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## The politics of AIDS: An analysis of the AIDS Coalition to Unleash Power

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**Graf, Brian Edward, M.A.**

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**THE POLITICS OF AIDS: AN ANALYSIS OF THE AIDS  
COALITION TO UNLEASH POWER**

**by**

**Brian Edward Graf**

**A thesis submitted in partial fulfillment  
of the requirements for the degree of**

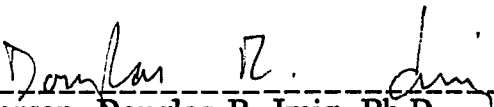
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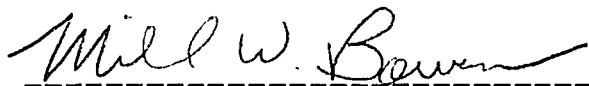
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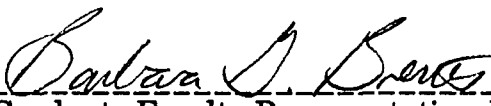
**Department of Political Science  
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## **Abstract**

Since 1987, the AIDS Coalition to Unleash Power (ACT UP) continues to pressure the government, corporate America, and society into confronting the AIDS epidemic. This work analyzes ACT UP as a movement organization. First, the organizational structure of ACT UP is discussed. All aspects (membership, leadership, revenue, etc) which make ACT UP a truly unique organization are elaborated upon. Second, the tactics and targets of opportunity of ACT UP are analyzed. Some of the groups more notable demonstrations are discussed in order to illustrate the evolution of ACT UP. Finally, ACT UP is analyzed in terms of how influential it has been upon both government and corporate policy.



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## Literature Review

"You can say all you want about denial, but this  
is happening to black people and to Hispanic  
people and to people who take drugs and to  
gay people and to babies born out of wedlock,  
and these are all people a lot of other people would  
just as soon weren't there."

*-Larry Kramer, Founder, ACT UP*

In June 1987, the Presidential Commission on AIDS called the nation's drug-development system "unresponsive"; its health-care system "overly burdened and unnecessarily costly," its health-education measures in "absence" (Shilts, 376). "If what you're hearing doesn't rouse you to anger, fury, rage, and action, gay men will have no future here on earth," exclaimed Larry Kramer, prominent New York playwright and gay activist, to an audience at the Lesbian and Gay Community Services Center on West 13th Street (DeParle, 1990). The crowd stirred uneasily as Kramer forced them to realize that, within five years, two-thirds of those in attendance would be dead - casualties not only of a virus, but also of an unresponsive medical-industrial complex.

Two days after Kramer's emotional plea, several hundred people reconvened, took a name and adopted a symbol and a mission. From that point forward, they would be known to the world as the AIDS Coalition to Unleash Power, or ACT UP. Their logo consisted of a pink triangle set against a black border and inscribed with "Silence = Death." While many gay rights organizations had invoked the pink triangle - which Nazis affixed to homosexuals in concentration camps - the ACT UP triangle differed in that it pointed upward in an attempt to disavow the role of victim. Their angry, and often overly zealous, mission is simple: To force

people to confront the AIDS crisis, and help get drugs for those dying of the affliction (Crossen, 1989).

Two weeks after the conception of ACT UP, seventeen members of the group were arrested at its first demonstration, held on Wall Street to denounce the business and government response to AIDS. At that time, a year's dosage of AZT, the pre-eminent AIDS drug, cost as much as \$10,000 (DeParle, 1990). ACT UP staged the Wall Street demonstration in order to protest the prohibitive cost of obtaining even one dosage of AZT. One thing that ACT UP has never been is silent.

It is difficult to determine whether ACT UP can be classified as a political organization or a social movement. This work seeks to explain the existence and success of ACT UP. Is ACT UP a "group" or a social movement? How does one judge the success of an organization such as ACT UP? Can a "group" like ACT UP influence governmental policy utilizing radical techniques of protest? Will the public accept ACT UP as a valid spokesperson in the fight against AIDS?

After considering the work of leading group theorists, this work will discuss the profound influence that ACT UP has had in forcing government officials and the public to confront the AIDS crisis. Theories discussed include James Wilson's pluralist theory, Mancur Olsen's theory of the economic nature of groups, and Schlozman and Tierney's focus upon the role of interest groups in American politics. It will be shown that these theories only partly account for a group like ACT UP. Since conventional group theory cannot account for a group like ACT UP, this work will use David Meyer's and Robert Gamson's theories of political movements to analyze ACT UP's existence, success, and influence upon government policy.

Chapter One will focus upon defining ACT UP and determining whether the organization constitutes a group in the classical sense or whether ACT UP represents a political movement. Chapter Two will discuss ACT UP as an organization - its history, membership, leadership, internal structure, etc. Chapter Three will discuss ACT UP's tactics, targets of influence, and highlight notable demonstrations. Chapter Four will conclude this work, discussing the strength of ACT UP and, using Gamson's criteria, will analyze the effect that the organization has had upon obtaining new benefits for its targets of benefit (that is, people living with AIDS).

### **Political Science and Group Theory**

The following group theorists seem to offer some explanation as to why a group like ACT UP exists. A wide variety of theorists exist who discuss interest groups and political movements. Below I discuss aspects of the most relevant discussants.

The pluralist school of political interest group theory, often dated from the work of Arthur Bentley, states that a group is a collection of individuals who, on the basis of some shared characteristic or interest, join together to promote that interest. This pluralist definition of a group serves as a base for theorists, though many have expanded upon its general premise. Prior to the widespread acceptance of pluralism, political scientists focused upon the constitutional role of institutions. Pluralism developed out of a realization that "there was much more to juristic political science than narrow institutionalism" (Garson, 12). As it became apparent that organizations, such as private groups, influenced the political process, the move away from defining power in terms of legal aspects embodied in

formal constitutions to the study of group dynamics grew steadily (Garson, 12).

Since World War II, interest in pluralist theory exploded "because of its utility as a framework for presenting the great mass of empirical, historical, and descriptive materials that political science has accumulated about the 'realities' of political organization" (Garson, 9). James Wilson, for example, uses the pluralist definition to describe a basic group, but once a group makes demands upon the government and its institutions in order to promote its interest, it becomes a political group. Schlozman and Tierney contend that this definition describes an unorganized interest. For them an organized interest is one that seeks joint ends through political action; that is, that the group promotes a collective interest through demands upon governmental institutions. Pluralism provides a useful starting point for examining ACT UP.

According to the pluralist definition, ACT UP could be defined as a political interest group. Though the backgrounds of the membership vary, almost all share a personal relationship with the epidemic that has killed tens of thousands of individuals in the United States (DeParle, B1). To the majority of the population AIDS is an abstract menace, to members of ACT UP it is a series of funerals - a procession of friends, relatives, and lovers given over to painful, protracted deaths (DeParle, B1). This common characteristic forms the basis for ACT UP. Members joined as a means of dealing with the dismal reality of the epidemic and the effect it has had upon their own lives. Members join in part to alleviate anxiety resulting from their own attempts to cope with life with AIDS, or from the loss of loved ones. The driving force which attracts membership is the frustration they encountered dealing with an apathetic public and unresponsive

government. Individuals join because they realize that "silence = death and action = life" - a phrase which summarizes ACT UP's mission. Members become involved because they believe that only through direct involvement will ACT UP affect change.

ACT UP provides more than just a forum for psychological self-help. The membership seeks increased research funds in order to find a cure, increased availability of drugs, and more funding for education and prevention programs. ACT UP focuses upon political ends. The great majority of the organization's members join in hopes of curtailing the spread of AIDS and preventing others from experiencing the loss of friends and loved ones through activities aimed at influencing government policy.

The organization's mission statement is clear: "To force people to confront the AIDS crisis, and help get drugs for those dying of the affliction" (Crossen, A1). Wilson would contend that ACT UP constitutes a political organization, for the group seeks to influence the outcome of government policy. This desire to exact a change in policy is illustrated by the fact that federal government officials, especially those at the National Institutes of Health and the Food and Drug Administration, represent the main targets of ACT UP activities.

Mancur Olson concedes the pluralist contention that organizations form in order to further the interest of their members, but denies the spontaneity of group formation. He contends that pluralists "take for granted that individuals in a political or social context will organize and act to further their collective interests" (Olson, 166). Olson studied groups that should have formed but didn't - the forgotten groups. The forgotten groups have the potential of coming together, but because of economic considerations they do not. For example, Olson argues that groups like



white collar workers or taxpayers will never mobilize as a group, for "the costs of group action would exceed the potential benefits" (Olson, 1965). The attraction of group membership is not so much in sheer belonging, but rather in attaining something by means of this membership (Olson, 1965). Individuals join a group because of tangible incentives, not because of a need to belong. Olson writes that organizations perform a function when there are common or group interests. Although organizations often serve purely personal, individual interests, their characteristic and primary function is to advance the common interest of groups of individuals.

One of the most common problems confronting interest groups is that the benefits of the group's efforts often cannot be limited simply to its membership. For example, if an environmental group successfully contributes to the adoption of stricter emissions standards for automobiles, all of society benefits from the cleaner air, not just the group's membership. This is known as the free-rider problem, where benefits won by group action cannot be limited solely to its membership. Rather, all of society benefits from the group's efforts. In order to overcome the free-rider problem, groups must offer tangible incentives, like group health insurance, in order to attract membership.

Olson, an economist, based his theory of group politics upon economic theory. He argued an individual will make a rational choice to join a group if the benefits derived from membership are greater than the costs associated with joining the organization. In order to maintain membership, the group must provide tangible incentives (particularly economic incentives) in order to attract and maintain a membership. Olson would argue that individuals who join ACT UP are not rational, for the cost in terms of time and money are greater than the benefits an

individual derives personally (Olson, 112). ACT UP does not provide any economic benefits or incentives to its membership, thus individuals are giving more to the group than they are receiving in benefits. These individuals, according to Olson, are not rational. These individuals are acting in a way *they* perceive as logical, for they are not concerned with their own personal benefit. Rather, they are concerned with one thing - stopping AIDS.

Again, it is clear that ACT UP fits the definition of a group. The primary characteristic and function of ACT UP is to raise public awareness of the epidemic and to make more drugs available for treatment. Thus, ACT UP seeks to promote the interests of its members.

Individuals join ACT UP because they have been personally affected by the epidemic through the loss of friends and lovers, not in search of some tangible reward. ACT UP's founder, Larry Kramer, described the link between the membership when he remarked that nobody "can understand what life is like for us unless you're one of us. There's not a week goes by unless someone you know dies" (DeParle, B1). Members of the AIDS organization are not motivated by any tangible incentive, rather ACT UP represents a fellowship linked by death. An expanded discussion of motivations for joining will be presented in Chapter Two.

Wilson argues that individuals join together, thus forming groups, for a variety of reasons. These individuals are rational, for the action of joining is taken on behalf of these reasons (Wilson, 31). An individual joins a group for any number of reasons. Their action, altruistic or not, is rational for it is based upon a particular reason. Wilson contends that the primary incentive for individuals to join a group is the attainment of some dominant reward. For Wilson, though, the rewards or incentives are not

entirely economic, but, like Olson, he stresses the self-interested motivations inspiring an individual to join a group.

Wilson, too, argues that incentives must be provided in order to attract and maintain an organization. He discusses four possible incentives a group can offer its membership. These include material incentives (tangible rewards), specific solidary incentives (intangible rewards such as the promise of an office or honor), collective solidary incentive (the promise of fun and fraternity), and purposive incentives (feeling of satisfaction having contributed to worthwhile cause) (Wilson, 106). Groups that do not provide any of the above to its membership are doomed to failure. Though people join for various reasons, as was stated earlier, ACT UP provides a purposive incentive to its members.

Schlozman and Tierney contend that people join organizations as a result of socialization. Observers, like Alexander deToqueville and Oscar and Mary Handlin, remark upon a strong spirit of volunteerism dominating U.S. culture. This spirit of volunteerism has developed an associational America, forming the distinctive character of the U.S. political system. The authors argue that an organization actively engages in pressure politics in order to transform market resources into political activity (Schlozman and Tierney, 13).

Schlozman and Tierney acknowledge groups must provide incentives in order to encourage membership stability. They offer three possible incentives. The first, material, refers to some tangible good such as a bumper sticker or sweatshirt. The second, solidary, again refers to the promise of fraternity and fun. The final incentive, purposive, reflects the notion that a certain degree of satisfaction and accomplishment must be achieved by members. Schlozman and Tierney offer similar incentives for

membership as Wilson, the only difference being that Wilson discusses the additional incentive of intangible rewards such as the promise of an office or honor.

Having discussed membership motivations, we now consider group success. It has been shown that the pluralist's motivations for membership do not completely account for ACT UP's membership. Ultimately, this work will determine the success of ACT UP, thus it is necessary to compare the group theorist's notion of what constitutes success with ACT UP. Olson defines success in terms of a group's ability to maintain membership and achieve its stated goal(s). Small, cohesive groups succeed in attaining their stated goals, for they are able to maximize the benefits available to the membership. Olson contends that small groups are the most successful, for "they are fortunate enough to have an independent source of selective incentives, [and] will organize or act to achieve their objectives" (Olson, 167). Only small groups can provide the necessary selective incentives which not only limit the distribution of benefits, but also encourage membership.

He argues that more does not necessarily mean better, in fact, just the opposite. Smaller groups are able to maintain a level of cohesion more conducive to group success. Larger groups, on the other hand, must contend with internal conflict and factionalism - both of which lead to inevitable destruction. Olson discusses tactics large groups utilize to ensure success and survival, but, again, he focuses upon economic groups such as labor unions. He recognizes the fact that his theory inadequately deals with large voluntary organizations like ACT UP, and thus the tactics he discusses regarding large group success are relevant, yet not necessary for this study.

Wilson offers two different models to explain group success.

Contrary to Olson, he argues that group goals may or may not be stated, and thus it may not be appropriate to judge an organization's success based upon goal attainment. First, the Goal-Model defines the organization as collectively oriented toward the attainment of a specific purpose. Effective decision-making holds the key to success, for a group's success or failure depends upon whether or not stated goals are achieved. This model assumes that all organizations have goals beyond membership satisfaction, and that an organization's behavior is motivated by a desire to attain its goals (Wilson, 82).

The Natural-System Model, on the other hand, views goal attainment as only one of several group functions. The maintenance of the system is the key to survival. Internal conflict determines external objectives, thus goals tend to fluctuate. The Natural-System model focuses upon the notion that the group's main objective is survival. Thus, political objectives will be altered or chosen in order to ensure survival.

Wilson attempts to measure success either by looking at the goals achieved by a group or by focusing upon the group's desire to survive. Neither of these models applies to ACT UP, for the group's goals tend to be ambiguous or very broad. Because of the ambiguity and over-generalized nature of their goals, it is difficult to isolate specific goals for analysis. The stated mission of ACT UP: to make a difference - to fight for people with AIDS (ACT UP, 1992). This opens a Pandora's box of issues, for this mission includes any and all issues which affect the lives of people with AIDS. Since it is difficult to isolate a single goal, it is difficult to assess whether the goal has been achieved, and thus cannot serve as an adequate measure of success. Measuring the increased availability of drugs would

be more feasible, but constitutes only a portion of the overall mission of the group. Because the group may succeed in increasing the number of different drugs available for treatment, it does not follow that public awareness will have increased as well. Due to the overall ambiguity of ACT UP's goals (i.e., defining "public" awareness) it is difficult to base their success upon whether or not their goals were achieved.

The Natural-System model assumes that because internal conflict exists, a group's goals will become clouded and undeterminable. This is not the case, for ACT UP experiences internal conflict of varying degrees every time the organization convenes. ACT UP's weekly meetings have been described as an exercise in creative anarchy, yet they remain focused upon their original mission (DeParle, B1).

Shlozman and Tierny argue that the ability of an organization to mobilize its resources and use them effectively in the attainment of their goals will determine success. The ability of a group to accumulate multiple resources will assist in goal attainment. For the authors, money is the primary resource necessary for success. Without funding the group cannot function or attempt to achieve goals, even if it maintains an adequate membership. The second resource includes the possession of information, expertise, and skills. Third, in order to exist at all, a group must attract members. Finally, a group's reputation is a valued resource, for only those groups who enjoy a favorable reputation will be welcomed in Washington. The above resources translate into power, and thus will influence group success. The number of resources possessed by a group will determine its ability to realize its goals, and thus determines whether a group will be successful or not.

Schlozman and Tierny focus upon organized, formal interests. A formal interest group retains a list of dues-paying members and operates a central office where day-to-day decisions are made. ACT UP neither retains a membership list nor charges dues. The organization does not operate a central office. Because Schlozman and Tierny's theory explains formal interests, it does not account for groups like ACT UP. Since ACT UP does not constitute a formal group, Schlozman and Tierny's theory does not adequately explain ACT UP.

It is argued by many group theorists that the size of a group determines how successful a group will be. Olson, Wilson, and Schlozman and Tierny all concede that the size of the group does influence its ability to achieve its goals. Though many would assume that larger groups are more successful, this is not necessarily the case. Because of their size, larger groups command more clout and are able to draw upon a larger pool of potential resources, but they are more apt to fail due to a number of factors. First, the free-rider problem which was discussed earlier. Because of this problem, it is more difficult for large groups to attract and maintain a membership.

Group cohesion, the ability of the group to act as a united organization, is determined by group size. Cohesion, again, has been offered by group theorists as a primary factor which directly impacts group success. The larger the group the more prone it is to factionalization. Internal conflicts divide membership and threaten to permanently divide the group. Policymakers are more apt to be persuaded by a group that represents a substantial portion of its members, rather than a mere fraction of total membership. A group's leaders must represent the group as a whole, not a particular faction. This can be measured by looking at

internal cohesion. If members of the organization, other than those chosen to lead, are claiming to speak on behalf of the group, it is obvious that those claiming to represent the group do not represent the group as a whole.

The traditional school of group theory fails to completely explain groups like ACT UP. Classical group theories focus upon formal organization and are unable to adequately explain the existence of informal groups, that is groups which do not maintain membership rolls, charge dues, etc. Informal groups, such as ACT UP, tend not to charge dues or maintain membership lists. They favor a decentralized power structure, never even considering a central office. How does one explain ACT UP? How can the success or failure of such a group be determined?

### **ACT UP as a Political Movement**

David Meyer contends that political movements represent an unusual and invariably transient form of political participation that occurs when state-sanctioned processes of popular participation cannot manage legitimate political conflict (Meyer, 1). It is difficult to define a social movement, but Meyer offers six criteria to describe and define movements. These six criteria will be used to determine whether ACT UP can be defined as a political movement.

First, a movement includes both political and personal transformation (Meyer, 2). Meyer argues that the two are linked because a movement attempts to change both state policy and the way participants live their lives. This is certainly the case with ACT UP. ACT UP seeks not only to influence and promote government AIDS policy, but also to change the way society deals with the issue. ACT UP labors to promote and instill the practice of safe sex, yet another goal inherent in the group's mission.



Ideally, the practice of safe sex will become second nature. This requires an extensive re-education program, thus ACT UP seeks personal transformation.

Second, a political movement will use means additional to those offered and accepted by mainstream society to pursue its goals (Meyer, 2). Organizations will use both conventional (participation in the electoral process) and nonconventional (demonstrations, civil disobedience) methods to promote their agenda. Though both are necessary, ACT UP has chosen to emphasize nonconventional means to influence government policy. Tactics utilized by ACT UP will be discussed further in Chapter Two.

Third, a political movement must be in a dynamic state of interaction with the political mainstream (Meyer, 2). A movement that ceases to draw support, membership, or rhetoric from the mainstream ceases to be dynamic or moving (Meyer, 2). According to Meyer, a movement is one that is located toward the edge of legitimacy which demands to effect structural political change. Though anyone can join, ACT UP tends to draw its membership from the mainstream, thus enhancing the group's legitimacy. Its membership continues to represent a cross-section of society as more and more professionals become involved. Additionally, ACT UP draws support from the educated middle-class, thus lending much needed legitimacy.

Fourth, political movements end when they are institutionalized, that is, when they have found a means of accommodation with established political institutions and society (Meyer, 2). Two types of institutionalization exist. A movement or group is marginalized when forced so far to the edges of legitimacy that it no longer has any serious interaction with mainstream politics (Meyer, 2). Once it has been pushed to

this point, the organization can be easily ignored. It can be argued that many of the feminist organizations have been marginalized. During the 1970s these organizations represented mainstream American women who supported the Equal Rights Amendment. Once the ERA failed to be ratified, these groups lost mainstream support and became dominated by radical feminists. These feminist organizations lost their legitimacy and were easily ignored.

An organization is coopted when it limits its goals to those that can be achieved without threatening in any way the political structures of the state (Meyer, 2). When a group is coopted, it does not necessarily follow that the group will no longer be in a position to affect change. Rather, since the group has adopted more realistic goals it may now be more effective. Meyer contends that a successful movement will generally be split and undergo both processes throughout its life, and most certainly, in its demise (Meyer, 2).

Fifth, a movement may contain one or more political movement organizations, but it also includes activity generated outside them (Meyer, 2). Much of the organization's activity is often unorganized or based in nascent, rather than established, groups (Meyer, 2). This refers to unorganized protests and demonstrations not sanctioned or sponsored by the group itself. ACT UP relies upon local organizations to orchestrate demonstrations and protests. Oftentimes, local gay organizations will spontaneously conduct demonstrations which are not sponsored by ACT UP, but are conducted on their behalf, following the Meyer model.

Finally, the reality of a political movement includes specific policy demands made upon the state, but it is not limited to those claims (Meyer, 3). A political movement's program includes an often unspoken, yet

shared, culture and lifestyle (Meyer, 3). Members tend to share personal as well as political values. ACT UP's members tend to be homosexual, though many are liberal heterosexuals who share many of the same values and views of the gay community.

Having established that ACT UP fits the pattern of a political movement, it is necessary to establish criteria for measuring success. Meyer, though alluding to success, does not define how success is to be measured. Meyer's theory distinguishes political movements from other types of political phenomena. He focuses upon the factors that cause or allow social movements to emerge and grow (Meyer, 3) rather than offering some measurement to determine whether a group successfully achieves its goals. In order to assess ACT UP's success we must look at William Gamson's theory of the challenging group.

### **ACT UP as a Challenging Group**

In order to be classified as a challenging group an organization must meet two criteria. First, it must seek the mobilization of an unmobilized constituency (Gamson, 19). ACT UP seeks to mobilize the public, specifically those affected by the virus either through infection or the loss of a loved one. Prior to the AIDS virus, these individuals (those affected by the AIDS virus) did not constitute a potential constituency.

Second, the group's antagonist must lie outside of its constituency (Gamson, 11). ACT UP's antagonists include both government officials and corporate leaders. The government is targeted not only because of its failure to respond to the AIDS crisis, but also because of its failure to demonstrate aggressive leadership in managing the epidemic. Corporate leaders, especially those representing pharmaceutical firms, are targeted

because they continue to produce drugs desperately needed by those who suffer at a cost which renders them prohibitively expensive. ACT UP's constituency continues to be those who have been affected by the virus. The efforts of ACT UP are aimed at those groups which have not been affected by the virus, but who control the government and corporate policy agendas. ACT UP claims that because these individuals have not been personally affected by the virus, they do not understand those who suffer, and thus are not responding to the crisis effectively.

William Gamson deviates from the traditional definition of a group in that he focuses upon the groups ability to challenge the status quo. Gamson argues that an organization, formal or informal, constitutes a group once the organization has a name which it has taken for itself or which has been given by others (Gamson, 16). It is an entity capable of taking action- of holding meetings, planning, issuing statements, calling demonstrations, and raising money. He refers to such a group as a challenging group; that is it attempts to challenge the current distribution of wealth and power (Gamson, 16).

ACT UP holds weekly meetings, and is more than capable of taking action. The organization plans, issues statements, calls demonstrations, and raises money (through direct mail and sales of tee-shirts and posters, fundraisers, and grants from other ACT UP chapters and AIDS organizations). ACT UP may best fit Gamson's definition of a challenging group.

To understand the nature of a challenging group, Gamson discusses three distinct "targets" of the group. These concepts enable a better understanding of the forces which drive ACT UP. First, the group's target of influence must be defined. The target of influence refers to a set of

individuals, groups, or social institutions which must alter their decisions or policies in order for a challenging group to correct a situation to which it objects. In the case of ACT UP the target of influence is threefold: the public, government, and corporate officials. The AIDS coalition seeks to raise public awareness of the AIDS epidemic, and thus the public constitutes a target. Government officials control public policy, especially funding for research, while corporate America continues to produce treatments at a prohibitive cost. Thus, ACT UP has targeted these entities who have made decisions which the organization seeks to correct.

Secondly, the target of mobilization must be identified. Those targeted for mobilization include individuals or groups whose resources and energy are necessary for the group to carry out its efforts at change. These individuals or groups constitute the organization's constituency. Mobilizing requires both activation of current membership (i.e., efforts to motivate those who already possess some degree of commitment), as well as the creation of new membership (i.e., motivate an individual to a high generalized readiness to act collectively). The organization focuses upon its constituency in its effort to mobilize. Many different groups support ACT UP. The group's membership includes homosexuals, heterosexuals, lawyers, doctors, teachers, laborers, men and women. Each of these groups has in some way been affected by the virus, and thus ACT UP seeks to mobilize those who have been personally affected by AIDS.

Finally, the group's target of benefits must be ascertained. The target of benefits refers to the individuals or groups whom the challenging group hopes will be affected positively by the changes which it seeks from its antagonist. The target of benefits can in some cases also be the same as its constituency (Gamson, 25). ACT UP not only seeks to increase the number

of treatments available to AIDS patients, but also seeks to eliminate discrimination against AIDS patients by raising public awareness. People living with AIDS are ACT UP's target of benefits.

ACT UP is an organization which seeks to influence government and corporate policy through the mobilization of those most affected by the AIDS virus. Their efforts are aimed at improving the quality of life for individuals diagnosed with AIDS. Using Gamson's three concepts allows a clearer understanding of ACT UP and its motivations.

### **Measures of Success**

This study will seek to determine and measure the success of ACT UP. Gamson offers two indicators used to measure success. First, has the group has been accepted by its antagonist as a valid spokesman for a legitimate set of interests? In order to measure acceptance, Gamson provides four indicators of the more positive relationship. First, is the group consulted by its former antagonists, thus indicating acceptance? Next, are they included in any negotiations? Is the group formally recognized by its antagonist as being legitimate? Finally, are the group's leaders included in the policy formation process? (Gamson, 42). Using these indicators it can be determined whether ACT UP has been accepted by its antagonist, thus achieving partial success in the form of group accommodation.

Second, success is dependent upon whether the group's beneficiary gains new advantages during the challenge and its aftermath (Gamson, 42). Whether the potential beneficiaries of the challenging group receive what the group sought must be determined. No assumption is made that the challenging group necessarily caused the benefits, but that results were

forthcoming, for whatever reason, during and immediately after the period of challenge.

Until now, no one has attempted to measure the success of ACT UP. Many praise the organization for making an impact, but fail to present empirical proof. Using Gamson's definition of success and the indicators for measuring this success, this paper will analyze and discuss ACT UP and determine whether the organization has succeeded in achieving its stated goals.

### **Data and Methods**

To determine whether or not ACT UP has been accepted as a valid spokesman, it will be necessary to establish the number of times ACT UP has been consulted by both government and corporate leaders. It will be shown that ACT UP has participated in Congressional hearings. Being invited to testify before a Congressional committee indicates a belief that the invitee has been recognized as being an expert in his/her particular field. It is difficult to determine the actual number of times that ACT UP has testified before Congress, for more often than not members do not testify on behalf of ACT UP. The organization, fearful of negative implications, hesitates to allow people to officially represent them. Instead, because ACT UP sends the people to testify, at the request of a Congressional committee, thier representation of the group is implied. Additionally, the membership of ACT UP fears being coopted by the government, and thus those testifying will do so as individuals not as members of ACT UP. Evidence will be presented to show that members of ACT UP's Treatment and Data Committee have indeed testified before Congress.

Another measure of acceptance would be to document the number of members of ACT UP who serve on advisory boards, both local and national. It will be shown that ACT UP participates on many national and local AIDS advisory boards. Evidence will also be shown to prove that high-ranking officials regard ACT UP as necessary participants in the policy-making process.

It is more difficult to measure whether corporate leaders have accepted ACT UP as a valid spokesman, but the impact ACT UP has had upon the availability and price of AIDS drugs can be measured. Specific incidents, from boycotts to boisterous demonstrations, will be discussed indicating corporate willingness to work with ACT UP. The number of times ACT UP has been mentioned in the print media since 1989 will be compared with the increase in the number of drugs available and the decrease in the cost of obtaining these drugs. If an increase in activity, indicated by media attention, coincides with an increase in the availability in the number of drugs and a decrease in cost, it can be inferred that ACT UP has had an impact on corporate, as well as government, policy.

The above data and methods will be used to determine whether ACT UP's beneficiary gains new advantages. Obviously, an increase in the number of treatment drugs available and a decrease in the cost of these drugs coinciding with an increase in ACT UP's activity, would indicate that new advantages had been gained. Specific instances will be cited to illustrate ACT UP's impact, especially its impact on the price and availability of AZT (the *only* antiviral drug approved by the government). Also, comparing group activity with increases in overall federal AIDS spending and increases in federal research expenditures would indicate advantages. An increase in activity coinciding with an increase in



research and overall AIDS expenditures would indicate an expansion of AIDS services.

**Outline of Subsequent Chapters**

Chapter Two focuses upon the organizational structure of ACT UP. This chapter will elaborate on membership, leadership, internal organizational structure, revenue, expenditures, and internal obstacles. All aspects which make ACT UP a truly unique organization will be discussed.

Chapter Three will discuss both the tactics and targets of opportunity of ACT UP. Some of the groups more notable demonstrations will be discussed in order to illustrate the evolution of ACT UP.

Chapter Four will conclude the work with an analysis of data gathered and specific incidents which indicated the effect the ACT UP has had upon both government and corporate policy. Using Gamson's criteria for success and the data and methods described above, the success of ACT UP will be assessed.

**Summary**

Chapter One focused upon the theories which dominate the current school of interest group theory. It was shown that neither Wilson's pluralist theory, nor Olson's economic motivations for group formation, nor Schlozman and Tierny's formal interest group study adequately explain the existence of ACT UP. Because ACT UP is too mobile for static models of group activity, it was necessary to look at the theories of Gamson and Meyer to define ACT UP as a political movement. Drawing from sociological literature, Gamson and Meyer provide criteria that not only explain the existence of ACT UP, but also offer a means of measuring the success of the group. This model will be used to test the hypothesis that ACT UP has had a profound impact on both government and corporate policy.

## Chapter 2

### ACT UP: The Organization

**"Welcome to ACT UP, a diverse, nonpartisan group of individuals united in anger and committed to direct action to end the AIDS crisis."**

*ACT UP's call to order*

It is a snowy Monday evening in New York, but nearly 350 individuals have braved the elements to gather at the Gay and Lesbian Center on West 13th Street in the Village. Three hours later, and three thousand miles away, approximately 100 individuals are gathered in a church in the predominantly gay Castro District of San Francisco. Though separated by a continent, the two meetings mirror each other. Emotional discussion, debate, and argument echo throughout the meeting halls. Members cannot agree over whether it is worth the trip to Washington only to heckle a Congressional hearing on AIDS, or perhaps it would be more effective to stage a "die-in" on Wall Street or the Golden Gate Bridge during rush hour. Still others contend that chaining themselves to the front door of a pharmaceutical firm blocking the sale of a would-be AIDS drug would be more successful. Mixed in with these cries for protest are reports on the newest AIDS drugs and reports from committees on housing and insurance (Crossen, B4). The meeting concludes without any unanimous decisions being reached. Though each of the factions vows to follow-through with its intended protests, the group as a whole agrees to support whatever action is taken on their behalf.

Such is a typical Monday meeting of the AIDS Coalition to Unleash Power (ACT UP). Similar meetings are held each week in 60 locations from Boston to San Diego (Morgan, 2). Self-defined in their flyers and media kits as "a non-partisan group of diverse individuals united in anger and committed to direct action to end the AIDS crisis," ACT UP pushes for greater access to treatments and drugs for AIDS-related diseases; culturally sensitive, widely available, and explicit safe-sex education; and well-funded research that is "publicly accountable to the communities most affected" (J. Gamson, 354). ACT UP encourages the participation of people with AIDS (PWA's) in all of their activities. The motivation is to change the distribution of resources and decision-making power; the principle guiding action is strategic, aimed at affecting policy changes.

This chapter shall examine ACT UP as an organization. Political movements manifest themselves in part through organizations (Zald, 121). A movement transforms itself into a movement organization as one of the movements goals becomes the maintenance of membership, funds, and other requirements of organizational existence (Zald, 121). Given that ACT UP seeks the maintenance of its organizational existence, it constitutes a movement organization and can be referred to as either a movement or an organization.

Beginning with the founding of ACT UP, we will examine the development of ACT UP from an underground, guerilla organization to what has been described as one of "the most disruptive, yet effective, pressure groups in the United States" (*Economist* , 27). The group's unique meeting format, membership, leadership, resources and budget, committee structure, and internal obstacles will also be discussed.

### **ACT UP: The Founding**

In the late 1970's and early 1980's, physicians in New York City and San Francisco were puzzled by the appearance of young, seemingly healthy, homosexual males who were diagnosed with pneumocystis carinii pneumonia (an extremely rare infection) and kaposi's sarcoma (a harmless skin cancer which normally inflicts elderly men of Mediterranean descent). This phenomenon continued to appear with increasing frequency, rapidly spreading to other segments of society, especially members of the intravenous (IV) drug user community.

The Centers for Disease Control (CDC), in 1981, officially announced "a unique and newly recognized syndrome characterized by a breakdown of the body's immune system and consequent vulnerability to infections healthy people ordinarily are able to fight off" (Gong, 3). Acquired Immune Deficiency Syndrome or AIDS, "the most serious epidemic to confront modern medicine, has become a commonly encountered clinical problem, especially in large cities" (Gong, p. 3).

AIDS represents a manifestation of the Human Immunodeficiency Virus (HIV) which results in severe damage to the immune system. Many individuals infected with the HIV virus remain healthy, whereas others experience a wide variety of clinical diseases. HIV, a fragile virus easily killed with soap, alcohol, hydrogen peroxide, or a bleach solution, spreads from individual to individual when mucous membranes or the blood stream are exposed to infected blood or semen.

The manifestation of the HIV virus results in a severely damaged immune system. Thus AIDS patients are vulnerable to a variety of air borne viruses, bacteria, protozoans, and fungi. These infections,

collectively categorized as opportunistic, begin in sickness and inevitably end with death. Opportunistic infections refer to those illnesses caused by organisms commonly found in the environment, but due to a weakened immune system, AIDS patients are unable to fight off these normally harmless infections. AIDS itself does not result in death, rather AIDS lowers barriers and enables the opportunistic infections to cause harm and eventually death.

Those most at risk include homosexual and bisexual males, IV drug users, multiple risk individuals (i.e., homosexual/bisexual IV drug users), promiscuous heterosexuals, and hemophiliacs who must rely on regular blood transfusions. Of those at risk, homosexual and bisexual men represent the greatest number of individuals infected with the HIV virus.

By 1987 nearly 40,000 individuals had been diagnosed with AIDS, over 20,000 had died, and the CDC estimated that at least one million individuals were infected (CDC, 1992), but the Reagan administration remained inattentive to the epidemic. No support services were instituted, and Reagan threatened to veto increases in AIDS research funding (deParle, A1). For seven years the disease had ravaged the gay community, but Reagan refused to mention AIDS publicly.

During this same period, the gay community was gripped with fear. Nobody could explain the origin, let alone offer a treatment, for the "gay plague." The gay community tried to ignore the problem, hoping that one day it would disappear as quickly as it had materialized (Shilts, 27). Gay activists became frustrated by the lack of response from both the government and the gay community. With the Reagan administration's refusal to acknowledge the existence of AIDS it became apparent that the

only way to prompt a response was to organize and force the president to face reality.

In March 1987, Larry Kramer, a playwright and advocate for people with AIDS, informed an audience at a gay community center that two-thirds of them could be dead within five years - casualties, he claimed, not only of a virus but also of an unresponsive medical-industrial complex (deParle, B4). "If what you're hearing doesn't rouse you to anger, fury, rage, and action, gay men will have no future here on earth," said Kramer (*Positive*, 1991). The AIDS crisis, according to Kramer, was being aggravated by institutional failures. The only way to respond was through action. Kramer urged all in attendance to demand change and work toward forcing the government to respond.

Two days after Kramer's speech several hundred people reconvened and took a name - ACT UP. Though its original rallying cry was "Drugs into bodies," ACT UP soon learned that AIDS opened a Pandora's box of problems relating to education, housing, health care, insurance, and scientific research - not to mention homophobia, racism, and classism, which have all contributed to the crisis (Handeleman, 85). Thus was born one of the "most disruptive, yet effective, pressure groups in the United States" (*Economist*, 27).

### **The Ultimate Democracy**

ACT UP functions as a decentralized, grass-roots organization. Each chapter functions independently of the others. For example, if ACT UP/New York wanted to encourage a boycott of Phillip-Morris products ACT UP/San Francisco or ACT UP/Houston would not have to follow suit. The chapters are loosely federated under the umbrellas of the AIDS

Coalition to Network, Organize and Win (ACT NOW) and ACT UP/Network.

ACT NOW does not mandate what actions are to be pursued or issue policy directives, rather the national organization functions more as an information exchange. ACT NOW holds an annual conference in Washington, D.C. each year attended by representatives of ACT UP chapters throughout the United States. The purpose of these conferences is to provide a support network for new organizations and share information on successful and not so successful forms of protest.

ACT UP/Network also serves as an information exchange between chapters, and an informal coordinating committee for national actions in Washington, D.C. Each chapter designates a Network contact who participates in conference calls with up to fifty different contacts throughout the nation. Conference calls are not scheduled, rather when any one Network contact wants to discuss a particular issue he simply initiates the conference call. A member of ACT UP/Golden Gate, who serves as the chapters contact, bemoaned the fact that this often leads to many 3:00 am phone calls (SF Anonymous, 1992). The ACT UP Network also holds a conference each year. Again, like ACT NOW, the purpose is to share information and help chapters which have recently formed.

Each of the ACT UP chapters holds meetings every Monday evening beginning at 8:00 pm and lasting well into the evening. According to Peter Staley, one of ACT UP/New York's original members, "The early meetings were about 100 people, and were just crazy. The group was fragile, emotional, nothing but cross talk. Every person gave a dramatic, emotional speech. There was plenty of creativity and drive; there just was no structure" (Handelman, 85).



At the beginning of each meeting, the meeting facilitator announces the rules for any newcomers. First, and foremost, smoking is absolutely forbidden (second-hand smoke poses a greater health risk to those who are HIV-positive than to healthy individuals). The group operates from a constitution called "the working document," based on an extremely loose version of *Roberts Rules of Order*. Anyone can raise a hand to speak for up to ninety seconds; motions can be called and seconded; and, in New York, after attending three meetings, anyone can vote - whether on spending funds, planning a mass action, or endorsing a piece of literature (Handelman, 85). The stipulation that one must attend at least three meetings in order to vote is unique to ACT UP/New York. Other ACT UP chapters allow new members to vote at their first meeting. New York's requirement is not strictly adhered to, for the group does not keep formal membership rolls, and thus really cannot determine whether an individual has attended at least three meetings.

Micki Jackson, one of ACT UP/Los Angeles' founding members, describes meetings as sheer torture. The intent of the group, according to Jackson, was to be ultra-democratic; yet because of this drive to include everyone, meetings border on anarchy. Because every attendee can speak for up to ninety seconds (no limit on how many times an individual speaks), issues are "talked to death." Proposals rise or fall based on the personality of the proposer, not the issue. The danger inherent in such a system is that one obsessed individual can dominate a meeting. This problem is compounded by the fact that some members have AIDS and suffer from dementia. Individuals will ramble on incoherently, yet because of the group's nature, no one will tell the individual to sit down. Jackson takes

pride in the fact that, though it may be flawed, ACT UP allows anyone and everyone to have a voice and vote.

Meetings tend to be long and drawn-out. Audience members illustrate points with an AA-style confessional or rephrase what's already been said (Handeleman, 85). Frequently, the meetings are bogged down by trivial disagreements over unimportant issues. For example, a recent meeting of ACT UP/New York was stalled by a two-hour debate over whether every piece of ACT UP literature should be translated into Spanish. It took two months of meetings for ACT UP/New York just to agree to rent a tiny office - which, to satisfy antiestablishment types, is called the Workspace (Handeleman, 85). According to Larry Kramer, "The problem with a grass-roots organization is every crazy has a vote (Simpson, 8).

Decision-making varies from chapter to chapter. ACT UP/LA and ACT UP/San Francisco require a simple majority for a motion to pass, whereas ACT UP/Golden Gate and ACT UP/New York require a two-thirds majority for passage. According to a spokesman at ACT UP/New York, the number of chapters which require a simple majority for passage is roughly equal to the number which require a two-thirds majority. It is understood that any motion which does not pass will not be carried out on behalf of ACT UP. Unless the motion receives the appropriate number of votes, the group will not lend its name to a demonstration, statement, or piece of literature. Again, according to Jackson of ACT UP/LA, it is difficult in a group which lacks any structure to control the actions of individual members. The only sanction is that the "rebel" members must face the group as a whole the following Monday to explain.

## **Membership**

ACT UP is not the first group to protest during the AIDS epidemic, but it is the first to draw a broad spectrum of people and unite them into a cohesive organization (Morgan, 2). The group is credited by gay activists as having sparked a new rise in nonviolent, nonpartisan, political advocacy among predominantly young, angry, and well-educated men and women between the ages of 24 and 34 (Morgan, 2).

ACT UP refuses to keep membership rolls. Their philosophy states that anyone who wants to become active is welcome. Once an individual experiences "burnout" or can no longer involve himself in the organization, he or she is free to leave. Individuals are not required to sign-in at the door, and with such a transient membership, it would be impossible to accurately estimate the total number of individuals involved in ACT UP as a whole. Micki Jackson, ACT UP/LA, contends that attendance, or "membership," fluctuates with the issue. For example, when California's Governor Wilson vetoed AB 101 (the Gay and Lesbian Anti-Discrimination Bill) in 1991, average attendance at meetings shot up from around 50 to 400 (Jackson, 1991).

ACT UP/New York boasts the largest weekly turnout with an average of 400 to 500 (ACT UP, 1992). ACT UP/San Francisco averages approximately 70, whereas ACT UP/Minneapolis will generally draw 25 or so individuals each week (ACT UP, 1992). Membership and attendance are a direct reflection of the incidence of AIDS in a particular area. The incidence of AIDS in New York, total number of cases for year end 1991, is 45.3 per 100,000 population (CDC, 1992). The incidence in California is currently 25.4, whereas the incidence in Minnesota is only 4.9 per 100,000

(CDC, 1992). Given that New York has one of the highest incidences of AIDS it stands to reason that ACT UP/New York would boast the highest membership.

According to a spokesman at ACT UP/Golden Gate the "burnout" rate for members is high. Involvement in ACT UP demands much of an individual in terms of both time and strength (physical and emotional). Many of the group's members are HIV-positive and therefore cannot overexert themselves, and thus will regularly attend meetings for 6 months to a year, depending upon their health status.

Because an individual no longer attends meetings does not mean that he/she is no longer involved. Many members do not attend meetings, but regularly participate in scheduled demonstrations. Micki Jackson assisted in the founding of ACT UP/LA, but she has not attended a meeting in approximately three years. It's not because she no longer supports the group, rather she no longer has the energy to endure the extreme agony which characterizes weekly meetings. Micki attends each and every demonstration ACT UP sponsors in the LA area. She has even travelled to Sacramento to demonstrate in front of the State Capitol when Governor Wilson vetoed AB 101.

The outward appearance of the group's membership is perhaps its greatest asset. Members of ACT UP look like Yuppies, act like Yuppies, and play the media like accomplished pros (Crossen, 1). Largely homosexual middle class professionals, their clean-cut looks gain them entry to the halls of government, finance, and religion, where they halt the proceedings by shouting, playing dead, or handcuffing themselves to a fixture. Overwhelmingly the group draws white, homosexual males. This does not

mean that women are not drawn to ACT UP, but they remain the minority. Few blacks or Hispanics, gay or straight, participate (J. Gamson, 356).

What compels individuals to join ACT UP? Predominantly all members are bound together by a conviction that the government has done too little too slowly to deal with the AIDS epidemic. Many are driven by the frustration of seeing friends and relatives die. Still others experience a very personal level of desperation: blood tests have indicated that they have been exposed to the AIDS virus (Morgan, 2). It is estimated that nearly one-third of the membership has tested positive for the HIV virus (deParle, 2).

The common thread uniting all members, both homosexual and heterosexual, is an overwhelming sense of frustration. Members experience frustration over the loss of a friend or loved one, or their own personal frustration as they cope with their seropositive status. This frustration stems from having experienced the indignation of both the government and society in general as someone they care for dies. Others feel frustrated because they have been forced to bear witness to the destruction of AIDS within their own neighborhood - the gay community.

### **Leadership**

Suspicious of power, the all-volunteer group refuses to have leaders except for a few administrative posts which rotate every six months. Four individuals are chosen by the group to act as facilitators at each meeting. Their only function is to ensure that order is maintained while issues are debated. A Coordinating Committee, made up of any member interested in attending and a member sent from each of ACT UP's standing committees, approves expenditures under \$1,000 and hashes out the wording in policy statements (Handeleman, 85). The Coordinating Committee also "sets" the

agenda for each meeting. This agenda, like ACT UP, lacks any structure. Basically, any issue that affects the lives of people with AIDS takes priority over budget reports, fundraising announcements, etc. A more detailed discussion of ACT UP's committee system will be discussed later in this chapter.

ACT UP functions without long-term leaders because when the group was formed, those who were not members of gay or AIDS social service groups feared that established leaders of existing service organizations would overly influence the group's activist course (Morgan, 2). The membership ensured that ACT UP would be free of any outside influence. Their intention is to become a more heterogenous organization composed of both homo- and heterosexuals. If the group becomes dominated by one or more pre-existing gay rights organizations, ACT UP would lose much of its political clout. This conflict between gay politics and AIDS politics, yet another internal obstacle, will be discussed at length later in this chapter.

### **Committee System**

Though weekly meetings are characterized by lively debate and chaotic discussion, the actual work is completed by a complex committee system. As ACT UP has matured it has spawned a complex bureaucracy of committees (New York has twenty-two) known as working groups (Handeleman, 85). The committees meet for a portion of the time at every other weekly meeting and sometimes during the week. Each committee has two facilitators chosen by those who attend the committee meeting. The facilitators can be recalled at any time by committee members.

Working groups are established to monitor every aspect of the AIDS crisis from housing to insurance to research and development. Each committee may have several subcommittees which work on specific, ongoing or limited duration projects (ACT UP, 1992). These subcommittees meet outside the regular meetings and organize themselves as they see fit.

In addition to subcommittees, ACT UP has formed caucuses and affinity groups. Caucuses are groups of people with a common link who exist to secure inclusion of their views and voices in the struggle against AIDS (ACT UP, 1992). The PISD (People with Immune System Disorders) Caucus is one such group. Caucuses meet outside of the general body meetings. Affinity groups are formed for specific actions outside ACT UP (ACT UP, 1992). Their plans are just discussed among group members as they are usually involved in some disruptive activity.

Following is a partial listing of ACT UP's committees (information obtained from ACT UP/LA membership flyer):

**Coordinating Committee** - only power of this committee is to set the agenda for the Monday night meetings. The committee also attempts to review the work of the standing committees in more detail than may be possible in the general meeting. The committee does not resolve policy issues, rather it attempts to clarify the issues involved and shape the discussion which will occur on Monday.

**Media Committee** - produces the newsletter (only the larger chapters can afford to publish), and works with print and television media to bring attention to the AIDS issue, via press releases, interviews and talkshows. The Video Collective chronicles ACT UP activities, and supports artistic efforts within the organization. The Speakers Bureau makes available speakers for groups and panels to create an open forum for the discussion of issues. The Archives maintains records of all activities.

**Public Policy** - works on a wide variety of public policy issues, particularly legislation at the county, state, and federal

levels, and organizers to counter activities of AIDSphobes like William Dannemeyer and Jesse Helms. The County issues subcommittee applies pressure on count health authorities to provide decent, humane and effective treatment for people living with AIDS.

**Fundraising/Finance Committee** - manages ACT UP's business affairs, oversee's the distribution and sale of merchandise, and organizes a wide variety of fundraising events, from parties to direct mail.

**Treatment and Data Committee** - keeps the membership informed of new drug treatment information, and advocates expanded and more rapid access to new treatment. Members participate in the tri-annual meeting of the AIDS Clinical Trial Group to ensure that the voice of people living with HIV is heard when formulation clinical trials in Washington, D.C.

**Agitating Committee** - provides technical and logistical assistance in planning and executing public demonstrations. The committee organizes training and support and produces signage, banners, props, and flyers. Legal (subcommittee) organizes legal representation and advice for members.

**Women's Caucus** - addresses issues specific to women and AIDS. It has organized nationwide endorsements of the call for the revision of the definition of AIDS, which will dramatically increase the availability of medical and social services for HIV-infected women.

**Networking/Outreach Committee** - works with other groups on issues of common interest to the AIDS community. ACT UP has been particularly active in the defense of women's health care clinics against fanatical right-wing groups. This committee maintains contacts and organizes demonstrations with ACT UP's nationally and internationally through ACT UP/Network. Youth and HIV Working Group organizes at high schools and colleges and advocates for the health of youth and their enrollment in clinical trials.

**People of Color Caucus** - advocates for education, services and early intervention in communities of color.

**Majority Action Committee** - so named because minorities now constitute the majority of those infected with HIV - given the fact that ACT UP was founded by and for gay white men, this working group attempts to attract minority membership.



**Prisoners with AIDS Advocacy Committee** - advocates for the most oppressed people living with HIV disease, those who are in custody.

**Insurance Committee** - guards against insurance companies shirking from their responsibilities to HIV-infected policyholders, and to people seeking insurance.

**Membership** - provides information to new and ongoing members of ACT UP who wish to know more about the organization.

**Gran Fury (New York)**- ACT UP's visual arts collective responsible for providing the organization with its eye-catching visual campaign.

Though the above working groups are considered to be the most important of the working groups, this does not mean that the work done by the other committees is not significant. Each of the working groups is responsible for monitoring a particular issue which directly affects the lives of people with AIDS. It is within these working group meetings that demonstrations and protests are proposed. For example, the Housing Committee, which tracks the development of affordable housing for people with AIDS who can no longer afford rent, will plan, and eventually coordinate, a demonstration in front of city hall or the housing authority calling for affordable housing. Each of the working groups prepares a report for the Monday meeting which discusses the status of its issue and makes recommendations for action. The group as a whole then debates and votes upon all recommendations.

### **Revenue, Budget, and Expenditures**

Each chapter of ACT UP independently raises its own funds. Revenue needs vary from chapter to chapter, depending upon its size and level of activity. ACT UP does not qualify for tax exempt status, and its political activity disqualifies it for government funding. The most

important sources of revenue include merchandise sales, benefits, direct mail, and grants.

For most chapters, merchandise sales account for at least one-third of ACT UP's revenue. In some cases, like ACT UP/Nevada, merchandise sales constitute their sole source of revenue. At each meeting a table displays ACT UP merchandise - "Silence = Death" T-shirts, sweat shirts, buttons, stickers, coffee mugs, and posters. ACT UP/Nevada recently planned to publish its own male version of *Sports Illustrated's* swimsuit calendar. ACT UP merchandise sells well and provides a steady source of revenue.

Another source of revenue is the benefit concert, dinner, etc. ACT UP/Golden Gate recently held a concert in the park which was well attended and generated enough money to "tide them over for a few months to come" (ACT UP/Golden Gate was unable to reveal the actual amount generated by this concert). ACT UP/LA sponsored a Beastie Boys concert at the Hollywood Bowl this past March and is planning an art auction for this summer. ACT UP/New York holds an annual art auction selling works donated by David Hockney, Christo, Annie Leibovitz, Robert Rauschenberg, and Keith Haring (Handeleman, 86). The third annual auction held in December, 1991, netted \$315,000. Benefits, though a major source of revenue, are not attempted by the smaller chapters because of the high costs of planning and executing these events.

Direct mail, like the benefits, are not attempted by the smaller chapters because of the prohibitive costs of production and mailing. Direct mail is not popular even among the larger chapters, like ACT UP/New York or ACT UP/LA, because they rarely generate enough revenue to justify the costs.

Finally, ACT UP chapters receive grants from other AIDS organizations like the American Foundation for AIDS Research (AmFAR), the Los Angeles AIDS Foundation, the Gay Men's Health Crisis, etc. (Jackson, 1992). Smaller or new chapters often receive grants for ACT UP/New York or ACT UP/LA. ACT UP will only accept grants from non-partisan AIDS service organizations in order to avoid any partisan influence. These grants are generally awarded for specific purposes. For example, AmFAR recently awarded ACT UP/New York a small grant to cover transportation and travel expenses for members of the Treatment and Data Committee testifying at a congressional hearing. Local AIDS foundations often provide funds to rent buses or vans used to transport members to and from demonstrations.

Only ACT UP/New York could provide current figures on its yearly operating budget of \$400,000. ACT UP/LA estimates its operating budget to be approximately \$350,000. The smaller chapters do not really have an operating budget and raise funds only when needed for a specific purpose.

The operating budget covers all expenses incurred by ACT UP. Though no one is paid by ACT UP (staff who monitor offices are all volunteers), many chapters maintain a Workspace and thus must cover all expenses relating to office management. Maintaining a Workspace constitutes the largest expenditure for ACT UP. Other expenses are kept at a minimum. Demonstrations are simple and require only basic materials like chalk, poster board, paint, etc. ACT UP/LA is perhaps the only chapter which publishes a weekly newsletter. Expenses for publication are low, for most of the work and materials are donated by members.

### **Internal Obstacles**

ACT UP, though the most successful of the AIDS political social movements, experiences three fundamental obstacles, or conflicts, internally. First, ACT UP's orientation towards theatrics suggests a clear delineation of performer from audience, yet actions are often planned by ACT UP members without an articulation of whom they are meant to influence (J. Gamson, 355). In ACT UP planning meetings, there is often an underlying confusion of audiences, and more often the question of audience is simply ignored. While brainstorming for new actions, there is almost never a mention of audience, and action ideas with different audiences proliferate (J. Gamson, 356). This is a result of the group's extremely loose organizational structure which acts against focused planning and action. During meetings, any individual can suggest an action. The group as a whole does not necessarily have to participate in every action. Actions are often taken on behalf of the group by a small minority. ACT UP, lacking any centralized authority, cannot control what action is being taken on its behalf, and thus is unable to concentrate on a specific audience. For example, in 1988 ACT UP protested Michael Dukakis in San Francisco, but not only was Dukakis nowhere to be found (in fact he was not even in California at the time), but also there was no media coverage and no one to witness the protest but passing cars.

A second obstacle is that, while ACT UP professes to be inclusive, and ideas are often brought up that target non-gay aspects of AIDS (issues of concern to intravenous drug-users, for example, or access to health care for those who cannot afford it), there are few signs that ACT UP in fact succeeds at including or actively pursuing non-gay members (J. Gamson, 356). Membership is not exclusively gay males, for a good portion of the

activists are women. Coalition-building is often discussed, but little excitement is generated for action not aimed at targets with particular relevance to lesbians and gays (Goldstein, 25). Another sign of ACT UP's failure to be all-inclusive is that there are few black or Hispanic members, gay or straight (Goldstein, 26). Despite their desired goal of inclusiveness, ACT UP continues to draw from and recreate the white, middle-class gay and lesbian community. ACT UP recognizes the fact that though minorities constitute the majority of the HIV population, they are underrepresented within the organization and are making a concerted effort to attract minority membership (Jackson, 1992).

A third and related problem is perhaps even more fundamental: AIDS politics and gay politics stand in tension (J. Gamson, 356). ACT UP is an AIDS activist organization built and run by homosexuals. This is not surprising given that among the population first hit by AIDS, the gay community stood alone in having an already established tradition and network of political and self-help organizations. AIDS activists find themselves simultaneously attempting to dispel the notion that AIDS is a gay disease (which it is not) while, through their activity and leadership, treating AIDS as a gay problem (which, among other things, it is) (J. Gamson, 356).

For older activists, ACT UP is gay politics - a movement continuous with earlier activism. They tend to link AIDS politics (safe-sex education) to the sexual liberation of earlier gay politics. This can be seen by the emphasis upon sex-positive actions: for example, throwing condoms into crowds creating a return to the old days of gay celebration (J. Gamson, 356). It can be argued that such an emphasis upon sexual liberation tend to blur, and even bury, AIDS issues.

For younger activists, those who came of age in the 1980's, it is important to maintain some separation between the two sets of issues (J. Gamson, 356). For example, in New York when a newspaper calls ACT UP a "gay organization," ACT UP's media committee sends out a standard letter correcting the error. These younger members of ACT UP focus more narrowly upon prevention and treatment issues, rather than upon how to continue to engage in anonymous sex safely.

The rivalry between gay politics and AIDS politics threatened to destroy ACT UP during its formative years. In Los Angeles, for example, an organization known as the Lavender Left attempted to control ACT UP and use it as a front for its own agenda. The Lavender Left was a radical group, not unlike today's Queer Nation, which resorted to violence directed at heterosexuals whenever a homosexual was "bashed." The Lavender Left could not attract the type of membership that ACT UP drew, and thus attempted to control ACT UP. This drove some members away, but within six months ACT UP/LA absorbed the Lavender Left, which, according to Micki Jackson, contributed to the strength of ACT UP.

This tension between gay politics and AIDS politics resulted in the breakup of ACT UP/San Francisco and ACT UP/Chicago. In both cities there are currently two ACT UP chapters, each with distinctly different agendas. In San Francisco, ACT UP/Golden Gate focuses solely upon AIDS issues, while ACT UP/San Francisco incorporates many gay-rights related issues. A similar situation exists in Chicago. Such tension poses the greatest threat to ACT UP as an organization.

## **Summary and Conclusion**

The AIDS Coalition to Unleash Power is a grass-roots, democratic, direct action organization dedicated to creating positive changes around AIDS in federal and local government, the media and medical industries through non-violent protest (ACT UP, 1992). The organization has become the most vocal in the fight against AIDS. The organization is a loose federation of local organizations located in over 60 cities throughout the United States. Each of the chapters functions independently under the umbrella organizations of ACT NOW and ACT UP/Network. ACT NOW and ACT UP/Network do not issue policy or action directives to local chapters, rather these organizations, or networks, function more as an information exchange providing local chapters with instructions on how to conduct successful civil disobedience.

ACT UP's membership is mostly gay, white men. Its goal is to influence government and corporate policy in the fight against the AIDS epidemic. ACT UP is suspicious of power and does not maintain any real leadership positions. Since the formation of the first chapter in New York in 1987 the organization has spawned a complex bureaucracy of up to twenty-two working groups which monitor every issue affecting the lives of people with AIDS.

ACT UP suffers from internal conflicts which at times impedes its ability to reach and influence a specific audience. It will be shown that though they oftentimes have difficulty reaching a specific audience, this is more a function of the loose-knit organizational structure of ACT UP rather than a failure of the group to influence.

## Chapter 3

### ACT UP: Tactics

All the polite candlelight marches of the early Eighties  
didn't do much to increase government funding.  
Confrontational protest is long overdue, and it's  
only going to get bigger...

Randy Shilts, *And the Band Played On*

Shortly after the formation of ACT UP/New York, organizers in Los Angeles launched ACT UP/LA. In an effort to draw both membership and attention to the AIDS crisis (a crisis which had decimated the film industry) ACT UP's founders planned a march up Sunset Boulevard from West Hollywood to the UCLA Medical Center and back. Until then (1987) it was taboo in Hollywood to admit you were a homosexual, let alone reveal that you had been infected with the HIV virus. In an effort to draw attention and membership, Steven Kolzack, casting director for *Cheers*, in an emotional address admitted both at a short rally in West Hollywood. He led marchers up Sunset Boulevard occasionally dropping onto the street as if he were dead, while another ACT UP member would hurriedly outline his "dead" body in white chalk. The more than 200 marchers would follow suit. Traffic on Sunset Boulevard was brought to a stand-still for more than two hours as the marchers slowly made their way to UCLA. The event was the lead story on all of the evening news programs and even made the front page of the *Los Angeles Times*. Los Angelenos had borne witness to their first "die-in," and ACT UP/LA had forced millions to face the AIDS crisis.

The "die-in" is but one of many ACT UP trade-mark demonstrations. This chapter will explore ACT UP's targets of opportunity (the intended target of their demonstrations), the group's tactics, and why they have



chosen those tactics. Finally, this chapter will highlight some of ACT UP's more notable demonstrations.

Before discussing ACT UP's targets of opportunity, let us first briefly review how the group decides which demonstrations to sponsor. First, any participant, or group of participants in ACT UP can propose an action by going through an existing committee, subcommittee, or caucus. The committee or caucus' coordinating committee representative will request a place on the agenda of a general meeting to bring the proposal for action before the floor. The body then debates and votes upon the proposed action. If it receives the approval of the appropriate majority, the action will be sponsored by ACT UP.

ACT UP, contrary to popular perception, is *not* a clandestine or underground operation. All actions and demonstrations are announced in the press and made public through the distribution of flyers and posters well in advance of the proposed event. A member of ACT UP/New York contends that except for precise organizational details, nothing they do is secret (Handeleman, 86). She continues that the organization is more powerful being open, and the minute they start trying to be secret, that's when they will be infiltrated and sabotaged (Handeleman, 86).

Infiltration and sabotage are not imagined fears of ACT UP. Each chapter jokingly begins each meeting by asking any on-duty policemen or other law-enforcement officials to identify themselves. Though no one has responded to this request, demonstrations are attended by both uniformed police and many suspicious characters in street clothes with video cameras (Handeleman, 86).

Micki Jackson, ACT UP/LA, reveals an incident where an individual, highly placed in the administration of LAPD, who asked not to

be identified, informed her of LAPD infiltration of ACT UP/LA. The LAPD had implemented a very complex and detailed scheme to infiltrate and sabotage the group. Undercover police would be chosen while they were still attending the academy. They were taught how to "dress" to attract, and how to "act" gay. They would then be sent to meetings. Once at the meeting, these young, very goodlooking and muscular men and women would identify, flirt with, and attach themselves to those they felt could be manipulated. Through this association undercover officers would promote violence and disruption. It was hoped by LAPD that by disrupting the group, ACT UP would not be able to focus on its goals. LAPD's actions became more noticeable when Governor Wilson vetoed AB 101. The number of undercover police sent to meetings increased tenfold. Jackson jokes that so many undercover police were sent that members were literally bumping into them while they were flat-footing (patrolling in uniform).

ACT UP continues to adhere to a policy of openly discussing planned protests and demonstrations. They are aware, not paranoid, of infiltrations, and thus are even more intent upon ensuring that all protests remain nonviolent acts of civil disobedience. Once they resort to violence, the authorities will have a case against them and will be able to disband ACT UP.

### **ACT UP's Targets of Opportunity**

ACT UP's targets of opportunity are both visible and invisible. First, and most often, the targets against which the anger and action of ACT UP are directed are clear and familiar: the state and pharmaceutical corporations (J. Gamson, 357). At other times the target is invisible and abstract: the socialization process, that is attacking societal stigmatization of those individuals infected with the HIV virus. Finally, intermediate targets appear, the visible institutors of the less visible process: the media, medical science, and the Roman Catholic Church (J. Gamson, 357).

First, the state is involved in the domination of people with AIDS. The state not only determines which treatments will be researched and developed, but also determines the level of funding AIDS research in general will receive. The state also determines which social welfare services people with AIDS will be eligible to receive. The federal government, according to ACT UP, has been less than responsive to the needs of people living with AIDS. Research and development of new treatments has been sluggish due to a severe lack of funds, while government approval of new drugs can take up to ten years (CDC, 1992). Additionally, people with AIDS are regularly deemed ineligible for federal welfare programs (Medicaid, food stamps, housing subsidies, SSI disability payments), because prior to becoming sick they made too much money and currently own too many assets (a house or car perhaps). The government has never seen fit to create a single agency to oversee the handling of the AIDS crisis, and thus the National Institutes of Health, the Food and Drug Administration, and the Centers for Disease Control - all of which are located in different states - have been proceeding disjointedly and competitively (Handeleman, 89).

ACT UP faults Presidents Reagan and Bush for the above inaction. Neither administration has been attentive to the AIDS epidemic. Reagan first mentioned AIDS publicly at a time when nearly 40,000 people had already been diagnosed and over 20,000 had died from the disease (J. Gamson, 359). Though calling AIDS America's number one health, the administration consistently avoided initiating a coordinated, adequately financed attack on the problem (Shilts, 456). President Bush has failed in four years as chief executive to find new heads for any of the three agencies overseeing the AIDS crisis. Reagan and Bush have become the common targets of ACT UP "AIDSgate" signs and tee shirts, as well as countless demonstrations and public advertisements charging that "the government has blood on its hands." In the case of the state, specific state institutions and actors are targeted, mostly through conventional means of protest. It is clear who is responsible for needless death and who is controlling resources, and thus ACT UP functions as a pressure group to protest and effect policy decisions (J. Gamson, 359).

Similarly, pharmaceutical companies are manifest targets of opportunity, for they control the prices of treatment drugs and make decisions about whether or not to pursue drug development (J. Gamson, 359). Drug company decisions are driven by profit motives, and thus ACT UP considers this a direct and visible instance of oppression, representing an obstacle to the physical survival of AIDS patients. In the case of AIDS treatment drugs, no alternative or generic brands exist. Each of the companies that owns the rights to a particular drug has an absolute monopoly over the distribution of that drug. Oftentimes the corporation sets prices at a level which renders them prohibitively expensive to AIDS patients. For example, as late as 1988 a year's dosage of AZT cost \$13,000 (J.

Gamson, 359). ACT UP deems this practice a threat to the lives of people with AIDS, and thus exerts pressure upon drug companies to charge reasonably affordable prices.

The most abstract of ACT UP's targets of opportunity is their attempt, through the use of symbols, to eliminate societal stigmatization of people with AIDS. According to Gamson, ACT UP's general strategy is to take a symbol or phrase used to oppress and invert it. For example, ACT UP explicitly challenges the kind of language used to discuss AIDS. In place of the "AIDS victim" they speak of "people with AIDS" or "people living with AIDS." In place of "risk groups," they insert the category of "risk practices." They talk about blood and semen (medical research has shown that given the fragile nature of the virus it dies when it comes into contact with oxygen, and thus saliva is not considered a means of transmission), rather than "bodily fluids," and they challenge the exclusionary use of "general population" (J. Gamson, 361).

This symbolic strategy runs much deeper than speech, however. The emblem adopted by ACT UP is the most obvious example of taking a symbol connected with oppression and inverting it. Using the pink triangle, ACT UP reclaims a former Nazi symbol for death. The slogan, "Silence = Death," not only connects gay action with gay survival, but also homophobia and inaction to death from AIDS (J. Gamson, 361). ACT UP's most common form of civil disobedience, the "die-in" (to be discussed at length later in the chapter), is an attempt to shift responsibility, for AIDS patients are more often than not dismissed as victims of their own sexual deviance. The "die-in" is an attempt to liken AIDS deaths to murders, victims not of their own deviance, but shot down by the people controlling the definition and enforcement of normality (J. Gamson, 361).

ACT UP attacks medical science because researchers not only reinforce social stigma, but also because they are out of touch with those attempting to live with AIDS. Researchers refer to AIDS victims, not people living with AIDS, and consistently use such exclusionary terms as general population and high risk groups. Most researchers, until last year at the International AIDS Conference in Montreal, had never before come into contact with individuals who were living with the disease they are attempting to eradicate. ACT UP contends that by not witnessing the actual progression of the virus in a human being, researchers do not fully comprehend the gravity of the situation. A virologist from the University of California at San Francisco remarked how helpful it was for researchers to finally meet and talk to people in Montreal with HIV (Brown, 36).

ACT UP challenges the media to stop perpetuating stereotypes responsible for AIDS-phobia. ACT UP/San Francisco recently shut down production of the NBC drama *Midnight Caller*. The show was to feature a bisexual man with AIDS who purposely infects others and is shot and killed in the end by one of his female partners (J. Gamson, 360). ACT UP objected to the show's playing upon the fear of the "killer queer," and the implication that it is justifiable to kill a person with AIDS. ACT UP attacks the media for its continual portrayal of people with AIDS as murderers. The media continues to print account after account of individuals who purposely infect unknowing sexual partners. They fail to mention that, of those with AIDS, the vast majority do not maliciously go out of their way to infect society.

The media is also a target of opportunity, for most papers will not even publish AIDS-related stories, or if they do, they are buried. For example, ACT UP has a long-standing quarrel with the *New York Times*,

for up until 1991, the paper even avoided the use of the word *gay* (Handeleman, 90). The *Times* does not employ a full-time AIDS reporter in Washington, where most of the news regarding new treatments is released, and typically the paper often puts very tentative (and unsubstantiated) "cure"-type stories on the front while burying all other AIDS stories (Handeleman, 90). The *Times* is not uncommon, for papers throughout the country to this day refuse to print any stories related to AIDS. A spokesman for Washington, D.C.'s Whitman Walker Clinic complains that "if you look at Legionnaires' disease (a virus which mysteriously killed about twenty middle-aged white men in the early 1980s), and you compare how the press responded to that to how they're dealing with AIDS, the difference is overwhelming. It's clear that if AIDS were primarily affecting middle-class straight white America, it would be more thoroughly reported" (Portner, 30).

Finally, the Roman Catholic Church represents a target of opportunity for ACT UP. The Catholic Church continues to advocate a policy condemning the use of any form of birth control. In particular, certain clerics (including the Pope himself) have vehemently opposed the use of condoms and have urged public officials to prohibit public distribution. ACT UP views the Church as a threat to the lives of hundreds of thousands of uninfected individuals. Specifically, the Catholic Church is perhaps the most influential institution for Latinos. The rate of infection continues to grow at an alarming rate within the Latino community.

Though the Catholic Church officially condemns the practice of homosexuality, ACT UP does not attack the church's stance. The organization attempts to separate itself from "gay politics," and thus attacks only the official condemnation of condom use. ACT UP defers to other

organizations, like Queer Nation, to attack the church's view that homosexuality is immoral.

### **Tactics**

ACT UP is committed to nonviolent, direct action to end the AIDS crisis. Any form of civil disobedience, whether it requires chaining oneself to the main entrance of a pharmaceutical company or blocking traffic during rush hour, is encouraged by ACT UP. The group neither condones nor encourages the use of violence in any of their demonstrations or actions. ACT UP has earned a reputation for being an extremely disruptive, yet effective, pressure group. The organization believes that the key to its success is the refusal to resort to any type of violence.

ACT UP realizes that in order to affect change the group must gain advantages of being on the "inside," that is working within the system. On the other hand, the organization refuses to allow itself to become coopted. In order to maintain this balance, ACT UP relies upon theatrics. Theatrics allow the group to maintain its image as a "radical" organization, while at the same time gaining it access to the halls of government. Many of ACT UP's actions are carefully orchestrated to ensure that the demonstrations still shock, but do not go so far as to offend. Following is a discussion of some of ACT UP's more popular tactics.

ACT UP distinguishes between two different types of demonstrations: regular actions and zap actions. A regular action (actions) is one which is planned to take place more than one general meeting after the one when it is proposed and approved (ACT UP, 1992). The zap action (zaps) is an action which is planned to take place before the next general meeting.



Because there is more time to work on them, regular actions allow for more thorough planning. The opportunity exists to do outreach outside of ACT UP, preferably coalescing with other AIDS organizations. Regular actions tend to be much larger than zap actions. A spokesman for ACT UP/LA contends that regular actions tend to be pro-active in their demands, that is, the group sets its own agenda of issues (such as its call for national health insurance). Zaps, on the other hand, tend to be reactive in nature, designed to respond to immediate issues.

Zap and regular actions may be either endorsed or unendorsed. An endorsed zap is one which has been voted upon and approved by the membership at the Monday night meeting. An unendorsed zap is one which may be announced at a meeting without a request for approval, or can be engaged in by members of the group with or without an announcement to the general body. However, unendorsed zaps and actions cannot under any circumstance use the ACT UP name and cannot assume that they will receive any funding assistance from ACT UP (ACT UP, 1992).

ACT UP uses a variety of tactics when pursuing an action. The most widely used tactic, recognized as the organization's trademark, is the die-in. The die-in, the first tactic ever used by the group, continues to be the focus of all actions taken on behalf of ACT UP. On cue, action participants will drop to the ground, while other members draw police-syle chalk outlines around each other's "dead" bodies. Additionally, the "Silence = Death" slogan is written sporadically between the bodies as a public reminder. The outlines and slogan remain in the streets and on the sidewalks until they are washed away by the elements, thus serving as a lingering reminder for passers-by.

The trademark zap of ACT UP is the practice of tying-up an individual's phone lines for a twenty-four hour period. This zap allows for increased participation for members can zap at home. The home, office, and fax number of a targeted individual (Bush, Cardinal O'Connor, the CEO of Burroughs-Wellcome, etc.) are disseminated to the membership at the weekly meeting and through word-of-mouth. On a specifically chosen date, members constantly call the target's home and office number so no other calls can get through. At the same time, members continuously fax ACT UP slogans to the target's office. This zap inhibits the target from conducting routine business, thus frustrating the individual, ideally forcing him or her to reconsider ACT UP's position.

Public "outings" are by far the most destructive, threatening, and controversial of ACT UP's tactics. "Outing" refers to the practice of publicly revealing the names of those public officials and figures known to be homosexual. At one time such a practice was considered taboo, for the gay community respected an individual's desire to remain "closeted." ACT UP, on the other hand, believes that it is its duty to "out" officials/figures who denounce AIDS policy while privately practicing homosexuality. Each week the organization publishes a magazine known as *Outweek* (often referred to as ACT UP's *Pravda*), listing the names of known homosexuals who continue to work against AIDS policies (Handeleman, 86). This practice has not only divided the homosexual community, but also has been the source of much tension within ACT UP. Many still believe that an individual's right to privacy should be respected, while others contend that the ends justify the means - "closeted" homosexuals will be less hostile publicly to AIDS policy initiatives.

Another popular tactic used by ACT UP is the age-old practice of boycotting. ACT UP regularly lists in *Outweek* those organizations or corporations which support anti-AIDS agendas or public officials. For example, in 1988 both Phillip-Morris and Miller Brewing Company heavily supported Jesse Helms' re-election bid for his North Carolina Senate seat. Jesse Helms argues that the small amount of federal money currently spent to fight AIDS would be better spent on reparative therapy for gays and lesbians (ACT UP, 1992). In response, ACT UP called upon all gay establishments and members of the community to boycott all Phillip-Morris and Miller products (Rameriz, C3). Other boycotts have included all products made by Burroughs-Wellcome in response to the outrageous price of AZT, and all products of Bristol-Meyers for their refusal to market a potential AIDS treatment drug (Rameriz, C3).

Finally, when all else fails ACT UP resorts to the ultimate tactic - shocking the public. Members will do whatever they deem necessary to shock the public and force them to recognize the AIDS crisis. This includes "kiss-ins" at local straight bars (where members will crowd onto the dance-floor during peak hours and begin kissing one another); throwing condoms at passing pedestrians while wearing condom hats or dressing like a giant condom; basically anything that will shock middle-class values.

The above tactics, though not exhaustive, represent those actions preferred by ACT UP. Though for the most part well orchestrated, ACT UP's actions are not free of detractors. Because of the group's unstructured nature it must contend with the problem of sheer unguided, spontaneous anger (Handeleman, 116). Some actions require advance scouting and careful choreography, but at many others people simply show up and act naughtily. This lack of control makes some feel liberated, others

frightened; any single member's actions can and will be attributed to the group (Handeleman, 116).

### **Notable Actions**

ACT UP develops and refines tactics with every demonstration. At its first action, the organization relied upon a tactic commonly used by other protest movements - the boycott. Burroughs-Wellcome, the manufacturer of AZT, refused to negotiate a reduction in the cost of the drug with ACT UP. The group responded by calling for a boycott of Burroughs' products, which include the cold remedies Actifed and Sudafed (Handelman, 82). Burroughs, unaffected by the boycott, still refused to negotiate price. ACT UP stuck *AIDS Profiteer* labels on the company's products on store shelves; still Burroughs would not budge. The group decided more drastic measures were necessary. Members of ACT UP barricaded themselves inside the company's offices in North Carolina, but to no avail.

Finally, a group of seven member, led by Peter Staley, a former trader, planned an "invasion" of the New York Stock Exchange. Their goal: to impede trading for as long as possible in order to draw attention to the "unreasonable" practices of Burrough's. For weeks the group prepared and planned their "invasion." Based on Staley's expired identification badge, seven fake badges were printed locally and distributed to the participants.

On the morning of September 15th the group rushed passed security guards, made its way up a short staircase to the balcony twenty feet above the trading floor, and unfurled a banner reading, SELL WELLCOME (NYT, 1989). Not since Abbie Hoffman tossed dollar bills onto the floor twenty-two

years before, had anybody interfered with trading (Handelman, 82). The protestors were arrested, but the action was featured on all three of the major networks. ACT UP not only captured national attention, but within two weeks Burroughs cut the price of AZT by 20 per cent (Handelman, 82).

Shortly after the Wall Street incident, ACT UP first applied its trademark "die-in." In an effort to halt John Cardinal O'Connor's influence in secular matters in New York City (he pressured the Board of Education to retreat on a policy of teaching safe sex and distributing condoms), ACT UP planned a protest in front of St. Patrick's Cathedral during high mass. While 4,500 demonstrators gathered outside and chanted, approximately forty members slumped silently onto the aisle floor inside the church (NYT, 1989).

The "die-in" effectively captured the attention of both the press and the parishioners attending mass. The most counterproductive event, evidence of ACT UP's inability to control individual members, occurred when one of the protesters went to receive communion. He took the wafer from his mouth and threw it to the ground. Because of that one person, the only mention in the media was of the desecration of the host, not the 4,500 protestors or the die-in or the 111 arrested (NYT, 1989). Subjected to intense criticism from the public, sympathetic politicians and gay organizations, ACT UP admitted failure.

ACT UP seeks to capture national attention, and thus will resort to drastic, almost desperate, measures which more often than not fail. In 1990, ACT UP demonstrators stopped the Rose Parade in Pasadena to call attention to the lack of treatments and funding for AIDS. Fourteen activists stepped in between a high school marching band and a float, unfurled three banners, and halted the parade for approximately two minutes (ACT

UP/LA News, 1990). The networks stationed their reviewing stands several blocks further up the parade route, and thus ACT UP did not capture media attention.

In another desperate attempt, three ACT UPers broke onto the set of the *CBS Evening News with Dan Rather*, chanting "Fight AIDS, Not Arabs!" during coverage of the Gulf War. Rather requested a commercial, but the network was not prepared to break, and thus the network went off the air for six seconds (NYT, 1991). Upon returning, Rather simply apologized for the "rude people." Rather did not draw attention to the protestors, thus ACT UP did not succeed in promoting their message.

Its most recent success occurred in 1991, when nearly two dozen members of ACT UP interrupted Arsenio Hall's opening monologue. A shouting match ensued between the talkshow host and ACT UP. The protestors were eventually removed, but taping never ceased and the incident was aired. Hall drew attention to the protestors by challenging them. Thus, ACT UP succeeded in capturing media attention and promoting their message.

The common element uniting all of ACT UP's actions is the desire to dominate the media, thus promoting their message. More often than not, many of ACT UP's actions appear desperate attempts to capture attention. The group is least successful in promoting their message when their actions appear the most desperate, for those they are trying to reach simply ignore them.

### **Summary and Conclusion**

ACT UP is a grass-roots, democratic, direct-action organization dedicated to creating positive changes around AIDS in federal and local

government, the media, and medical industries through non-violent public protests. ACT UP disavows the use of any violence and will denounce any individual claiming to act on behalf of the organization who resorts to violence.

ACT UP distinguishes between two different types of protest. First, the regular action, referring to a well-planned event that will occur at some future date. Second, the zap action, referencing an event which will be held before the next weekly meeting. ACT UP utilizes several different tactics, its trademark being the die-in, when implementing an action.

Over the years, ACT UP has orchestrated many radical actions. Their main purpose: to not only force the American public and federal government to become active in the fight against AIDS, but also to motivate the media to accurately cover the epidemic and disseminate information.

## Chapter 4

### ACT UP: Success

..The anger and the passion that fueled the street actions is now also being channeled by many members into deep, thoughtful, and thorough work on the many and various committees. I believe that ACT UP is our only hope for progress and the future...

*Larry Kramer, founder, ACT UP*

Larry Kramer describes ACT UP as the one organization that has done more in three and a half years than all the AIDS and gay organizations all over the world put together have accomplished in ten (Kramer, 1). ACT UP focuses upon six targets of opportunity: the government, the media, corporations (especially pharmaceuticals), the Roman Catholic church, medical research establishment, and societal stigmatization of people living with AIDS. The last three chapters have discussed the theoretical framework for analyzing this group, the organizational structure of ACT UP, and tactics and targets. We now focus on determining whether ACT UP has been successful in its endeavors.

Several factors contribute to the success of ACT UP as an organization. Success can be defined as affecting change in both political and social policies. These factors which influence success include organizational structure, tactics and the demographic makeup of the group. The organizational structure allows for a continuous flow of new ideas and a seemingly endless supply of volunteers. The tactics, specifically their theatrical nature, allow the group to maintain a radical image while at the same time gaining it access to policymakers. Finally, the demographic makeup (young, professional, conservative-looking



homosexuals) contributes to success by gaining members access to the corporate and governmental offices.

In this chapter, using Gamson's measures of success, both qualitative and quantitative data will be used to determine whether we can label ACT UP a successful challenging group. It is necessary to use both qualitative and quantitative data because in certain instances the success of ACT UP cannot be measured quantitatively and we must rely upon qualitative recounts of particular instances and their results.

Gamson offers two indicators to measure success. First, has the group been accepted by its antagonist as a valid spokesman for a legitimate interest? In order to measure acceptance, Gamson provides four indicators of the more positive relationship. First, is the group consulted by its former antagonists, thus indicating acceptance? Next, are they included in any negotiations? Is the group formally recognized by its antagonist as being legitimate? Finally, are the group's leaders included in the policy formation process (Gamson, 48)? Using these indicators, based upon data presented, it can be determined whether ACT UP has been accepted by its antagonist, thus achieving partial success in the form of group accommodation.

Second, success is dependent upon whether the group's beneficiary (people living with AIDS) gains new advantages during the challenge and its aftermath (Gamson, 48). Whether the potential beneficiaries of the challenging group receive what the group sought must be determined. No assumption is made that the challenging group necessarily caused the benefits, but that results were forthcoming, for whatever reason, during and immediately after the period of challenge.

This chapter will discuss each of the six targets of opportunity, applying both of Gamson's criteria in order to measure success. Finally, an overall assessment of ACT UP's success will be presented based upon how successful the group has been in obtaining new advantages for people with AIDS.

### **The Government**

First, has ACT UP been accepted by the government as a valid spokesman for a legitimate set of interests? This can be measured by looking at data such as whether ACT UP has testified at Congressional hearings, whether the group has been asked to sit on any committees generating policy, and finally whether governmental officials consult members of ACT UP and view their input as valid.

ACT UP's Treatment and Data (T&D) committee has led ACT UP's battle to reform the way the government regulates the testing and release of drugs. Members have become experts on all treatments either approved or under development. According to ACT UP/New York, members of T&D regularly testify at government hearings, beginning in 1989 (Handelman, 86). In 1989, ACT UP shifted from being merely reactive to a more participatory role. Members had protested at two government hearings on the approval process for AIDS and cancer drugs and were invited to testify about the release of two new drugs - pentamadyne and DHPG (Handelman, 86).

ACT UP continues to testify at hearings dealing with the release and development of new treatments. Following is a list of the number of times ACT UP has testified at a Congressional hearing since 1987 (the year ACT UP was founded):

**Congressional Testimony by ACT UP  
(Treatment Hearings)**

<b>Year</b>	<b># of ACT UP Testimonials</b>	<b># of Hearings</b>
1987	0	2
1988	0	5
1989	1	3
1990	3	2
1991	1	1
1992 (thru Feb)	0	0

*(Source: CIS Index to Government Publications)*

The above data indicate the growing acceptance by governmental officials of ACT UP as a spokesman for treatment and data issues.

ACT UP formed in 1987, thus we can not expect that the group would be invited to testify during that year. In 1988 five hearings were held regarding potential treatments for AIDS. Not one person living with AIDS was invited to testify. ACT UP pressured the government through demonstration after demonstration at the National Institutes for Health. They demanded to be included in the decision-making process. Given that the following year ACT UP was invited to testify at one of three treatment hearings, the government began to include ACT UP in the decision-making process. Since 1988, the government has become increasingly receptive to ACT UP - as is demonstrated by the increasing number of ACT UP testimonials.

Another measure of acceptance is the number of committees ACT UP serves on which develop public policy. To date, ACT UP sits on one national committee - the National Institute for Allergic and Infectious Disease's (NIAID) AIDS Clinical Trials Group (ACTG). The AIDS Clinical Trials Group sets the controls and limits involved in treatment trials. ACT

UP has long advocated a loosening of these controls so more individuals would qualify for the trials, more results could be tabulated more quickly, and thus treatments could be approved more quickly. ACT UP attends each of the tri-annual meetings of the ACTG as an observer. Observer status allows ACT UP to influence the controls placed on trials without the ability to vote. The NIAID's invitation to sit on the committee further indicates increased governmental acceptance of ACT UP as a legitimate spokesman.

Locally, the County Subcommittee of ACT UP's Public Policy Committee works with local government to promote AIDS policy. ACT UP/LA was instrumental in working with the LA County Board of Supervisors in the establishment of an AIDS Ward at LA County Hospital (ACT UP/LA News, March/April, 92). Other successes include ACT UP/LA and ACT UP/New York working with their respective school boards to implement sound safe sex programs and make condoms available to students.

Finally, ACT UP is regularly consulted by government officials who are responsible for the federal AIDS response - the National Institutes of Health (NIH), the Food and Drug Administration (FDA), and the Centers for Disease Control (CDC). The NIH coordinates all research efforts, while the FDA approves all treatments. The CDC tracks all AIDS cases, and thus does not directly affect public policy. Dr. Anthony Fauci, director of NIAID, contends that members of ACT UP "are better informed than many scientists can imagine" and bring a "special insight" that can "be helpful in the way [NIAID] designs" studies (Cotton, 669). Fauci further contends that he has a difficult job, for he must "go back to the conservative establishment and say, 'We need to work with these people'" (Handelman,

85). Fauci views ACT UP as a group of "intelligent, gifted, articulate people coming up with good, creative ideas" (Handelman, 85).

The Ellen Cooper, Director of the FDA, regularly meets with ACT UP on issues dealing with the approval of new treatments. ACT UP advocates a more liberal approval program which would make drugs available more quickly to people with AIDS. Cooper meets with ACT UP in an attempt to reassess current approval guidelines and develop, if necessary, new guidelines which would make drugs more readily available. The FDA and the NIH (especially NIAID) directly impact the lives of people with AIDS, whereas the CDC does not. The directors of both the FDA and NIAID recognize ACT UP as a valid spokesman for people living with AIDS, thus indicating governmental acceptance.

Second, has ACT UP generated new advantages for the group's beneficiary? This can be measured by looking at the number of drugs approved by the FDA since the formation of ACT UP, the parallel track program, and the amount of money spent by the federal government on AIDS research.

By 1987 the only drug to be approved by the FDA was an anti-viral drug known as AZT. AZT was the *only* treatment available to people with AIDS. The drug inhibits the ability of the virus to reproduce (it does not prevent or treat opportunistic infections), but is only effective for a short period of time. After the drug's effectiveness diminishes, AZT can no longer be used as a treatment. ACT UP's original battle cry was "Drugs into Bodies." The group advocated prompt approval of several experimental and developmental drugs.

Following is a list of currently approved treatments and the year they gained FDA approval:

<b>Drug</b>	<b>Year Approved</b>
AZT	1987
Ganciclovir	1989
Aerosolyzed pentamidyne	1989
Injectable pentamidyne	1989
Recombinat Human Alpha Interferon	1989
Fluconazole	1990
Pediatric AZT	1990
Foscarnet	1991
DDI	1991
Erythropoietin	1991

*(source: CDC AIDS Information Clearinghouse)*

In 1987 only one drug (AZT) had gained FDA approval, but since 1989 nine additional treatments have been approved. The FDA credits ACT UP's pressure tactics for the increased number of treatment approved. The approval process can take up to ten years, but according to the FDA's Cooper, ACT UP forced the FDA to realize that many people living with AIDS did not have ten years to wait for additional treatments (Handelman, 85). It is obvious that through the efforts of ACT UP people living with AIDS have gained new advantages - the increased number of treatments now available to increase the life expectancy of people with AIDS. According to the CDC, in 1987 the life expectancy from the time of being diagnosed with full-blown AIDS to death was one year. Today, due to the increased number of treatments, people living with AIDS can expect to live an average of five years (CDC, 1992).

Experimental drugs go through trial phases before being released: In phase I, the drug is tested for toxicity; in phase II, it is tested to determine if it shows enough different, positive effects to make it worth releasing; and in phase III, similar tests are done in larger populations

over longer periods of time (Handelman, 85). ACT UP, working with NIAID's Fauci and the FDA's Cooper, developed what has been termed the greatest breakthrough in the treatment of AIDS - parallel track testing. With parallel track, in cases of serious illness, drugs that had passed phase I would still be put into clinical trials but would also be released immediately to patients who did not qualify for the trials (Handelman, 85).

This greatly increases the number of treatments available to people with AIDS, for now the most serious cases can be treated with experimental drugs prior to approval. The AIDS Clinical Trial Group authorities, as well as Health and Human Services Secretary Louis Sullivan, credit ACT UP with forging the parallel-track program (Cooper, 669). Through the efforts of ACT UP, people with AIDS, again, have gained new advantages.

Finally, federal expenditures on AIDS research indicate new advantages for people with AIDS. Federal AIDS researchers develop the experimental drugs which fight opportunistic infections attacking people with AIDS. The more research conducted, the more treatments available.

Following is a chart which illustrates the budget of the Public Health Service (PHS). The PHS, a division of the Department of Health and Human Services, supports research into the causes, prevention, and potential cures of AIDS:

### Federal Research Expenditures Since 1987

<b>Fiscal Year</b>	<b>Amount Spent (dollars in millions)</b>
1987	902
1988	962
1989	1,301
1990	1,590
1991	1,886
1992 (Appropriated)	1,967
1993 (Pres. Budget)	2,068

*(source: Public Health Services, Division of PHS Budget)*

According to Michon Kritsehmer, a PHS staffer, it has been a constant battle to continuously increase the amount of funds appropriated each fiscal year. Congress and the President have proposed cuts in AIDS research in an effort to balance the budget, but due to pressure tactics of ACT UP these attempts have been thwarted (Kritsehmer, 1992). Kritsehmer credits the actions of ACT UP for saving the PHS budget. The increases, though small, do allow for increases in research and development each year. ACT UP's efforts have allowed for continual increases in government expenditures on AIDS research, thus allowing for further development of additional treatments. With each new development, the life expectancy of people with AIDS increases, thus ACT UP has gained new advantages for its beneficiary.

### The Media

ACT UP contends that the media has continuously spread misinformation, perpetuating stereotypes and causing many to panic. Their only goal, in terms of the media, is to force the media to print the facts, not dwell on hearsay. For example, prior to the adoption of parallel track, Gina Kolata, *New York Times* medical reporter, wrote a front-page



article suggesting that clinical trials were having trouble getting volunteers because the new system allowed people to get the same drugs without adhering to clinical regulations (Handelman, 90). NIAID's Fauci demanded a retraction from Kolata because the clinical trials were being delayed by ordinary bureaucratic paperwork problems and the actual disbursement of the drug. The program of expanded access simply allowed the drug to be used by people who wouldn't qualify for the trials anyway. Kolata's article resulted in pressure upon officials to discontinue the parallel track program.

The *Times* did not retract the story, but ACT UP sent Kolata 300 Christmas cards informing her that the organization was scrutinizing her facts (Handelman, 90). The next time an article on AZT was to be printed, Kolata phoned ACT UP for details. Kolata said, "I want to get every fact correct. I don't want to get 300 cards on this" (Handelman, 90). ACT UP's actions led to direct results. The *Times* medical reporter consulted ACT UP, thus accepting it as a legitimate spokesperson.

Another indicator of whether ACT UP has been accepted by the media as a spokesperson is to measure the number of newspaper articles written about ACT UP and its activities. An increase in the number of non-demonstration/protest stories would indicate a willingness on the part of the media to accept ACT UP as a viable group. The following list was taken from a count of articles (dealing with AIDS, not demonstrations) in which ACT UP was mentioned:

### Non-demonstration Articles Regarding ACT UP

Year	# of Stories
1987	0
1988	3
1989	10
1990	37
1991	29
1992 (as of 10 April)	4

(source: InfoTrack, *National News Index* and the various indexes of each publication)

The above articles were printed in *The New York Times*, *The Los Angeles Times*, *The Wall Street Journal*, and *The Christian Science Monitor*. It is obvious that a definite increase occurred from 1987 to 1990 in the number of times ACT UP was mentioned in articles other than those chronicling its demonstrations. This indicates a willingness of the media to accept ACT UP as a legitimate spokesman. The decline following 1990 indicates that, overall, ACT UP's success has been limited, for the number of stories dealing with AIDS printed during that same period increased from 613 to 645 (InfoTrack, *National Newspaper Index*).

It is more difficult to determine whether ACT UP has gained new advantages for people with AIDS through the media. Only one account exists of a direct relationship between an article printed in a newspaper (at the urging of ACT UP) and a policy response. In early 1990, ACT UP initiated a campaign against the media for their delay in releasing the news about the effectiveness of lower doses of AZT. *The New York Times* responded with a story entitled "Federal Delay in Lowering Standard Doses of AIDS Drug is Assailed" (Handelman, 90). Within a few weeks, the FDA cut the standard dose of AZT in half. The lower dose was more effective, for patients could remain on AZT longer without experiencing the harsh side-effects of the higher dosage. It really cannot be determined that the cut in

the standard dose of AZT resulted from the story printed in the *Times*, so we can only infer that there exists a probable linkage. Based on the evidence gathered, we cannot determine whether ACT UP has been successful in gaining new advantages through the media.

## **Corporations**

First, and foremost, ACT UP targets pharmaceutical corporations because of their pricing practices and unwillingness to push for the early release of treatments. Since the infamous Stock Exchange protest in 1989, pharmaceutical companies have been willing to consult with ACT UP. In 1990, executives from Bristol-Myers initiated a meeting with members of ACT UP regarding parallel track and the release of its newly developed anti-viral drug, DDI. Bristol-Myers was surprised that this group had access to the powers that could approve its product and, having watched what happened to Burroughs, knew not to inflate the price (Handelman, 89). Shortly thereafter, Hoffmann-LaRoche pharmaceuticals, manufacturer of the newest anti-viral drug DDC, filed an early-release petition with the assistance of ACT UP. Burroughs-Wellcome continues to consult ACT UP over the price and effectiveness of AZT. Burroughs worked with ACT UP in securing FDA approval of lower doses of AZT.

Pharmaceuticals recognize the access that ACT UP possesses with the FDA, and thus consult them when filing for early release. This tendency to consult ACT UP indicates an acceptance of ACT UP as not only legitimate, but also a necessary factor when working with the FDA for approval.

ACT UP, through its actions aimed at corporations (especially pharmaceuticals), has gained new advantages for its beneficiary. First, when AZT was originally released, Burroughs-Wellcome set the price at \$10,000 for a year's dose. Only after being threatened with a Congressional inquiry did they lower the price per year to \$8,000 (CDC AIDS Information Clearinghouse). Within weeks of the Stock Market demonstration, Burroughs reduced the price of AZT twenty percent, to \$6,400 a year

(Handelman, 82). Since 1989, through the continual efforts of ACT UP, Burroughs has reduced the yearly cost of AZT to \$2,620.80 (CDC AIDS Information Clearinghouse). Today, AZT is more affordable and thus accessible to people living with AIDS.

Through consultation with ACT UP, Bristol-Meyers and Hoffman-LaRoche were able to obtain early release approval from the FDA for DDI and DDC (both anti-viral drugs less toxic than AZT). It is through this relationship and acceptance of ACT UP that the drugs were approved for early release, and as a result 5,000 patients no longer able to take AZT were given either DDI or DDC (Portner, 31). A definite advantage was gained for people with AIDS.

Throughout 1990 and early 1991 ACT UP initiated a boycott of all Philip Morris products because of its support for Jesse Helms (who ACT UP views as a threat to the survival of people with AIDS). ACT UP urged all establishments owned by homosexuals and sympathetic heterosexuals to boycott the sale and use of Philip Morris products. In May of 1991 Philip Morris announced that in response to the boycott organized by ACT UP it would increase donations to AIDS service and research organizations (Ramirez, D4). ACT UP's efforts resulted in an increase in funds available for support services and research - an advantage gained for people living with AIDS.

### **The Roman Catholic Church**

ACT UP protests the church's involvement in secular affairs. For example, it was Cardinal O'Connor who influenced the New York City Board of Education to abandon the implementation of safe sex education and the distribution of condoms in NYC high schools (Handelman, 90).

ACT UP has sponsored countless national protests aimed at changing the church's anti-condom policy, but to no avail. The Catholic church neither consults ACT UP nor accepts it as a legitimate organization. Obviously, since ACT UP is not viewed as a legitimate spokesman, the group has been unsuccessful in obtaining any new advantages from the church (such as allowing AIDS patients to be admitted in Catholic hospitals and nursing homes) for its beneficiaries .

### **The Medical Establishment**

The *Journal of the American Medical Association* refers to ACT UP as a group of "scientifically astute activists" who have made possible dialogue that should have significance well beyond today (Cotton, 666). Following ACT UP's disruption of the Fifth International Conference on AIDS in Montreal, the group was invited to participate in the Sixth conference held in San Francisco in 1990. ACT UP was a formal part of the proceedings. San Francisco marked the first time that scientists shared a platform with AIDS activists (Brown, 36). Researchers even went so far as to take to the streets with ACT UP to protest the U.S.'s travel restriction on people with HIV (Brown, 36). Jonathan Mann, former head of the World Health Organization's Global Programme on AIDS, stated that ACT UP "challenged clinical research and shook deeply [their] assumptions about the role of infected and ill people" (Brown, 36). Researchers were intrigued with ACT UP's political savvy, consulting with them on how to secure funds for a global assault on AIDS. ACT UP has not only been accepted by the medical establishment as a legitimate organization, but also includes them in the negotiation process over treatment development and policy alternatives.

In terms of new advantages gained by this more positive relationship, ACT UP has been able to increase the sensitivity of researchers toward people with AIDS. While in San Francisco, researchers who did not normally come into contact with patients found it helpful to meet and talk with people with HIV (Brown, 36). Researchers and people with AIDS attending the meeting "declared their firm intent to participate in, rather than simply submit to, processes of prevention, care and research" (Brown, 36). The new advantage gained by people with AIDS has been that researchers recognize the human side of AIDS, and that through the cooperation of ACT UP the two groups can work together to push for additional funds for research and development.

### **Social Stigmatization of People with AIDS**

It is difficult to measure whether the public views ACT UP as a valid spokesperson for a legitimate interest. The only way to measure any probable impact on the public would be to measure Americans' compassion and tolerance toward people with AIDS. Increased compassion and tolerance would indicate a new advantage, but we cannot determine whether ACT UP is responsible for no public opinion poll has attempted to measure why attitudes have changed. By comparing public opinion in 1987 with that of 1991, we can only infer that ACT UP has had some sort of impact on how the public views people with AIDS.

Since 1987, ACT UP has launched a massive campaign, through the use of visual advertising, to change people's attitudes. In Chicago, for example, ACT UP purchased advertising space on the public buses and trains. The poster, which read "Kissing Doesn't Kill," sparked intense debate. The message, that casual contact does not spread AIDS, seems to

have worked. When interviewed, Chicagoans responded that before the posters appeared they were not aware that kissing was not a means of transmission. Based upon this attempt to influence public opinion through advertising, we can only infer, not prove, that ACT UP has impacted public opinion.

Following are some questions asked in a Gallup poll designed to measure whether the public was becoming more or less tolerant of people with AIDS:

	Agree	Disagree	No Opinion
<b>AIDS sufferers should be treated with compassion</b>			
1991	91%	6%	3%
1987	78%	7%	15%
<b>The government is not doing enough about the problem of AIDS</b>			
1991	60%	32%	8%
1987	53%	37%	10%
<b>In general, it's people's own fault if they get AIDS</b>			
1991	33%	63%	4%
1987	51%	44%	5%
<b>I would refuse to work alongside someone with AIDS</b>			
1991	16%	80%	4%
1987	25%	65%	10%
<b>People with AIDS should be isolated from the rest of society</b>			
1991	10%	86%	4%
1987	21%	71%	8%

(source: Gallup Reporter 1991)

The above data indicate that Americans are increasingly becoming more compassionate and tolerant toward people with AIDS. Some of the increases were quite dramatic. In 1987, for example, a slight majority of Americans agreed with the statement that it is an individual's own fault if he contracts AIDS - more recently only one in three agrees. Though it is difficult to say with any certainty that ACT UP is responsible for changing



people's opinions, thus increasing compassion towards people with AIDS, we can infer that ACT UP's continuous effort to change people's attitudes through eye-catching advertisements has been a limited success.

### **Summary and Conclusion**

Gamson provides us with certain indicators for measuring the success of a challenging group. Analyzing ACT UP's impact on each of its targets of opportunity, we set upon the task of determining whether ACT UP has been successful. Can we call ACT UP a "successful" challenging group based upon Gamson's indicators?

The government not only recognizes ACT UP as a legitimate spokesperson, but also invites the organization to participate in the policy making process. The government invites ACT UP to testify at hearings, to participate on policy-making committees, and is recognized by officials responsible for overseeing the government's response to AIDS as a necessary source of input. According to Gamson's theory ACT UP has indeed succeeded in gaining new advantages for its beneficiary based upon the more favorable relationship with its former antagonist. Thus, we can conclude that ACT UP has successfully influenced one of its primary targets of opportunity.

Determining whether ACT UP has been as successful with the media is not as easy. The media does consult with ACT UP on stories dealing with AIDS. This indicates an acceptance by reporters of ACT UP as a legitimate spokesperson, but the number of articles dealing with AIDS, in which ACT UP was consulted, increased from 1987 to 1990 but declined after 1990. This indicates limited acceptance by the media. In terms of gaining new advantages for people with AIDS, it can only be inferred, not

proven, that ACT UP's relationship with the media brought about the FDA's approval of lower doses of AZT. Overall, ACT UP has not been completely successful with the media.

Corporations, especially pharmaceuticals, recognize the political clout and savvy ACT UP possesses. By recognizing them as a legitimate spokesperson and working with them, pharmaceuticals are able to wade through the bureaucracy and easily obtain early release approval for their experimental AIDS treatments. New advantages gained by this relationship include the lower cost and increased availability of treatments. The organization even succeeded in obtaining a pledge from Philip Morris to make available funds for AIDS research and services. Overall, ACT UP has had tremendous success with actions aimed at corporations.

In no way has ACT UP been successful in achieving its stated goals regarding the Catholic Church. The Church not only refuses to accept ACT UP as a legitimate spokesman, but also will not include the group in any policy negotiations. ACT UP has not been able to secure any new advantages for people with AIDS.

ACT UP's fifth target of opportunity, the medical research establishment, has accepted it as a valid spokesperson, and views its input as both valuable and necessary. Since 1989, the group has been invited to the annual meeting of the International Conference on AIDS, where it participates in scientific discussion over potential treatments and educates researchers on how to increase funding for their research. The new advantages secured by ACT UP include a more positive relationship between researchers and people with AIDS, as well as increased funding for research and, thus, additional treatments. ACT UP has been

successful in achieving its goal of securing more available treatments for people with AIDS.

Finally, ACT UP attempts to influence public opinion regarding people with AIDS. Americans are definitely more compassionate and tolerant toward people with AIDS, but it is difficult to determine whether ACT UP is responsible. ACT UP sponsors an aggressive advertising campaign designed to promote the notion that AIDS is not spread through casual contact. It can only be inferred that ACT UP was somewhat responsible for changing public opinion. In terms of fighting societal stigmatization of AIDS, we can conclude that ACT UP has been somewhat successful, though not entirely.

Based upon the data presented above, of ACT UP's six targets of influence the group has been tremendously successful with three, can claim limited success with two, and failed with only one. Given that ACT UP has existed for only five years and the relative success rate of its tactics, we can agree with Larry Krammer that "in three and a half years, ACT UP has done more than all the AIDS and gay organization all over the world put together have accomplished in ten" (Krammer,1).

## **Conclusion**

ACT UP formed in response to government, corporate and public refusal to acknowledge AIDS. At first, the group focused upon increasing the number of available treatments, but its agenda has since grown to include any objective (i.e. housing, insurance) which affects the lives of people living with AIDS. It has been shown that ACT UP cannot be easily explained or analyzed using traditional group theory. Traditional group theory focuses upon organized interests, that is groups which maintain offices, hire lobbyists, and offer certain economic or tangible incentives to attract membership. Given the nature of the organization, we define ACT UP first as a political movement, more specifically as a challenging group.

David Meyer provides certain criteria in order to determine whether a group constitutes a political movement. Based upon his criteria ACT UP can be defined as a political movement. Meyer attempts to define the point at which a political movement ends. According to him a political movement ends when it is institutionalized, that is when they have found a means of accommodation with established political institutions and society (Meyer, 2). First, a group is institutionalized when it is forced so far to the edges of legitimacy that it no longer has any serious interaction with mainstream politics (Meyer, 2). Second, a group is institutionalized when it limits its goals to those that can be achieved without threatening the political structure (Meyer, 2).

Though Meyer attempts to offer some indication of when a movement dies, he does not offer any clear measurements. How can it be determined if a group is pushed to the far edges of legitimacy? Many would argue that

ACT UP exists on the edges of legitimacy. Though ACT UP draws its members from the mainstream, oftentimes individuals, driven by misplaced anger, are pushed to the edges of legitimacy. Meyer does not offer any means of measuring whether a group has been “pushed” to the edges of legitimacy. Therefore, we cannot accurately determine whether ACT UP exists on the edges of legitimacy because some would argue that it does while others would disagree.

Additionally, Meyer argues that a group is coopted when it limits its goals to those that can be achieved without threatening the political structure. ACT UP definitely threatens the current political structure, but oftentimes they will set achievable goals. This does not mean that they have been “coopted,” rather the group seeks to capture attention through success. According to Meyer, capturing attention leads to resource mobilization. ACT UP seeks to mobilize resources against the continued spread of HIV/AIDS. In order to maintain the public’s attention, ACT UP must successfully achieve certain goals. We cannot assume that because ACT UP establishes a few goals which do not threaten the political structure, it has been coopted.

### **ACT UP: A Final Analysis**

Today, the incidence of AIDS continues to climb, especially among heterosexual teen-agers. Though the number of available treatments has increased dramatically since 1987, researchers complain of a continuous struggle for funds and an emphasis upon treatments not a cure. The National Institute of Allergy and Infectious Diseases announced in 1990 that a vaccine would be ready by the end of the decade, but this vaccine may only be 60 per cent effective (New Scientist, 37). As the number of diagnosed

AIDS cases continues to climb, demands for health care, housing, and other support services threaten to strain both the political and social systems. Though deaths, discrimination, inaction and bureaucratic bungling continue, ACT UP claims many successes. Reductions in outrageous prices for drugs, early access to experimental drugs, and increased funding for treatment and research are but a few of the successes achieved by ACT UP. According to ACT UP their work is far from over.

Beset with problems, such as a high burnout, high membership turnover, and the inability to control the actions of misguided individuals, ACT UP maintains a fragile balance. Every demonstration sponsored by ACT UP could potentially destroy the group through negative press coverage and the eventual erosion of support. ACT UP has thus far successfully isolated itself from misguided actions and has been able to capitalize upon negative press coverage - but what of future prospects?

This work attempts to analyze and explain ACT UP as an organization. As a challenging group, ACT UP seeks to alter the current political structure. ACT UP focuses upon improving the quality of life for people living with AIDS. As more and more people are diagnosed, will ACT UP be able to meet the demands? As more people test positive for the HIV virus will the organization be able to cope with an increased membership? Will ACT UP be able to absorb a more diversified membership as increasing numbers of minorities succumb to AIDS? This study in no way seeks to answer all of these questions. Only through future analysis will ACT UP's full potential or failure be realized.,

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