

■ DEFINITIVE DIAGNOSTIC METHODS FOR DISEASES INDICATIVE OF AIDS

The following methods have been designated as definitive by the CDC for diagnosis of diseases indicative of AIDS.[2]

TABLE 2.

DISEASES	DEFINITIVE DIAGNOSTIC METHODS
Cryptosporidiosis	Microscopy (histology or cytology)
Cytomegalovirus	Microscopy (histology or cytology)
Isosporiasis	Microscopy (histology or cytology)
Kaposi's sarcoma	Microscopy (histology or cytology)
Lymphoma	Microscopy (histology or cytology)
Lymphoid pneumonia or hyperplasia	Microscopy (histology or cytology)
Pneumocystis carinii pneumonia	Microscopy (histology or cytology)
Progressive multifocal leukoencephalopathy	Microscopy (histology or cytology)
Toxoplasmosis	Microscopy (histology or cytology)
Candidiasis	Gross inspection by endoscopy or by microscopy (histology or cytology) on a specimen obtained directly from the tissues affected (including scrapings from the mucosal surface); not from a culture
Coccidioidomycosis, cryptococcosis, herpes simplex virus, and histoplasmosis	Microscopy (histology or cytology), culture, or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues
Tuberculosis	Culture
Other mycobacteriosis	Culture
Salmonellosis	Culture
Other bacterial infection	Culture

continued on next page

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3. A genetic (congenital) immunodeficiency syndrome or an acqui immunodeficiency syndrome atypical of HIV infection, such as c involving hypogammaglobulinemia.

B. Indicator diseases diagnosed definitively:

1. Candidiasis of the esophagus, trachea, bronchi, or lungs.
2. Cryptococcosis, extrapulmonary.
3. Cryptosporidiosis with diarrhea persisting >1 month.
4. Cytomegalovirus disease of an organ other than liver, spleen, lymph nodes in a patient >1 month of age.
5. Herpes simplex virus infection causing a mucocutaneous ulcer th persists longer than one month; or bronchitis, pneumonitis, c esophagitis for any duration affecting a patient >1 month of age
6. Kaposi's sarcoma affecting a patient <60 years of age.
7. Lymphoma of the brain (primary) affecting a patient <60 yea of age.
8. Lymphoid interstitial pneumonia or pulmonary lymphoid hype plasia (LIP/PLH complex) affecting a child younger than 13 yea of age.
9. *Mycobacterium avium* complex or *M. kansasii* disease, dissemin ated (at a site other than or in addition to lungs, skin, or cervica or hilar lymph nodes).
10. *Pneumocystis carinii* pneumonia.
11. Progressive multifocal leukoencephalopathy.
12. Toxoplasmosis of the brain affecting a patient >1 month of age.

II. With Laboratory Evidence of HIV Infection

Regardless of the presence of other causes of immunodeficiency (Section I.A., above), in the presence of laboratory evidence of HIV infection, any disease listed above (Section I.B.) or below (Sections II.A. or II.B.) indicates a diagnosis of AIDS.

A. Indicator diseases diagnosed definitively:

1. Bacterial infections, multiple or recurrent (any combination of a least two within a two-year period), of the following types affecting a child <13 years of age: septicemia, pneumonia, meningitis, bone or joint infection, or abscesses of an internal organ or body cavity (excluding otitis media or superficial skin or mucosal abscesses) caused by haemophilus, streptococcus (including pneumococcus), or other pyogenic bacteria.
2. Coccidioidomycosis, disseminated (at a site other than or in addition to lungs or cervical or hilar lymph nodes).
3. HIV encephalopathy (also called "HIV dementia," "AIDS dementia," or "subacute encephalitis due to HIV").
4. Histoplasmosis, disseminated (at a site other than or in addition to lungs or cervical or hilar lymph nodes).

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INCONCLUSIVE EVIDENCE (NEITHER FOR NOR AGAINST INFECTION)

a. a repeatedly reactive screening test for serum antibody to HIV (e.g., ELISA) followed by a negative or inconclusive supplemental test (e.g., Western blot, immunofluorescence assay) without a positive HIV culture or serum antigen test, if done; OR

b. a serum specimen from a child <15 months of age, whose mother is thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test, even if positive by a supplemental test, without additional evidence for immunodeficiency as described above (in I.b.) and without a positive HIV culture or serum antigen test, if done.

■ DEFINITIVE DIAGNOSTIC METHODS FOR DISEASES INDICATIVE OF AIDS

The following methods have been designated as definitive by the CDC for diagnosis of diseases indicative of AIDS.[2]

TABLE 2.

DISEASES	DEFINITIVE DIAGNOSTIC METHODS
Cryptosporidiosis	Microscopy (histology or cytology)
Cytomegalovirus	Microscopy (histology or cytology)
Isosporiasis	Microscopy (histology or cytology)
Kaposi's sarcoma	Microscopy (histology or cytology)
Lymphoma	Microscopy (histology or cytology)
Lymphoid pneumonia or hyperplasia	Microscopy (histology or cytology)
Pneumocystis carinii pneumonia	Microscopy (histology or cytology)
Progressive multifocal leukoencephalopathy	Microscopy (histology or cytology)
Toxoplasmosis	Microscopy (histology or cytology)
Candidiasis	Gross inspection or endoscopy or on microscopy (histology or cytology) on a specimen obtained directly from the tissues affected (including scrapings from the mucosal surface), not from a culture
Coccidioidomycosis, cryptococcosis, herpes simplex virus, and histoplasmosis	Microscopy (histology or cytology), culture, or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues
Tuberculosis	Culture
Other mycobacteriosis	Culture
Salmonellosis	Culture
Other bacterial infection	Culture

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A. All the other causes of immunodeficiency listed above in Section I.A. are excluded; AND

B. The patient has had either

1. *Pneumocystis carinii* pneumonia diagnosed by a definitive method; OR

2. a. any of the other diseases indicative of AIDS listed above in Section I.B. diagnosed by a definitive method; AND

b. a T-helper/inducer (CD4) lymphocyte count <400/cubic mm.

■ LABORATORY EVIDENCE FOR OR AGAINST HIV INFECTION

What follows is an attempt to sort out the laboratory-based indications for or against infection with HIV.

LABORATORY EVIDENCE FOR INFECTION

When a patient has disease consistent with AIDS:

a. a serum specimen from a patient >15 months of age, or from a child <15 months of age whose mother is not thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test (e.g., enzyme-linked immunosorbent assay [ELISA]), as long as subsequent HIV-antibody tests (e.g., Western blot, immunofluorescence assay), if done, are positive; OR

b. a serum specimen from a child <15 months of age, whose mother is thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test (e.g., ELISA), plus increased serum immunoglobulin levels and at least one of the following abnormal immunologic test results:

- reduced absolute lymphocyte count
- depressed CD4 (T-helper) lymphocyte count
- decreased CD4/CD8 (helper/suppressor ratio) as long as subsequent antibody tests (e.g., Western blot, immunofluorescence assay), if done, are positive; OR

c. a positive test for HIV serum antigen; OR

d. a positive HIV culture confirmed by both reverse transcriptase detection and a specific HIV-antigen test or in situ hybridization using a nucleic acid probe; OR

e. a positive result on any other highly specific test for HIV (e.g., nucleic acid probe of peripheral blood lymphocytes).

LABORATORY EVIDENCE AGAINST INFECTION

A nonreactive screening test for serum antibody to HIV (e.g., ELISA) without a reactive or positive result on any other test for HIV infection (e.g., antibody, antigen, culture), if done.

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Kaposi's sarcoma

A characteristic gross appearance of an erythematous or violaceous plaque-like lesion on skin or mucous membrane. Presumptive diagnosis of Kaposi's sarcoma should not be made by clinicians who have seen few cases of it.

Lymphoid interstitial pneumonia

Bilateral reticulonodular interstitial pulmonary infiltrates present on chest x-ray for >2 months with no pathogen identified and no response to antibiotic treatment.

Pneumocystis carinii *pneumonia*

(a) A history of dyspnea on exertion or nonproductive cough of recent onset (within the past three months); and (b) chest x-ray evidence of diffuse bilateral interstitial infiltrates or gallium scan evidence of diffuse bilateral pulmonary disease; and (c) arterial blood gas analysis showing an arterial oxygen partial pressure of <70 mm Hg or a low respiratory diffusing capacity (<80 percent of predicted values) or an increase in the alveolar-arterial oxygen tension gradient; and (d) no evidence of a bacterial pneumonia.

Toxoplasmosis of the brain

(a) Recent onset of a focal neurologic brain abnormality consistent with intracranial disease or a reduced level of consciousness; and (b) brain-imaging evidence of a lesion having a mass effect (on computed tomography or magnetic resonance imaging) or the radiographic appearance of which is enhanced by injection of contrast medium; and (c) serum antibody to toxoplasmosis or successful response to therapy for toxoplasmosis.

■ EQUIVALENT TERMS AND INTERNATIONAL CLASSIFICATION OF DISEASE (ICD) CODES FOR AIDS-INDICATIVE LYMPHOMAS

The CDC has defined the following terms and codes to describe lymphomas indicative of AIDS in patients with antibody evidence for HIV infection.[3] Many of these terms are obsolete or equivalent to one another.

TABLE 3. ICD-9-CM (1978)

CODES	TERMS
200.0	Reticulosarcoma lymphoma (malignant): histiocytic (diffuse): reticulum cell sarcoma pleomorphic cell type or not otherwise specified
200.2	Burkitt's tumor or lymphoma malignant lymphoma, Burkitt's type

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TABLE 2.

DISEASES	DEFINITIVE DIAGNOSTIC METHODS
HIV encephalopathy (dementia)*	Clinical findings of disabling cognitive and/or motor dysfunction interfering with occupation or activities of daily living, or loss of behavioral developmental milestones affecting a child, progressing over weeks to months, in the absence of a concurrent illness or condition other than HIV infection that could explain the findings. Methods to rule out such concurrent illnesses and conditions must include cerebrospinal fluid examination and either brain imaging (computed tomography or magnetic resonance) or autopsy.
HIV wasting syndrome*	Findings of profound involuntary weight loss >10 percent of baseline body weight plus either chronic diarrhea (at least two loose stools per day for >30 days) or chronic weakness and documented fever (for >30 days, intermittent or constant) in the absence of a concurrent illness or condition other than HIV infection that could explain the findings (e.g., cancer, tuberculosis, cryptosporidiosis, or other specific enteritis).

* *For HIV encephalopathy and HIV wasting syndrome, the methods of diagnosis described here are not truly definitive, but are sufficiently rigorous for surveillance purposes.*

■ SUGGESTED GUIDELINES FOR PRESUMPTIVE DIAGNOSIS OF DISEASES INDICATIVE OF AIDS

The following guidelines for presumptive diagnosis of diseases indicative of AIDS have been established by the CDC in its 1987 revisions.[24]

Candidiasis of esophagus

Recent onset of retrosternal pain on swallowing, and oral candidiasis diagnosed by the gross appearance of white patches or plaques on an erythematous base or by the microscopic appearance of fungal mycelial filaments in an uncultured specimen scraped from the oral mucosa.

Cytomegalovirus retinitis

A characteristic appearance on serial ophthalmoscopic examinations (e.g., discrete patches of retinal whitening with distinct borders, spreading in a centrifugal manner, following blood vessels, progressing over several months, frequently associated with retinal vasculitis, hemorrhage, and necrosis). Resolution of active disease leaves retinal scarring and atrophy with retinal pigment epithelial mottling.

Mycobacteriosis

Microscopy of a specimen from stool or normally sterile body fluids or tissue from a site other than lungs, skin, or cervical or hilar lymph nodes, showing acid-fast bacilli of a species not identified by culture.

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Children with HIV infection/AIDS must have these needs addressed now!

Medical

1. All children including foster care children must have access to clinical trials.
2. Children must have access to new and effective therapies before approval by the FDA.
3. Children must be allowed to enroll in drug trials after phase 1 trials have been completed in adults and a drug has been found to be effective.
4. Vaccine trials must be started in children after phase 1 trials in adults.
5. Children must be allowed the use of medically indicated pain medication.
6. Clinical trials of medicines for the treatment of HIV must be conducted in the communities where the children live.
7. The research and testing of treatment for opportunistic infections must be expanded.
8. Informed consent forms used in the trials must be written in a language understandable to lay people and in a providers first language. The consent form must be read aloud if the family requests it and the families must be given adequate time to make an informed decision about enrolling a child in a clinical trial.
9. Research must focus on when the virus is transmitted to the child in the birth process in order to avoid giving mothers potentially toxic drugs during pregnancy.
10. Health care of HIV positive parents and their HIV positive children must be coordinated to have medical services available to mothers and children at the same site and on the same day. Gynological services to HIV positive mothers must be provided at the mothers primary treatment site.

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11. Hospitals and government officials must recognize that children with HIV infection are living longer and better monitor their medical infections. It is also necessary to more accurately diagnosis children's opportunistic infections that may be more similar to those found in the adult populations. Improved and more frequent monitoring of children on new medications would substantially lower the possibilities of drug toxicities.
12. The American Academy of Pediatrics must conduct trainings on pediatric HIV infection and standards of care to insure that all providers are able to recognize and treat pediatric HIV infection.
13. Adequate time must be spent with a childs caregiver by medical providers to insure that quality of life issues (rashes, behavioral problems) are adequately dealt with and appropriate referrals made.
14. All child health stations should offer HIV counseling and testing of children.
15. Parents and caregivers of children with HIV/AIDS must be fully represented on all hospital and government advisory committees dealing with HIV disease. To facilitate this process, funds for transportation and baby sitting must be available prior to the meetings.
16. Medical information on how to care an HIV positive child must be given to all caregivers immediately after diagnosis by the childs primarily care provider. This information must be presented in a clear and concise manner and in a caregiver's natural language. This information must include special diet and nutritional needs of children, a description of clinical trials, a listing of community dentists, drug toxicites, the right to refuse treatment, and problems a child might face that would involve emergency care.
17. There must be research conducted on nutritional co factor's in AIDS and HIV infection in children and recommendations made to hospital and clinic providers.

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Money Needs

1. Natural and foster parents of HIV positive children must have benefits that reflect the cost of caring for medially fragile children. Currently natural mothers receive only welfare payments although their children are just as sick as the special needs children in the foster care system.
2. Increase federal disability benefits to enable children and their parents with HIV/AIDS to live independently.
3. Change the eligibility criteria for medicaid and medicare coverage to facilitate early intervention and treatments and services.
4. Encourage congress to eliminate the 24 month waiting period for medicare eligibility.
5. Insure that the SSI applications of children with HIV infection be processed and funds delivered in a three month waiting period, since children are often not diagnosed until they are quite ill.
6. Support a program of universal health care. This program must be equitable, adequately funded to provide access to all treatments of people living with HIV disease, including non pharmaceutically based treatments as well as indigenous medicines and programs in practice in community organizations.

6. Social security must recognize diagnosed HIV sero positivity in children as a condition entitling them to full SSI benefits. These benefits must be increased to meet the actual needs of children with HIV infection.

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Foster Children 's Needs

1. Shorten the length of time required to complete adoption of children with HIV infection.
2. Pre adoptive foster parents must be allowed to made medical decisions for an ill child, with the childs physician.
3. Foster parents of children with HIV infection must be given immediate and full medical coverage which includes medicade.
4. Foster agency workers must be fully trained in all aspects of HIV infection in order to fully counsel foster parents.
5. Foster parents must be given the option of transferring to a specialized foster care unit that services HIV positive children when one exists.
6. Foster parents must have adequate special needs reimbursement rates within two months of HIV diagnosis of the child.

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Quality of life Issues

1. All HIV infected children must have adequate developmental testing done and should be referred to therapeutic nurseries if indicated. Parents must be regularly counseled about problems that might arise in a school setting due to a childs HIV status and the parents options in coping with these rights.
2. Parents and caregivers of children with HIV positive children must have immediate access to support groups that include counseling on disclosure issues and bereavement counseling.
3. Parents and caregivers must have immediate access to safe and adequate and medically appropriate housing. Shelters and hotels fail to meet the needs of children with HIV infection.
4. There must be immediate implemention of regional toll free hotlines run by parents of HIV positive children, to provide access to treatment options, social support and referrals.
5. Respite services must be available on a 24 hour basis to all parents and caregivers of HIV positive children.
6. Natural mother's who are HIV positive must have immediate access to home care to prevent foster care placement of their children. Mothers whose chemical dependency has resulted in their children being placed in foster care should have priority access to drug and alcohol treatment slots.

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Since its birth one spring evening four years ago in the Lesbian and Gay Community Services Center in Greenwich Village, the AIDS Coalition to Unleash Power has grown to thousands of members in New York and in more than 70 chapters in the US and worldwide. ACT UP's direct action approach, often using vocal demonstrations and dramatic acts of civil disobedience, focuses attention on the crucial issues of the AIDS crisis. ACT UP's work has been instrumental in educating the public and creating dialogue with drug companies and politicians to help end the AIDS epidemic. Here are some highlights...

ACT UP

March, 1987 Outraged by the government's mismanagement of the AIDS crisis, concerned individuals unite to form the AIDS Coalition To Unleash Power. Our first demonstration takes place later in March on Wall Street, the financial center of the world, to protest the profiteering of pharmaceutical companies (especially Burroughs Wellcome, manufacturer of AZT). 17 people are arrested. Shortly after the demonstration, the Food and Drug Administration (FDA) announces it will shorten its drug approval process by two years.

June 1, 1987 ACT UP joins other national activist groups in civil disobedience at the White House in Washington, DC. In a display of AIDS-phobia, the police wear rubber gloves while arresting protesters. Another demonstration is held at the Third International Conference on AIDS.

June 4, 1987 When Northwest Orient Airlines refuses passage to people with AIDS (PWAs), ACT UP erupts in protest at the airline's New York offices. Two suits are brought against Northwest. The policy is reversed.

June 21, 1987 ACT UP's four-day, round-the-clock protest at New York City's Memorial Sloan-Kettering Hospital, one of four AIDS Treatment Evaluation Units (ATEU's) in the City, demands more clinical trials of promising drugs other than AZT and more people with AIDS in the trials.

September 9, 1987 ACT UP protests the inadequacies of the newly-formed Presidential Commission on AIDS when it meets for the first time in Washington, DC. Several ACT UP members give testimony.

January 15, 1988 ACT UP demonstrates at the offices of Cosmopolitan. ACT UP NY's Women's Caucus organizes first ACT UP action focused on women and HIV. 500 people protest article by psychiatrist telling heterosexual women they could have unprotected vaginal intercourse with an HIV+ man and be safe. Documentary about the action, "Doctors, Liars, and Women: AIDS Activists Say NO to Cosmo," produced by two Women's Caucus members, shown around the country, wins awards and is in the permanent collection of the Museum of Modern Art.

March 24, 1988 To celebrate our first anniversary, ACT UP returns to Wall Street. More than 100 activists are arrested; ACT UP receives major media coverage and issues central to the AIDS crisis are reported. The concept of "AIDS activism" gains credibility.

May 1-9, 1988 ACT UP branches around the country mount nine days of protests focusing on specific, unattended aspects of the epidemic such as IV drug use, homophobia, people of color, women, testing programs, prison programs and children with AIDS. More than 50 cities participate.

October 11, 1988 ACT UP, joined by the national ACT NOW coalition, closes down the FDA outside of Washington, DC. More than 1,000 activists stage a series of demonstrations which result in almost 180 arrests. The event receives international press coverage. A historical event, shutting down the FDA represents to a vast audience the lethargy of this dysfunctional bureaucracy, which is in charge of testing and approving possible AIDS treatments.

February 2, 1989 ACT UP protests the FDA's new protocols for the drug DHPG (Ganciclovir), as these new protocols would deny many current DHPG users access to the drug. Due to this action, the FDA makes DHPG available under "compassionate use" while it reconsiders its protocols.

March 2, 1989 Protests and continued pressure at the FDA pay off. The FDA approves the use of DHPG, the only drug available to treat cytomegalovirus, which can cause retinitis, pneumonia and colitis.

March 28, 1989 ACT UP's second anniversary protest draws 3,000 to New York's City Hall, making "Target City Hall" the largest AIDS activist demonstration to date. ACT UP protests the inadequacy of New York's AIDS policy under Mayor Edward Koch. About 200 activists are arrested.

April 21, 1989 ACT UP/NY joins ACT UP/Atlanta to protest a South Caroline provision that would allow PWAs to be quarantined. The same day, using steel plates and rivets, four ACT UP members barricade themselves into a Burroughs Wellcome office in North Carolina. They demand a cut in the price of AZT, still the most expensive medicine in history at $8,000 for a year's dosage.

May 2, 1989 Based on the testimony of AIDS activists, the FDA Advisory Committee finally recognizes DHPG and Aerosolized Pentamadine for approval.

June 4-9, 1989 ACT UP demonstrations at the Fifth International Conference on AIDS in Montreal cause a significant change in AIDS treatment research. ACT UP presents the revolutionary concept of parallel track drug testing, in which drugs already found to be non-toxic are placed in both clinical trials and released simultaneously to patients who do not qualify for the trials. The next week, ACT UP members are invited to discuss parallel track with Dr. Anthony Fauci, Director of the AIDS program at the National Institute of Allergy and Infectious Diseases. Days later, Fauci announces parallel track publicly, and the government appoints a panel (including an ACT UP member) to write procedural standards.

That same week, ACT UP meets with Bristol Myers, the manufacturer of the anti-retroviral ddI, to demand ddI's release to patients who can no longer tolerate AZT. ddI is soon released to 5,000 patients.

September 14, 1989 Seven ACT UP members infiltrate the New York Stock Exchange and chain

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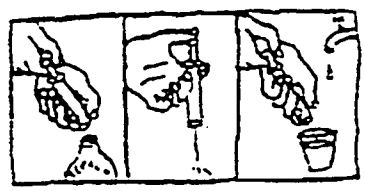
A CAPSULE HISTORY OF ACT UP

themselves to the VIP balcony. Their miniature foghorns drown out the opening bell, and a banner unfurls above the trading floor demanding "SELL WELLCOME." Other ACT UP members snap photos which they then sneak out and send over newswires. ACT UP once again makes history by stopping trading on the Stock Exchange floor. Four days later, Burroughs Wellcome lowers the price of AZT by 20%, to $6,400 per year.

October 2, 1989 In response to the alarming rise of HIV infection in adolescents, ACT UP's Youth Brigade (later known as YELL-Youth Education Life Line) begins distributing condoms and safer sex/ clean needle information outside the New York City schools.

December 2, 1989 ACT UP holds its first major fundraiser, an art auction cochaired by David Hockney and Annie Leibovitz. A record price is bid for a work by the late artist and ACT UP member Keith Haring, and ACT UP raises $350,000.

December 10, 1989 ACT UP and WHAM! (Women's Health Action and Mobilization) co-sponsor a "Stop the Church" demonstration. 4,500 protesters gather outside St. Patrick's Cathedral to decry the Church's opposition to safer sex education, violent homophobia, and attempts to block access to safe and legal abortions. 111 people are arrested. The news media choose to focus on, and distort, a single Catholic demonstrator's personal protest involving a communion wafer.



Christmas, 1989 ACT UP send *New York Times* AIDS reporter Gina Kolata a Christmas card zap to protest her biased, distorted and just plain ignorant AIDS coverage. Shortly thereafter, Kolata phones ACT UP for specific information when ACT UP condemns scientists, congresspeople and reporters for delaying release of vital news about the effectiveness of lower doses of the highly toxic drug AZT. A major article appears in the *Times*, and within weeks the FDA cuts the standard dose of AZT in half.

January 3, 1990 ACT UP stages the first in a three-part series of actions in Albany to protest New York State's severe lack of attention to the AIDS epidemic. An ACT UP member interrupts Gov Mario Cuomo's State of the State address and engages Cuomo in a brief debate while demonstrators protest outside the Capitol.

January 8-9, 1990 ACT UP/NY and ACT UP/Atlanta present 2 days of demonstrations in Georgia. 63 people are arrested lying down in the street at the State Capitol demanding the immediate repeal of Georgia's sodomy laws. The next day hundreds besiege the federal Centers for Disease Control (CDC) headquarters with signs, banners and costumes protesting the CDC's narrow definition of AIDS (which excludes gynecological illnesses and illnesses more common to people of color and children). 49 are arrested. In the week following the demos, ACT UP/Atlanta's membership triples.

January 25, 1990 ACT UP learns that Galaxy Carpet Mills has instituted a health insurance policy that will not cover costs for any HIV-related treatment unless an employee can prove "involuntary" HIV infection. A phone zap ensues. ACT UP floods Galaxy switchboards in protest. One month later, the company reverses this ruthless policy, and insures all employees.

January, 1990 ACT UP spearheads an investigation into newly-elected New York City Mayor David Dinkins' selection of Dr. Woodrow Myers for Commissioner of Health. It finds out that as Indiana State Health Commissioner, Myers endorsed and attempted to implement mandatory HIV testing, partner tracing and quarantine. After ACT UP protests at City Hall, Dinkins states that mandatory testing, partner tracing and quarantine will not be tolerated in New York City.

February 13, 1990 ACT UP returns to Albany in the second of our three-part New York State Capitol action. 13 ACT UP members seize the Division of Budget offices, chaining themselves to desks (all are arrested). Hundreds of others protest in the Capitol Concourse and the Legislative Office Building, disseminating information on the State's negligent response to all aspects of the AIDS crisis, and demanding increased AIDS funding in the new fiscal year State budget.

March 6, 1990: A group of ACT UP members exchange clean needles for used ones along with safe drug injection instructions, condoms and safer sex/AIDS prevention information with intravenous drug users (IVDUs) on a Lower East Side street corner. Six of the ACT UP exchangers are arrested (it is a crime to possess syringes in New York State). ACT UP's Needle Exchange Committee is formed, dedicated to decriminalizing needle possession, safer injection education and drug treatment on demand.

March 28, 1990 For the third Albany action, more than 2,500 people descend on the New York State Capitol to inform Governor Cuomo and the State Legislature that State AIDS funding is murderously inadequate. A banner dropped over the front of the Capitol Building reads, "Health care is a right!" The Governor's mansion is literally wrapped in red tape; red handprints and stickers announcing that "The Government has Blood on its Hands" appear everywhere.

April 20-23, 1990 ACT UP activists from all over the country converge on Chicago to target the national headquarters of the American Medical Association (AMA) and health insurance companies also headquartered there. Women activists take over the intersection in front of Cook County Hospital with mattresses, declaring it the "Cook County Women's AIDS Unit" since no women with AIDS are allowed treatment in the hospital. The Cook County Hospital AIDS Unit admits its first women two days later. A People of Color Conference also convenes to discuss and coordinate AIDS activism in diverse communities.

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May 21, 1990 ACT UP/NY organizes a national action to "Storm the NIH (National Institutes of Health)." One thousand protesters demand more AIDS treatments, especially for the opportunistic infections that kill PWAs, an end to the severe underepresentation of women and people of color in clinical trials, and the formation of a Women with AIDS Committee at the NIH.

June 16-23, 1990 Members of ACT UP/NY join AIDS activists from around the world at the Sixth International Conference on AIDS in San Francisco. Demonstrations throughout the conference highlight issues of importance to the AIDS community. ACT UP/NY's Treatment and Data Committee issues its 1990 Treatment Agenda which outlines the direction the AIDS research community should be taking in the coming year and becomes one of the most talked about documents at the conference. The PISD (People with Immune System Disorders) caucus introduces the San Francisco Plan, which outlines the civil and medical rights of people with immune systyem disorders.

July, 1990 *Women, AIDS & Activism*, developed originally by ACT UP's Women's Caucus in 1989, is published. It is the first book to chart the natural history of AIDS in women. The Women & AIDS Book Group has also made *Women, AIDS & Activism* a landmark manifesto for safer sex for women, women's activism, health activism, and activist techniques.

July, 1990 As a result of continuing pressure, NIAID officials meet with women from ACT UP/NY and ACT UP/DC, who make ten demands including a conference on women with HIV and a women's committee for the ACTG system. NIAID agrees to hold the conference.

July-August, 1990 In a month-long series of actions, coinciding with a number of AIDS conferences, ACT UP/NY and the newly-formed ACT UP de Puerto Rico work to increase AIDS awareness in Puerto Rico where, despite the highest rate of new AIDS cases in the Western hemisphere, almost no treatment is available for PWAs and safer sex education is blocked by the Catholic church. Two hundred people of all ages and orientations march from the Capital Building to the Governor's mansion demanding all forms of AIDS prevention (including condoms, safer sex guidelines and clean needles for IVDUs) be distributed island-wide. ACT UPs/NY and Puerto Rico demand immediate availability of drugs for PWAs and increased Medicaid coverage to pay for all forms of treatment.

October 2, 1990 ACT UP/NY joins ACT UP/DC to protest the Department of Health and Human Services (HHS) discrimination against women with AIDS.

November, 1990 The ACT UP/NY Treatment and Data Committee releases the "Countdown 18 Months Plan," a set of scientific procedures and demands designed to implement treatment and research for controlling the five currently most devastating opportunistic infections (Cytomegalovirus, histoplasmosis, pneumocystis carinii, toxoplasmosis and mycobacterium avium complex).

November, 1990 Gov. Cuomo cuts New York State AIDS funding by 40% just four days before his re-election. In response, 100 AIDS activists pack his "Victory" party and interrupt his election acceptance speech with cries of "Shame!" and "Cuomo Balances the Budget with People's Lives!"

December, 1990 First National Women and HIV Conference, Washington, D.C.

December 3, 1990 ACT UP/NY and AIDS activists from all over the country return to the CDC in Atlanta and again demand the immediate expansion and revision of its narrow definition of AIDS as well as a future policy of updating the list every six months.

December 8, 1990 ACT UP and WHAM! return to St. Patrick's Cathedral for a "Stop the Church" anniversary. Cardinal O'Connor creates excellent publicity for the action by getting a restraining order against ACT UP. What was planned as a small demonstration attracts over 1000 protesters. Signs and chants include "Expel O'Connor from the Public Schools" and "Just say no' is not enough: Teach safer sex!"

January 7, 1991 Hundreds demonstrate outside the Manhattan Criminal Court building on "Judgment Day" while six activists from "Stop the Church" are sentenced. The Safe Sex Six, although convicted by a hostile judge who could sentence them to six months in prison are compared by the same judge to Gandhi and Martin Luther King and given sentences of community service.

January 16, 1991 Lead by the YELL (Youth Education Life Line) Committee of ACT UP, activists and high school students demand immediate approval of the condom distribution plan proposed by Public School Chancellor Fernandez. YELL and the students also demand that the "counseling" and parental consent portions of the plan be withdrawn and replaced with a revised AIDS education program that deals honestly with AIDS transmission, prevention and sexuality.

January 23, 1991 ACT UP declares a "Day of Desperation" in New York City. This action, designed to target every aspect of City life, demands that everyone realize that every day is a day of desperation for those in the AIDS community. Day of Desperation began when activists invaded PBS and CBS Evening News broadcasts on the night of the 22nd. On the 23rd a morning demo began on Wall St. and more than 2000 protesters marched with coffins that were delivered to City, State & Federal officials responsible for perpetuating the AIDS epidemic. An action at the State Office building in Harlem demanded an end to the City shelter system; the Latino/a Caucus invaded the Bronx Borough President's office; Alternative and Holistic Committee videotaped Dr. Emilio Carillo's promises to add immuno-enhancing nutritional programs and acupuncture to City hospitals. At 5:07 pm, Grand Central

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Station was the setting for a spectacular and massive act of civil disobedience as ACT UP took over the station. A banner announcing "One AIDS Death Every Eight Minutes" was hung over the arrivals board. 263 people were later arrested as the group attempted to march to the United Nations.

February 1991 NIAID announces it has formed a Women's Committee for the ACTG system.

February 5, 1991 Three ACT UP members, arrested and charged with bias-related felonies for spray painting "O'Connor Spreads Death" on the sidewalk in front of the Cardinal's residence, are subjected to anti-gay verbal and physical harassment by New York City police.

February 11, 1991 At an impromptu demonstration ACT UP has called to protest the recent police brutality, police, unprovoked, charge at the non-violent demonstrators with their nightsticks swinging. One of three demonstrators arrested is brutally assaulted in police custody. Soon after a working group is formed to address police brutality.

February 27, 1991 ACT UP celebrates one of its most concrete victories against the AIDS virus as the New York City Board of Education passes, 4-3, a plan to distribute condoms to high school students in the public schools. ACT UP's Youth Education Life Line Committee was an important part of the coalition that lobbied and pressured the board for the plan's passage.

February, 1991 Ten people, who had been charged with possession of needles with the intent to distribute them to IV drug users on the Lower East Side, were aquitted by a judge who agreed that the "Necessity Defense" applied to their case. The judge ruled that the activists' actions were justified by the need to try to save the lives of people vulnerable to HIV infection.

March 1991 Upon learning of a plan by Mayor Dinkins to cut City AIDS funding, breaking Dinkins' post-election promise that AIDS funding would be exempt from budget cuts, ACT UP created another loud demonstration that could be heard in City Council chambers. Most of the cuts were restored to the budget in subsequent weeks.

May 3, 1991 ACT UP/NY, together with ACT UPs from all over the state and STAND UP/Emmaus House, went to Albany to HIT THE DOCS (Department of Correctional Services). We demanded medical treatment for prisoners with AIDS and declared that: "Living with AIDS in prison is cruel and unusual punishment."

May 31, 1991 ACT UPs from the East coast descended upon the National Insurance Association in Washington, DC, to protest health profiteering and marched to the Capitol Building to demand comprehensive national health care from the US Congress.

June 16-22, 1991 The International AIDS Conference in Florence, Italy, was short on good news for PWAs but did involve an unprecedented number of HIV+ people, on panels in the conference and in the streets. Scientists joined activists in a march on the US Consulate to protest the exclusion HIV+ foreigners from entry to the US. ACT UP obtained a promise from the organizing committee to cancel the conference in Boston if the policy is not changed.

July 9, 1991 ACT UP returned to the DOCS, this time at the New York State Office Building on 125th Street to demand an end to the exclusion of HIV+ prisoners from the family reunion program. The next day, a class action suit was filed on the prisoners' behalf by Prisoners Legal Services. Within a month, the policy was changed.

August 1991 The Centers for Disease Control (CDC) revised the definition of AIDS to include anyone with a T-cell count of 200 or less. They also added two gynecological opportunistic infections to the definition. While not good enough to include thousands of women living with AIDS, this revision was an important concession by the CDC and proved that the exhaustive endorsement campaign waged by ACT UP during the past year worked, by applying constant pressure from all sides.

September 1991 ACT UP's YELL (Youth Education Life Line) Committee led the way to victory in defeating an amendment to the condom distribution plan of the New York City Board of Education which would have given parents the right to "Opt-out" and bar their children from receiving condoms in school.

September 1, 1991 2000 AIDS activists marched on President Bush's vacation home in Kennebunkport, Maine to demand leadership and to declare that THE AIDS CRISIS CAN END. After a die-in on the road to the Bushs' house, activists unrolled a fifty foot long banner which outlined a 32-point plan to end the AIDS Crisis. The next day the President said that he was more moved by the demonstration of the unemployed the week before. "That one hit home" he said, "because when a family is out of work, that's one that I care very much about."

September, 1991 Action against legislation for mandatory testing of healthcare workers.

September 30, 1991 ACT UP targets President Bush at the White House, declaring that George Bush is getting away with murder, with over 120,000 Americans dead from AIDS. In a loud and angry march to the White House, activists demanded that the President stop his deliberate policy of neglect. 84 people were arrested in acts of civil disobedience that included chaining themselves to the gates of the White House and to each other. Bush spent the day in Disney World.

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