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**The evolution of the Canadian AIDS Society: a social movement organization as network,  
coalition and umbrella organization**

**Derek G. Steele  
Department of Sociology, McGill University, Montreal  
August 2000**

**A dissertation submitted to the Faculty of Graduate Studies and Research in partial  
fulfilment of the requirements of the degree of Doctor of Philosophy**

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**Canada**



**ABSTRACT**

**The evolution of the Canadian AIDS Society: a social movement organization as network, coalition, and umbrella organization**

**Derek G. Steele**

This study presents a history of the Canadian AIDS Society (CAS), which began as an informal network of 16 local AIDS Service Organizations (ASOs) in 1986 and grew to 120 member organizations by the time of the renewal of Phase III of the National AIDS Strategy in late 1998. There are two main objectives of the study: 1) to look at why the organizational forms of the collection of groups evolved as they did; 2) to examine the outcomes and effectiveness of these organizational forms for CAS and its member organizations.

Interviews were conducted with founding members of CAS and later staff and activists. Members of a subsection of local General Service Organizations (GSOs) were interviewed regarding group relationships to CAS and involvement with other organizations in their communities. Documentary research on materials produced by CAS (now publicly available in the AIDS Committee of Toronto library) was carried out. Some documentation was also available for local organizations. *The Globe and Mail* index was used to research CAS national level work.

This dissertation uses the concepts network, coalition and umbrella organization to develop an understanding of why CAS formalized and the positive and negative outcomes of this for member groups and the organization itself. The issues of insider/outsider

organization, motivation, identity, framing and ideology are discussed in relation to their impact on both CAS and a subsection of member organizations.

CAS developed as a network, coalition, and umbrella organization. This evolution was in response to the purpose and goals of CAS <sup>\$</sup> at a national level, Ottawa based <sub>=</sub> representative of member organizations interacting with the government and gathering and producing information useful to local work. CAS became increasingly formalized over the period under study, seeking and gaining access to government and other elites, as at least a semi-insider organization.

## **RÉSUMÉ**

**La Société canadienne du SIDA  
en tant que réseau, coalition, et organisation protectrice**

**Derek G. Steele**

Cette étude présente l'historique de la Société canadienne du SIDA (SCS). Cette organisation a débuté en 1986 en tant que réseau informel composé de 16 organismes locaux de lutte contre le SIDA. Elle s'est étendue jusqu'à 120 organisations membres à la fin de l'année 1998, lors du renouvellement de la phase III de la Stratégie nationale contre le SIDA. Les objectifs principaux de cette étude sont: 1) de voir pourquoi les structures organisationnelles du regroupement des différents organismes ont évoluées de cette façon; 2) d'examiner les résultats et l'efficacité de ces structures pour la SCS et ses organisations membres.

Les entrevues ont été réalisées avec les membres fondateurs de la SCS, le personnel de la société de même que les militants. Les membres d'une sous-section locale des "Organisations de services généraux" (OSG) ont été interrogés concernant les relations du groupe avec la SCS ainsi que leur implication avec d'autres organismes dans leurs communautés. L'analyse s'est également basée sur les documents produits par la SCS (maintenant disponibles pour le grand public à la bibliothèque du Comité du SIDA de Toronto). De la documentation supplémentaire était également disponible de la part des organismes locaux. L'index du quotidien *The Globe and Mail* a été utilisé pour étudier le travail de la SCS sur le plan national.

Cette thèse utilise les concepts de réseau, de coalition et d'organisation protectrice afin de développer une compréhension des raisons derrière la formalisation de la SCS ainsi

que des effets positifs et négatifs qui en découlent, autant pour les regroupements membres que pour l'organisation en soi. Les thèmes d'organisation intérieure/extérieure, de motivation, d'identité, de mise en contexte et d'idéologie sont discutés par rapport aux impacts produits sur la SCS et sur une sous-section d'organisations membres.

La SCS s'est développée en un réseau, une coalition et une organisation protectrice. Cette évolution répondait aux buts et objectifs de la SCS au niveau national puisque les représentants des organisations membres en poste à Ottawa pouvaient interagir avec le gouvernement afin de rassembler et de produire de l'information utile au travail local. Durant la période étudiée, la SCS est devenue de plus en plus formalisée, à la recherche d'un accès au gouvernement et aux autres groupes d'élites. Cet accès a été obtenu et la SCS peut du moins être qualifiée d'organisation semi-intérieure.

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**Glossary**

**ACT--AIDS Committee of Toronto**

**AIDS--Acquired Immune Deficiency Syndrome**

**ASO--AIDS Service Organization**

**CAS--Canadian AIDS Society**

**CHS--Canadian Hemophilia Society**

**GSO--General Service Organization**

**IDUs--Injection Drug Users**

**OAN--Ontario AIDS Network**

**PAN--Pacific AIDS Network**

**PHA--Person Having AIDS**

**PLWHIV/AIDS--Person Living with HIV/AIDS**

**PWA--Person With AIDS**



## **CHAPTER ONE**

### **INTRODUCTION: SOCIAL MOVEMENT THEORY AND THE SOCIOLOGY OF AIDS**

The focus of my research is the Canadian AIDS Society (CAS), founded in 1985 and most recently describing itself as a “coalition of more than 100 community-based AIDS organizations across Canada” (Canadian AIDS Society, 1998). CAS has evolved into its present form from a collection of sixteen founding member organizations and is now the foremost national AIDS organization in Canada (Roy, 1995). My research is theoretically concerned with how organizations come together to cooperate, the type of structures they adopt, how these develop, and the outcomes this has for centralized groups and their member organizations. In this regard, I look at the Canadian AIDS Society from the perspective both of activists who were involved in a leadership role at the national level and of a selection of local organization members. In discussing the nature of CAS as a collection of member organizations I focus on a number of theoretical concerns within social movement theory.

This chapter is an overview of the literature which informs my dissertation and of the methods that were used in carrying out this research. As I will show, much has been written within Sociology about AIDS generally, with strong connections to literature on social movements and community organizations. However, little has been written about

AIDS in Canada.<sup>1</sup> This dissertation attempts to expand on research on the Canadian response to AIDS, on the literature on AIDS activism by social movement organizations (SMOs), and on social movement theory, particularly with regard to research on coalitions, networks and umbrella organizations.

I begin with a review of relevant social movement literature, discussing three substantive theoretical concerns: networks, coalitions, umbrella organizations. I then go on to consider a number of other issues: insider/outsider organizations, motivation, identity, interorganizational relations, frames and ideology, and outcomes. My goal is to show the broad connections between these areas as they bear on my research. Gaps in the literature are highlighted alongside contributions of my study to social movement theory. Next, I focus on the AIDS literature within Sociology, showing how this vibrant field informs my work and thought. I then emphasize the main points from both these fields. This is followed by a discussion of the research methods that I used in gathering data for this dissertation. I close the chapter with a preview of the remaining chapters.

## SOCIAL MOVEMENT THEORY

My overarching concern is with the problem of creating an organization through which member organizations can cooperate. I identify three possible forms, *networks*, *coalitions* and *umbrella organizations*, which are not dealt with substantially in the literature.<sup>2</sup> Broadly each can be defined as follows: a *network* is basically a loose formal or

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<sup>1</sup> The major exceptions to this, which are discussed here, are Cain (1993; 1995; 1997); Brown (1997); Kinsman (1997); Lavoie (1998); and Rayside and Lindquist (1992a; 1992b).

<sup>2</sup> The Canadian AIDS Society might be argued to fit into any one of these categories. While it clearly describes itself as a coalition (CAS, 1990), interview respondents seemed to prefer the term *network* when describing CAS prior to incorporation. *The Globe and Mail* described the organization in separate articles

informal grouping of organizations, largely for the purposes of sharing information; a *coalition* is more formalized, providing a connection between organizations and allowing for shared resources and information without necessarily impinging on member organizations' autonomy in any way; an *umbrella organization* is the most formalized of the three theoretical concepts, being an autonomous organization acting on behalf of its constituents without necessarily having to consult them. The concept of umbrella organization is under-theorized, a problem which I hope to overcome. There is some overlap between the literature on social movements and AIDS but I keep my discussion largely separate; for the most part there are clear distinctions because of the nature of HIV/AIDS and the communities it has most affected.

My starting point is the lack of research on the ongoing work of social movements: there is an expressed need to look at movements over time (Meyer and Staggenborg, 1996, McAdam, McCarthy and Zald, 1996). I emphasize aspects of social movement theory which allow the development of a perspective not only on the rise of social movement organizations but also on their ongoing activity. Zald and McCarthy highlight that there has been little research on the variety of social movement organizations' relationships and on the interaction between organizations (1987:161). They argue that there are three major types of relationship: competition; conflict and ideology; cooperation. My discussion focuses on (formal) cooperation, which finds many expressions. My research contributes in two ways: I look at a movement over time and provide a strong focus on inter-organizational relations.

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as both a network (Taylor, 1991) and an umbrella organization (Mickleburgh, 1991). It is of course

## Networks

Of the three substantive theoretical concepts (networks, coalitions and umbrella organizations) the literature on networks is the most abundant.<sup>3</sup> Neidhart and Rucht go as far as to argue that social movements are “mobilizing networks of networks” (1991:453; cf. Diani, 1995, who agrees on this point<sup>4</sup>). Diani points to the “complex set of exchanges that ultimately make up a social movement” (1995:xiii). This is at the core of networking-- formal or informal relays of information, ideas, ideology, frames and resources. This can be between individuals (e.g. in the form of overlapping memberships (Staggenborg, 1986)) or in common leaders (Morris, 1984) or between organizations.<sup>5</sup>

At the level of organizations, both Rosenthal et al. (1985) and Phillips (1995) study networks of women’s movement organizations. Rosenthal et al., focusing on nineteenth century women’s reform, highlight the importance of networks for introducing ideas into the wider discourse. This in turn gives SMOs better access to the broad support base necessary to achieve goals, or at least favorable outcomes. In agreement with Diani, they see shared ideas and ideology as crucial to establishing links. Drawing on Curtis and Zurcher (1973), they argue that movements are multi-organizational fields, essentially networks of organizations. While CAS itself acts as a network, it is also part of a wider network of organizations concerned with AIDS and related factors. Although this is beyond the scope of my current research, the effects of multiple network memberships is

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possible that it was all three.

<sup>3</sup> Much of the network literature is on interpersonal and recruitment networks, such as kinship and friendship ties (Broadhead et al., 1998, Klandermans and Oegma, 1987, and Zurcher and Olson, 1980). This will be explicitly dealt with only to the extent that it is relevant to networks of organizations.

<sup>4</sup> Diani argues that networks are core to the pursuit of goals. He also discusses the importance of framing issues and ideology in keeping coalitions together (cf. Staggenborg, 1986).

an interesting area for future research. Weak ties are seen as beneficial, allowing for a broader dissemination of ideas through a diverse network (Rosenthal et al. 1985).

Phillips (1995), having mapped the network of organizations reasonably considered among the Canadian Women's Organizations that she is studying, configures the relationship between these organizations. She questions whether or not more than one network is at work, as do Rosenthal et al. (1985).<sup>6</sup> Both of these works are helpful in pointing to ways in which relationships between organizations can be configured to include strength of ties and the centrality of various organizations within the network.<sup>7</sup>

Given that more than one network may be in operation, cross movement networking can often be seen (Carroll and Ratner, 1996, cf. Staggenborg, 1998, della Porta and Rucht, 1993). Tying together networking and framing, Carroll and Ratner emphasize the importance of both. Networks are crucial for the recruitment and mobilization of resources. For this to be effective there must be sensitivity to diversity (possibly through framing). They, like Rosenthal et al., see movements more as "multi-organizational fields" than as communities (Carroll and Ratner, 1996:614).<sup>8</sup>

The importance of networks in providing ongoing strength to social movement organizations is evident. There are a number of different forms of ties between groups, which can develop as part of a network (or networks). It is clear that organizational ties, friendship ties, and overlapping memberships are all important to mobilization and

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<sup>6</sup> CAS can be seen to be a part of more than one network at any given time, assuming that it can be seen as a network in and of itself.

<sup>7</sup> Staggenborg (1998) argues that a map of the movement can be filled out through interviews and document review. This is how I have conducted my research.

<sup>8</sup> Lune (1998) discusses community based organizations specifically in the context of AIDS organizations in New York City (cf. Schneirov and Geczik, 1996, on submerged health networks)

movement longevity. From this literature, the network could be described as central to the development of social movement theory and to my present study of CAS.

### Coalitions

Given that one of the questions behind my research is the extent to which CAS acted as a network, coalition and umbrella organization (or whether or not it might be said to be any combination of these at different stages of its development), it is clearly important to identify the characteristics of each as distinct from the others. The literature on coalitions, however is more sketchy than that on networks; only a few studies on coalitions of organizations have been carried out (Meyer and Staggenborg, 1996, Staggenborg, 1986).<sup>9</sup>

Curtis and Zurcher (1973) argue that interorganizational relations are all but crucial to social movement success (an idea reflected in Diani, 1995, and Rosenthal et al., 1985, writing on networks). While literature on coalitions is somewhat scarce, there is material on alliances and conflicts within social movements (cf. McCarthy and Zald, 1987) and on the effects that these have (Meyer and Staggenborg, 1996; della Porta and Rucht, 1995; and Klandermans, 1989). Curtis and Zurcher write about affiliations at both individual and organizational levels. Unions between the anti-pornography groups they studied were found to be based on common ideology, interests and audiences.<sup>10</sup> A core concept (already used in the discussion of networks) is the “multi-organizational field”--

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<sup>9</sup> Meyer and Staggenborg (1996) note that the field of coalitions has been undertheorized.

<sup>10</sup> The literature on framing discusses the concept of social movement audiences in greater depth (see McAdam, McCarthy and Zald, 1996).

the idea that organizations are part of a coordinated system (Klandermans, 1992; Curtis and Zurcher, 1973).

Gerhards and Rucht (1992), looking at two protest campaigns in West Germany, take up the idea of “multi-organizational fields.” They look at “micromobilization” groups and argue that it is only through deliberate coordination and integration of these that success is achieved. In their analysis, this is facilitated by “mesomobilization actors,” whose sole purpose is to connect groups by providing structural and cultural integration in common frames of meaning (cf. Snow and Benford, 1992). This multi-organizational level will be important in studying CAS. The Canadian AIDS Society might be argued to be a mesomobilization actor.

Kleidman, looking at the American Peace Movement, discusses the central tension in coalition formation between “building a movement for fundamental long term change” and “quickly mobilizing to respond to threats” (1993:ix). He sees this as a conflict between focusing on the coalition itself and effecting change at the local level. Kleidman identifies three areas of conflict: professional versus grassroots organizing; broad coalition versus independent campaign organization; and national focus of political pressure versus strong base of local support (1993:3). It can be assumed that these are tensions any national coalition would face in trying to draw support from local groups. An organization, like CAS, which grew out of local groups (rather than vice versa)<sup>11</sup> could be an exception. Early in CAS’s history member organizations and CAS had leaders and workers in common and may, therefore have been able to overcome or avoid altogether pressures arising out of differences between local and national interests.

In her work on coalitions of organizations Staggenborg (1998; 1988; 1986) makes two arguments relevant to my dissertation: that coalitions are most likely to form when organizations are faced with extraordinary opportunity or threat (Staggenborg, 1986; cf. Kleidman's point about threats); and that the professionalization and formalization of a SMO will facilitate coalition work.<sup>12</sup> It is important to ask how coalitions are formed, how they come to recruit member organizations, and how organizations come to be a part of coalitions which already exist. Staggenborg (1986) sees ideological conflict as the most notorious obstacle to the maintenance of coalitions.

A related concept, social movement communities, which must share goals that they collectively seek to advance, is developed by Staggenborg in a later paper (1998). This is explicitly connected to della Porta and Rucht's concept of the social movement family: "a set of coexisting movements that regardless of their goals have similar basic values and organizational overlaps and sometimes may even enjoin for common campaigns" (Staggenborg, 1998:3). Staggenborg also argues that organizations can attain certain cultural changes, which smooth the way for favorable outcomes for later organizations.

Feree and Hess (1994) explicitly deal with coalitions, arguing that while groups may come together ideologically, they can remain organizationally diverse. "Coalitions" here is used in a looser sense than that of coalition organizations but this ideological component is important. They discuss a web of women's organizations, which provides the coordination necessary for broad-based coalitions around single issues (cf. Staggenborg, 1998, on ideology).

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<sup>11</sup> This was pointed out to me in a personal communication with Michael Sobota, a former CAS board member (October, 1999).

<sup>12</sup> The professionalization of CAS is discussed in Chapter 2.



From the literature, coalitions take many forms: formal; informal; short or long term; with broad-based or narrow support; relying on a centralized organization or decentralized. I intend to situate CAS within this literature in order to show that it is a central organization of a broad-based, formal, decentralized coalition of organizations with a concern for AIDS, sharing goals and at least a loose ideology.<sup>13</sup>

The literature on interorganizational relations has largely been covered in the section on coalitions. It is important to highlight that there is strong potential for conflict and competition when organizations come together. It has already been noted that the interorganizational aspect of social movements is all but essential to organizational success (Curtis and Zurcher, 1973, Diani, 1995, Rosenthal et al., 1985; on conflict see Klandermans, 1989, della Porta and Rucht, 1995, Meyer and Staggenborg, 1996).

### Umbrella Organizations

Umbrella organizations are barely mentioned in the literature (and certainly not discussed theoretically). In some ways this concept overlaps with networks and coalitions. An umbrella organization acts as an overseer, performing a coordinating function similar to a mesomobilization actor (Gerhards and Rucht, 1992). I discuss the extent to which this function has been carried out by CAS in Chapter 3. The literature suggests that an umbrella organization is a group developing themes (ideology, strategy, overall goals), which are the basis for action (see especially Maseko, 1997).

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<sup>13</sup> CAS was formed by a number of General Service Organizations (GSOs) (the subject of chapter 5) and therefore has a definite role established by activists *after* local organizations. It is a formalized but not necessarily centralized coalition.

Stathyusen (1991), discussing the peace movement in Belgium, says that one of the umbrella organizations there “hoped to make these themes the basis for a pluralist...coalition that transcends the traditional cleavages between, for instance, socialist and Christian organizations” (179). This group, however, had local committees and suggests a more controlling or hierarchical structure than a network or coalition would imply.<sup>14</sup> Stathyusen’s research hints that umbrella organizations are also able to unite diverse groups by rising above past ideological divisions. This also suggests a break with network and coalition literature, which states that agreed-upon ideology is crucial (Feree and Hess, 1994, and Staggenborg, 1986).

The clearest discussion of the role of umbrella organizations is found in Laumann et al. (1978). Writing on interorganizational relations, they look at the difference between “coalitional” and “federative” contexts, arguing that “this distinction essentially rests on the degree to which organizations are willing to cede their autonomy and resources to a more inclusive subnetwork” (Laumann et al., 1978:474). They go on to state that an umbrella organization acts in a federative context as “a special purpose organization endowed with the prerogatives of acting on behalf of the entire set of constituent organizations” (Laumann et al., 1978:474). From this, an umbrella organization can be clearly distinguished as a centralized organization functioning for member groups, which are not autonomous or, necessarily, a part of the decision making process. Hansen (1986), however, discusses a democratic umbrella organization.

Vickers et al. (1993) also contribute to this understanding in their discussion of the National Action Committee on the Status of Women (NAC) as an “umbrella structure”

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<sup>14</sup> The CAS philosophy embraces the autonomy of local organizations (see Chapter 2).

founded by a “coalition of thirty odd member groups” (1993:4). While they do not state what an “umbrella structure” is, they see NAC as managing different coalitions. For the longest time, CAS did not play such a management role but I will argue that in certain spheres of activity it did represent organizations from across the country (most notably during negotiations around the National AIDS Strategy). Vickers et al. argue that “women’s movements in Canada have produced umbrella structures capable of aggregating most strains of feminism and representing their views to governments” (1993:71). The absence of sharp ideological differences allowed for this development. This might be argued to be the case for CAS in going before government as well as for umbrella structures more generally.

Maseko (1997:353, 358) argues that centralized organizations function in a distinct way to umbrella bodies. He argues that an umbrella organization needs strong structures affiliated with elites in order to exist. Within this context it then performs a coordinating function.

The sketchiness of this section is a reflection of the gap in the literature in this the most undertheorized of the three concepts which underpin my own research. No sharp distinction between coalition and umbrella structure is made in the literature: for example, Vickers et al. (1993) and Stathusen (1991) disagree on whether or not an agreed upon ideology is necessary for an umbrella structure, as it is for a coalition. This is a gap that I hope to fill to some degree, through application of the concepts *network*, *coalition* and *umbrella structure* to CAS; this will also allow me to theoretically develop these

concepts.<sup>15</sup> I believe that umbrella organizations are seen as more strongly and formally centralized than either networks or coalitions, with a far lesser degree of autonomy available to member organizations. I will show that this is not the form that CAS took, having deliberately chosen a decentralized ideology of autonomy for local organizations, with the benefits and drawbacks that this may bring for local groups and their clients.

### Insider/Outsider Groups<sup>16</sup>

The issue of insider/outsider groups is important within the social movement literature. Morris (1984) writes about different civil rights organizations playing off of one another's strengths and differences in order to move towards common goals (those that have access to elites working with those not bound by elite allegiances in any way, etc.). For the purposes of this section 'inside' can be taken as referring to groups who gain access to power and 'outside' to those who lack this access.<sup>17</sup> Barkan (1986), writing about internal conflict within the civil rights movement, also alludes to an outside, which was beneficial to the more conservative groups (who had access) as they pushed their claims from the inside. The threat of communist activity was used by conservative groups to gain the ear of those in power.

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<sup>15</sup> From this outline CAS would appear to fit much more within the definitions for networks and coalitions than with umbrella organizations. In interviews umbrella organization was a term that activists reacted against.

<sup>16</sup> Maxine Wolf of ACT UP/NY, an AIDS activist group based in New York, discusses the importance of insider and outsider groups explicitly at the ACT UP/NY website ([www.actupny.org](http://www.actupny.org)). Brunni (1997) writes about the use of threat by US AIDS groups to speed up the search for a cure. Some activists work with researchers on AIDS/HIV treatments (Wachter, 1991). These actors can essentially be seen to have moved from a position on the outside of the power structure, in opposition to pharmaceutical companies, to an inside position co-operating with the very companies they formerly protested against.

<sup>17</sup> This is perhaps a false dichotomy in that there are organizations which attempt to straddle the line between inside and outside, using both insider and outsider tactics.

Haines (1988) looks at positive and negative radical flank effects. Radical flank effects are the gains or losses felt by more moderate groups as a result of action by more militant ones. There is an obvious connection through this literature to coalition work, particularly because radical and moderate groups within the literature are clearly seen as working together and playing off one another in pursuit of common goals.<sup>18</sup>

### Motivation

Looking at sources of motivation aids understanding of why organizations choose to cooperate, particularly in initial mobilization. Motivation may help show why particular organizational forms were chosen in light of specific achievable goals.

Pinard's "comprehensive motivation model" (1983:31) is the most useful theoretical idea for understanding actor and group motivation. He argues that "an actor (or a group of actors) must be moved at the same time by *internal motives*, which can be thought of as the internal states or forces pushing the actor to action, and by *external incentives*, which represents the potential rewards "out there" pulling the actor into action, and finally by some *expectancy of success*, that is, "perceived expectations that the objectives pursued will actually be achieved" (Pinard, 1983:32). Internal motives come from ideal deprivations and ideologically articulated material, expressed as *relevant grievances*.<sup>19</sup> Aspirations can also be tied in to Pinard's model, playing a role in the motivations of actors and becoming more important with the move towards more routine or institutional forms of collective action. External incentives are also important and

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<sup>18</sup> Schneider (1992) discusses the importance of this within the AIDS literature.

necessary but not sufficient as motivation for action. Pinard argues finally that without the expectancy of some success actors and groups of actors would not be motivated to take action: this is a problem for an organization confronting long term unresolved problems, which must make gains to keep supporters from giving up.

Expanding Pinard's model, it is possible to say that groups would be motivated to join with one another by, say, use of shared resources (i.e. greater mobilizing potential), shared interests and goals. Expectancy of success could be created through a coalition or in a network, likely leading groups to work in union with others rather than alone, and could lead organizations to submit to an umbrella structure, if internal and external motives were also present.

Klandermans and Oegma discuss recruitment networks and show why individuals might join organizations, particularly because of kinship and friendship ties (1987). This might be extended to looking at why whole organizations unite. Motivation may be rooted in friendship networks, shared ideology, etc. (Staggenborg, 1986, Pinard, 1983). The benefits that groups accrue from being part of a larger network or coalition (or from adhering to an umbrella organization) are also dealt with to some extent within this theoretical concept.

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<sup>19</sup> From interviews, I understand AIDS activism in Canada to have originated within the grievances that the gay community had about lack of government action (which could be seen as a form of deprivation within this model).

## Identity

Identity is of core importance in the social movement literature on gay and lesbian organizations.<sup>20</sup> Given its role in the formation of many organizations it is also important in the formation of coalitions or networks. A number of authors highlight the contribution of identity to the stability and longevity of SMOs (Valocchi, 1999; Clemens, 1996; Stoecker, 1995). This can be connected to Kleidman's (1993) work in that coalitions have a perceived tension between national and local identities (cf. Oliver and Furman, 1989).

A key question is whether or not groups based on a particular identity are able to reach out to other populations and their organizations to form coalitions or create a network. In the case of AIDS, are predominantly gay groups able to reach out to women or intravenous drug users? Several social movement theorists note that identity is fluid within movements, open to change, and constantly negotiated (Gamson, 1995; Jordan, 1995; Stoecker, 1995; Friedman and McAdam, 1992). It may, therefore, be possible to see that a new identity, coming out of a common experience in relation to HIV/AIDS, actually became more important than the gay identity on which groups originally mobilized (for further discussion of AIDS organization identity see Gamson, 1989).

Jordan argues that "any experience that can be collectively articulated is a potential unifying force for a social movement" (1995:683-684). Identity talk affects activists' perceptions of social dramas as well as group and personal identity and can, in this regard, be tied to framing (Hunt and Benford, 1994). Changes in identity, seen above as positive (i.e. allowing for greater unification) also, however, may lead to the demise of SMOs

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<sup>20</sup> Lehr (1993) says that identity is key to AIDS Organizing--the starting point for most organizations. To what extent has it been important for CAS? This is the starting point for study of Canadian GSOs in my dissertation.

because of the strain resulting from constant negotiation (Stoecker, 1995). Identity questions are clearly important to coalition and, less so, network formation with either fluid identity or a clear identity around which organizations can rally playing a key role in unity between and within groups. This can also be tied to ideology, which comes out of gay identity within marginalized groups.

### Frames and Ideology

Frames are important to the extent that they can be used to unite organizations. Ideology is the more complex base from which frames can be developed (see Oliver and Johnstone, 2000). Stoecker (1995) identifies frames as the key issue in recruitment and also argues that frames can be generated by collective action. According to this argument, without a common frame or ideology there would be no coalition (Feree and Hess, 1994; Staggenborg, 1994). While it has a long history in social movement theory (Gamson et al., 1982; Snow and Benford, 1992), the framing works which appear to be most relevant here are recent (Tarrow, 1994; McAdam, McCarthy and Zald, 1996). Ideology runs deeper, informing thinking, reasoning, educating and socializing and may lead an organization to position itself in certain ways (Oliver and Johnstone, 2000).

Frames can be understood to be the “conscious strategic effort by groups of people to fashion shared understandings of the world and of themselves that legitimate and motivate collective action” (McAdam, McCarthy and Zald, 1996:6). Frames provide a common understanding on which groups can mobilize or coalitions can unite.

Carroll and Ratner (1996) explicitly discuss how common frames are used to build ties between diverse groups. Frames can be an important element in the networking



process. Master frames, they argue, allow heterogeneous groups to ally themselves with one another in political struggle. Given the importance already placed on coalition for social movement outcomes (Staggenborg, 1998), frames are an important mobilizing agent (Diani, 1995, Rosenthal et al., 1985, Zurcher and Curtis, 1973). However, frame disputes can split movements apart (Benford, 1993).

This is related to the emphasis on ideology in Staggenborg (1986) and Zurcher and Curtis (1973), to Gerhard and Rucht's (1992) discussion of culture, and to Rosenthal et al.'s (1985) argument that weak ties between organizations in a network allow ideas to be brought into the wider discourse. While emphasizing the importance of organizational determinants, Staggenborg (1986) considers that it is ideological conflict that is most likely to split apart coalitions between certain types of organization. Her emphasis on cultural components (1998) can be connected with this, with common culture bringing common understanding or a common frame within which to work.

Diani (1995) also considers the importance of frames with regard to networks. Framing (i.e. the way in which social movement organizations define themselves and their issues), he argues, will have a huge effect on the search for allies and the building of networks (Diani, 1995). For example, it would be problematic if similar ideas were framed in dissimilar ways as this would be a barrier to networking of information. In this regard, Benford (1993) writes about frame disputes and conflicts between alternative versions of reality. Organizations he studied had problems agreeing on how to resolve questions. The disputes that arise are about presenting a reality that will maximize mobilization. This raises questions as to how frames are developed and as to how disputes can be avoided.

Framing, therefore, is an essential component in the study of coalition building and networking among SMOs. According to the authors I discuss, the use of frames is central in bringing organizations, even movements, together. Ideology, in turn, is the foundation of this. Network building and the establishment of CAS as a coalition may be seen to depend on this framing issue.

### Success/Outcomes

A number of authors note the importance of coalition/interorganizational work for successful outcomes (Burstein et al., 1995, Steedly and Foley, 1979; see Schneider, 1992, on AIDS organizations in this regard). At the core of this research is Gamson's (1975) work, in which he argues that "it is useful to think of success as a set of outcomes" (28). He points to two measures of success: the group's acceptance by elites as a legitimate representative; and the distribution of new advantages to the group's beneficiaries (cf. Zald and McCarthy, 1987). In the case of coalitions the group's beneficiaries could be seen to be members of the coalition. According to Gamson there are four possible acceptance outcomes: at the constitutional level; into negotiations; formal recognition; inclusion (cf. insider/outsider status theories on access to elites). Advantages are measured as perceived by different actors involved in the situation and outside informers (e.g. historians; see Gamson, 1975:36). Gamson argues that a radical competitor may allow for acceptance of more moderate groups but will not lead to new advantages (cf. Haines, 1988, who surely sees the possibility of new advantages through this sort of work).

Steedly and Foley (1979) build on Gamson's work, arguing that the number of group alliances is the second most important predictor of movement outcomes (behind

target displacement, which if it is a goal is likely to lead to organization failure--a point that Gamson makes with regard to revolutionary groups). Groups which have help from outside organizations are more successful in achieving their goals. In relation to this, they argue that the more specific the goals the more likely an organization is to achieve them.

Burstein et al. (1995) also argue for the importance of interaction among SMOs (as well as with targets in the political context) for successful outcomes. Resources are key; outcomes are argued to be dependent on these and not on the characteristics of the organization. Essentially, Burstein et al. define success as the achievement of the movement's goals (i.e. its formally stated objectives). They note that "future research on movement outcomes should be designed to take into account the bargaining among SMOs, their targets and important organizations in the wider environment" (1995:295).

Outcomes, then, are closely related to alliances between SMOs and across movements and therefore intimately connected to coalitions and networks of organizations. Key to understanding their importance is the fact that they can be understood in terms of acceptance of organizations or in relation to the advantages that they are able to win. In my dissertation the focus on these allows for an examination of the consequences of different organizational forms of collective activity. A study of outcomes will allow for a better understanding of coalitions, networks, and umbrella organizations and their impact.

Overall this literature can be tied together under the research question of how and why SMOs work together--and what strengthens or weakens the ties between groups. I give a fuller summary of how this material connects with my current research and with AIDS Organization research generally in my discussion of work on AIDS.

## HIV/AIDS LITERATURE

There has now been a lot of work on the Sociology of HIV/AIDS and a number of studies on the different facets of the epidemic including the following: social movements (Schneider, 1992; Gamson, 1989); gender (Goldstein and Manlowe, 1997; Patton, 1994; Richardson, 1988; Kübler-Ross, 1987); epidemiology (see Hooper and Hamilton, 1999); medical aspects (Patton, 1990); medical sociology and the sociology of science/knowledge (Epstein, 1996); community organizing (Altman, 1994; Ariss, 1994); gay and lesbian identity (Roecker, 1998).<sup>21</sup> Much of this is informative, expanding on the social movement literature already discussed and developing an understanding of HIV/AIDS and of the contribution of my dissertation. To make this literature manageable and comprehensible I divide my discussion into several sections: a general one on the most informative work on AIDS and its impact throughout society; a section on AIDS social movement literature, directly tied to the above literature review; a section on community organizing, which is closely tied to SMO literature; and a section on AIDS in Canada. As Cohen and Elder (1989) note "since its discovery AIDS [is] as much a social phenomenon as a medical one"<sup>22</sup> and as such it has been widely written on, drawing on all aspects of human experience.

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<sup>21</sup> There is also, of course, a lot of popular literature on AIDS, not least And the Band Played On (discussed here). There are also several films (mainstream and independent), which have dealt with HIV/AIDS, and magazines devoted to a discussion of HIV/AIDS, most notably, POZ and Advocate.

<sup>22</sup> Epstein argues that the HIV thesis (that the human immunodeficiency virus leads to AIDS) is a social phenomenon, not just a scientific one (1996:92)

### General

A number of books attempt to give a general history of the progress of AIDS in the West.<sup>23</sup> One major focus is the spread of the disease, beginning with cases in certain African countries and from there moving out into the rest of the world. Randy Shilts' And The Band Played On (1987) is still the most informative attempt at a comprehensive history of AIDS and its effects, particularly in the US.<sup>24</sup> He also focuses on the gay community (at the time that the book was written the disease was still largely confined to big urban centers with significant gay populations). This is certainly the most established text on the gay community's reaction to AIDS and is a reference point for many others approaching the topic.<sup>25</sup> A recent addition to this literature is The River, an exhaustive epidemiological search for the source of HIV/AIDS. It remains to be seen how widely this book will be accepted.<sup>26</sup>

Works which have a more specific focus but also add fascinating and more up to date detail to Shilts' work abound within the sociological literature. Several are worthy of mention here and in the following sections.<sup>27</sup> Epstein presents a "study of how varied classes of AIDS experts, diverse conceptions of scientific practice, and distinct claims of knowledge about AIDS have all been generated out of relationships of cooperation and conflict in the US since the early 1980s" (1996:2). His argument that what is known about HIV/AIDS comes out of this mix makes much of the work of general interest in

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<sup>23</sup> For a summary of writing on AIDS in the developing World see Clelan and Ferry, 1995.

<sup>24</sup> For another general early history containing startling information see Black, 1986.

<sup>25</sup> One interviewee in my research noted the impact that it had on then Minister of Health Perrin Beatty.

<sup>26</sup> The author's controversial conclusion that AIDS is a result of a polio vaccine administered in the 1950s may make a lot of the research in the book undeservedly neglected. The detail of the research is, however, very impressive and the narrative thrust compelling (Hooper and Hamilton, 1999).

contributing to the understanding of social factors around HIV/AIDS, as science and politics interact and clash in the creation of knowledge.<sup>28</sup> Much of the work details activist intervention and raises questions about the importance of groups with both insider and outsider statuses.

Garfield (1994) attempts to summarize for the UK what Shiltz did writing about the US. Again, the author tells a compelling story and details the interaction between science, politics, activists, the entertainment industry and others.

Adam (1992) and Schneider (1992) both highlight important aspects of the study of HIV/AIDS. Adam, in particular, sets parameters within which the disease can be studied so that research can lead to a more effective understanding of AIDS and its social aspects.<sup>29</sup> Most importantly for the research that I am carrying out here, he states:

Social research and state and corporate responses still tend to lag behind initiatives taken by frontline AIDS workers and community-based organizations responding to immediate needs. Sociology may have a particular contribution to make in understanding the AIDS awareness movement. (Adam, 1992:14)

This ties together much of the initiative behind my research. A similar point is made by Schneider, in many ways the starting point for my study.<sup>30</sup> She argues that one of the best

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<sup>27</sup> Ulack and Skinner (1991) give a relatively early summary and collection of articles from the perspective of the social sciences. Pollak, Paichler and Perret (1992) look at AIDS as a problem for sociological research.

<sup>28</sup> For a concise summary of Epstein's work (and of recent literature on gay and lesbian activism) see Cook (1999:685-686).

<sup>29</sup> There are a number of important areas highlighted in these works which are not directly relevant to this research but which have informed my general approach to and reading of the literature. Adam proposes that AIDS research can give those who are HIV+ a voice by focusing on the following areas: 1. How AIDS information is produced and distributed. 2. How an AIDS folklore evolves and is integrated into everyday life. 3. How medical and social services are distributed. 4. How drug research, production and distribution are socially organized. 5. How the state responds to AIDS. 6. How people living with HIV infection respond to illness. While this dissertation does not directly take into account the position of PLWHIV/AIDS I have attempted to listen to those activists with whom I have conducted interviews and, as far as possible, to tell their story.

<sup>30</sup> But see also discussion of Handelman in the next section.

ways to look at different dynamics in response to AIDS is to look at the processes by which large urban AIDS organizations have confronted the disease. Are new organizations resistant to or encouraged by earlier organizations? Does competition help or hinder? This very much relates to examination of coalitions of SMOs.<sup>31</sup>

### Social Movements

Much of the literature on AIDS activism can be directly linked to the social movement literature already discussed. Coalitions, networks of organizations, identity questions, and framing are all discussed in the AIDS organization literature and are relevant to an understanding of HIV/AIDS in a social context and in my own work.

My own interest in AIDS activism was sparked by a Rolling Stone article on the AIDS Coalition To Unleash Power in New York (ACT UP/NY) and much of my early reading focused on this organization (Handelman, 1990).<sup>32</sup> from this article it was immediately apparent that this was a diverse, dynamic response to the epidemic. Through other reading it is clear that this was happening in separate demographic groups and classes, and to various degrees (cf. Cohen, 1998; Corea, 1992; Kübler-Ross, 1987).

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<sup>31</sup> Schneider also stresses that race, class and gender are determinants of much of the response to AIDS. Situating AIDS as a social issue compounded by other social problems is useful to an understanding of the wider relevance of HIV/AIDS disease. Cf. Perrow and Guillén: "Every major social problem is worsened by this epidemic" (1990:126). Altman (1994:76) says that in some cities AIDS is a disease defined by poverty and race.

<sup>32</sup> For a more personal perspective on activism see Kramer's Reports from the Holocaust: The Making of an AIDS Activist (1989). Kramer is, in many ways, the catalyst who led to the formation of ACT UP and an account of this is given here and in Handelman.

The most thorough social movement analysis of an ACT UP<sup>33</sup> group is Gamson's 1989 study of ACT UP/San Francisco. Gamson uses New Social Movement theory to discuss activism and the particular attempts of ACT UP/SF to get and keep AIDS on the political and public agendas (cf. Sheperd, 1997, who gives an oral history of AIDS activism in San Francisco). In dealing with a social movement organization in the political realm Gamson also touches on questions of identity and framing (related to identity in that it is how the group perceives and presents itself to wider society). Gamson's article most solidly points to analytical use of social movement theory to analyze the workings of an organization.

Perrow and Guillén (1990) discuss what they assess as the failure of AIDS organizations, specifically in New York but also in the US as a whole. They study several organizations formed in response to the failure of existing groups.<sup>34</sup> They point to the fact that the diversity of AIDS problems required a unified response, which again ties back to the idea of coalitions, either long or short term, and networks, which can provide a coordinated response.<sup>35</sup>

Writing about gay and lesbian organizing in response to HIV/AIDS Lehr says that affirmation of gay identity is the starting point for many organizations; it is important to fight stigma. She also argues that alliance formation is essential if AIDS is to be confronted effectively. Much of her discussion concerns identity issues for AIDS-related

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<sup>33</sup> Ariss (1994) writes about ACT UP/NY and the role that emotion plays in the group's activism, comparing its activism to two Australian groups. cf. Cohen (1998), who also discusses ACT UP and repercussions in detail but not from a social movement perspective.

<sup>34</sup> Among them the Gay Men's Health Crisis (GMHC), a precursor of ACT UP, a number of whose members, including Larry Kramer, came from GMHC.



organizations (1993), and she also points to dangers in focusing on identity formation: “identity politics emphasizes the formation of culture, which leads away from a focus on the strategies necessary to bring about change” (1993:248). Overall, the challenge is for diverse organizations from different communities to work together. The emphasis on gay identity may be a barrier to this in certain instances (cf. Gamson, 1989).

Social movement organizations are also the focus in Petchy et al. (1998), who write about the very different responses of two AIDS SMOs in separate US cities. They argue that the key variables in organization mobilization are prior social movement mobilization and the receptivity of the local health authority.<sup>36</sup> On prior organization, they write that the network that activists were able to build up was very important to the outcomes achieved by one umbrella organization. A large framework of relationships affected the alliances formed. While this dynamic is different on a city scale, as compared to the trans-Canadian relationships that I am looking at, I will show that personal contacts are also an important part of networking and coalition formation in the Canadian AIDS Society.

### Community Organizations

The literature on community organizations focuses on the efforts of local groups rather than on the ties with those outside specific communities, which is more the domain

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<sup>35</sup> Heiwa Loving provides a tree of all the organizations connected to ACT UP/NY. She shows a diverse network of AIDS organizations working on different problems towards a stated common goal: ending AIDS (1997:45). Lehr says that ACT UP was the model for many other groups (1993).

<sup>36</sup> It is interesting that they note that the role of the voluntary sector (and its size) has decreased in the area that they studied beginning in 1993-95. This decreasing role for community organizations is repeated in the interviews that I conducted for the second part of my research. Several respondents noted that there

of social movement theory. However, while the perspective and theoretical concerns of the studies are different many of the groups studied are SMOs. There are connections between the two literatures. A number of the ideas already discussed come up again in community organization literature.

Altman (1994) provides the fullest summary of community organization work on AIDS. In common with several of the other authors discussed, he points to the fact that the course of the disease is dictated by poverty levels, not by epidemiology. Its effects in the developing world are very different from those in the North. Altman argues that community control is a key issue in terms of "pace, shape and manner of change and decision-making" (1994:9). All of the organizations that he studies are closely tied to the communities most affected by the AIDS epidemic. He argues that community groups are human rights oriented and focused on 1) action against discrimination and 2) ensuring equal access to information, support and care (1994:18). Where gay movements are institutionalized there has been a better response from government. This can be connected to the theoretical literature on insider/outsider organizations in that organizations on the inside have different outcomes from those on the outside. Altman also points to the failure of extant national organizations as the catalyst for much of the activity by community-based organizations. Ultimately, "the community sector has been vital in helping create the social, political and cultural response to HIV/AIDS" (1994:157). According to Altman this grassroots response has been worldwide.

While Small argues that self help and community empowerment are important he states that alliances are also crucial (1997:16). However, in alliance formation and

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had been cutbacks and fewer staff employed now than was the case three or four years ago. This is an

coalition building there is the potential for clashes with identity politics. Small writes about white and gay/ black and gay identities as potential barriers to coalition. His question is whether or not being a person living with HIV/AIDS (PLWHIV/AIDS) can be a master status overcoming other identity questions. Does affirmation necessarily undermine affiliation (Small, 1997:18)? Small argues that the community based organization response to AIDS in Australia has been successful and that the most affected communities have been included.

Networking and partnerships between community organizations is something that Huber discusses in detail (1996). The organizations that he studies network through the sharing of print resources and medical information. He argues that one would expect organizations connected to an umbrella organization to share resources. This is relevant to CAS in that I expect groups to share information etc. without necessarily going through the central organization in Ottawa.

### AIDS in Canada

This is, perhaps, a peculiarly under-researched area and I build largely on the work of a few authors. Cain, alongside the authors in the previous section, writes about community based organizations, often in connection to the State. In one article he looks at the formalization/professionalization of organizations over time and asks what the political implications of this are (Cain, 1993). He sees AIDS Service Organizations' (ASOs) work as increasingly a partnership between the State, professionals, community organizations and PLWHIV/AIDS. According to his research, alternative services are consequently

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important area for further research.

becoming increasingly like conventional ones. Competition is also seen as a problem in that it dilutes the political effectiveness of organizations by diffusing their dissatisfaction: "Internal and external factors such as these can alter the ideological orientation of organizations, the types of services they offer, the kind of clientele they reach, and their ability to respond to changing community needs" (Cain, 1993:667). In a later paper, Cain further develops his argument that bureaucratization has left local Canadian organizations unresponsive to changes in their environment (1997:332). Networks are useful, although stronger organizations tend to benefit from weaker ones rather than vice versa. He argues that there is a risk that workers, not clients, will define which services are needed.<sup>37</sup> He concludes that "the relationships between organizational actors need to be managed as the network of HIV-related services becomes increasingly complex" (1997:341). These concerns and questions are directly relevant to my own research, particularly with regard to Canadian networks.<sup>38</sup>

Rayside and Lindquist (1992, 1992a) discuss AIDS in Canada in some depth in two separate articles. They look at the governmental response, or lack of it, to AIDS issues and the community response (focusing on Toronto, Vancouver and Montreal). Their history of community organizing and the state role is fairly comprehensive, although they perhaps fail to get to the guts of the response at local levels.<sup>39</sup> Roy examines AIDS Service Organizations (ASOs), including CAS, from the perspective of PLWHIV/AIDS.

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<sup>37</sup> This was expressed to me clearly in an interview with one local ASO worker, who stated that the local organization was dictating the services provided and that clients were not getting the services that they needed (interview, January, 2000).

<sup>38</sup> A further discussion of these topics (emphasizing the role of the State, which is beyond the scope of my own research) is found in Cain (1995).

<sup>39</sup> Kinsman (1997) also gives a broader perspective on the response to AIDS in Canada. I discuss his work more fully in the next chapter.

This is a detailed study of the emergence of a national PLWHIV/AIDS response to AIDS and I borrow from it throughout this dissertation.

Lavoie outlines the response in the city of Montreal, telling a story of conflict between organizations and the local government. This is an informative analysis of the tangled responses in one city. The story of AIDS activism in Montreal is marked by a number of splits between groups with language differences as well as ideological ones leading to the break-up of groups or formation of new organizations (Lavoie, 1998).<sup>40</sup>

The most dynamic Canadian city study is Brown's on responses to HIV/AIDS in Vancouver and the factors that influenced organizations' activism.<sup>41</sup> Using oral histories and interviews with activists, Brown focuses on "radical democratic citizenship" (1997:32) within the gay community, particularly ACT UP/Vancouver's role as an activist group that was able to go further than state funded organizations. This is a positive "radical flank effect" (Haines, 1988) in that radical actions by ACT UP led to government concessions towards more moderate groups. Brown notes, however, that for the most part "messy confrontations" do not suit the Canadian sensibility and posits this as the reason for the failure of ACT UP groups in Canada.<sup>42</sup>

### Summary

There are a number of recurring themes within the literature, which I have reviewed in the above two sections. There is a significant amount of overlap both within

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<sup>40</sup> Le Comité Sida Aide Montréal (C-SAM) is discussed further in Chapter 5. While it is of key importance in the history of the Montreal response to AIDS, it folded in 1994 (Lavoie, 1998).

<sup>41</sup> Brown is used in Chapter 5, when I discuss local organizing by general service organizations.

<sup>42</sup> Contradicting this, Nevitte (1999) collected data on protest campaigns by Canadians using World Values Surveys and found that Canada was actually one of the more protest prone countries.

and between the social movement literature and what I have termed the AIDS literature. Within this dissertation I specifically develop ideas about networks, coalitions and umbrella organizations, drawing widely from social movement literature. This is closely related to AIDS literature generally, which has a strong focus on the relationships among organizations (whatever form these may take).

## METHODS

I came to this research very much as an outsider to the groups that I studied and this is reflected in the research methods that I used, relying in particular on interviews with activists and on only limited document research.

Most of my data comes from interviews with key informants. Brown (1989) used leaders within an organization as informants and that is the method that I followed here, speaking with executive directors of organizations, with board members of CAS, and with long time local activists (many of whom had since gone on to other community based work or political work in other spheres). In the first round of interviews with those involved directly with CAS, I used a snowball sample. After getting the name of a CAS executive director and interviewing him, I asked him and subsequent respondents to give me the names of other people with whom they thought it would be useful for me to speak. After several interviews it became clear that the same activists were being mentioned again and again and they form the core of the sample (cf. Curtis and Zurcher, 1973, who used a similar method in building up a list of interviewees in their research). I conducted eleven interviews in this first round, ranging in length from forty five minutes to an hour and forty five minutes. Many of the questions related to the history of the Canadian AIDS Society

and were drawn directly from the theoretical background outlined within this chapter.

Some of the most important questions asked were as follows:

- How did the coalition of CAS member organizations come about?
- Are there any organizations that CAS is modeled on?
- What was the ideology behind the formation of CAS?
- Were members of CAS involved with other HIV/AIDS organizations?
- How does CAS measure success?
- Were all CAS member organizations in existence before joining CAS or did some groups form in response to CAS?
- Do/did CAS member organizations have anything in common other than their concern with AIDS?
- What role has gay identity played in CAS?
- In what ways has CAS changed from its original form/goals/mandate?

All of the questions were open ended and respondents, for the most part, were effusive and thoughtful in their responses.

In a second round of research, I looked at work at the local level and local organizational ties to CAS, using Roy's list of sixteen General Service Organizations (GSOs) (1995:98) in cities of more than 200,000 people to locate organizations. Roy establishes GSOs as groups providing a variety of services to the communities in which they are based and not, therefore, specialized organizations dealing with particular populations. I focused on these as a manageable subset of organizations<sup>43</sup> based on interviews with key informants.<sup>44</sup>

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<sup>43</sup> I made attempts to look at an individual organization or subset of smaller groups in depth. However, this was not possible, a fact I argue can likely be attributed to funding cutbacks faced by smaller groups (c.f. Armstrong and Juras, 1997:33: "Community-based HIV/AIDS organizations are suffering from fatigue. Constant under-funding and uncertainty about future funding has lead to tension between the need for advocacy to maintain existing levels of support, while at the same time coping with increasing demand for services").

<sup>44</sup> As such it is often incomplete with gaps in knowledge not able to be filled because of the lack of direct access to groups (the interviews being conducted by phone). Contact addresses were found for all but two of the groups and one group (the Comité Sida Aide Montréal – C-SAM) has ceased to exist. However, one group chose to fax information rather than allow an interview and one group responded cursorily to my request for an interview, giving only very general answers to my broadest questions. The interviews I did

There are a number of published studies of ASOs from which I have drawn some information, particularly for comparative purposes. Armstrong and Juras (1997) give a brief summary of AIDS community activism in Canada in their report to the United Nations. Armstrong is a former executive director of CAS and I quote him extensively throughout my dissertation. CAS itself conducted a survey of 63 member organizations and services in 1995/6 (Canadian AIDS Society, 1996): this provides useful general information on the activities of CAS member groups. Cain (1993, 1995) produced two documents on ASOs and also discusses the Comité Sida Aide Montréal (C-SAM) briefly (1995: 59-60): his interim report (1993) looks at three ASOs (including the AIDS Committee of Toronto (ACT) and the Hamilton AIDS Network (HANDS), where I gathered information for this chapter). Cain notes the lack of research in this area: "Despite their importance in the Canadian response to the HIV epidemic, AIDS Service Organizations have been the subject of relatively little systematic study" (1993:1). In Working Together he expands on this earlier work looking at 12 organizations (4 of which are GSOs -- the two discussed earlier and the AIDS Network of Edmonton (ANE) and AIDS Vancouver). Further information on AIDS Vancouver, where I was unable to conduct an interview, was provided in Brown's RePlacing Citizenship (1997), which is a detailed study of AIDS Activism in the Vancouver area.<sup>45</sup> These groups represent a "vibrant network of community based organizations [which] has grown to span the country from coast to coast" (Armstrong and Juras, 1997:26).

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conduct lasted between half and hour and an hour and a half. Information on C-SAM was gathered at the Archive Gai du Quebec in Montreal.

<sup>45</sup> This was also recommended to me by one of the members of staff at that organization.



I also carried out some documentary research. Access to most CAS documents was not possible because they are not organized or accessible to the public. I was, however, able to obtain access to Annual Reports for all of the years since CAS's incorporation. Two key strategic documents were also made available to me and were useful in establishing what CAS's overall goals were at specific points in time (the extent to which these goals were reached is harder to establish). The Archive Gai du Quebec provided detailed archival documentation on one Montreal CAS member organization, which is no longer active. I also reviewed *Globe and Mail* articles on CAS using the *Globe and Mail* index. Finally, the most complete AIDS library in North America is held by the AIDS Committee of Toronto (ACT) and I was able to review a lot of information there, particularly on ACT as a CAS member organization.

#### Plan of the Dissertation

The dissertation is organized as follows: Chapter 2 is a history of the Canadian AIDS Society in the context of AIDS in Canada up until 1998, when the most recent phase of the National AIDS Strategy was secured: Chapter 3 is an examination of CAS as network, coalition and umbrella organization and is an attempt to apply these concepts to the group throughout its history: Chapter 4 expands on this, looking at a number of other issues as they inform the major ideas of the previous chapter: Chapter 5 gives a general history of AIDS organizations at the local level and of their ongoing connection to CAS: Chapter 6 looks at the various issues raised in chapter 4 in relation to the local organizations. Finally, in conclusion I discuss the points that can be drawn out of this examination of the Canadian AIDS Society.

## **CHAPTER TWO**

### **A HISTORICAL SUMMARY OF THE CANADIAN AIDS SOCIETY**

**Mission statement of the Canadian AIDS Society:**

To fight AIDS by strengthening community-based efforts and by speaking as a national voice with the experience and resources of member organizations.

(from the opening page of ACTIONS/DIRECTIONS Conference Programme, AIDS Committee of Toronto, 1986)

Until 1988, the story of HIV/AIDS in Canada was very much one of neglect on the part of the government, leading to an increasingly concerted effort by local organizations frustrated by bureaucratic inactivity (Kinsman, 1997; Krever, 1997; Rayside and Lindquist, 1992a, 1992b; and Sears, 1991).<sup>1</sup> In this chapter I begin by summarizing the history of HIV/AIDS organizing in Canada before going on to focus in detail on the Canadian AIDS Society from 1985 to 1998.

### **A HISTORY OF AIDS ORGANIZING IN CANADA**

Kinsman (1997) presents the federal response to the AIDS epidemic as consisting of five stages, which will be apparent in the history that follows. These stages are: 1) In the early eighties the government basically ignored AIDS/HIV. 2) In the mid eighties some funding was allocated to community groups in the form of job-creation moneys and grants directly to community groups. There was, however, a basic hostility between these groups and then Health Minister Jake Epp. 3) There followed, with Perrin Beatty as Health Minister, a period of consultation and a focus among community groups on treatment-

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<sup>1</sup> Each of these authors highlight that government inaction was a direct catalyst for community action by different gay and lesbian communities across Canada. This has been true in other countries as well (Sandfort, 1998; Epstein, 1996; Gamson, 1990; Garfield, 1994; Shilts, 1987; Watney, 1987).

based activism, with community groups taking an active role in determining treatment for People Living With HIV/AIDS (PLWHIV/AIDS). 4) There was then a falling off of activism at the federal level and a corresponding cutback in Federal funding. 5) As a result of this there was a remobilization of AIDS organizations (Kinsman, 1997:217-220).

The Laboratory Centers for Disease Control's (LCDC) first reported AIDS case was in February 1982, shortly after the first cases were reported in the States (Shilts, 1987). Little attention was paid to this initial report. Only late in 1982 and early in 1983, when problems with the blood supply began to emerge, did the government begin to take notice. Concern was raised within the Canadian Hemophilia Society<sup>2</sup>, and a general sense of alarm intensified with increasing awareness of the deadliness of AIDS (Krever, 1997)<sup>3</sup>. The immediate response on the part of the government and the Red Cross, however, was to ask that "persons at high risk of contracting AIDS not donate blood" (Krever, 1997:xxi). This was perceived as a direct reference to homosexual males as is discussed more fully below.

Canadian gay and lesbian activism had displayed some strengths since the early seventies (Smith, 1998) so by the time that HIV/AIDS became prevalent in the early eighties there were already a large number of pre-existing organizations. By early 1983

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<sup>2</sup> Over the whole period of the blood scandal 47% of Canadian Hemophiliacs were infected with the AIDS virus (Farnworth, 1994). The scandal and its consequences are clearly summarized in the Krever Commission Report. The government was found to have failed to take action to protect the recipients of blood transfusions even after it recognized that the blood supply had been tainted with HIV (see also Kinsman, 1997). Only after 1985 was the risk through the blood supply greatly reduced.

<sup>3</sup> The Commission of Inquiry on the Blood System in Canada Final Report, 1997, (Canadian Government Publishing), chaired by Justice Horace Krever, is perhaps the clearest account of the early progress of AIDS/HIV in Canada. CAS became involved in the Inquiry seeing it as a chance to show the part that mobilization in the gay community played early in the epidemic. That the gay community could in no way be held responsible for the spread of the disease was one of CAS's main assertions (see Canadian AIDS Society Annual Report, 1993-1994). For a brief summary of the origins and findings of the Commission see Kinsman, 1997:319.

there were 25 reported AIDS cases in Canada. In April the AIDS Committee of Toronto (ACT) formed out of the gay community in Toronto, using job creation grants from the government to hire six staff. This was the clearest example of early gay activism around the AIDS issue in Canada (Rayside and Lindquist, 1992a). The Toronto gay community took action over the announcement that gay men with multiple partners would be excluded from giving blood. This response on the part of the gay community was prompted by the fear that all gay men would be viewed as AIDS carriers (Krever, 1997), resulting in increased stigma and exclusion. AIDS Vancouver also became active at this time (see chapter 5).<sup>4</sup>

ACT's main purpose was health promotion and most within the gay community across Canada advised that members not donate blood and take steps to protect themselves along health care lines. But the first pamphlets put out were about more than blood. In these pamphlets ACT took the somewhat controversial route of writing "frankly about gay sexuality and the particular sexual practices of gay men" (personal communication from Russell Armstrong, August 2000). The government made contact with members of the gay community after a preliminary list of key figures was drawn up.<sup>5</sup> However, a lot of this early relationship with the gay community seems to have been botched by the government and, more specifically, the Canadian Red Cross.<sup>6</sup>

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<sup>4</sup> Michael Brown discusses the history of AIDS organizing in Vancouver in *RePlacing Citizenship* (1997). In a personal communication with a member of AIDS Vancouver I was told that this was the best place to go for a detailed history of the organization.

<sup>5</sup> I understand that this was a list of suggested contacts to build up a relationship with the gay community in Toronto drawn up for the Red Cross

<sup>6</sup> The Krever Commission report noted that there was a failure to take the needs and demands of the gay community seriously into account (Krever, 1997:252). The gay community was effectively excluded, leading to fears that all gay men would be seen as carriers (or potential carriers) of the AIDS Virus. It was only in July of 1983 that the gay community was formally approached (Krever, 1997).

The importance of the gay community providing information to its members throughout this period cannot be overestimated. As Rayside and Lindquist (1992a:37) note, "AIDS...mobilized gay communities in an unprecedented way." Internal networks, external allies, and community consciousness, which already existed within the gay community, were vital to this mobilization. The importance of this for the success of AIDS/HIV organizations has been written about elsewhere<sup>7</sup> and is certainly important here, as will be evidenced in my discussion of CAS's history.

According to the Krever Commission Inquiry, the Federal and Provincial response continued to be disappointing. Most of the Provinces were reluctant to give support to active gay groups because of their sexual orientation (the major exceptions to this appear to be Manitoba and Ontario; Quebec<sup>8</sup> in particular and the other Provinces generally seem to have assumed that existing health policy would be adequate).<sup>9</sup> Sears (1991) argues that the government response was "fragmented and lacking direction" (42) from 1981-85, the year that initial overtures about the formation of CAS were made. This precipitated a growing challenge to the ideology of expertise (Sears, 1991). The lack of government action allowed AIDS community activists (alongside their allies) to become established as the real experts from an early stage (Rayside and Lindquist, 1992a).<sup>10</sup>

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<sup>7</sup> For further information on and examples of the importance of prior organization for AIDS activism see Sandfort, 1998; Patton, 1994; and Schneider, 1992.

<sup>8</sup> Lavoie, 1998, discusses the community response in Quebec in some detail.

<sup>9</sup> The decentralized political system in Canada in part explains the highly uneven response to the epidemic. Conservative moralism in Quebec and elsewhere was a big factor in the initial slowness of the response to HIV/AIDS (Rayside and Lindquist, 1992a).

<sup>10</sup> For an informative popular description of this process in the AIDS Coalition to Unleash Power (ACT UP) see Handelman's article in *Rolling Stone*, May, 1990. Epstein gives a more general description of this process throughout the US (1996:350-353). This is also touched on in the film *Longtime Companion* (dir. Norman René, 1990), to my mind still the best recounting of the initial impact of AIDS/HIV in the US.

Until 1985 federal and provincial government believed that existing health care practices would cope with the problem. This led to later accusations of homophobia: that the government (intentionally, unintentionally) misunderstood the magnitude of the HIV/AIDS problem, which was affecting a relatively small and undesirable part of the Canadian population (a personal communication from Russell Armstrong, August 2000, clarified this point). As a result more and more community groups formed and it was clear to those most affected by the disease that the gay community was creating and providing a more effective response to the epidemic than any government agency (Kinsman, 1997). Government funding did help, however. In 1985 funding from the federal government was made more widely available to community groups and it was out of a meeting of a number of representatives from these groups that the Canadian AIDS Society began to take shape. Activists took the lead coordinating a nationwide effort.

Thus government inactivity precipitated community activity. Without an effective response on the part of the government the most affected community needed to take action. The pre-existing network of gay and lesbian organizations was also vital to the speed of the community response to AIDS. These themes are apparent in the story of the Canadian AIDS Society and perhaps became more relevant with the attempt by CAS to offer a national response with repercussions throughout local and provincial activism.

## A BRIEF HISTORY OF THE CANADIAN AIDS SOCIETY

Much of the information on the formation of CAS and its early activity was gathered in the interviews I conducted.<sup>11</sup> My intention here, drawing from these interviews, is to present an account of CAS as it developed into a complex national bureaucratic<sup>12</sup> organization. I provide a historical context for discussion of the formation and history of CAS as a network, a coalition and an umbrella organization and the consequences of this in subsequent chapters.

There appear to be few academic articles on the Canadian AIDS Society and it was not possible to gather much historical information from previously published material. The key exception to this is Roy's study of the involvement of Persons Having AIDS (PHAs) in organizations across Canada (Roy, 1995). Roy gives useful information on CAS's organizational structure, dividing the different member organizations into several categories. Rayside and Lindquist (1992a; 1992b) also provide insight into AIDS organizing in Canada and into CAS's role within this. Cain (1995a) produced a report, which includes some CAS member organizations, for Health and Welfare Canada.<sup>13</sup>

I see CAS's story as falling into three distinct phases. First there is the period in which the organization was formed and became active prior to its incorporation and

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<sup>11</sup> There is limited documentation available and access was difficult. In personal communication with CAS staff it became clear that documents were not organized or catalogued and that I could not access them. I therefore rely on detailed interviews with supplementary information from Roy, 1995, the ACT Library in Toronto, and CAS Annual Reports.

<sup>12</sup> While many activists use this term negatively (personal communication with Joan Anderson, December 1999) it is here intended to indicate more systematic administration on the part of the organization as it developed a sophisticated structure. Gamson (1975) utilizes the term to describe organizations which have several levels of leadership, member lists, and documentation of the structure of the organization (Zald and McCarthy, 1987:162).

<sup>13</sup> Further information on AIDS organizing more generally in Canada can be found in Roy Cain's published work (Cain, 1997; 1995; 1994; 1993) and in Kinsman's (1997) article on government attempts at control of local organizations through the National AIDS Strategy.

achievement of charitable organization status. The broad goals of CAS became apparent as the group moved forward in a relatively unsophisticated way, acting as a network in which individuals called upon other individuals (rather than the organization) for information.<sup>14</sup> Second, following incorporation there was a great deal of development within CAS as staff were hired (a process of ongoing expansion until very recently). The organization as a whole became a lot more politically sophisticated (a process that had, of course, begun earlier), meeting government leaders and others on their own terms. CAS came into its own as a nationally representative voice for AIDS Service Organizations (ASOs) across Canada. This is a complex period in which CAS is best understood as a coalition of organizations with some ongoing network features; face to face contact ceased to be the norm, being replaced by a more formalized structure. Third, CAS stabilized as the leading national AIDS organization and, with the government adoption of the National AIDS strategy as an ongoing funded program after 1998, it may well change the scope of its activity beyond negotiations around the National AIDS Strategy. A lot of those currently involved in CAS are more oriented towards management and related skills than were the AIDS activists of the previous generation of organizers.<sup>15</sup> These developments are beyond the scope of this current research but may be important in relation to developing social movement theory on generations or waves of activism, changing relations with the state and the like (cf. Staggenborg, 1988).

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<sup>14</sup> These goals are clear from interviews. There was a common set of objectives articulated by all activists discussing this period.

<sup>15</sup> This was a common theme in a number of the interviews with early activists, discussed in more detail below. This stage of development for CAS was characterized in quotations such as the following, from a former CAS employee: "In the initial years I don't think people were doing it for the money. I think things have changed. Now people are looking at AIDS work as '...this would be a wonderful place to work and I'll get paid to do the same thing!'" (personal interview, 1999).



I discuss each of the first two phases in the development of the organization in detail and then briefly consider what seems to be happening with the organization in the third phase that I have identified. This fits with Kinsman's (1997) summary of the five stages of the relationship with the federal government: Kinsman's first two stages correspond to the period of CAS's formation, prior to incorporation; his third stage corresponds to when CAS incorporated and took a more active role in national level responses to AIDS; Kinsman's stage 4 is formalization, which continues into his stage 5, when CAS again actively campaigned for renewal of the National AIDS Strategy. While each stage of evolution is distinct it is also clear that developments are continuous, with no radical change in CAS goals or ideals. As I discuss in the next chapter, there is a great deal of overlap between the three main concepts that I use and this is also true of the structure of the phases of development outlined here.

#### Formation and pre-incorporation

The first national AIDS Conference in Canada was held in May of 1985 in Montreal (Rayside and Lindquist, 1992a), initiated by Richard Burzynski, an activist from Montreal, who sought Federal funding to facilitate early meetings: "The aim was in some way to coordinate a number of different approaches - sharing information and articulating some kind of agenda of approaching the federal government to coordinate a way. The important thing was having a national voice" (interview with Richard Burzynski, March, 1999). One of the interviewees noted, and this is key, that early meetings and the subsequent formation of CAS were only possible because of "the good graces of the federal government and Health Canada allowing us to hold meetings" (interview with

Michael Sobota, March 1999).<sup>16</sup> There was also provincial funding and support for some of the early board meetings. While this initial Montreal meeting did not in itself lead to a lot of concrete action, conference attendees recognized that something needed to be done, even though they were not able to identify what this would be:

There were a dozen or fifteen of us that were there. At that meeting we discussed wanting to form some kind of network and probably some kind of organization. But without knowing what that would be and how we could make that happen. And we also talked a fair bit about needing to push to get new groups started in some major cities in the country.

(interview with Michael Phair, April 1999)

Although Rayside and Lindquist say that CAS formed out of this meeting it seems from interviews and quotations such as the one above that actually a more informal network of activists, who maintained contact throughout the coming year, was its most concrete result. A steering committee was formed, which met throughout the year and dealt with many of the ongoing questions that had been raised at the initial meeting. However,

In my mind, that meeting was the genesis of what became the national organization, although we did not call it that, I don't think, at the time. Nor did we know how it was going to function or operate. Different people were asked to volunteer to do different kind of things in the interim. For the next number of months and I would say that very little of that got done.

(interview with Michael Phair, April 1999)

As the above quotation shows, this was the beginning of a dialogue, which led to a second national conference in Toronto in 1986, ACTIONS/DIRECTIONS, and the formation of CAS proper, although it would be two more years before it was incorporated (and was

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<sup>16</sup> This federal funding and its centrality has already been noted in connection to the formation of ACT (Rayside and Lindquist, 1992b) and was important in 1985 when it was offered to already extant groups (Krever, 1997). Local organizations seem to have waited for or needed (or perceived the need for) core federal funding in order to establish themselves within their communities. One local executive director said, "It's important to have a charitable tax number so you can raise money to do the work you do and also we had to be incorporated to receive funding from the government." (Interview, March 1999). Russell Armstrong said that "...advocacy was required to obtain that investment. It seems to be the Canadian way

eligible to receive core federal funding<sup>17</sup>). ACTIONS/DIRECTIONS had a number of general education sessions on aspects of HIV and AIDS. It was also the first national meeting of CAS delegates from community ASOs across the country (AIDS Committee of Toronto, 1986).

The founding members of CAS, all of whom were present at this conference, are listed in the CAS constitution (Canadian AIDS Society, 1990a:1) as follows:

Newfoundland and Labrador AIDS Association; Metro Area Committee on AIDS (Halifax); Comité Sida Aide Montréal (C-SAM); AIDS Committee of Ottawa; The Kingston AIDS Project; AIDS Committee of Toronto; AIDS Committee of Windsor; AIDS Committee of Thunder Bay; AIDS Committee of London; Winnipeg Gay Community Health Centre Inc.; AIDS Regina Inc.; AIDS Saskatoon; AIDS Calgary Awareness Association; AIDS Network of Edmonton; AIDS Vancouver; AIDS Vancouver Island. A board was also formed at this meeting, with Michael Phair, an activist from Edmonton, as the first chair. In this period there seems to have been a significant amount of sharing of information between groups, something which became increasingly formalized with CAS's development. Michael Sobota, the executive director of the AIDS Committee of Thunder Bay at the time and attendee at the inaugural meeting, said that his group borrowed models of organizational structure and AIDS information

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to go for public funding because, so often, it is available." This is an interesting point for comparison with organizations in the US, which raised funds privately.

<sup>17</sup> The perceived necessity of federal funding in order to get the organization going is interesting. The role of funding in CAS's subsequent history is clear. At this point in time it enabled face to face meetings. It was seen as vital that organization leaders and members from across the country meet with one another: while there was no core federal funding, activists were able to make Federal travel expense claims, which allowed them to travel and meet with one another several times a year. Local organizations also saw incorporation as significant (local executive director interview, November 1999) because of the charitable status and the ability to apply for grants that this brought. With an ever-increasing number of groups

distribution from the AIDS Committee of Toronto. A network had been in existence at least since 1985<sup>18</sup> and this aspect continued with CAS's formation and was of primary importance for some groups (interview with early local organization member, April 1999). In this regard, the Ontario AIDS Network (OAN), formed in 1985, was something of a parallel organization to CAS, although very early on the relationship appears to have become symbiotic, with each group exchanging ideas and information with the other:

So Ontario was already organizing itself provincially and it would serve as a model for other provinces as we evolved. But that was critical to the Canadian AIDS Society because the Ontario groups as they proceeded to evolve strongly, were the strong membership of the Canadian AIDS Society. Ontario had a very strong role and was highly represented on that first CAS board.

(interview with Michael Sobota, March, 1999)

Many OAN member organizations were also CAS members and this overlap was significant to the burgeoning AIDS scene in Canada.<sup>19</sup> Individuals, when they did so, connected informally rather than as formal representatives of groups

Ontario groups (particularly Toronto) were important but there were also individuals from Montreal, Vancouver, Edmonton, who were playing a significant role in CAS's formation. It was Richard Burzynski, a member of the Comité Sida Aide Montréal (C-SAM), who made the initial and subsequent applications for federal funding for the AIDS Conferences and who went on to become CAS's first Executive Director in 1988. Michael Phair, now a city councilor in Edmonton (then the first elected chair of the CAS board), was also a key figure, highly praised as central to CAS's formation by many

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throughout much of the period that I am studying this also foreshadows future conflict over somewhat limited resources.

<sup>18</sup> From the review of the history of AIDS in Canada it is certain that there was at least an informal network in place. Executive Directors were talking with one another and sharing information and the Ontario AIDS Network (OAN), as discussed in the body of the chapter, was acting more formally.

interviewees. From this early stage, then, CAS was trans-Canadian, although very much focused on the larger urban centers in the early years.<sup>20</sup> There was, however, a conscious effort to garner the opinion of members from smaller towns (e.g., Thunder Bay, Kingston). The board was very aware of the potential division between the larger and smaller locations and did attempt to preempt conflict. Much of the groundwork for this was carried out by the Ontario AIDS Network (OAN), which, according to Michael Sobota, tied together almost all of the Ontario groups. The Ontario groups were, therefore, already very much embedded in a network, while other provinces, particularly Quebec, were in some ways marginalized. The Atlantic AIDS Network (AAN), which was formed in the mid nineties, was also important in connecting groups with one another and CAS representatives attended AAN meetings.

The motivation for the formation of CAS came from the fact that activists felt that too little was being done elsewhere and if gay men (the most affected and infected population) did not stand up for themselves then no one else would. As an organizer involved in gay and lesbian rights activism since the seventies noted:

I've gradually, since 1980, been involved in leadership in one form or another in the gay lesbian and bisexual communities here in town as well as provincially through the coalition for Lesbian and Gay Rights in Ontario. So this responding to the epidemic was a natural extension of that kind of liberation work.

(interview, March 1999)

Indeed, an important part of the early work was just to get the word 'gay' on the agenda; speaking about the Toronto meeting, Michael Phair, prominent in CAS's formation and as

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<sup>19</sup> For further discussion of overlapping networks see Carroll and Rainer, 1996; Feree and Hess, 1994; Phillips, 1991; Staggenborg, 1986; Galaskiewicz and Marsden, 1978.

<sup>20</sup> The geography of Canada has a part in all of this. Many groups are physically isolated from one another and it is only in the larger urban centers that several groups have been able to co-exist. Further Federal cutbacks will likely set even this back (see also Roy, 1995)

its first chair, said, "I think we finally got a session that had the word 'gay' in the title" (interview, April, 1999).

This period is marked by the fact that it was difficult to form constructive relations with the federal government, particularly while Jake Epp was the Minister of Health. A number of respondents spoke about meetings with him and about his subsequent burning in effigy following a 1988 conference. This was the most widely reported action<sup>21</sup> in this early period. A prior meeting with Jake Epp is described in the following quotation:

And in fact I sat on the program organizing committee. I went out to Ottawa on a couple of occasions to meet at the public health organization offices where we had these meetings representing Canadian AIDS Society and then I also managed to meet with some federal and other people at the same time for planning and organizing that conference.

We also set in motion a meeting with Jake Epp, who was the minister [of Health] at the time, who was not eager to meet with us and certainly at that time did not want anything to do with AIDS and didn't think it was anything they should be touching with a ten foot pole. In the end, with the assistance of Health and Welfare and I believe with Canadian Public Health kind of pushing on the side, we did manage to set up a meeting with Jake Epp, where we could talk about what we saw going on and what kind of support there needed to be from the Federal government for community based initiatives around HIV.

And again there were three or four of us from the Canadian AIDS Society that attended. Actually there might have been 6 or 7 of us--a number of people attended...As part of it we brought along some condoms. And you have to remember that these were the days before people knew what condoms were essentially in this country. I mean, quite frankly, it's hard to believe today. But at that time no-one talked about condom-safe--it was just unheard of virtually. And we brought along a number of them and threw them on the table and he almost backed away from it. It was obvious that he was just very uptight about all of this and we're talking about taking men's penises and putting them in buttholes and etc. I mean we were that kind of thing. And there needed to be public education and bla bla bla bla. And that there needed to be financial resources for public education across the country. And money for community organizations. And we were starting to talk about there needed to be a National AIDS Strategy to address what was happening on a variety of kind of levels. Although he didn't say a whole lot, we

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<sup>21</sup> This was initiated by AIDS ACTION NOW! (AAN!) and CAS gave the demonstration at the AIDS Conference in Toronto its support after the plan had been formulated (personal communication with board member, December, 1999).

were more pushing for the Canadian AIDS Society specifically that time. It was an interesting meeting.<sup>22</sup>

When I think back I think, Oh my God, I can't believe it. I don't think we accomplished anything very specific or a great deal other than we were able to say we had a meeting with him and get him to realize there were people talking and concerned about it. I think from a bureaucratic perspective that that was useful. That there were some people in his administration that were concerned and interested in the area and were trying to push to get some things done and from that perspective it was useful.

(interview with Michael Phair, April 1999)

Another activist noted that Epp's chief of staff said in a meeting, "My constituents won't go for us funding gay groups" (personal communication with activist, December, 1999).

Government homophobia was clearly present. These incidents show how much things have changed.

Throughout this period (again prior to the hiring of the first staff) the board was responsible for all CAS contact throughout the provinces, which meant essentially that individuals and not organizations were the point of contact: "So what I remember from the early years of CAS is connecting with people. I don't remember connecting with 'the organization'" (interview with long time local organizer, April 1999). This reinforces the idea that it was a network of individuals becoming aware of and subsequently contacting one another. It is not clear from interviews how newer organizations found out about CAS (there were over 50 member organizations by 1988). It appears that organizations either went to the federal government for information and were then directed to a CAS board member or that smaller groups heard about larger organizations working in their area and went to them for information. There does not seem to be a whole lot of evidence of CAS encouraging the formation of local groups, although this is alluded to above and Michael

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<sup>22</sup> A lot of the developing CAS agenda, and the work that they went on to do in subsequent years was summed up in this meeting.

Phair was responsible for helping establish groups in Calgary and Regina through personal contacts that he had in these towns. It is clear, however, that CAS did try and 'recruit' AIDS Service Organizations (ASOs). A letter to "Community organizations working in AIDS/HIV who are not already members of the Canadian AIDS Society" (Canadian AIDS Society, 1993) from the National Programmes Director invited organizations (based on information sent out earlier) to join CAS for a membership fee of 0.2% of their budget (a minimum of \$100 and maximum of \$4,000). Richard Burzynski also worked to get federal support for local organizations before the National AIDS Strategy was in place. The OAN, which was meeting quarterly at this time, informed its new member organizations of CAS and most of the Ontario groups belonged to both. Ontario also had a head start because of the history of struggle for gay liberation, which had been heightened in the early 1980s (around the issue of Bathhouses in 1981; the invasion of the offices of "Body Politic" magazine in 1983); groups had mobilized before AIDS, providing a pre-existing organizational base for the movement.

The board, from its first election, met in different cities across the country in a deliberate attempt to get to know people and to be known at the local level, thus consolidating the network through important face to face contact (interview with Michael Phair, April 1999). This worked with varying degrees of success but overall helped to establish CAS as a national organization and as a credible voice in AIDS-related issues.

The other ongoing significant forum for member groups to voice their opinions are the Annual General Meetings (AGMs). This is also where the CAS board is elected by the membership present at the meetings. AGMs were often emphasized in interviews as the key forum for (local) member groups to meet as equals (see chapter 3). Prior to 1988 they



were important for the election of the board and for policy decision-making. The need to respect the autonomy of local organizations was recognized early on. This was particularly evident from an incident when the board met in Vancouver, which was experiencing a split between the conservative AIDS organization and its PHA (Persons Having AIDS) members, who soon formed the first PLWHIV/AIDS group in Canada. Kevin Brown, who shortly after became a member of the CAS board, was the founder of this organization.

The difficulties that CAS faced in this encounter are best summarized in the following quotations from Michael Sobota and Michael Phair, who discuss the same meeting:

There were some difficulties going on in Vancouver internally when we met there. Some of us wanted to be interveners and throw our weight around and fix things. Others argued that, no that's not our role we must be very respectful of member organizations and never intrude on what's going on internally. So there would be quite a bit of time taken up in discussion on the board about what is legitimately our role because we all came from the background of advocacy and if we thought someone was being treated inappropriately we wanted to jump in and yell about that. We were activists. And we were slowly beginning to learn and slowly beginning to get our political maturity that that's not the way to treat member organizations. You need to be more respectful of their own internal processes even if we believed that they were doing things that we didn't approve of. It wasn't our right to dictate to them. That was hard. That was very hard in those early years to respect that and to let local issues be solved locally. We felt we were the vessels of some wisdom and either vainly or foolishly [laughs] we wanted to impart that wisdom as we moved around.

(interview with Michael Sobota, April 1999).

The board was unable to gain access to the room where meetings were to be held, which was indicative of the splits within the community. No one showed up from the central organization to open the building. As Michael Phair explained,

I knew as the board chair in trying to get this organized out there and the room and where and all the rest that things were amiss because I was having a terrible time getting it organized. In fact, when I got there the place was locked and we couldn't get in. There I am from Edmonton in Vancouver. After finding a couple of others we can't get in nor do we know how to get a hold of anybody to let us

into this place. I mean it was just a nightmare from the beginning in that regard. So then instead of being able to try and have our meeting we've got all these other people and groups who have shown up and present their case and tell us that we should be doing something about the other groups. By this point there were three groups. There was the group that was technically still in power, there was a new grassroots group of folks that were trying to throw them out, and then there was the PWA group. So we as a board really accomplished nothing for the organization that weekend and we certainly accomplished absolutely nothing with the Vancouver groups.

(interview with Michael Phair, April 1999)

The completion of CAS's formalization as an organization came with its incorporation and the hiring of the first three staff: Richard Burzynski as ED, a secretary, and Grant McNeil as administrative assistant. They were hired by the board and quickly established themselves as important to CAS's development.

#### Incorporation and subsequent history

The incorporation of the organization and the hiring of these first staff occurred along with a growing political sophistication within CAS. This is perhaps best illustrated in two separate stories of political organizing around the time of CAS's incorporation. The first story deals with an event prior to incorporation, sometime in 1987:

I remember the board of CAS...We had organized a lobbying day in Ottawa. We were going to hold an annual general meeting of the Canadian AIDS Society and bring representatives of our members there one day in advance so we could lobby members of parliament. Well we weren't very good at our own strategy. We thought this was a good thing to do but we neglected to check calendars etc. and schedules and dates and times and this whole event happens when parliament was not in session. So most MPs were not in Ottawa. Very few were. We held this kind of elaborate wine and cheese social party and invited every member of parliament to come. I think we got a couple of federal bureaucrats. I don't think we got one single MP present at our wine and cheese where we were attempting to raise our own profile and make ourselves known...because of our own bad planning.

(interview with Michael Sobota, March, 1999)

This second quotation deals with an incident two years later in 1989.

My strongest memory of that kind of networking had to do with deliberate, very careful lobbying of Health Canada. My sense was that with Richard Burzynski and Joan Anderson's leadership, CAS did a very sophisticated job of that at that point. One board meeting we came to Ottawa. There was a reception at the opening of an arts show. But before we as board members went to the reception Richard and Joan reviewed with us all of the invited guests, which included a wide variety of government bureaucrats, some politicians and other national organizations like the Canadian Hemophilia Society and other national coalitions like that. They went down the list of the guests and who they were and named messages that would be valuable for us to convey or reinforce if we happened to be talking to any of the guests that were invited and that's the most elaborate kind of strategizing around lobbying that I had ever seen to that date.<sup>23</sup>

(interview with key early CAS board member, March, 1999)

CAS members clearly started out as novices in terms of their knowledge of how Ottawa worked. They did, however, learn from their mistakes, which accounts for the difference in sophistication between the two incidents. Political progress came around the appointment of Perrin Beatty as the Minister of Health in 1988. His appointment resulted in much smoother relations with the government,<sup>24</sup> which several respondents argued was personality based. As the key activist quoted above said, "I'm convinced that personalities are crucial in all of this" (March, 1999) Another interviewee even pointed out that after Beatty's appointment the new minister read And The Band Played On<sup>25</sup> and believed that this was at least in part responsible for his more favorable disposition towards CAS. By this stage "[w]e had a working relationship with the minister of Health, Perrin Beatty, and

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<sup>23</sup> For similar examples of this kind of sophisticated lobbying in the US see Sheperd, 1997; Epstein, 1996; Wachter, 1991; Handelman, 1990; and Shilts, 1987.

<sup>24</sup> This assessment finds some support in Kinsman (1997:217). He states that "...the emergence of a new treatment based activism, which gained wide support among the community-based groups, forced Beatty to take up a new orientation when he became health minister in 1988...based on a conceptualization of "partnership" with community-based groups and represent[ing] at least a partial and limited break with past policies in recognizing some of the treatment-information concerns of PLWA/HIVs."

<sup>25</sup> Randy Shilts' popular history of AIDS organizing in the US, And the Band Played On was also turned into a film by HBO (dir. Roger Spottiswoode). It gives a broad strokes history of the progress of AIDS in the US and even features a sociologist in a somewhat prominent role as a member of an epidemiology team.

we had established ourselves on Parliament Hill as a credible organization.” (interview with a prominent activist and early board member, March 1999).

Progress was made at the national level, with CAS becoming more and more of an insider organization. By this, I do not mean to imply that it was in any way co-opted, only that it was increasingly seen by the government as a legitimate organization, which at least had the ear of those in power. This status came from increased political awareness and government funding. There was also growing political sophistication at a local level, which CAS fostered and helped develop through “Advocacy Packs” and other materials, which showed how best to approach MPs and local political figures.<sup>26</sup> CAS also had forms which organizations used to give feedback to the central office, which could then keep track of political organizing at the local level. This sort of work can be seen in the following quotation from one of the local executive directors (my questions are in bold):

So Charles Roy, who’s now an ED of ACT...he and I were [CAS] partners and I remember him coming to London and we were supposed to meet with Chrétien—it was during election year. And we met with one of his bureaucrats instead, which is typical isn’t it? But putting the information forward that we wanted and making him sit there and listen to us for half an hour when he said he only had ten minutes. So we did that kind of stuff and then lobbying among our MPs we did a lot of that. **And that was all encouraged by CAS?**

Oh absolutely.

**And they also provided information in terms of how to do that?**

They had and still have a fabulous binder on how to meet your MP and how to put your issues forward and then a report that you send back to them. So that they can keep a tally on it.

(interview with Executive Director of an organization in a medium-sized city and CAS board member, February, 1999)

As a result of all this activity, CAS was able to move from being what Michael Sobota describes as “new kid on the block” to a national voice representative of over 100

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<sup>26</sup> The extent to which these have been used by groups throughout the country is not clear from current research, although they have been important for organizations in certain instances.

autonomous local organizations. Alliances were also built with other organizations concerned with AIDS, most notably the Canadian Hemophilia Society (CHS). Prior to the Krever Commission report on the tainted blood scandal, CAS argued that there should be no special cases and no compensation for hemophiliacs who had been infected during blood transfusions. There was fear that compensation for some but not all PLWHIV/AIDS would represent a distinction between innocent and guilty PLWHIV/AIDS. Support for compensation was only given after the findings of the Krever Commission pointed to negligence on the part of the government. One interviewee regarded the earlier position as a mistake: “ [I]n retrospect, I don’t think that that’s a position that we should be proud of” (interview with key activist, March, 1999). However, another activist pointed out that pushing this issue raised the need for sensitivity on public announcements and Beatty and the CHS responded to this. In return CAS agreed not to attack the decision to compensate (personal communication with activist, February 1999). There were other issues of conflict with the Hemophilia Society, most notably on questions of gay identity and language issues around sexuality and, again, the notion of innocent and guilty PHAs. This was a distinction that was made by CHS and the term “innocent victims” was used (personal communication with activist, February, 1999). The working relationship between CAS and CHS seems to have grown healthier in pursuit of a National AIDS Strategy and subsequent renewals of the strategy, however little it may touch on the actions of local organizations.

One other significant area of conflict that it was historically important for the Canadian AIDS Society to resolve was the involvement of PHAs within CAS. This is

discussed in some detail in Roy (1995).<sup>27</sup> However, it is important to note several things embodied in CAS's constitution (Canadian AIDS Society, 1990a). There was one designated seat on the board of directors for a PHA from 1988 onwards. PHAs became more and more visibly involved and meetings were held for PHAs prior to the Annual General Meetings (AGMs) starting in 1991. At the 1990 AGM in Winnipeg it was decided that there would be a representative number of board members who were PHAs (Roy, 1995). For each of the five regions into which CAS divided the country there was to be one board member who was a PHA and one whose status was unknown. This policy has continued into the present period and may well have averted a split within CAS. The inclusion of PHAs has meant that they were unable (or that it was unnecessary) to get a national PHA coalition off the ground (as revealed in an interview with longtime activist, March, 1999).

[T]heir [a national organization for PHAs] first meeting was in Montreal shortly after the annual general meeting of the Canadian AIDS Society... back in '91... I remember it very clearly. And then the Canadian AIDS Society board members met with the emerging executives of this emerging organization... The main driving force behind this national coalition of people with HIV was Doug Wilson, a PWA in Toronto. After his death it just fell upon some very weak leadership and just sort of fizzled away. So it never went anywhere. I think they applied for funding from Health Canada and they were turned down.

While showing the necessity of government funding, this reveals that CAS was respectful of the new organization and that inclusion of PHAs on the CAS board was not the direct cause of the PHA organization's decline.

A lot of CAS's energy for a number of years was focused on the development and subsequent renewals of the National AIDS Strategy. The high level of attention given to

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<sup>27</sup> See Roy, 1995:25-29.

this activity is apparent in the annual reports. Justification for concentration on the strategy is first given in the 1989-90 Annual Report:

An important and large part of our work focused on the National AIDS Strategy. We took stands on different occasions, wrote briefs and participated in meetings, so as to obtain from the federal government concrete action in the areas of prevention and education; treatment, care and support; and human rights/discrimination. In so doing, CAS wanted to ensure an effective Canadian response to AIDS. (Canadian AIDS Society, 1990)

The strategy was originally established in 1990 by Health and Welfare Canada in direct response to “intense pressure exerted by community activists, health professionals and non governmental organizations” (de Burger, 1995:1). From 1986 onwards a number of ‘stakeholder’ groups were involved in a process of feeding back information to Health Canada on government policies on AIDS. CAS’s most sophisticated and detailed response was contained in Working Together: Towards a National AIDS Strategy in Canada (Canadian AIDS Society, 1989). The report established the need to “set an aggressive agenda against AIDS. It must include the partnership of people with AIDS/HIV and community based AIDS Service Organizations” (83) and presented a number of guiding principles which the Society wanted in the strategy. The government strategy highlighted partnership in the areas of education and prevention; biomedical initiatives; care, treatment and support; support to non-governmental organizations; co-ordination and collaboration; and \$112 million over three years (\$37.3 million annually) was allocated to the task (Health and Welfare Canada, 1991). This was an attempt at a comprehensive response to the AIDS epidemic in Canada, providing resources for research, to community groups, and for health care.

In spite of the detailed strategy, it was incumbent upon various stakeholder groups (including CAS) to campaign for renewal and expansion of the strategy into a second phase, as reported by four stakeholders in the Canadian AIDS News:

Current federal AIDS funding dries up as of March 31st 1993. In response, AIDS organizations representing care, treatment, education and research have launched a fall campaign to keep AIDS a priority... Representatives of the Canadian AIDS society, Canadian Hemophilia Society, Canadian Association for HIV Research and Canadian Public Health Association have endorsed a fall action strategy to secure renewed and expanded funding for the next five years.  
(Canadian AIDS Society, Canadian Hemophilia Society, Canadian Association for HIV Research, Canadian Public Health Association, 1992:1)

While the strategy was renewed for a second phase at the increased amount of \$211 million over five years (\$42.2 million annually), this was seen as inadequate for the tasks facing activists and policy-makers. Richard Burzynski, speaking on behalf of CAS as Executive Director, said it was a "Brutal blow to the kinds of things we're trying to do across Canada on AIDS" (York, 1993:A7). The inadequacy of the response was further noted in the Canadian AIDS News:

It is encouraging to see a funding increase for AIDS work at a time when other federal programs are being reduced. However, it is also worthwhile to note that the Parliamentary Ad Hoc Committee on AIDS and four national organizations (the Canadian Public Health Association, the Canadian Hemophilia Society, the Canadian AIDS Society and the Canadian Association for HIV Research) had advocated that at least \$55 million annually was required to address the needs presented by this communicable disease. (de Burger, 1993:1)

The second phase of the strategy was, therefore, seen as inadequate and temporary (having been renewed only for five years) and in light of this attention was given to the renewal of the strategy after the 1995 AGM:

...at the AGM in 1995 of CAS the membership pushed CAS at that point to show some leadership in that we needed to protect the future of the National AIDS



strategy and there was a resolution at that point that the renewal become the number one priority of the Canadian AIDS Society.

(interview with Russell Armstrong CAS executive director, May 2000)<sup>28</sup>

There was, then, a major struggle on the part of CAS and other stakeholder groups<sup>29</sup> to secure the strategy. This was an arduous process with difficult relations between stakeholders and the government until the general election was announced and it became clear that the Strategy would be renewed in some form.

My impression from hearing Russell Armstrong seemed to be that the Canadian AIDS Society seemed to have less access than had been the case in the past. But my impression is that that has changed with Alan Rock. For Alan Rock to announce for example that the National AIDS Strategy funding is now ongoing and there will not have to be huge advocacy efforts put into getting it renewed every five years is evidence of more accessibility. What influences that is priorities that the government itself places on HIV and AIDS.

(interview with early board member and key gay and lesbian organizer, March, 1999)

The renewal came about very quickly and the stakeholders argued that “the severe time constraints meant that there was insufficient opportunity for both the consultant team and the stakeholders to examine in detail the extensive quantity of information” (National HIV/AIDS Stakeholder Group, 1997: 1). One major result of this for CAS was that it acted on behalf of (rather than with) member organizations: “I think people recognized the leadership and they allowed the leadership to proceed” (interview with Russell Armstrong, May 2000). This is further explored in my discussion of CAS as an umbrella organization in a leadership role (chapter 3).

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<sup>28</sup> In an earlier interview Russell Armstrong had said that “...during that time, when I was Executive Director, that was the number one priority and that’s where about 80% of my time went” (February, 1999).

<sup>29</sup> The stakeholders had expanded from the original four to ten organizations: Canadian Aboriginal AIDS Network, Canadian AIDS Society, Community Treatment Information Exchange, Canadian Association for HIV Research, Canadian Foundation for AIDS Research, Canadian Hemophilia Society, Canadian

While there has been no increase in funding, one major advance in Phase III of the strategy is that it is no longer limited to five years: "...the government of Canada has approved annual funding of \$42.2 million to continue HIV/AIDS efforts. Previous HIV/AIDS initiatives were time-limited. This new funding will ensure the sustainability of our efforts well into the 21st century" (Health Canada, 1998:3).

Throughout the Annual Reports the lack of a long term government commitment to AIDS/ HIV was seen as a problem. While 1997 was something of a crisis year, with regard to the National AIDS Strategy and questions around whether or not CAS would continue to receive funding, major questions were resolved by Phase III of the strategy, even though the levels of funding continue to be inadequate in the eyes of the ASO community (Campbell, 1997).

#### Ongoing Development of CAS

In the contemporary period the CAS board and AGMs are still of primary importance with regard to contact with and feedback from member organizations. There has been continued growth; membership rose to more than 120 organizations across the country. Through a concerted effort, CAS also attracted funding from corporate sponsors listed in the Annual Reports. As a result of expanding sponsorship and general development within the organization, the staff grew to 22 employees<sup>30</sup> working in CAS

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HIV Trials Network, Canadian Public Health Association, Canadian Treatment Advocates Council, and the Interagency Coalition on AIDS and Development (National HIV/AIDS Stakeholder Group, 1997).

<sup>30</sup> With the exception of 1996-97 there have been significant increases in the CAS personnel budget since the first annual report from 1988-89, with increased government grants accounting for some of this growth within the organization. This level of government support seems rather extreme relative to other groups (cf. McCarthy and Zald (1987) on this aspect of professional movements). They question the

offices by 1998 (making it a surprisingly large organization). Funding for the core staff over this period came from the modest Health Canada operating grant but the majority of staff have been paid through funds granted for specific projects. CAS's success at securing these has been the major contributor to staff growth but also left the staffing levels vulnerable at the end of projects, when efforts were made to secure ongoing funding. Particularly for a social movement organization, CAS is highly formalized and of key importance in terms of influence and position within AIDS organizing in Canada (see Roy, 1995).<sup>31</sup> This development has resulted in differences between founding and early members and the newer more bureaucratized staff. Several of the interviewees noted that there was increasing professionalization of AIDS work, with which they were uncomfortable: they feel that it is necessary to have bureaucratic skills but it is also important to closely connect with AIDS as an issue.<sup>32</sup>

For the most part the hiring practices of Canadian AIDS Society have reflected the hiring practices amongst AIDS organizations in general, which means that the process tends to be more politically motivated than skills based. That you get elected for...your ability to express the dominant points of view, rather than the fact that you have solid management training or whatever. When I was first hired, you know, I was hired for my knowledge about HIV/AIDS not for my previous experience as a manager. I think that people looked more towards my political abilities than they wanted to know whether I could run an organization.

(interview with Russell Armstrong, February 1999)

This changing demographic might present an interesting area for future study with regard to 'generations' of SMO workers and the move (perhaps) from an ideological to a bureaucratic base. This will be discussed in a later chapter with regard to CAS's role as an insider and outsider organization.

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commitment of staff hired into government funded positions, while noting that this support provides resources which can allow for the expression of grievances.

<sup>31</sup> Roy says that there are several national organizations but that CAS is certainly the most important.

The overall structure of CAS up to the renewal of the National AIDS Strategy in late 1998 was formalized very much along lines that were established in the late eighties, during the initial period of CAS formalization. There was a effort to get PHA representation on the board formalized. At first, this was simply not seen as an important issue, with all appointments and elections based upon the knowledge and skills of individuals. However, once PHAs found a voice and wanted to be included, there was a struggle to realize this and then to revise their representation on the board. Seats on the board for PHAs were first guaranteed at the Winnipeg AGM in 1990.

The board of directors and the PHA board are important now, as they were then, although reporting to provincial groups has been formalized. The INFOCAS newsletter goes to individual member organizations along with annual reports and various strategic and advocacy documents. The extent to which this is relevant to constituents of member organizations is questionable but CAS is nevertheless seen as carrying out important work. One local AIDS organization worker said "As a worker today I have no relationship with CAS. I am not completely aware of what they do but I trust that they're doing something useful" (interview with a local worker previously involved in CAS, April 1999).

## CONCLUSION

What is perhaps most interesting is the development and formalization of CAS, displaying features of a network, coalition and umbrella organization (as I argue throughout my dissertation). It is already possible to see something of why CAS went

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<sup>32</sup> For an earlier comment on this see footnote 15.

through a formalization process, developing organizational forms along the lines I discuss throughout my dissertation, alongside consequences for member groups and CAS itself.

The commonalities and differences both between member organizations and CAS and its external allies raise important points regarding the usefulness of coalitions in advancing a set of goals. CAS representatives hoped these would be embodied in the National AIDS Strategy. CAS's developing sophistication is important to this question, with bureaucratic structure paralleling CAS's expansion and diversification. In connection to this, CAS has always presented itself as a coalition of organizations. The extent to which this is true (and the differences between network, coalition and umbrella organization -- all forms of collective organizing)) is the focus in subsequent chapters.

### **CHAPTER THREE**

#### **NETWORK, COALITION, UMBRELLA ORGANIZATION**

From my discussion of the concepts *network*, *coalition* and *umbrella organization* in Chapter 1 it is possible to show where each is distinct and where there is overlap between the three. Each can be summarized as follows. A *network* is made up of a complex set of exchanges among individuals relaying information, ideas and in some cases resources back and forth among organizations; shared ideology and the potential to work together on common problems (when diversity within the network is embraced) may also be important features. *Coalitions* of organizations also share ideology and there is distribution of information, ideas and, in some cases, resources. But there is also a deliberate coordination and integration within the coalition, with some focus by organizations on the coalition itself facilitated by formalization of a central organization. *Umbrella organization* structures are coordinated but are also more centralized and hierarchical, with less grassroots participation, at least to the extent that an umbrella organization acts on behalf of member groups and manages the coalition.

There is overlap between these concepts in the areas indicated although some distinctions can be made between the organizational forms. A network is characterized by an elaborate set of exchanges not necessarily present in the other organizational forms. A two-way or multi-directional flow of information is implied and there is no reliance on a centralized coordinating body. In a coalition organizations are part of a coordinated system and there is some formalization by a central organization in order to facilitate

coalition work. This coordinating aspect distinguishes a coalition from a network. An umbrella structure has greater management features and has a representative function (which, while it may or may not be undemocratic, is certainly centralized) not present in the other two forms.

While I have already discussed these concepts in some detail in chapter one, here I tie them specifically to CAS. The aim is not only to relate these terms to CAS but in doing this to more clearly define them as concepts useful to the study of social movements. Overall, I hope to give a clearer understanding of the dynamic within the Canadian AIDS Society from its inception up to 1998 and to understand why or why not this is the best organizational form for this particular group. I argue that network, coalition and umbrella organization can be seen as overlapping *stages of organization personality* in the formalization<sup>1</sup> process of a central organization. The effects of this on local organizations will be discussed in chapter 6 and the conclusion. A number of authors discuss the growth of organizations and the changes or stages of development that they go through (see, for example, Gamson, 1982). However, I am attempting to make a new argument here. Rather than CAS exclusively acting as a network, coalition or umbrella organization over time it came to be all three. Seeking specific outcomes, CAS developed characteristics of each organizational form. For the formalization of AIDS organizations generally see Epstein (1996), Wachter (1991) and the special issue of POZ on ACT UP/NY after ten years (March, 1997), which reflects at length on the changes that one HIV/AIDS organization has gone through.

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<sup>1</sup> I want to note here that the overall structure of CAS is formalized very much along lines established in the late eighties. Reporting back to member organizations and provincial groups is formalized in the

I now turn to discuss the concepts *network*, *coalition* and *umbrella organization* as they relate to CAS; the main thrust of my argument is that each ideal type comes to be seen in CAS's organizational structure (although CAS may never fully take the form of an umbrella organization or structure). While CAS has features which allow me to identify it as a network, coalition and, to a more limited extent, umbrella organization these do not always display distinct characteristics and can be seen to overlap at different stages in CAS's story.

I just think that forming coalitions and networks has been part of AIDS ever since the beginning. And CAS came along at the appropriate time when there was enough of a base of local organizations to support something on a national level.

How does that come about? I'm not sure that I can say that I know. But I know from the work that I did before the time that I got involved in AIDS that forming alliances was part of getting things done...because the issues were large enough but the opposition was big enough that you couldn't do it by yourself. You needed to build support.

(interview with Russell Armstrong, February 1999)

Throughout this chapter I relate the concepts network, coalition and umbrella organization to the development of the Canadian AIDS Society: from pre-formation, through consolidation as a more formal network into its incorporation and subsequent development as a coalition into the late nineties. I show that these concepts overlap with CAS acting more as a network, coalition or umbrella organization at different stages in its development but with each organizational form present after it was initially developed. This chapter is divided into a discussion of each of the core concepts, which are related to the historical development of CAS established in chapter 2. I consider each concept chronologically: CAS displayed network features earliest, then coalition and finally



umbrella organization. There is overlap between the sections, which reflects the fact that single concepts are rarely adequate to explain the development of the organization. I divide sections of the chapter as follows: 1) I look at the period of the pre-formation of the organization and the nature of early meetings; 2) the 1985-88 period prior to incorporation, emphasizing the dynamic nature of the relationship between CAS and its member organizations; 3) the incorporation of the organization and what changed with this; 4) the formalization of the organization into its recent history. It is also my purpose to show the causes and consequences of these developments for the effectiveness of CAS as an organization.

## NETWORK

As noted in chapter one, a network is a loose formal or informal grouping of organizations united largely for the purposes of information sharing but also to support one another in a variety of ways. This can be expressed in a complex set of exchanges and might extend as far as a limited sharing of resources, ideas, ideology and frames in working towards shared goals. Organizations within a network might be expected to share at least the same broad characteristics and to have, if not the same goals, at least an informal shared philosophy or set of ideals. The “philosophy” may be as informal as ideas shared by friends: indeed, friendship ties can be seen as an important part of networking (see Klandermans and Oegma, 1987, Snow, Zurcher and Olson, 1980), and this was certainly the case in at least the early years of CAS. A network is characterized by face to face, or voice to voice, contact, by the exchange of ideas and shared philosophical support

more than the distribution of shared resources. I argue that CAS worked exclusively as a network for the period prior to its incorporation (1985-88).

### Pre-formation

CAS was a network before it was anything else. Initial contacts were made between individuals as Richard Burzynski contacted activists across Canada and organized the first meetings in 1984 and 1985. In establishing themselves local organizations networked with other groups to get information on how to provide specific services. From 1984, when a number of groups had been formed across the country, there was networking going on beginning with what Michael Sobota calls “a group of energetic and like-minded individuals” (interview, April 1999) reaching out to other individuals and organizations. Michael Phair describes this and the friendship ties which, to an extent, made it possible:

...we received a letter from Richard Burzynski for the first conference. We attended the meeting. [An HIV+ member of the group] ended up spending much of his time with other HIV infected persons there and it was his first experience with persons with HIV. He'd never known or met anyone else for himself. So he'd spend a lot of time with those folks.

Guy and I spent more time at the organized meetings, if I can call it that, and talking to people and as part of that talked with Richard. Guy knew some people in Montreal so in fact we stayed with them. I got to know a few of the other people who were with Richard and involved in kind of putting together this meeting.

(interview, May 1999).

This was the beginning of networking between individuals across the country able to meet somewhat informally, face to face. Michael Phair describes the goal of this particular rendezvous: “At that meeting we discussed wanting to form a network--and probably

some kind of organization--but without knowing what that would be and how we would make that happen" (interview, May 1999). Richard Burzynski, discussing the same meeting, states that "the aim was in some way to coordinate a number of different approaches--sharing information and articulating some kind of agenda of approaching the federal government. The important thing was having a national voice" (interview, March 1999).

Both quotations point to the building of a formal network, growing out of what was established at the first meetings. Information sharing was key in this according to Richard Burzynski but he also goes further, arguing that what was needed was a national voice for AIDS Service Organizations (ASOs). The emphasis on sharing information is very much a feature of a network. One participant in this early meeting talked about it as inspiration for further networking and the formation of the Ontario AIDS Network (OAN):

The delegates from Ontario began to talk about, Hey, it was great to network with people across Canada but why can't we do it here in Ontario? So work began to create OAN. So, very quickly, I think the meetings of the Canadian AIDS Society were beginning to spawn interest and development of regional networks.  
(interview with a former prominent CAS board member, March 1999)

Several of these groups called themselves networks, for example AIDS Network of Edmonton and AIDS Network of Calgary. As I discuss in chapters 2 and 5, the regional networks are still in place, most prominently the Ontario AIDS Network (OAN) and the Pacific AIDS Network (PAN). The whole of the subsequent year was characterized by this networking at a national, provincial and, perhaps to a lesser extent, local level. As yet, there was no CAS board and after the 1985 Montreal meeting organizing was done by very informal face to face or voice to voice contact, building a network and working

towards the more concrete organization discussed by Michael Phair and Richard Burzynski. A network was, therefore, established and its members clearly looked to build on this and make something of it. This is comparable to the web of organizations discussed by Feree and Hess (1994) as a coalition, in that it was very loose at this point in time. CAS's growing network and this looseness also allowed for the introduction of ideas into the wider discourse (Rosenthal et al., 1985). Weak ties, in this instance because the organization was just beginning, meant that ideas were spread broadly; the central idea at this point in CAS's history was the development of a national organization.

The strengthening of network connections developed out of the perceived need for a national organization, which could build on the skills of local AIDS Service Organizations (ASOs). Networking had been used previously and was already a strength of the gay community across Canada. Only through networking and communication among organizations could this skills base be accessed. Through networking activists were successful in laying the groundwork for the formation of a national organization with representative voices from across the country. Early networking was, therefore, a key element in mobilizing CAS as a collection of organizations (see Carroll and Ratner (1996) on the crucial contribution of networks to mobilization).

#### Formation of CAS as a formal network (1986-88)

It was at the Toronto meeting in 1986 that the Canadian AIDS Society was formed. At the first meeting in 1985 "Richard [Burzynski] thought that he could continue to get enough money from the feds to keep some sort of liaison going among the people who met and see whether we could start to put together a framework for some kind of

organization” (interview with Michael Phair, May 1999). The liaison did take place and the position of what the national organization would be was essentially established at a second national meeting in Toronto in 1986. CAS would be representative of a growing number of organizations across the country and would provide information and support to allow groups to connect with one another:

The Canadian AIDS Society was also smaller and although I was never on the board I was at least involved in CAS because it started much more as a networking organization and as a way for people working in AIDS to connect with other people working in AIDS and then it grew to become something on top of that.  
(interview with local activist since 1986, April, 1999)

Following the meeting in 1986 the main goal still seems to have been the transmission of information and building of ties between groups from across the country. Information on available treatments and therapies, legislation, models for community action, safer sex guidelines, as well as ‘how to’ advice on setting up telephone hotlines and other services was distributed. This information was also presented at the Actions/Directions conference in 1986 (Canadian AIDS Society, 1986). Alongside this networking there was increasing structure, which I discuss in the section on coalitions. One of the early board members (who came onto the board in 1987) responded to a question about what CAS was doing for local groups in this period in the following way:

Well, it was kind of to connect with the national perspective. And to be able to be a certain point of accountability. To be reporting about what CAS was doing and to get input. And also as time went on, a real role for us was [teaching] them and learning about how to do lobby work so they could apply that to their local issues. To assist them to participate in national lobby work.  
(interview with prominent CAS board member, March 1999)

While the issue of creating a unified national perspective might be characteristic of a coalition, the information sharing and the input sought from local organizations are still

strongly suggestive of CAS acting as a network. This is further reinforced by the fact that the board at this time established the practice of traveling to different provinces to hold meetings with local organizations (see chapter 2), enabling CAS board members to get an overview of local groups and to connect with them at a personal level. This also made board members aware of the problems and triumphs that ASOs were confronting and allowed input from local organizations on what they wanted from the Canadian AIDS Society. The CAS ideology of autonomy for local organizations was characteristic of a network or coalition in that there was no hierarchy and no dictates coming from a central organization (as would be the case if CAS had acted as an umbrella group). The extent to which this changed is discussed throughout the rest of the chapter. Aside from ideology, it is possible that CAS could not in any way establish a hierarchy (a form common to umbrella structures) because it formed out of local organizations rather than vice versa.

From interviews with CAS board members, it is clear that CAS did little to aid the establishment of local organizations. At least one exception to this was Michael Phair, who used friends to establish and encourage groups in Regina and Calgary respectively:

One of our priorities was encouragement of the development of new local community organizations. That's partly why we did that. And then the hope was that you would initiate new ones in the region that needed to be done. I mean, in theory that's part of the reason, I encouraged Calgary. And I also encouraged Regina because there was nothing in Saskatchewan initially...and then Saskatoon really got going on its own.

What happened with Regina is that at the time a good friend of mine who was at the University here [Edmonton] ended up going to the university of Regina and I got him to get started. in fact, he became their first executive director eventually.

**Would you say a lot of it worked along those friendship lines?**

I suspect people knew somebody to get them into the situation somehow. In Calgary I remember I talked with one of the gay groups in Calgary that I knew. And they were the ones that told me that someone else that I didn't know was

talking a little bit about needing to or trying to pull a few people together to look at AIDS. So then I followed that up.

(interview, April 1999)

This was an instance where networking between individuals was effective in establishing new groups and bringing more organizations into CAS (see Klandermans and Oegma, 1987; Snow, Zurcher and Olson, 1980, who also discuss friendship networks). CAS may not have been directly involved in specific local groups but it did encourage federal funding of ASOs and supported the formation of community groups through the AIDS Community Action Programme (ACAP). Perhaps this was a priority in early stages of networking but not later on. In any case many healthy groups managed to consolidate themselves before joining CAS and/or one of the provincial networks.

It was pretty easy to get people involved because groups were forming in most parts of the country. There was a larger Canadian dynamic and very quickly we were able to build this structure and provide ongoing information. And there were a lot of gay groups that also came to focus on HIV--most of the groups were gay based.

(interview with Richard Burzynski, March 1999)

Local groups, therefore, could never act as branches of a centralized organization in this or any other period of CAS activity: even groups that were established by CAS members were based on friendship ties and, therefore, were not hierarchical. The founding member organizations had existed autonomously before CAS and in this period acted as a network facilitated by the growing central organization, which was about to become incorporated and to receive more substantial government funding. Ongoing network activity was a consequence of earlier inter-organizational activity and the development of some friendship ties. The network, the most informal and flexible of organizational forms, grew out of informal relationships. The small size of the gay and AIDS communities in Canada

must have had an impact on this. Network continued to be an effective organizational form and increased CAS's effectiveness both in bringing new member organizations and in enabling CAS to present a unified front in ongoing activities, with individuals able to quickly and easily call on one another to mobilize at the local level.

### Incorporation

The main change that came with incorporation was that CAS ceased to exist exclusively as a volunteer organization. It received government funding and was able to rent offices and hire the first staff persons, as detailed in chapter two. The collection of organizations within the Canadian AIDS Society would grow substantially over the next few years into the early nineties. But where the organization can be argued to have existed almost exclusively as a network before incorporation it began to take on more features of a coalition, which is how it was identified in the first annual report:<sup>2</sup>

In all the lobbying, organizing and coalition-building that has gone on in recent years, it has become clear that frontline community groups are at the forefront of the fight for a just and compassionate response to AIDS in Canada. As a coalition of community-based groups from St. Johns, Newfoundland to Victoria, B. C., the Canadian AIDS Society serves as an important mechanism for transmitting national information and breaking news to the local level, while serving as a coordinating point for local concerns on issues ranging from emergency drug release to the impact of homophobia on the Canadian response to AIDS. (Canadian AIDS Society, 1989)<sup>3</sup>

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<sup>2</sup> CAS and ACT UP were very different groups beyond their basic goal of confronting AIDS (ACT UP being a confrontational activist group in a way that CAS was not) and yet they appear to hold the same basic ideals with regard to decentralized democratic organization. This may be owed to the fact that they both came out of gay organizing in the seventies and early eighties but requires further research. The word 'coalition' reflects a decentralized ideology as much as the specific organizational forms which the groups developed.

<sup>3</sup> There is a section of this annual report entitled "Building Networks." The networks discussed are, however, with other national organizations whose primary concern is not AIDS/HIV – the Canadian Public Health Association, the Canadian Hemophilia Society, the Canadian Red Cross Society, and the United Way Canada. The impact of this networking may be crucial but is beyond the scope of my current research. See Carroll and Ratner (1996), Staggenborg (1998), della Porta and Rucht (1993).



Even though CAS identified itself as a coalition at this point, the “lobbying, organizing and coalition-building” was predominantly a period of active networking between individuals within the organization who were primarily involved in local member organizations. But CAS was also increasingly a “coordinating point” for concerns common to different communities. This is a coalition characteristic discussed in the next section. The coalition could not be built without serious networking between members of local organizations and, increasingly, the CAS board. Positive outcomes came from this networking. The board itself was made up of members of local organizations who concurrently worked at local and national levels. This connection might have created tension between local and national organizing (Kleidman, 1993), but it was avoided through ongoing connection between local and national levels, in the form of common board members, which allowed for fluid communication. This networking aspect was important until the society was established and able to focus on other issues within its organizational development using more formal lines. Ongoing networking between individuals continued to draw board members from across the country. This meant that CAS continued to be inclusive, which increased its effectiveness in avoiding splits, which were more of a problem for other North American social movement organizations.

While CAS began to develop as a coalition with its incorporation and increasing formalization, several aspects of networking continued.

When we started the Canadian AIDS Society it was about people working in AIDS feeling isolated and not knowing how to deal with their work. A part of what this was--and for me the biggest thing of what this was--a professional network and a supportive system. So what I remember from the early years of

CAS is connecting with the people. I don't remember connecting with 'the organization.'

(interview with long time activist with close ties to CAS, April 1999)

There was ongoing contact between individuals, which according to my definition is characteristic of a network. This also seems to be reflected in the fact that friendships and networks of friends were also still an important part of the organizing that CAS was doing at a local level.

But I knew some of the folks in AIDS ACTION NOW! (AAN!). I recognized what tensions had been there between (CAS and AAN! in 1989) and wanted to establish a relationship. [Their rep] and I met regularly so that we could keep that kind of communication link.

[Friendship] was one of the ways. I had a certain credibility that made it easier. Because some of the activists were mistrustful of what was seen as a non-activist group [CAS] that was trying to work with the government.

(interview with Joan Anderson, March 1999)

Friendship ties in this instance partially overcame activist mistrust of CAS as an incorporated insider organization.<sup>4</sup> However, with the increasing formalization of the organization these friendship ties and face to face contact became less frequent, the collection of organizations grew more diverse and the number of activists who personally knew one another decreased. While necessary, this had a negative impact on relations with some member organizations (see chapter 6) and CAS's ability to work effectively. Most of the original activists who are still involved in AIDS work in some capacity now work with other organizations or as consultants.

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<sup>4</sup> This is discussed further in Chapter 4, looking at CAS's role as an insider and an outsider organization.

## Formalization

With an increasing number of member organizations and more permanent staff in the Ottawa office CAS operated less and less exclusively as a network. The organization necessarily took on more and more coalition characteristics, particularly as contact between CAS and member organizations became less spontaneous. Indeed, the necessary formalization is a distinct coalition characteristic. I use the word “necessary” following Vickers et al. (1993:3), who “start from the premise that women’s movements, at least in Canada, *must* establish institutions to be successful, because the achievement of their goal of equality requires the organization of activity over a number of generations” [my emphasis]. I argue that AIDS activists in Canada also needed to establish institutions because the work on HIV/AIDS, if not taking literal generations (although that is probably also true) at least takes several generations of activists, as I discuss in Chapter 2. There is, of course, still networking within the coalition. Communication was formalized in the INFOCAS newsletter and the main forum for contact with and feedback from member organizations in this period was the Annual General Meeting (AGM):

Well there were basically annual meetings, which for all intents and purposes is a mini conference, because it would go on for three days. And there would be workshops, plenaries, guest speakers, keynote speakers. Plus there would be all this business that’s gotta be transacted.

(interview with former CAS employee, March 1999)

**And is the main forum for that debate the annual general meeting?**

With the membership, yes. There’s a resolution process which usually takes up most of the last day. There’s usually twenty or thirty resolutions that get put forward and a lot of them provide substantial direction to what the programme priorities should be for the organization.

(interview with Russell Armstrong, February 1999)

This point is reinforced in the CAS workplan for 1994-95, which states that “many of the activities in the workplan emanate from resolutions which were adopted at the 1993 AGM” (Canadian AIDS Society, 1994c:2). It is interesting that the organization, which is increasingly professionalized (with, for the most part, an annually increasing budget and staff), attempts to maintain a participatory democracy, an aspect of both networking and coalition building and maintenance. This distinguishes CAS from most umbrella organizations, only a few of which worked closely with a grassroots base (see Hansen, 1986). One local executive director, who had also served on the CAS board said that,

Along with the AGMs, meetings once a year, I would access them for a lot of information because there were things coming down here that I'd think, I don't have the information to go out and fight the big fight. And they [CAS] were like the hub of a wheel and would provide all the information or could call and access it for us, which was critical.

(interview, March 1999)

This respondent speaks in the past tense and in the more recent period it seems clear that this sort of “pick up the phone” option is one that is used much less than in the past.<sup>5</sup>

For the most part the formalization of the organization and professionalization of the staff was the end of consistent and exclusive networking among organizations and between CAS and member groups. There was a decrease in face to face contact and information sharing, features which made CAS exclusively a network. Formalization and work along more professionalized lines is characteristic of some coalitions and is apparent in this phase of CAS's development: “In the time that I've been at CAS [full time since 1993] its moving more towards wanting a basic skills set. Looking for professional abilities and understanding that a lot of stuff about HIV/AIDS can be learned” (interview

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<sup>5</sup> I discuss this further in my analysis of local organization contact with CAS in chapter 6.

with Russell Armstrong, February 1999). With a more professionalized (and increasingly large) staff coming in from other fields there was less room for friendship ties and face to face contact, which characterized earlier periods. A significant part of this was the growth in the number of member organizations, which can be charted through the available annual reports: there were twenty-seven groups at the time of incorporation, sixty by 1991, “more than a hundred community-based AIDS organizations across Canada” by 1994 (Canadian AIDS Society, 1994) and more than 120 organizations in the present period. With increasing size it appears inevitable that the organizational form changed from predominantly network to coalition. And while some coalitions do engage in networking (also the case with CAS) my argument here is that features which made CAS exclusively a network were no longer as prominent after incorporation, when CAS worked more and more as a coalition of organizations and less and less as a network of individuals. I argue the causes and consequences of this change in the next section.

CAS had roots in networking, developed from earlier connections within the gay community between individuals across Canada. This network formation and development are rooted in prior organization. The subsequent network of AIDS activists was effective in allowing founding member organizations to unite from the mid eighties onwards. CAS’s development as a strong national voice (indeed, the only effective long term national voice representing ASOs) was a direct consequence of this. Without this foundation later work as a coalition and umbrella organization would not have been possible. Had CAS remained exclusively a network it is also likely that it would not have gone on to later gains as an effective organization.

The period of networking at CAS can be directly related to the characteristics of networking outlined earlier. CAS introduced ideas into the wider discourse through the network (Rosenthal et al, 1985) and falls under Niedhart and Rucht's (1991) definition of a social movement as a "mobilizing networks of networks" (1991:453). This is seen in the connections between CAS member organizations but also in the formation and subsequent activity of the OAN and PAN groups, which serve a networking function within their regions. Friendship ties and overlapping memberships with groups like the OAN and between member organizations and CAS were also important (cf. Staggenborg, 1986) in terms of the dissemination of ideas and the consolidation of CAS as a credible national voice. As is apparent throughout the rest of this chapter, the networking between groups was crucial to all that has followed, laying the groundwork for coalition and subsequent umbrella structure activity.

## COALITION

I think CAS started as a network. The point for me that it shifts from a network to a coalition is the point that it shifts from individuals to agencies. And so now I think it is a coalition and I think that it speaks on behalf of agencies. And that's fine with me but it's different than the old professional network.

(interview with local AIDS organizer, April 1999)

While coalitions can involve networks, they also have unique characteristics that set them apart. A coalition is more formal than a network. There is less personal contact between individuals and a more structured relationship between organizations, allowing for shared resources<sup>6</sup> and information without necessarily impinging on member organizations' autonomy in any way. While coalition-building requires networking, the

coalition itself becomes something distinct. The ideology or goals around which organizations in a coalition rally must also be more formalized or clearly stated than they would be for a network. Discussion of CAS's development as a coalition, following the same historical lines established in the previous section, will make this clear.

### Formation/Pre-incorporation

In this period of activity, most notably in the increasing links between groups from 1984-86 (specifically in the Montreal Conference of 1985), there was a great deal of networking but very little of the coordinated action characteristic of coalition work. It was Richard Burzynski, more than the organization, who went to the government for funding to enable activists to meet, and who encouraged the network and its eventual formalization in CAS. However, I argue that this period and the one immediately prior to incorporation did involve coalition-building as the network of connections between organizations grew and a common ideology behind AIDS organizing in Canada developed.<sup>7</sup> I also argue that the period of coalition building prior to the development of a formal coalition was a long one (relative to the entire history of AIDS organizing in Canada up to 1998) and that there was much overlap between the *network* and *coalition*. The extent to which these can be seen as distinct phases is open to question here and it would be false to force the distinction between them.

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<sup>6</sup> The central organization shared resources with the AIDS Committee of Ottawa when they moved into the same office space in 1988.

<sup>7</sup> Indeed, there was an ideology common to AIDS organizations in the West generally, which may largely be owed to the fact that the gay community was the first population to be affected by HIV/AIDS. Gay organizing in the seventies was largely based on identity and empowerment, personally and politically (see and Garfield, 1994; Lehr, 1993; Shepard, 1997; Shilts, 1987). This carried over into AIDS organizing from the early eighties in the US and from 1983 (the year ACT formed) in Canada.

Much of this overlap is evident in the flurry of activity at and following the second national meeting in 1986, when a lot about the structure of the fledgling organization was decided:

And that meeting was pulled together exclusively to focus on whether we wanted to put together some kind of national organization or group, as opposed to the first one, which had a number of sessions: medical stuff and almost a conference kind of thing, which was fine, which was great. But this one was really focused on, Do we want some kind of organization? And we got, at that meeting, quite a bit hammered out in terms of a framework--first of all there was an agreement that there needed to be a national organization, that it needed to be made up of the non-government volunteer AIDS organizations--and in those days they were all gay and lesbian organizations across the country, although we didn't say you had to be that, so we avoided any kind of real debate... And then a number of us took on different tasks related to putting together a national organization and one of the things that I was involved in from that meeting was to put together a set of bylaws and constitution kind of and hammer that out--the actual language and how it would actually work and what the kinds of positions would be and how people would be elected and how long they'd serve and all that.

(interview with Michael Phair, May 1999)

Beyond sharing information, individuals worked together as representatives of local organizations to achieve common goals and to establish a formal organization.

Establishing a formal organization required coalition building in order to get others on board and work more consistently towards common goals. Building an organization out of the network initiated this coalition building phase of development. This was a period of coalition building more than coalition activity, which appears to have begun only when CAS was incorporated and received government funding to pursue its goals. Even at this early stage, however, individuals saw the benefits of having a national organization and this led to coalition-building through networking and the development of parameters along which a board could be elected and the organization could be run, as described above by Michael Phair.



### Incorporation

As is apparent in my discussion of CAS as a network, it was clearly identified as a coalition in its annual reports and elsewhere as it received funding and became incorporated. At this time there were still only twenty seven member groups and from interviews it is apparent that much of the contact was face to face or voice to voice. Local organizers were able to pick up the phone and call individuals in the CAS offices for information, advice or help. While these network features were in place, CAS was also developing as a coalition. Staggenborg (1986) argues that coalitions are most likely to form when organizations are faced with extraordinary opportunity or threat. The "threat," which came from government inaction<sup>8</sup> on AIDS issues in the absence of local pressure, was what led to active networking on the part of Richard Burzynski and others.<sup>9</sup> This can be seen in the following quotations.

I went out to Ottawa on a couple of occasions to meet at the public health organization offices where we had these meetings representing the Canadian AIDS Society...and then I also managed to meet with some federal and other people at the same time for planning and organizing that conference. We also set in motion a meeting with Jake Epp, who was the minister at the time, who was not eager to meet with us and certainly at that time did not want anything to do with AIDS and didn't think it was anything they should be touching with a ten foot pole.

(interview with Michael Phair, May 1999)

This shows the beginnings of some coalition activity coming from the desire to be a more effective presence. The group began to counter and challenge government inactivity. The

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<sup>8</sup> Inaction on the part of government also led to the formation of ACT UP (Kramer, 1989) and a number of other US AIDS organizations.

<sup>9</sup> Alternatively, one might argue that AIDS was the threat and that government inaction created outrage and was therefore a mobilizing agent. The threat was perhaps really felt at the interpersonal level as people lost friends to AIDS.

difficulty of arranging a meeting with the then Minister of Health certainly points to a wider “threat” to marginalized communities.

We did however have some contact with the Canadian Public Health Association, which under the Mulrooney government was, we think foolishly, given a fairly large amount of money to have a kind of AIDS Section of the Canadian Public health association. And they were given money to develop the first ever national television commercials around HIV and AIDS. And these commercials were quite a disaster. They basically featured nice little scenes of heterosexual families sitting at home, for example in their living room by the fireplace with parents modeling AIDS information that they would give to their nice clean and white heterosexual kids. There was never a mention of the g-word--gay. Or any of the stigmatized populations--injection drug users or even immigrants at that point. There was nary a mention of any of that. This was all about how good Canadian families need to protect their kids. Well, we were appalled and angered by these commercials that this was an enormous waste of money on what we felt was kind of generic pabulum. And so that was quite controversial in the development of the early years of the Canadian AIDS Society.  
(interview with Michael Sobota, April 1999)

Initially, then, the government did not pay attention to gay men and injection drug users (IDUs), and it was only through the community response that action came to be taken.<sup>10</sup> CAS attempted not to remain marginalized and the coalition developed as a source of strength. Ignoring the groups most affected by AIDS could be taken to be a threat to the community and a part of the homophobia that CAS countered throughout the period under study. The interactions among activists talking about a response led to action.

The “opportunity” (both opportunity and threat were present at different stages of CAS’s development but were different from those observed by Staggenborg, 1986) came in the incorporation of CAS and its subsequent ability to present itself as a national voice. As a more formalized coalition than had been the case prior to incorporation CAS could present a unified voice. There was also a much more solid funding base to work from.

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<sup>10</sup> Roy (1995) also writes about the importance of the community response as the only one that was effectively reaching out to marginalized communities.

Moreover the representatives of ASOs had unprecedented access to the government through a central organization based in Ottawa. The exponential growth in number of member organizations would seem to support this hypothesis. ASOs across the country perceived some benefit in being connected to this national voice (see chapters 5 and 6). Opportunity, then, comes in the growth of the network into a coalition of organizations and the availability of federal funds to make this possible. Opportunity also existed in the chance to build on the momentum from the more informal period of activity up until 1988:

When we got a signal from Health Canada that they were going to grant us--I believe it was a fairly substantial operating grant, somewhere in the region of \$3 - \$400,000--we knew that we would be able to open an office and employ our first staff. Grant McNeil was our very first employee, even before we had Richard. He was on a contract with us, sort of working as an admin. assistant to the board, helping us get our board meetings organized quarterly around the country and making sure our paperwork flowed back and forth to each other.

(interview with Michael Sobota, April 1999).<sup>11</sup>

Out of the funding and employment of the first staff CAS was able to organize more systematically along lines already established prior to incorporation. In its formalization CAS was increasingly effective as a coalition, sending out more information to groups and presenting a more coordinated front (e.g. in member groups lobbying MPs on common issues). This was facilitated by Grant McNeil and others as well as the board as it met around the country, paving the way for CAS to act more as a coalition. That is, CAS began acting as a unified voice representative of AIDS Service Organizations (ASOs): "CAS answers to the member organizations. We don't answer to CAS" (interview with local organizer, former CAS board member, March 1999). The fact that CAS, to some degree, was answerable to local organizations is important and further suggests that the

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<sup>11</sup> To some degree CAS also changed the political climate through its cultural and political achievements, which Staggenborg (1994) argues can lead to success for later social movements.

collective was increasingly a coalition organization. The autonomy of local organizations has been discussed as a core CAS ideology in chapter 2. This suggests that CAS was a decentralized organization in that it did not co-opt local groups into the perspective of the national organization. Ongoing accountability to local organizations (see chapters 5 and 6), suggests that the group more solidly became a coalition at this stage, as opposed to remaining a more diffuse collection of groups exchanging information, or a central organization simply generating information for local groups.

These developments in organization were significant but not a sharp break following incorporation. There was a natural evolution towards the characteristics of a coalition with the information exchange and informality indicative of a network slowly changing as CAS became more representative of local organizations and more formalized in its own organization.

The major outcome of this activity is that CAS developed as a unified voice with increasing credibility in Ottawa. Meanwhile, member organizations had access to and a say in the running and development of CAS as a coalition. The central organization was able to work on behalf of a united collection of organizations across the country. CAS organizers chose a decentralized form to allow presentation of the Canadian AIDS Society as a legitimate national organization confronting government inactivity. While networking was an important part of the ongoing relationship with and recruitment of member organizations, it was necessary for CAS to be developed as a coalition with the clout of member organizations behind it in order to be effective in Ottawa. I discuss the nature of the outcomes in Ottawa below.

### Formalization

Following incorporation there was a great deal of growth both in the number of employees in Ottawa and the number of ASOs that became member groups. This is reflected in organization formalization. Increasingly CAS dealt with organizations rather than individuals, which one activist identified as “the point for me that it shifts from a network to a coalition” (interview with a local organizer, April 1999).

Board members visited member organizations as one way of maintaining contact:

Yeah, I attended all of the Ontario AIDS Network Meetings as an Ontario representative on the CAS board. I connected with the member groups of CAS that were in Ontario was primarily through that. And then I visited most of the groups, with the exception of the northern groups, while I was on the board of CAS. That is to say the Ontario groups. Now in addition to the Ontario groups, I had contact with a group in Newfoundland, a group in Fredericton, a couple of groups in Montreal, a few groups in Toronto, Saskatoon, Edmonton and a couple of groups in Vancouver.

(interview with former CAS board member, March 1999)

Perhaps the main coalition aspect in this is the accountability to local ASOs throughout this period of time as distinct from acting on behalf of groups without being answerable to them.<sup>12</sup> CAS continued (and continues) to distribute information (e.g. in the INFOCAS newsletter and in surveys, responses to policy documents, etc.) but this became one way communication in many instances. Less information came from local groups and local organizers were less aware of CAS work: “As a worker today I have no relationship with CAS. I am not completely aware of what they do but I trust that they’re doing something useful”<sup>13</sup> (interview with local organizer, April 1999). However, to a large extent this may be dependent on the worker: “CAS has always communicated lots of resources and

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<sup>12</sup> The effectiveness of this from the perspective of local organizations is discussed in chapter 6.

information and alerts of various kinds to the member organizations. So it's certainly something that I've monitored and benefited from" (interview with local worker and former CAS board member, April 1999).

The difference between the above two positions suggests that there is a certain haphazard element to CAS contact with local ASO workers and that this contact is dependent on some factor beyond CAS control such as the voluntary co-operation and input of local workers. In this period, then, CAS ceased to be exclusively a network and developed as a coordinated coalition of ASOs from across the country.

While CAS did not display all of the characteristics of a coalition (e.g. organizations were not part of a coordinated system--their autonomy remained paramount) CAS's development as a coalition proceeded from 1988 onwards with the adoption of formal membership requirements and the emergence of an ideology centering on the autonomy of local member organizations. After the initial period of development as a coalition the organization became increasingly formalized. This is probably what allowed it to be a representative voice rather than simply an information network. This representativeness enabled the group to speak out on a number of national level issues such as the National AIDS Strategy. Had the organization remained exclusively a network this would not have been possible. With formalization, CAS was able to act as a "mesomobilization actor" (Gerhards and Rucht, 1992), providing integration and common frames of understanding. CAS was able to work at the formal government level, while retaining input from member organizations, making it an effective coalition working with

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<sup>13</sup> While it may be the case that local workers do not have contact with CAS, my research shows that executive directors are apparently more aware of the work of the organization: at least executive directors of founding member organizations.

and for member ASOs. In order to make gains at the national level it was necessary for CAS to interact with the government and this work was effective, as I show in my discussion of umbrella organizations.

## UMBRELLA ORGANIZATION

An *umbrella organization* is centralized and formalized, acting as an overseer on behalf of member organizations and coordinating actions without necessarily consulting them; the central organization directs not only the actions of local organizations but also the character of the movement and the nature of its engagement with the outside world. While there is a gap in the literature on this concept, umbrella organizations display three basic characteristics: they develop themes for member groups to follow; member groups cede autonomy to the umbrella structure/organization, which then has the power to act on behalf of those groups; the umbrella organization performs a management role and coordinating function. In most regards CAS does not fit with the definition of umbrella organization in any of the stages of its development. Rather than again presenting the stages in CAS's formation and development from the perspective of umbrella organization I wish to more straightforwardly show the characteristics of umbrella organizations that CAS has not developed. I will then discuss the features of the organization which are characteristic of an umbrella structure. It will then be possible to return to an overview of the theoretical concepts and make an argument for each as an overlapping stage in organizational development, through formalization.

Several features distinguish CAS from other umbrella organizations in the literature. First, and most importantly in terms of historical development, CAS was formed

by member organizations. Local groups were not founded by the national organization.<sup>14</sup> As has been shown throughout this chapter, the central organization was held accountable to member groups through AGMs, meetings between board members and local organizations, and through a process of consultation. This was especially true in the period of CAS's formation and early development but continued to be a core value of the organization. A high degree of grassroots involvement has been maintained. According to the definition of umbrella organization developed here, member groups cede autonomy to the umbrella organization: this was certainly not the case with CAS member groups, which remained entirely autonomous.

Second, the ideal of autonomy of local organizations strongly mitigates against CAS developing umbrella organization characteristics, which are by nature more centralized, according to the literature. CAS has no involvement in the actions, policy, ideology, membership, or services of local organizations.<sup>15</sup> CAS in no way managed or coordinated the work carried out at a local level and in this sense was completely decentralized as a collection of ASOs from across the country. This is characteristic of a network or a coalition but not an umbrella structure. As long as there is a democratic ideal within Canadian ASOs this seems unlikely to change.

Third, while CAS has developed as a bureaucratic organization, this feature is not sufficient to bolster an argument that CAS is an umbrella organization. The bureaucratic form that the organization took was established to serve local organizations by providing

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<sup>14</sup> The umbrella structure discussed by Vickers et al. (1993) came together as a result of a coalition of over thirty organizations but most other sociologists discuss umbrella groups which were established separate from local organizing, in the hope of creating some sort of coalition (see Stathusen, 1991; Laumann et al., 1978; and Maseko, 1997; discussed in chapter 1).

<sup>15</sup> This may be problematic in some cases, as discussed in chapters 5 and 6.



information and support in the form of publicity for certain national actions. Bureaucracy allowed for effective communication between the central organization and member groups but these groups were free to use this information as they pleased. There was no centralized CAS policy. It was true that there is a shared ideology but this was fairly loose and defined in different ways by different individual and group members of CAS.

Fourth, CAS did not develop “grand themes” for member organizations to follow, as is characteristic of umbrella organizations. The ideology came from local groups and, while it was broadly shared, it was not centralized. CAS did not direct even the broad goals of local organizations. The strongest suggestions for action were in the form of guidelines that CAS sent out, which were established in consultation with member groups.<sup>16</sup>

While these features of CAS’s history and organizational structure show that in many ways it has not functioned as an umbrella organization, some of CAS’s policy and actions, and questions raised by interviewees, point to features of an umbrella organization. The fact that the organization represents ASOs at a national level is notable in this regard. Most significantly in the negotiations around the National AIDS Strategy, CAS representatives spoke on behalf of member ASOs across Canada. While there was consultation with ASOs at AGMs and in the form of questionnaires sent to local groups, the extent to which this was effective for gathering the broad range of opinion is questionable.<sup>17</sup> To some extent, member organizations, wittingly or unwittingly, ceded autonomy to CAS with regard to decisions in negotiations around the development of the

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<sup>16</sup> It is possible that larger groups and the central organization essentially developed these themes for smaller groups.

**National AIDS Strategy.** One respondent, who was closely involved in CAS for several years went so far as to say the following:

Nominally [CAS] calls itself a coalition but its verging towards a very institutional structure. It's not by any means fluid anymore. There's a lot of rules but on the other hand there does have to be that core to keep something as large as the Canadian AIDS Society together. A hundred and twenty some members of incredible diversity. We've had this discussion a lot. When you're eight members, when you're fourteen well there's a lot you can do but when you've got 125 its a different way of operating and it gets perceived as no longer coalition based, no longer fluid, very bureaucratic. But that's maybe not the truth.

(interview with Russell Armstrong, February 1999)

The extent to which CAS was able to be representative, avoiding a more centralized umbrella structure, was threatened by the size of the organization and the number of member ASOs. Involvement as a stakeholder and the speed at which negotiations took place made it necessary for CAS to act in a representative manner, responding to outside pressure from the government to negotiate quickly. While the outcome in the negotiations was a good one, this may have alienated some member organizations (see chapter 6).

The formalization of the organization, necessary because of its size, may have made it difficult in the last few years to act as a coalition and may make a more centralized organization in which CAS provides an umbrella structure necessary, just as the development from network to coalition was necessary. This will only be possible if the autonomy of local organizations is divorced from what would be a centralized decision making process. Alternatively, the form that CAS took since the mid nineties has been a hybrid of network, coalition and umbrella organization. CAS acts in conjunction with groups on certain issues but not on others.

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<sup>17</sup> This is yet another point which will be discussed in chapter 6, analyzing local organization response to CAS initiatives.

CAS's development as an umbrella organization was at least partially caused by the complexity of negotiations around the National AIDS Strategy. The pressure to work quickly and effectively was particularly heavy in negotiations for Phase III. The achievement of ongoing funding for AIDS work in Canada is a huge gain for the Canadian AIDS Society, bringing benefits to many member organizations. CAS's activity as an umbrella organization was key in accomplishing the renewal of the strategy.

## CONCLUSION

CAS, as a collection of organizations, and as a representative voice in Ottawa, displayed an evolving set of characteristics which developed in conjunction with the number of member organizations, the size of the paid staff in Ottawa, and the work that the organization carried out at a national level and with local organizations. This evolving character is seen through the theoretical concepts discussed here. Beginning as a very loose and informal *network*, CAS became a *network and a coalition* within a few years of its formation. That is, it took on a more formal and bureaucratic structure in order to manage its relationship with and best represent local organizations. With increasing formalization, this coalition developed to a point where it displayed some of the characteristics of an *umbrella organization*. That is CAS took on more of a leadership than a representative role and began speaking on behalf of member organizations at national level meetings with government and other agencies concerned with HIV/AIDS issues. In concrete and theoretical terms there is a great deal of overlap between these concepts, as I discuss in the opening of this chapter. While CAS has become more bureaucratized and formalized, it has also continued to act as a coalition and to use networking as a means to create and coordinate protest and lobbying activity. The

structure for this formalization was in place at least since incorporation in 1988 and quite possibly earlier (even, perhaps, with the election of the first board in 1986). There has been a changing dynamic within the organization and in its relationship with member organizations, which is evident throughout my exploration. The speed of negotiations for renewal of the strategy meant that CAS lost ongoing input from member groups (I deal with the effects of this more locally in chapter 6). With the development of the organizational character and ongoing formalization as a network, coalition and umbrella organization, CAS was increasingly effective in Ottawa as a representative of ASOs' needs and demands, making significant gains alongside other national partners in negotiations with the government.

In the following chapter I expand on these concepts, making them clearer through drawing on other issues introduced in chapter 1, which will broaden my discussion with regard to CAS and allow me to develop the argument with regard to the evolution of collections of organizations over time. I discuss a number of issues in relation to CAS and to the three core characteristics of this chapter.

## **CHAPTER FOUR**

### **CAS: INSIDER OR OUTSIDER ORGANIZATION, MOTIVATION, IDENTITY, FRAMES AND IDEOLOGY, OUTCOMES**

Having outlined the development of the Canadian AIDS Society as a network, coalition and umbrella organization, I turn to an examination of other issues in the social movement literature which add to my understanding of these characteristics and of CAS's development as an organization. These other issues, discussed in chapter 1, are a part of the Canadian AIDS Society's development as a social movement. CAS had an evolving organizational form; in this chapter I show the effect of these features on general outcomes for the organization and, in the remaining chapters, for its member organizations.

In this chapter I discuss the following issues: 1) CAS's position as an outsider and an insider organization, which relates to the use of one or several organizational forms; 2) motivation both for individuals forming CAS (mobilization) and for development of the group as a national organization; 3) the identity of CAS 4) the frames used by CAS members and staff (particularly in presenting CAS to the media and through documentation) and the ideology behind these frames, which is related to motivation; 5) the outcomes of actions for CAS (and ultimately for member organizations). These factors are fluid over time, changing with CAS's increasing formalization and general development. I discuss how these concepts inform an understanding of CAS's activity into the late nineties, and how its relationship with member organizations and the government

affected this development. In discussing these issues I show that there was a dynamic organizational development in CAS's workings and relationships with member organizations. I relate each of these issues to outcomes for CAS and to the necessity of organizational development in order to attain desired outcomes. I discuss the effect of these features on specific outcomes for the organization, tying them to the characteristics analyzed in the previous chapter.

CAS has displayed diverse features in its development, the totality of which are beyond the scope of my current work. However, to the extent that they are relevant here they are discussed in the following.<sup>1</sup> The dynamic nature of each concept, and of CAS as an organization, allows for a vivid portrait of development in the group, building on the description in previous chapters.

#### Insider/Outsider Organizations

Within the social movements literature, particularly on AIDS, alliances between insider and outsider organizations are much discussed: insiders tend to be more moderate than their activist counterparts, with access to government or other elites (see Brunni, 1997; Wachter, 1991; and Haines, 1988). The particular stance of a group affects its ability to form alliances, particularly if to other organizations it appears to be in the pocket of the elites to whom it attempts to gain access. Insider and outsider positions, therefore, have an impact on outcomes. There is a discrepancy here in that while access to elites might have a negative impact on the ability to form alliances with other groups, thus

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<sup>1</sup> This dissertation does give a fairly full history of the development of CAS but it is not comprehensive because I have not been able to carry out research on the full range of member organizations. Certain aspects of CAS's story clearly come into focus, while others do not.

decreasing mobilizing potential, it can also be seen as a mark of success, following Gamson's (1975) discussion of outcomes. The stance of CAS's founders and of the developers of the organization (which might also be tied to frames) may have affected its ability to network and ultimately to form a coalition or to serve an umbrella function. With this in mind, I hypothesize that a coalition organization such as CAS will choose both roles to the extent that this is possible. CAS walked a line between insider and outsider status and displayed characteristics of both an insider and an outsider organization, using access to government while remaining critical and holding a contrary stance at least for several years following its incorporation. Therefore, it was able to maintain a broad based appeal to ASOs. This was a position that interviewees said they actively pursued. In theoretical terms it would allow for broader general goals and the best range of outcomes for an organization like CAS.

In CAS's more murky pre-history it seems safe to assume that all AIDS Service Organizations (and early member groups) were outsiders, having been formed almost exclusively by gay men, dealing with a group of highly stigmatized HIV+ individuals, and having little access to mainstream sources of power--political and otherwise. A good example of this is given in a *Globe and Mail* article in which Michael Phair, the first CAS board chair and founding member of the AIDS Network of Edmonton, described the appropriation of resources (such as photocopying) when the government was, he argues, slow to provide money to local organizations (*Globe and Mail*, April 22, 1994:A3). The outsider status of ASOs and the populations that they served is also evident in the accusations of homophobia directed at the government for its lack of action on AIDS in the early 1980s (*Globe and Mail*, Nov. 8th, 1995). However, CAS was not a complete

outsider without access to the government: even before incorporation CAS received funds from the government for meetings and Richard Burzynski and others were able to get the attention of government figures, though this did not result in much government action.

We [the CAS board in 1986] were meeting, I think, about quarterly and simply at the good will of Health Canada, which allowed a small amount of money to flow through the Edmonton Network. They were the responsible body that was given a small amount of money, principally to see that the board of directors of the Canadian AIDS Society could continue to meet and continue to develop. Michael [Phair] got that funding--he was responsible for it.

(interview with Michael Sobota, April 1999).

Ironically, this was the same Edmonton group as had previously appropriated government resources before 1986. So even at a very early stage of CAS networking and formation, the group was receiving support from the government. However, CAS also supported some external pushing prior to incorporation. Taking from the government while maintaining a critical stance was an important part of CAS's development.

And so there were people coming to the conference, who had decided that they were going to have a rally and hang Jake Epp in effigy, or whatever. And I have to say that I as chair of the Canadian AIDS Society and some of the rest of the board initially were quite uneasy about it. Well, also the Canadian Public Health--it was the first time they were dealing with a group like ours, and the feds, and they were all not happy--they were uncomfortable with us in the first place and they all wanted us to kind of control this and finally, probably because there was no other choice a couple of us on the board and myself had enough sense to kind of say, Wait a minute. People want to do this--Good. Let's just do it and not worry about it. It's going to happen anyway. Let's just be part of it and not let any of this other stuff stand in the way. So that took place as part of it and of course that got a lot of coverage. Other parts of that conference did get coverage too but certainly the hanging of whasisname in effigy did as well. I guess it was one of the first semi-radical national things to take place around AIDS. There were certainly some things that were radical and pushy happening at the local levels but I think this was probably the first real kind of national thing.

(interview with Michael Phair, May 1999)



CAS did not engage in much ongoing radical activity at the national level but burning the Minister of Health in effigy (or at least publicly supporting that) shows a willingness to identify with outsider organizations in Canada.

With incorporation in 1988 and “the first grant provided by the Ministry of Health in Ottawa” (interview with Richard Burzynski, March 1999) one would expect from the literature that there would have been more of a push to have greater inside access, or that the group would have been co-opted to some degree. But several of the respondents emphasized that CAS walked a line between the inside and the outside. Rather than choosing exclusively either to work alongside the government and other bureaucratic institutions or to maintain a more distanced position, they sustained a difficult balance between the two. One early board member from this period strongly argued that there should be both an inside and an outside, even though she saw this as a much more complex and difficult position to maintain than one stance or the other. A volunteer political consultant had written a paper recommending that the organization be on the inside<sup>2</sup> but board members seem to have felt that CAS needed to be able to maintain a critical stance. In this regard, Joan Anderson, a former board chair, argued that CAS was always up front about its activity with the Ministry of Health.

AAN! and CAS linked efforts leading up to the National AIDS Strategy. AAN! was doing public demos on the streets and at CAS we used these to support our meetings with the Minister (Beatty), about the growing frustration and need in the community...we didn't dump on the activists or apologize (to government) but acknowledged that their actions were understandable given the deaths and frustration. That strategy has been consistently used over the years.

(personal communication from Joan Anderson, August 2000)

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<sup>2</sup> This was a confidential paper giving confidential advice and is not available.

In practice walking this line appears to mean that CAS continued to work with the government on a number of fronts (particularly the National AIDS Strategy) while also remaining critical of certain government policies.

Sometimes member groups would accuse you of being co-opted. Internally when you're in a meeting with a cabinet minister its a little bit like an audience with the Pope. You did have to observe certain politesse and protocols while still trying not be as aggressive as you can around issues. I believe that for the most part CAS's record shows that it struck a good balance.

(interview with Michael Sobota, April 1999)

The balance lay in CAS's ability to maintain a critical voice even while having access to and a relationship with the government: "Oh CAS is definitely on the inside as far as the government goes but also at the same time--if a good strategy would be for us to do a die in<sup>3</sup> CAS would do it" (interview with a former CAS board member, March, 1999). CAS did, therefore, gain access to government fairly quickly and this is something that was maintained:

Earlier my sense was that they very much had access. They in fact had direct access to the Minister, particularly in Perrin Beatty's time. They were very influential and could have very frank discussions with him. That was extraordinary for a non-governmental organization to have. It seems to have varied in terms of who the minister was. I'm convinced in all of this that personalities are crucial. A few years ago there seemed to be frustration among leadership of the Canadian AIDS Society. My impression was that the Canadian AIDS Society seemed to have less access than had been in the past. But my impression is that that has changed with Alan Rock. For Alan Rock to announce for example that the National AIDS Strategy funding is now ongoing and there will not have to be huge advocacy efforts put into getting renewed every five years is evidence of more accessibility.

(interview with former CAS board member, April 1999)

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<sup>3</sup> This is a demonstration where protesters disrupt events by acting out deaths in order to put across the message that lack of action, bigotry, etc. is causing AIDS deaths. Probably the most famous instance of this was the ACT UP "Stop the Church" action against Cardinal O' Connor in New York in 1987 (Handelman, 1990). It is interesting that the members see the 'die-in' strategy as unconstrained by their semi-insider status.

The emphasis on access to government is an indicator of insider status and is also a good outcome for CAS in that influence and some degree of power develop with this. It is interesting that so much, at least from the perspective of several of the respondents, is dependent on the personality (as well as party allegiance and the political climate at the time) of government ministers. For example, there was a big change in access between the terms of Jake Epp and Perrin Beatty.

Perrin Beatty was very supportive--he was the first health minister who was. Jake Epp was not. The cabinet shuffle occurred in the summer and [Perrin Beatty] went away on vacation and he read And The Played On while he was on his vacation. And he came back infused and enthused and an ally to do things with us and the energy change was like night and day. I remember that.

(interview with Michael Sobota, April 1999)

It would seem to be a weakness that CAS was dependent on personality but this might be tied to trust that needed to be built up in order to exist as both an insider and an outsider organization. Also, CAS, as with any non-governmental organization, was an insider on certain issues and able to influence policy but only a limited decision maker at the government level, for example in input into the National AIDS Strategy. CAS was eventually only one of ten stakeholder organizations. While it was an important player, it is difficult to measure the level of power and influence that CAS representatives actually had.

Commenting on CAS's activity more recently and on decisions that had to be made regarding negotiation with government and taking an activist or a moderate position, one recent CAS employee said,

Well, as the issues change, and as government has changed the way it does business. I mean, as an organization, you have to make a choice about what you are going to do. You can be an activist organization and refuse to collaborate, take very strong points of view and compromise nothing. People who do that are very

brave and organizations that have managed to pull that off are very valuable. But the CAS position has always been a little bit more moderate of that in the sense that we, having relationships with the minister of health, with federal government politicians and bureaucrats is very important. Having functional relationships. And maintaining those relationships means, sometimes, compromising. You know, we were able to bring a lot of strengths to the table in terms of renewing the National Aids Strategy but it's a real different negotiation than a lot of people anticipated because we couldn't just sit there with one position and not waver. We had to bargain. We had to give things up. We had to agree to that and get this, kind of thing. And CAS was able to provide effective leadership because...that's the kind of relationship we have. And had it been a group like AIDS ACTION NOW!, you know, I'm not sure that it would have gone the way it did because they don't work that way.

(interview with Russell Armstrong, February 1999)

Insider status affected strategy: "maintaining those relationships" with government sometimes meant compromise, for example in Phase III of the National AIDS Strategy. It is clear that a relationship was built up with the Ministry of Health and that perhaps as the relationship within CAS moved from being between individuals to between member organizations, so the relationship with the government moved from individuals to departments and at this level CAS worked as an umbrella organization. This is elaborated in the National AIDS Strategy negotiations, where CAS's acceptance as an important and legitimate stakeholder is clear.

That's a matter of strategy and tactics and in a major situation like trying to get this new Strategy, you need everything they've got. So, you know, I was able to build personal relationships with people like the Minister of Health, etc., etc. and become a trusted confidant at the minister's office and all that stuff. Meanwhile people at AIDS ACTION NOW! were interrupting the Prime Minister's election speeches and doing all these things that got incredible media attention. And we would never, CAS would never despair at anything anybody did but we would say either that, We didn't know anything about it or, They weren't acting on our instructions or anything like that--just to keep the whole game going.

(interview with Russell Armstrong, February 1999)

So CAS continued to walk a line throughout the period under study. It is interesting that it was both insider and outsider, maintaining links to government agencies

and individuals and to outside groups. Furthermore CAS performed insider and outsider functions in negotiating and pushing. While access to elites was evident from very early on, access increased over time and participation in negotiations around the National AIDS Strategy parallels the increased professionalization and formalization of CAS. The organization continued to hold an outsider perspective, focusing on activity with ASOs and, as was the case before renewal of Phase III of the National AIDS Strategy, ready to mobilize over government inaction. CAS needed to walk the line between insider and outsider status in order to achieve the best range of outcomes in relation both to the government and to member organizations (discussed in chapters 5 and 6). The maintenance of insider status (and the positive outcomes which are an important part of this) is tied to the increased formalization of CAS and its umbrella organization characteristics, which became increasingly prominent with each stage of the National AIDS Strategy. Network characteristics are more closely related to insider status, outlined in chapter 6. CAS acted more as an insider organization, with increasing access to government and other elites, as time went on.

### Motivation

As I discuss in Chapter 1, motivation for action by groups can come from three elements. According to Pinard (1983) all three are necessary: internal motives, which are forces pushing the actor to take action; external incentives, which are the rewards in the environment pulling the actor to action; and expectancy of success, the expectation that goals will be achieved. I discuss the internal motives of individuals in forming CAS, looking at the formation of the network (the need for a nationally representative voice),

the building of this into a coalition, and development as an umbrella organization. What were the motives for organizational development in the form that it took? In Chapter 6 the question is the extent to which ASOs saw themselves as weak and in need of external support before joining CAS.<sup>4</sup> On the whole motivation is related to the pursuit of positive outcomes.

Staggenborg (1986) highlights the need for organizations to pool resources and form coalitions in order to effectively respond to opportunities and threats within their environment (Oliver et al. (1985) present a different reasoning regarding mobilization--if I don't do it no one else will). Forming alliances was seen by activists as the way to get things done (see also Schneider, 1992).

...forming alliances was part of getting things done...because the issues were large enough but the opposition was big enough that you couldn't do it by yourself. You needed to build support. So, a lot of the early leaders in HIV/AIDS were experienced community activists. Forming coalitions and working together is really part of effective community activism.

(interview with David Garmaise, former CAS employee, February 1999)

The opposition was so big and powerful that it was not possible for isolated individual groups to take it on.

It's a whole bunch of factors that result in the growth of community-based AIDS work and as organizations develop they looked to belong to a group of organizations that was like them for mutual support, to help, you know, solve common problems. Having a sense of solidarity has always been very important for AIDS organizations. At the local level everyone felt under siege in various ways and faced a lot of different opposition to their existence. Knowing that you're part of this growing network across Canada is very important.

(interview with Russell Armstrong, February 1999)

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<sup>4</sup> Founding member organizations, well represented in my sample of groups, were mostly coming from a position of strength and if there was any weakness that led them to come together it was the complete lack of representativeness at the national level, which was a distinct disadvantage. The study of weaker organizations is an important area for future research.

This is clearly about the internal motives for the formation of the CAS organization, expressed in the need for connection with other groups fighting the same fight. The knowledge that one group was not alone in the struggle was an important factor from this statement. The reasons given for its formation by one of CAS's founding board members, also make this clear.

And that meeting [in 1985, the First Annual Canadian AIDS Conference] was pulled together exclusively to focus on whether we wanted to put together some kind of national organization or group, as opposed to the first one. And we got, at that meeting, quite a bit hammered out in terms of a framework--first of all there was an agreement that there needed to be a national organization, that it needed to be made up of the non-government volunteer AIDS organizations.

(interview with Michael Phair, May 1999)

The sharing of information was another motivation.

We were such a minority at that time...a big piece of it was sharing information as well, not reinventing the wheel but getting together and sharing information, this was pioneer work--this was brand new work. AIDS was different. So getting together, supporting each other was a big piece of it and sharing information was a big piece of it. And we were all AIDS Service organizations, we all did advocacy, education and support.

(interview with early CAS board member, March 1999)

Information sharing can be seen as both an internal motive (related to groups providing support for one another) and part of the expectancy of success. Another internal motive for action was government inaction, which was expressed as a grievance. It was felt that if gay men did not stand up no-one else would. CAS itself added to this at the local level, advocating on behalf of ASOs: "I would reiterate in the early years advocacy was the main thing. And the work that Richard Burzynski and Michael Phair did around that to advance the AIDS agenda" (interview with early CAS employee, March 1999).

External motivation was rooted in the need to have a national voice for local AIDS organizations and this in itself was seen as something that would create opportunity for ASOs:

Well, I think the first thing and the major thing...was to provide that forum where people from across Canada could have a national agenda. And increasingly trying to deal with the Ottawa machinery and deal with the bureaucratic machinery and trying to articulate in a much more thematic way the population and its agenda to the federal government and trying to work with the federal government and the bureaucracy. CAS was able to provide a forum all over the country--to debate what it is that you are trying to achieve.

(interview with Richard Burzynski, March 1999)

This is reflected in the agenda for the 1986 Second Annual Canadian AIDS Conference, organized by the AIDS Committee of Toronto "on behalf of the Canadian AIDS Society" (AIDS Committee of Toronto, 1986): the mission of the Canadian AIDS Society is given as, "To fight AIDS by strengthening community-based efforts and by speaking as a national voice with the experience and resources of member organizations." (Canadian AIDS Society, 1986: introduction). A number of the sessions at the conference were devoted to education on key AIDS issues (e.g. "AIDS and the workplace: legal and human rights issues") and to organizing and supporting groups at the local level (e.g. "How to set up and maintain a community-based AIDS organization" and "Striving for control: the impact of AIDS on affected communities"). This appears to be the "forum for debate" to which Richard Burzynski refers.

The motivation is tied to the need for a national voice which could deal with government bureaucracy and articulate the needs of local organizations forcefully at the government level. This, if well done, creates resources (at least information, which groups can use) and opportunity for ASOs, increasing mobilization potential. These are external



incentives for formation of CAS and for groups to join. Internal incentives will be discussed more fully in relation to ideology. The analysis of local ASOs in chapters 5 and 6 is also revealing in terms of internal and external motives for groups joining CAS, essentially a question of what they gain from adhering to a large national organization. The CAS founders came from local organizations and their motives may, therefore, reflect those of ASOs coming into CAS: to have a strong voice for advocacy.

All elements of the motivation model are present. Internal motives came from the grievances that organization members felt and the inability to achieve goals if they did not unite (Russell Armstrong, quoted above in an interview (February 1999), says that they felt "under siege"). The external incentives (and goods to be obtained) are directly related to the advantages of unity. That is, the ability to help solve common problems, to pool resources, and to share information in order to reach goals. All of this was tied together with an expectancy of success.

Internal and external motives and the expectancy of success were all at play to some degree and were behind the formation and development of a national level organization. CAS was able to mobilize itself and member groups on the basis of the internal and external motives discussed above and because of expected positive outcomes for those affected by AIDS in Canada. This was an important part of mobilization and the ongoing work of attracting new member organizations and support from (and alliances with) other groups. The extent to which this continued to be true is discussed more fully in the next chapter. CAS was motivated to act in a way that would bring good outcomes not only in initial mobilization but also in the development of the group as a network, coalition and, for certain goals, a more bureaucratic umbrella organization.

## Identity

The main question here, drawn specifically from the AIDS literature (see Lehr, 1993, and, for a more general discussion, Stoecker, 1995), is the extent to which gay identity played a role in CAS's activity and development. The magnitude of identity change in CAS is also important, reflecting the changing demographic of HIV/AIDS in the Canadian population.<sup>5</sup> There are also questions related to the pursuit of an insider role: To what extent did CAS's identity as a political insider or outsider affect CAS or the relationship with and between member organizations? This question was important for CAS in the late eighties and early nineties. To what extent could CAS be identified as an organization that was completely inclusive of PLWHIV/AIDS and what was their role in the organization? This was the subject of the debate within CAS, "Who Does AIDS Belong To?" (see Manning, 1990), which a number of respondents discussed. While the effects and full analysis of reaching out to other populations and organizations is beyond the scope of my research, CAS's somewhat fluid identity (Stoecker, 1995) changed along with the AIDS demographic. An increasing number of member organizations were not based on gay identity and the staff at the Ottawa office (and in local ASOs) came more and more from outwith the gay community. Identity also had an impact on outcomes and the ability of CAS to act as a network, coalition or umbrella organization. This was especially true with regard to initial mobilization, which might not have been possible without gay identity at the core and prior organization and networking within the gay community. The development of the organization, particularly the stance against

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<sup>5</sup> More recently there are an increasing number of women and intravenous drug users who are infected. These groups are not traditionally represented by the ASOs, many of which were begun by gay men, as discussed in Chapter 5.

homophobia, is also related to identity and impacts goals and outcomes. One clear example of this was government slowness to meet with CAS as a 'gay' organization. Networking developed based on gay identity and a common AIDS agenda.

Gay identity has been important throughout CAS's history; while it has been a source of tension, it was also a source of strength, particularly in prior organizing by the gay and lesbian communities in the seventies. It was important for many who were involved that this was an organization in which they could be open about their sexuality:

I mean, so many of the people who were working for CAS were gay and so many of the member groups were staffed by people and had people on their boards who were gay--it was just such a major presence. I don't think we sat around and talked about it much, so I don't know how important it was in terms of our focusing on gay issues but it was hugely important in the sense that everybody was just so open about being gay and working for CAS. I remember feeling that this was the first place that I had ever worked where I could be so open.

(interview with David Garmaise, March 1999)

The experience of gay identity within CAS had public and personal impacts. At a personal level this was very important but it is clear from a number of interviews that there was something of a split between what was implicit and what was explicit regarding gay identity:

Well my opinion is that it was quite significant and very very important. There was, I think, a sense that--for myself as someone who's gay and many of the others who were at that time, not all but most, that if we didn't do it as gay people--didn't work at this--then no-one would and that many people would be glad to see us just get sick and die here. And I think that was extremely significant in much of what many of us did at local and national levels. I think it was probably at an organizational level implicit and at an informal level much more explicit. We certainly talked about campaigns aimed at gay men and how we could get gays and lesbians to be more vocal and push and what gay organizations might be involved and active. We talked about the gay press and some of that...at an informal level we were probably much more explicit.

(interview with Michael Phair, May 1999)

Questions of gay identity were important and may well have been part of the motivation for taking action (as is evident in this quotation). But the fight against homophobia was not necessarily central to organizational goals, particularly because, while CAS was an organization founded by gay men and largely serving that population in its early years, it was not a gay organization (interview with early board member, March 1999). This desire not to be seen exclusively as serving the gay community<sup>6</sup> but as broad based and far-reaching within different Canadian communities perhaps explains the implicit/explicit split and is related to seeking positive outcomes for all Canadians affected by HIV/AIDS, not just the gay community.

The tension between explicit and implicit gay identity was also present from the earliest stages of CAS's dealings with external agencies (Josh Gamson's (1989) article on ACT UP notes this strain).

And there were a lot of gay groups that also came to focus on HIV - most of the groups were gay based. I think at one point there was, when the grant first came, there was real fear that we wouldn't get money for a gay organization - there was a lot of homophobia around. There was an internal feeling of, Let's not shout who we are too loudly. In organizing, in the office, it was all gay men. Certainly out and proud of it but at the same time trying to keep a balance in the national office - or in dealings at the national level and it was a delicate step and I think within a couple of years that delicate step became, We are no longer going to be delicate. More and more you found people more and more comfortable with these issues.  
(interview with Richard Burzynski, March 1999)

Gay identity, therefore, was thought initially to have an effect on dealings with the government. The government was accused of homophobia a number of times by CAS.

This was particularly true of the early years when AIDS came to North America. Russell Armstrong asserted in a *Globe and Mail* article (O'Shaughnessy, 1995) that there had been

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<sup>6</sup> This is much discussed at the local level not only by CAS member organizations but by ASOs generally. It is certainly something with which ACT UP had to deal (Handelman, 1990).

a “distortion” around the risk of getting AIDS that he blamed on homophobia.<sup>7</sup> Initially homophobia was seen as synonymous with attitudes towards those who were HIV+ in the West. Being identified as a gay organization was problematic for CAS but it was also a source of strength at a personal level, as I have already shown. Politically, gay identity was the bedrock for later HIV/AIDS organizing and had an impact on CAS as a new and developing group.

Gay and lesbian liberation efforts were one of the foundational perspectives from which the HIV/AIDS movement grew. So key members who were activists of the movement were first gay and lesbian liberationists and that’s the perspective from which they came, although there was a variety of perspectives around what that liberation meant and the degree to that. For a lot of gay men the HIV/AIDS movement was their national liberation movement in a way that there had not been resources to have a previously funded explicit gay/lesbian/bisexual liberation movement. It’s been really hard to have an ongoing national gay/lesbian/bisexual coalition.

(interview with a former CAS board member, April 1999)

This was further articulated by Stephen Manning (1990) in his discussion of who AIDS belongs to:

The volatile mix of gay liberation and lesbian feminism that runs through AIDS movements has provided us with a means to attack the deadly silence and prohibition which government, medicine and social services bring to AIDS responses. Gays and lesbians know how to articulate the links between sex and identity, pleasure and justice. Such a sexual politic is crucial if we are not to become agents of the state in regulating our own communities” (1990:4).

CAS was strongly gay identified in these early years. Another example is in an early meeting with a government representative.

...a Health Canada officer, who I think at the time was representing the Health Canada region of British Columbia. He was present with us at that meeting. And we were being admonished to tone down what we were saying about gays and AIDS—that the proposal to the federal government should not unduly emphasize

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<sup>7</sup> This comes out again and again in a number of *Globe and Mail* articles on the trial in connection to the Krever Commission Inquiry: see *Globe and Mail* articles from April 22nd, 1994 (p. A3); October 13th, 1995 (p. A7) and November 8th, 1995 (p. A3).

that. That it would be received better if we tried to place ourselves somewhat more, quote/unquote “in the mainstream” rather than look like we were dealing with this chiefly minority population. I remember us having some quite loud arguments about that point.

(interview with Michael Sobota, March 1999)

The fear of homophobia was real, expressed by a government representative and highlighted by CAS in newspaper reports. However, gay identity was an important part of the motivation for the group forming and was something that directed the choice of some of CAS’s actions over subsequent years and had an impact on outcomes. In discussing the same meeting further, Michael Sobota highlights the diplomatic dynamic at work:

So it was a startling meeting for me and it was very much an eye-opener for how the Canadian AIDS Society would have to steer a political course through its early years. When we had all started with some brash radical energy, at a national level we were going to have to be a little bit more polite and a little bit more professional and a little bit more discrete in what we were proposing or what we were doing.

(interview with Michael Sobota, March 1999)

It is clear that the need to steer a political course impacted framing in meetings with government and possibly affected outcomes. CAS could be seen by many organizations as a safe place to go.<sup>8</sup>

From CAS documentation, the Society countered homophobia on a number fronts. In documents such as Homophobia, Heterosexism and AIDS (Canadian AIDS Society, 1991), and The Canadian Survey of Gay and Bisexual Men and HIV Infection: Men’s Survey (Morrison, 1993), which was derived from a poll of over 4,000 men on attitudes towards sexuality in the time of AIDS, CAS confronted societal homophobia. These documents (and statements in Annual Reports, *The Globe and Mail* and elsewhere) pointed to the importance of confronting homophobia if AIDS was to be effectively

stemmed within Canadian communities. CAS reached out primarily, but not exclusively, to gay men and specifically targeted homophobic attitudes as worsening the AIDS epidemic, both politically and personally. There is a close identification with the gay community within CAS documents and advocacy of a strong gay identity as the healthiest response (Morrison, 1993). Identity affects action, which, with ideology and frames, impacts outcomes.

While gay identity was of ongoing importance there were also other identity questions that came to the fore, and gay identity was not equally important throughout CAS's development.

I would say initially yes [CAS had a strong gay identity]. But I think that was typical of many AIDS organizations back in the early years given where they were being born from. And back in the early years there was such a public perception of AIDS as a gay disease that it was just natural that it attracted a lot of gay men and lesbians to the work because you could be open about who you were. You could be very comfortable in your workplace and you could make a difference. I am not so sure now AIDS organizations are necessarily gay-identified any more.

(interview with early CAS employee, March 1999)

It is perhaps less useful, with the changing demographic of AIDS for ASOs generally, and CAS in particular, to be as strongly gay-identified as in the past. This was explicitly discussed by a couple of organizers at the national level who have been more involved in recent CAS work.

The leaders of the Canadian AIDS Society at the staff level--all of the senior staff level, all the executive directors have been gay men.<sup>9</sup> You know, open, gay-positive men, who have used that as a source of strength about what they do and as a guiding light in terms of how to get through this complexity. CAS has never billed itself as a gay organization, nor do I think that it would ever have done that, necessarily. Although it did publish a paper in 1989 that was basically a transcript

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<sup>8</sup> I discuss this and the extent to which gay identity was important for local organizations in chapter 6.

<sup>9</sup> This is not true of the most recently appointed executive director (in early 1999, following the first of my interviews), which perhaps reflects something of an overall changing identity and the professionalization of the organization. Russell Armstrong comments on this in chapter 2.

of a speech given by an executive director<sup>10</sup> of a group in Toronto about who owns AIDS and that paper came down solidly on the side of, Gay men principally own this issue and that everyone else is an ally to that issue. And I guess that reflected at the time certainly what the leadership of the Canadian AIDS Society felt. And I know that it said really what everyone else felt. But when I started I sort of felt that it was a difficult position to hold because, whereas local organizations might be able to get away with something like that and not have it backfire, at the national level as soon as you say that one group is privileged over the others you immediately get just overwhelmed with charges of inequality and then all these groups are organizing against you. Either establish separate organizations or just trying to bring a process to change the balance.

(interview Russell Armstrong, February 1999)

The changing identity of the organization, and the effect that the broadening membership had on this is reflected in the comments of one board member who continues to be involved at the local level.

Well I remember then...as in, In the Beginning. I think I was one of the very few straight people involved. And now there are a number of straight people involved but its not a case of straights versus gays. We talk about, the face of AIDS has changed. We're dealing, for instance, with a lot more women, straight men, needle users, sex trade workers, families, children. And we have to adjust for that and to adjust is to learn what the needs are because the needs are different and how, for instance, a group of women work in a support group is very very different from how a group of gay men used to work in a support group. But at the same time be very cogniscant that we cannot stop providing the services that we have because still the largest segment of the population that we serve living with HIV are gay men. And so we still go to drag shows...I mean it's still all part of our culture. And its part of our culture that we're very proud of and with CAS I know it's still the same thing. It's adding to it's not subtracting from or doing instead of.

(interview with local worker and former CAS board member, March 1999)

This is about the changing demographic of AIDS, also apparent in the wide variety of CAS member organizations, many of which represent groups not primarily made up of gay men (e.g. women's groups and groups based on ethnic identity). From this quotation and elsewhere, the changes in CAS's identity are more implicit than explicit, as was the case when the group's identity was first established. The change comes with different

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<sup>10</sup> This is Who does AIDS belong to?. Stephen Manning's paper, which I quote from earlier. In it,



generations of activists: the founders and first round of AIDS member organizations were much more strongly identified as gay men than has been the case recently. The recent change has to do with the altering face of AIDS and perhaps more specifically with the increased formalization of CAS and the related search for more qualified workers. Changes in composition of affected communities and the work done by ASOs (and, therefore, CAS) are also important. CAS did not engage in identity politics as much as if it had been more exclusively an outside organization needing to focus on identity as a rallying point and directive for action. The motivation for involvement in CAS came not so much from identity questions as from seeking certain outcomes: specifically, information and financial resources from the government. The benefits of CAS's gay identity are more personal than political or universal, although the identity of the organization was an important part of early mobilization.<sup>11</sup>

The question of identity, and the role of particular constituent groups (PLWHIV/AIDS, gay men), was much discussed and debated in the issue, "Who Does AIDS Belong To?" The ultimate accepted answer appears to be gay men.

[CAS] did publish a paper in, I think it was in 1989, that was basically a transcript of a speech given by an Executive Director of a group in Toronto about who owns AIDS and that paper came down solidly on the side of, Gay men principally own this issue and that everyone else is an ally to that issue.<sup>12</sup> And I guess that reflected at the time certainly what the leadership of the Canadian AIDS Society felt.

(interview with Russell Armstrong, February 1999)

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Manning refers to gay and lesbian contributions

<sup>11</sup> However, the changing identity has possibly alienated some of the founding member organizations, or at least the founders of those organizations, who keenly felt the move away from gay identity politics (see chapter 6).

<sup>12</sup> In this document Manning (1990) states that, "I believe the three characteristics [for assessing the claim of a community to moral leadership of the issues of AIDS and HIV infection] I have described best fit the gay communities of Canada" (3) and "Community-based AIDS organizations and gay and lesbian communities need each other. The crisis of one is the crisis of the other" (7). Manning was the executive

However, the debate largely centered on PLWHIV/AIDS and the place that they should have in CAS. This is discussed in Roy (1995) and seems to have been resolved with the granting of certain board positions exclusively to those who were HIV+ so that they would constitute a significant part of the board. There have been no major conflicts over this since 1991 and groups nationally focusing on and run by PLWHIV/AIDS were not able to get off the ground. In response to a question about this Charles Roy gave a detailed response:

I don't think that I would necessarily use the word "own" but I know others have. I think the primary tension that I remember that year was around the issue of subsidies to attend the annual general meeting. The Canadian AIDS Society provided two subsidies per group for people to attend the annual general meeting. The people with HIV Committee of the board, that I chaired had proposed that we have a meeting before the annual general meeting, which would be this forum. There wasn't a lot of objection to that--there was some minor objection--but where the controversy came in is where we also proposed, in order to ensure that people with HIV can get to this meeting, that one of the two subsidies that the groups got needed to be used by a person living with HIV who was also coming to the forum. And that created great controversy. I think now its just kind of accepted. Like many things, when you first propose it seems radical and then over time you wonder what the big fuss was about. But at the time it was very significant because historically groups sent their executive directors and the chair of the board. And that was never any question that those were the two people that went to the CAS AGM. And what we were doing was, we're challenging that saying that you need to ... if the executive director or the chair of the board is a person living with HIV then you don't have a problem you can send both. But in the vast majority that wasn't the case. People with HIV weren't in positions of leadership in organizations and would never be able to get into a position of leadership unless they were given opportunities to increase their knowledge and growth. And one of the ways in which they could do that was by coming together with other people with HIV from across Canada, some of whom have experienced greater empowerment within their organization and we can exchange strategies and knowledge and information around that. And that by doing this in fact we would be building a community of people building communities where people with HIV were in the future taking more leadership roles and in fact looking to the future so that this might never be an issue at some point because there would always be people with HIV involved at a high level within organizations. So that

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director of the AIDS Committee of Toronto at the time. His paper also highlights something of the struggle to walk a line between the inside and outside. He is harshly critical of societal homophobia.

was our goal was to achieve that and once we'd achieved it we no longer needed the policy because people with HIV would be coming to this forum anyway because they'd be, like myself, an executive director of a large organization or a chair of the board. But back then there were very very few people, as my research uncovered. There were very few people with HIV that were in leadership positions in the AIDS movement. Unlike today. There's been a huge change.

(interview with Charles Roy, March 1999)

Identity questions did not coalesce over a long period of time around this issue and again were more an informal aspect of the character of CAS than a formal one. But the identity issue in terms of involvement of PLHWHIV/AIDS and the debate about who AIDS belonged to were important and were visibly confronted by the CAS board and employees and by many of the member organizations. Embracing PLWHIV/AIDS in the larger organization meant that the group was able to be more united as a whole, involving organizations that would otherwise have become marginalised. More unity, diversity and greater size (and income) of CAS were tangible outcomes of this.

One final area in which one might expect to see questions of identity come to the fore in a social movement is around conflict between forging a national identity and maintaining grassroots activity (Kleidman, 1993). The extent to which this was perceived as a problem by members of the CAS board varied over time (see chapter 6).

I think local groups understand that when we visit with bureaucrats or politicians it is for the greater good of the movement and...its dealing with funding for smaller groups. We're not just in there lobbying for funds for CAS but we're lobbying for funds for the greater AIDS movement. I think they understood that it was for their benefit that we were doing it.

(interview with nineties CAS board member, March 1999)

Michael Phair argues that there was a tension but the group was able to deal with it. In the early years of the organization the local and national levels were seen by Phair in very similar terms in relation to funding and the benefits that were sought.

Oh, I think there was some tension about that all the time. And I think that's typical of all national organizations. One of the things that helped us get through that is because so many of us were so heavily involved at a local level, where resources were so scarce and we were having to work so hard. But we were also able to say that in order to do some of that local level we've gotta hammer at the national level to get some of this going. It's a hard thing for many of us to do because there was also so much to do also at the local level but we did it. But yes, definitely some tension and I suspect there always will be around the national groups. If National groups are honest.

(interview with Michael Phair, May 1999)

This did not become a huge problem, as it has for other national coalitions (Kleidman, 1993).<sup>13</sup> Regional differences never became more important than national goals. The founders of the organization came from the local level and were able to maintain a balance. There was also little conflict over identity questions.

Looking at CAS's recent history, with 120 member groups, there is diversity: women's groups and ethnically diverse organizations and other distinct identities are represented.<sup>14</sup> The extent to which CAS nationally is still seen as a gay identified organization may simply be a throwback to earlier days when AIDS was more closely identified with gay men. The implicit gay identity of the organization remains to an extent but does not seem to have been explicit since the Who does AIDS belong to? document from 1989. The fluidity of identity and the ability to emphasize or de-emphasize gay identity in particular situations or documents is an important factor in building CAS as a

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<sup>13</sup> From the perspective of local organizations this may be very different. I would also hypothesize that where groups had no real interpersonal connection to the national scene this was more of a problem. The missing figures here are those who never joined CAS, who would have to be the subject of a much larger study. It is also possible that Canada's small population had a positive impact.

<sup>14</sup> Examples of several of these groups are: AIDS and Disability Action Program, BC Coalition of People with Disabilities; Healing Our Spirit, BC First Nations AIDS Society; Positive Women's Network; Feather of Hope Aboriginal AIDS Prevention Society; The Miriam Child & Family Support Group; Families and Children Experiencing AIDS - Camp Chrysalis; Africans in Partnership Against AIDS (APAA); Alliance for South Asian AIDS; Prevention Centre for AIDS Services of Montreal (Women). Many, but by no means all, of these groups are based in Canada's larger cities.

coalition of diverse local organizations and particularly in developing relations with the government, as was noted by Michael Sobota.

The changing demographic of those affected by AIDS led to changes in emphases of identity but may not have had much effect on organizational identity itself. The formalization of CAS, however, affected the make-up of the staff, leading hiring practices away from the gay community towards those who were more professionally qualified but without specific knowledge of AIDS and the gay community in Canada. While some organizations may have been alienated by this process (see chapters 5 and 6), this was good for mobilization in negotiation with the government and the ability to get relevant information to an increasing number of organizations. CAS's successful resolution of identity questions, particularly in the early nineties, paved the way for later work.

### Frames and Ideology

Ideology, like identity, is important in uniting member organizations and for the pursuit of common goals, and is expressed in collectively understood frames. The frames of an organization, like the identity, can be perceived from its actions (see McAdam, 1996, on framing through tactics). CAS's frames are clear in the actions it took upholding gay rights, opposing homophobia, seeking increased funding of ASOs and supporting the empowerment of local groups. Framing followed from a more complex underlying ideology, which shaped the pursuit of goals, and related outcomes, is shaped by ideology (Oliver and Johnstone, 2000, who discuss the relationship between ideology and frames).

With regard to framing, questions of insider and outsider status were important to how members and staff wanted the group to be perceived. How was the group to present

itself to government figures? Recall Michael Sobota's comment that "...the Canadian AIDS Society would have to steer a political course through its early years..." (interview, April 1999). This can be understood to be a form of framing through actions, as can much of CAS's activity. A more deliberate framing policy was not apparent in interviews but can be seen from CAS documentation. The way that the board professionally presented itself was also relevant.<sup>15</sup> "Not only was [CAS] receiving significant funding to do projects. Having the ear of the minister but not at all hesitating to do difficult challenges of the minister and of government. And I think that's part of the sophistication" (interview with former board member, April 1999). Again, the National AIDS Strategy was an important forum for framing through action and attempts to get good stories out to the media.

The approach that I always took and, I think, the approach worked through the organization is very traditional: issue management techniques and positioning techniques of your issues across the broadest audience possible. What we try to do is say that AIDS is a national issue--an issue for every voting citizen in this country and these are the reasons why. Fortunately or unfortunately, because of the way that AIDS has touched so many people, directly or indirectly, you can touch a chord in a lot of different people. So, through a three year process of trying to renew a national strategy around AIDS we try to get good media stories that portray issues in ways that they were national issues.

(interview with Russell Armstrong, February 1999)

The emphasis, at least from this staff member's perspective, was on framing the AIDS "problem" as a national issue with an impact on everyone. This is an example of enlarging a frame to encompass more potential beneficiaries (Snow et al., 1980). At a national public level this was often done through press interviews and Mr. Armstrong appears prominently in these.

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<sup>15</sup> See Handelman (1990) for a discussion of ACT UP's presentation of itself, learning government and medical jargon in order to more effectively campaign on certain issues.

There are several issues through which the organization was able to present itself publicly. As I have already discussed, a number of *Globe and Mail* articles mention CAS's stance against homophobia and its criticism of the government's slowness to respond to the emerging AIDS crisis. Much of this coverage came around CAS's action in court over the tainted blood inquiry. Doug Elliot, CAS's lawyer, was prominent in newspaper reports highlighting the failure of the government and the Red Cross to take more concrete action to stop the spread of AIDS to the population at large. This was tied to accusations of homophobia. The struggle for equality and the rights of gay people was demonstrated in these reports and in CAS's court action. This was an important part of the organization's framing, which was a result of the tactics CAS adopted (see McAdam (1996), who makes the point that framing is not always a formal ideological expression). Tactics and action were CAS framing processes. Other issues were also reported in the *Globe and Mail*, most significantly the attempt to stop the Red Cross from releasing the names of five HIV+ men (August 18, 1995 A4) as well as other aspects of the Krever Commission inquiry. These attempts to get stories into the media and on to the public agenda were somewhat successful, although the outcomes of this are not clear. Frames and shared values were also articulated through the community action principles and membership criteria which CAS established.

CAS's early ideology focused on advocacy for local groups. As a staff member recalled, looking back to the late eighties and early nineties:

Definitely on advocacy. The Tories were in power. AIDS was so new. Just trying to get the funding levels increased overall. Because AIDS was only being dealt with within in a very small unit of the National AIDS Center headed up by Greg Smith. Way back in the early years. And then that was replaced by the Federal Center for AIDS and then eventually the AIDS Secretariat and then all the AIDS

units now. But I think initially and through certainly Richard Burzynski's term [1988-93] as Executive Director advocacy was the main issue. Certainly, working towards a first National AIDS Strategy.

I would reiterate in the early years advocacy was the main thing.

(interview with former CAS employee, March 1999)

This is tied to the emphasis on being a national voice discussed earlier. CAS took this role in order to best serve local organizations, building on information sharing, which was the main goal for the organization prior to its incorporation in 1988. However, while this was part of organizational development as a coalition, it was also tied to autonomy of local organizations as a defining ideology in terms of the board's interaction with organizations and, for better or worse, seems to be ongoing into the present period (see chapters 5 and 6).

While much of the group's ideology, like identity, is implicit rather than explicit, it was formalized in policy documents.

One of our organizing principles is a concept that we called 'health from below.' The Canadian AIDS Society produced--and I was a member of the working group that produced it--a wonderful and startling document called Homophobia, Heterosexism and AIDS. This was chaired by a board member from Calgary at the time... But it was the first document to link those issues together. In it we tried to pinpoint what were some of the common threads of membership in the Canadian AIDS Society. What did bring us together... we believed in health from below, not from top down kind of stuff that we organized in our communities and tried to provide services that would improve health. That was one of the concepts. What else? We believed in collective activity, we believed in advocacy as opposed to being neutral bureaucratic institutions. We believed we would always be cutting edge and pushing the boundaries. We were certainly aware that we work in a capital 'P' political field but that wasn't going to stop us from pushing edges and talking about things like heterosexism and homophobia.

(interview with Michael Sobota, April 1999).

#### Homophobia, Heterosexism and AIDS: Creating a More Effective Response to AIDS

(Canadian AIDS Society, 1991) is an impressive 60 page document cataloguing the history of discrimination, homophobia and heterosexism and their connection to AIDS,



and proposing a “health-from-below” model as the best response. The model’s core ideology can be summarized in the following paragraph from the document:

Within this model the PLWA is the person who has central control of his/her own care. In this health model, the wall between service providers and service receivers is removed: it is not “healthy people” looking after “those poor sick people.” Rather than people “doing to others,” what evolves is a dynamic partnership (41).

The implementation of this, according to the authors, was hampered by heterosexism, but they present the model as the best way to deal with AIDS in the affected communities and more widely through government and other institutions with whom gay and lesbian groups formed partnerships. There was competition over limited resources. One of the goals was to implement a new, more egalitarian model as groups faced “a constant challenge to remain true to their values and resist becoming like mainstream social service agencies” (Canadian AIDS Society, 1991:42) (i.e. hierarchical and top-down), which had been ineffective. Specific suggestions were also made for action that community groups could take. There was a clear ideological challenge within the document to remain egalitarian and present a different form of care. The effects of this stance are dealt with more fully in chapter 6. The egalitarian ‘health from below’ model ensured ongoing relevance to organizations. CAS provided information and tried to guarantee resources but the implementation of action was the responsibility of local organizations aware of local needs and able to act more effectively within their communities.

This document and Michael Sobota’s comment quoted above emphasize health from below and decentralized authority (tied to local group autonomy) for both health care and the organization of CAS. Decentralization seems to have been emphasized until the later stages of the National AIDS Strategy, when there was more centralization in

order to have representation in negotiations for the different phases of the strategy. The decentralized organizational structure was intended to allow more input from local organizations. However, it is not clear (as I discuss in chapters 5 and 6) that this was fulfilled, particularly in the recent period. The ideology of local group autonomy, rather than empowering local groups as the CAS founders desired, left some ASOs isolated. The necessity of centralization and formalization, discussed in chapter 3, conflicts with the ideology and results in the isolation of several groups and inhibits CAS's network characteristics. Had the framing question been confronted more explicitly this might have been avoided or a different relationship with member organizations might have been established. However, the wider, more inclusive frame allowed broad appeal to member organizations and potential members (Canadian AIDS Society, 1993) thus strengthening the CAS membership base.

### Outcomes

Throughout this chapter I have related several organizational characteristics to outcomes. In this section I focus specifically on goals and strategy of the organization in relation to outcomes. None of the activity was very rigorous, as several activists noted. I follow Gamson's (1975) two-fold discussion of outcomes: first, at the organizational level the fate of the group itself is the most important question and I discuss this in some detail (particularly whether or not it was accepted as legitimate); second, the distribution of advantages to member groups, which I discuss in chapter 6. I also want to tie this to the rest of the chapter, showing the effects of these issues on the outcomes for CAS and in

relation to organizational forms. I want to tie outcomes to each of the organizational issues discussed in this chapter.

From the interviews and documents it is clear that success was not measured concretely by CAS, even in follow-up to the two strategic plans (Canadian AIDS Society, 1991b, 1994c), which were not reviewed after their completion.

The other measure would be the programs we were able to implement and the studies we were able to do, the documents we were able to produce. We didn't have a very good system of evaluating their effectiveness or their degree of usefulness. So mostly it was feedback from member groups informally or formally. They would sometimes let us know what they thought, particularly if they had criticisms whenever we issued a paper or a report or a new document. And then there was the AGMs<sup>16</sup> where we got feedback in a more general sense. That's a good question because we really didn't have any sophisticated mechanisms set up to evaluate success.

(interview with former CAS employee, March 1999)

At best, success was measured by such means as public opinion research but this does not indicate outcomes that CAS was solely responsible for:

We have commissioned public opinion research. We haven't asked people about the organization specifically but we've looked at attitudes around HIV/AIDS and known that, although we're not responsible for change 100%, we do contribute--our organizations do contribute. We do establish goals in terms of policy work and advocacy. We want this decision to go this way. We want these particular laws changed. There isn't a very good way of assessing how much effort goes into that verses the return on it. In a technical way the issue of evaluation is a big one. It doesn't have a formal evaluation process and I think we measure success in terms of the financial support that we get, the membership base and how the membership continues to be involved. When your membership is apathetic it's a good sign that you're not really doing anything anybody's interested in. But when they're fighting on the floor of the AGM and yelling at you and trying to get you to do something it's a good indicator that it means something.

(interview with former CAS employee, February 1999)

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<sup>16</sup> I was able to gain access to one AGM Programme (Canadian AIDS Society, 1994), which may not be representative of AGMs as a whole. It does, however, show a high degree of member organization involvement in the AGM and there are documents from before and after the meeting which demonstrate information gathering and feedback to member organizations.

This interviewee discussed three measures, which seem to be reasonable indicators of success: financial support from external sources and elites; membership base and size; and membership involvement.<sup>17</sup> These show positive outcomes for CAS.

Access to elites, acceptance as a legitimate organization, and financial support, increased for CAS throughout the period under study. From its earliest history CAS had some access to government support; although at first this was minimal, it later increased (with incorporation and then with the National AIDS Strategy in 1990 and its subsequent renewals in 1993 and 1998). This is the single most significant source of funding and indication of acceptance at the institutional level; the fact that this funding is ongoing bolsters this viewpoint.<sup>18</sup>

This institutional acceptance is further evidenced in ongoing financial support from several major corporations in Canada. Since 1994 the annual reports have indicated support from private corporations and in 1997 and 1998 dollar amounts donated by different groups were shown. There are a diverse range of corporations and institutions giving support, indicating acceptance. Examples are Glaxo Wellcome Inc., Molson Companies Donations Fund, Levi Strauss and Co. Canada, Purolator Courier Ltd. and Warner/Chappell Music Canada Ltd. This can be tied to insider status and the acceptance of CAS as a legitimate representative of those concerned with HIV/AIDS across Canada.

The growing sophistication and development as a coalition discussed in Chapter 2 is also a part of this success in fundraising. CAS was able to effectively lobby for funds

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<sup>17</sup> Membership involvement could also be measured through looking systematically at feedback that member groups have given to CAS over a number of years (e.g. in return on surveys). This is, however, beyond the scope and means of this research.

from the public and private sectors and to meet the government and other national level organizations, negotiating in terms that were understood bureaucratically.

Outcomes can, once again, be measured in relation to the National AIDS Strategy and CAS's role as one of ten major stakeholders in this process, as a voice for groups across the country. The renewal of Phase II of the strategy was described by one respondent as a "concrete measurement of success" (interview with former board member, March 1999). This is further borne out in the perspective of a former CAS employee:

We went through several campaigns at the national level that involved the renewal of the National AIDS Strategy. A lot of the work at CAS was focused around the National AIDS Strategy. And it went through several versions. There was, I guess, three phases. We're in the third phase now, which has been called the Canadian Strategy on HIV/AIDS. We had to first of all lobby for the government to develop the first strategy, the first phase and then we had to lobby for the government to renew it twice. And those campaigns were successful and that was one measure.  
(interview with early CAS employee, March 1999)

That CAS was able to get to and stay at the table for these negotiations is important, as is the role that it played in fighting for funding for local groups: "It didn't exist then so there were no federal dollars able to flow out into the regions in those early years. That came later with the very first National AIDS Strategy" (interview with Michael Sobota, April, 1999). Recognition of AIDS as a serious national problem requiring a hefty financial input from the government, which increased somewhat over the years (although not by as much as CAS demanded)<sup>19</sup> is an important aspect of this. The National AIDS Strategy is

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<sup>18</sup> Not so positive is the story at the local level, where cutbacks appear to be the norm. In fact, cutbacks may have hampered this research, insofar as in-depth access was difficult to obtain because organizations pleaded lack of resources.

<sup>19</sup> Richard Burzynski went as far as to call the five year funding commitment in Phase II (1993) of The National AIDS Strategy a "Brutal blow to the kinds of things we're trying to do across Canada on AIDS" (*Globe and Mail*, March 12th, 1993, p. A7).

significant not only in showing CAS's acceptance as legitimate but also because of the advantages secured for constituents in the phases of the strategy.<sup>20</sup>

With regard to member organizations, CAS fosters growth, although the main resources shared are information (as in the network stage discussed in Chapter 3). But financial benefits begin to come to local organizations with National AIDS Strategy funding, which is secured by CAS, as was shown in the quotation from Michael Sobota.

And more broadly:

I think there's no question that the existence of Canadian AIDS Society and the network of contacts that it provided, even at the early stage, helped other groups to form and grow. You know, it's still a big issue when groups want to start. About, you know, where you get information about how to do this? Where do we find people who've been through this before. That's still a common request to the Canadian AIDS Society. So, in a positive sense the existence of CAS has fostered the growth of community-based organizations.

(interview with Russell Armstrong, February 1999)

A broad sense of agreement at the AGMs is an important part of measuring how well CAS was doing.

Because you bring together say a hundred different people, it could be AIDS that initially attracted people that were very different--if you've got a hundred people you've got a hundred different sets of needs, you've got as hundred different views and opinions--what should be done and when it should be done. And I think that's part of what CAS always has, in the context of the AGM: you bring together all your member organizations and you know full well that you bring together one hundred groups you're going to have one hundred different sets of agendas. You're going to have one hundred sets of needs. What was interesting though is how they could manage, not necessarily manage everyone's different interests but look for the commonalties among all the member organizations and then come out the other end. Otherwise CAS was so many different groups and then you have regional differences and regional tensions and local tensions with groups from the same city and then provincial tensions, the west versus the east, what have you. It's sort of the Canadian dynamic at play.

(interview with early CAS employee, March 1999)

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<sup>20</sup> The strategy phases indicate another form of coalition work, and possibly the importance of networks outside of CAS, as it worked alongside other national organizations such as The Canadian Hemophilia

The benefits to constituents are discussed further in chapter 6, where I lay out the advantages and disadvantages of membership in CAS from the perspective of local organization members. CAS staff and board members do, however, say a lot about the member organizations here and while they were all involved in CAS, they also belonged to local groups.

Each of the issues discussed in this chapter (outsider/insider status, motivation, identity, framing and ideology) had a significant impact on outcomes. While CAS representatives attempted to walk a line between insider and outsider organization, CAS worker access to government shows the group to have been more of an insider organization. CAS was fairly successful in gaining access to government figures, to funding, and an important place at the table for National AIDS Strategy negotiations over a ten year period. CAS was established as a legitimate voice in Canadian politics. The ties to government, and the fact that the group wanted to be seen as legitimate meant that it had to pursue insider status and the credibility that this brought to negotiations with the government. This affected a lot of CAS activity and impacted the outcomes for the organization, particularly its ability to secure funding.

The motivations behind CAS (and, later, member organizations) actions also impacted outcomes for the group. The inability of ASOs to achieve goals on their own, together with grievances over lack of government action, helped CAS establish itself as a representative national coalition. This is also true of external incentives (most notably the advantages of unity, the setting of national agenda, and the potential of speaking as a national voice). All of this is tied together with the expectancy of success. Without these

motivations it is difficult to see how CAS could have developed as an organization and endured over time as it has.

The identity question encompassed in the paper Who does AIDS belong to? impacted the effectiveness of CAS in the late eighties and early nineties. Identity, alongside motivation, was key in early mobilization. Gay men, as a marginalized group, formed local organizations (see chapter 5) and the Canadian AIDS Society on the basis of their identity. This was also the focus of later mobilization and action, reaching out to gay men and opposing homophobia at a national level. However, some groups may have been alienated by this emphasis. CAS responded to challenges to be more inclusive of PLWHIV/AIDS. While member groups include organizations representing women and ethnic minorities, this has not had a big impact on organizational identity but has made gay identity more diffuse. That CAS is not a 'gay organization' is important and allows the group to be more inclusive. Recently there has not been a strong CAS identity, which may diminish its effectiveness within the gay community. The inclusiveness of the organization, however, is a strength, boosting the membership size and income of CAS, and increasing the number of beneficiaries.

CAS's ideology and the frames developed from this (at least in action that the group took) have also impacted the effectiveness of the organization. Decentralization has impacted groups at the local level negatively in several instances (chapters 5 and 6), not least in that it is difficult to get feedback from local groups. This affected organizational structure, making it necessary for CAS to work more as a representative umbrella organization when negotiating at the national level.



Positive outcomes can best be seen in CAS's emergence and continued existence throughout the period under study as an effective voice at the national level with some benefits permeating down to local groups. Longevity and its existence as the only national HIV/AIDS organization are an important part of this assessment as are the financial aspects discussed above.

## CONCLUSION

This chapter builds on chapter 3 to give further details on CAS's development as a network, coalition and umbrella organization, aspects of which can be seen to be advanced in the theoretical issues I discuss here. The fluid nature of a number of these, displayed by CAS in different stages of its development, point to a continuum of organizational growth and change. Although identity of the organization was mainly rooted in ideas of gay identity this was not solidly fixed, particularly when CAS ceased to operate exclusively as a network. The change in CAS identity is a consequence of organizational formalization. As CAS becomes more professionalized there is a decreasing emphasis on identity personally and, to a lesser extent, politically. CAS's role as an insider or outsider organization was also fluid. There was a line between the two that the group attempted to walk but it was increasingly an insider as it grew in size and increased representativeness (e.g. in negotiations around the National AIDS Strategy). CAS began as an outsider but the organizational goal from an early stage was to be effective in national politics. With incorporation and the establishment of CAS in Ottawa, cultivating a relationship with the government, the group moved to more of an insider position. This is parallel to the organizational development of CAS as a network and a coalition. CAS's ability to work as

an insider (while remaining critical of the government on several fronts) increased with formalization and has been most effective in CAS work as an umbrella group in National AIDS Strategy negotiations. Frames and ideology are more constant. CAS's emphasis on 'health from below' and decentralization continued throughout the period under study. Framing by the organization has not undergone any dramatic change. The main measures of outcomes in this chapter are institutional but were positive for the group. CAS was accepted as a legitimate voice by the government and by many ASOs across the country. The necessity of insider status in order to achieve positive outcomes sought by CAS is widely accepted.<sup>21</sup> CAS's overall strategy is unclear. However, the ideology of the organization is explicit and evident in tactics, discussed throughout the chapter. At their most basic strategies involve the maintenance of relationships with government and local ASOs. By maintaining relationships with both local communities and national powerholders there is a broader chance for favorable outcomes. For the most part outcomes for the organization were positive, as is clear in my discussion. CAS developed as outlined in this chapter, parallel to the organization's evolution as a network, coalition and umbrella organization. It is an interesting story.

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<sup>21</sup> This is true even for AIDS ACTION NOW! (AAN!), which is now more accepted and accepting at the level of government negotiation—as was brought out in comments from one CAS board member early in this chapter.

## **CHAPTER FIVE**

### **PATTERNS AND DIFFERENCES IN CANADIAN AIDS SOCIETY GENERAL SERVICE ORGANIZATIONS**

In previous chapters I have looked at CAS as an umbrella organization, coalition and network and established that it displays all of these organizational features in some of the years under study, discussing the outcomes of this at the national level. In the next two chapters I look at a subsection of ASOs. In particular, I examine the similarities and differences among these groups. This chapter contains a general history of organizing among the sampled groups. I show the evolution of these organizations, reflecting CAS's own growth; I discuss the development of relationships between organizations and within communities and the outcomes of peculiar forms of organizing. In chapter 6 I discuss these organizations using the issues from chapter 4, relating the sampled organizations to CAS as a network, coalition and umbrella organization. The focus of the discussion in that chapter is how the organizations relate to CAS.<sup>1</sup>

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<sup>1</sup> In the interests of maintaining the anonymity of respondents, a number of whom were concerned about being identified from their comments, I have chosen to name neither specific groups nor interviewees unless quoting from already published sources (the exception here is Joan Anderson, who gave explicit permission for the use of her name). In light of this, I have also chosen not to discuss provincial differences in detail. It is clear from other chapters that there have been ongoing tensions between member groups from different Provinces. This was true for BC and Quebec, as discussed in Chapter 2. Research expanding on this study would further illuminate the effect of provincial divisions between groups at both political and organizational levels. I have also edited slightly to clarify speakers' meaning and to disguise location where necessary. While the biographical detail of earlier chapters is muted, I

## A GENERAL HISTORY OF CANADIAN AIDS ORGANIZING

I now focus on a number of different aspects of General Service Organizations (GSOs, see Roy (1995) and my discussion in chapter 1), highlighting commonalities and differences between these groups. My purpose is to show how local organizations worked and to note where coalition/collective organizing was important locally and nationally. If these groups have much in common or if there is a lot of shared information, this strengthens the hypothesis that CAS was a coalition or network (which has already been established in previous chapters); if there was little decision-making power at the local level then this would point to an umbrella structure. In this chapter I focus on the local level, going on to discuss the connection to CAS explicitly in chapter 6. I also relate the nature of the relationship with CAS to the outcomes both for local organizations and for CAS, showing how and why CAS operated in particular ways and the consequences of this action.

The areas I discuss include: background and roots; funding; organizational structure; services; ties with other organizations. I relate most of the information to organizational development up to the renewal of the National AIDS Strategy for phase III in 1998; there was a peak of activity for many organizations during the early 1990s and groups offered a full range of services in this period. Some groups have faced more recent decline (particularly smaller groups, as discussed earlier) but others, including many of these GSOs, have gone from strength to strength in terms of funding and service provision. An in-depth longitudinal study of developments in each area under discussion is important for future research.

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present a vibrant picture of local organizing among the earliest AIDS Service Organizations across

### Background and Roots

GSOs, all of which were founded in the eighties, may differ significantly from other CAS member organizations in terms of background. All of these groups have roots in the gay community:

In responding to multiple challenges, gay communities developed sophisticated skills in advocacy and community mobilization. Gay communities also became accustomed to giving money to support groups fighting the various causes of social oppression. All of this formed a strong base upon which to mobilize quickly and effectively in the face of HIV/AIDS. (Armstrong and Juras, 1997:26).

The importance of prior gay organizing for CAS is highlighted in chapters 1 and 2 (and was also important for AIDS organizing in the US). This is key for the groups under discussion here, although there are varying degrees of formality to this. Most groups began with gay men getting together to discuss what needed to be done. Several respondents noted that groups had begun around kitchen tables. One organization started when "Five Gay men in the area got together and discussed the issue of HIV--well AIDS at the time--around one of their kitchen tables at night and realized that they needed to do something or wanted to do something about what was happening" (interview, December 1999). Another respondent spoke at greater length about this dynamic in a different organization.

To my knowledge in 1983 two gay men that were also in a relationship, were partners, discovered that they were also HIV+ and they were amongst the first...to be diagnosed. They shared this information with a couple of their friends and what happened--as the legend goes--the two of them sat down with two other people...around a kitchen table... and they decided that some sort of organization

needed to be created because they were really alarmed about not only the lack of care and support but also the fear around contagion and that sort of thing.  
(interview, January 2000)

These quotations show very informal beginnings primarily among gay men, as do others:

“Through socializing and stuff we had that ongoing discussion and then we decided we would form a small committee” (interview, November 1999). The personal and intimate nature of the meetings is highlighted: individuals who were in some way directly affected by the epidemic met with friends and acquaintances in order to decide what action needed to be taken. The one major exception to this is the AIDS Committee of Toronto (ACT), which came out of a much more organized effort within the gay community and about a year ahead of other early groups across the country:

Before a single case of AIDS had been reported in this city--even before AIDS was called AIDS--people in Toronto's gay community were coming together to confront it. *The Body Politic* had published its first major piece on AIDS in October 1981...Another group, Gays in Health Care, was planning a public forum on AIDS and hepatitis, to be held at Ryerson on April 5 [1983]. The March 12 group met again on March 22 and agreed to take to that forum a proposal for an “ongoing AIDS committee.” (Anderson and Bébout, 1996:1-2)

The committee quickly became a “very decentralized at first” ACT, which went on to be of central importance throughout Toronto, and, later, Canada prior to the formation of CAS and the Ontario AIDS Network (OAN).

While not exclusively involving gay men (“it started out of a group of gay men--gay men and women, but primarily gay men”--interview, March 2000), this was essentially the community from which all organizing came. This was primarily due to prior activity (and a willingness to confront the problems that AIDS and HIV infection were bringing), though on a lesser scale than in Toronto. Nevertheless, in many cities there were

formalized channels and the importance of prior gay organizing is clear in a number of instances. For example one respondent noted,

We decided we would form a small committee with the gay and lesbian civil rights group--it was called the Gay Alliance Towards Equality...That was in 1987 and like many ASOs it was formed from a grassroots movement out of the gay and lesbian communities. There was certainly a recognized need for HIV services in this area at a time when systemic discrimination was so great, especially homophobia and racism. I think at that time people responded to what were huge gaps in services and were really taking care of members of their communities... My understanding is that they were quite instrumental in organizing people from those communities to actually form the [group]. So they submitted proposals for funding and really established the organization. Not exclusively people from those communities but certainly there was a large representation from those communities.

(interview, November 1999)

There are, therefore, two stories of the foundation of groups. Gay friends either gathered informally to develop a response and found organizations or, more formally, established groups within the gay community lent expertise or resources or both to the founding of organizations specifically focused on tackling AIDS/HIV and its effects within their communities. In the next chapter I look at questions of identity as they relate to this for organizational outcomes. All of these groups were founded out of local networks and not national ones, prior to any national activity on the part of CAS or any other centralized group (with the exception of ACT, which I discuss in this chapter). Organization members, however, were aware through network connections of what was going on elsewhere (enough that when they came together to form a national group they were able to do so) and modeled themselves after one another to a certain extent.

## Funding

Funding is connected to the way in which groups got off the ground, and to whether or not they were funded privately or through the government. This is important because it shows whether or not groups were able to attain bureaucratic legitimacy at provincial and federal levels, which is one of Gamson's (1975) measures of outcomes. Also, groups that were able to get federal and provincial grants relatively early pointed the way for CAS in its initial applications for funding, particularly given that those who applied for this funding (most notably Richard Burzynski, who had been involved in the Comité Sida Aide Montréal (C-SAM), one of the first community groups set up in response to AIDS in Quebec) were previously involved locally.

Like CAS, many groups from an early stage went to the government for support. However, some were able to establish themselves through private donations: "Their entire organization was funded on donations. No funding from anywhere else. They moved...and by that time they were attracting large numbers of volunteers" (interview, January 2000). In this instance the resources were financial and human, which continued to have an impact on the work that groups were able to do. Another respondent talked about a group getting funding locally, although it did, along with all the groups I studied, quickly seek federal money:

...in terms of how we got organized, we did some of our own fundraising, primarily in the gay community. Little fund-raisers at the clubs, tried to do some social events where we could... Anyway, we got together enough money to do some of the first pamphlets, at least to create some awareness to people that this wasn't something going on in the States that wasn't going to affect us here. We got our first grant from a small foundation, who gave us, I think it was \$5,000 to



set up a telephone information line and gave us enough money so that we could hire someone to write a funding proposal to the Feds and rent our first office.  
(interview, November 1999)

It is interesting that money was needed in order to effectively seek government funding.

Federal and provincial money later become important for both these organizations.

However, HIV/AIDS initially affected a specific community and the response came from the affected community, not only in terms of organizations and finances but also volunteers, who still play a key role in many organizations (Canadian AIDS Society, 1996).

Many groups sought incorporation and relied on the government for funds and charitable tax status:

Getting the charitable tax number, getting incorporated. All the business of going from a group of folks who were doing really good work to becoming legitimate in the eyes of those people out there and applying for funding and receiving it...It's important to have a charitable tax number so you can raise money to do the work you do and also we had to be incorporated to receive funding from the government.

(interview with local executive director, March 1999)

This was a process through which organizations had to present themselves to government in order to achieve charitable status. Reliance on government funding was apparently due to the fact that it was too expensive to fund a group privately over the long term; tax breaks and government funding were necessary simply to survive and also to provide continuous services. This reliance on government funds, however, involved costs and consequences. In at least one instance the early turn from private to government financial support caused an irreparable split in what had been a predominantly gay run organization:

...and there was a strong volunteer board at the time as well. And around (and I may have the dates wrong) 1985 and '86 there was an opportunity for some government funding and...the board, as its been related to me, was split on the

whole concept. More or less half of the board, which was made up of people that were there from 1983--gone through the completely voluntary years--felt that to accept government funding would be a mistake. They didn't want the perceived control to come from that. They felt that governments would start controlling what [they were] going to be doing and that kind of thing. They opposed any government funding. They wanted to keep the organization strictly donation based and fund-raised based in its funding. The other half of the board was in favor of government funding, wanted it and felt that we needed it so that what happened was there was a split. The board went with government funding. As its been related to me the people who were against that left the board at that time. So that was the first falling out. And a good chunk of the people who had been there since 1983 left or participated in a more distant manner.

(interview, January 2000)

In some cases, then, the move towards government funding was controversial and perhaps harmful to local organizations. But the story is generally more positive as most organizations benefited from government financial aid. This began with AIDS Vancouver:

...one of the first formally constituted community-based HIV/AIDS organizations, [which] approached a regional Health Canada office for financial support to deliver prevention programmes... Health Canada, at the time, was well positioned to respond since its policies and general funding programme incorporated principles of health promotion and community development. Funding was provided in gradually increasing amounts to local community organizations to provide targeted prevention programmes... (Armstrong and Juras, 1997:29)

Government funding allowed groups to establish themselves in ways that otherwise might not have been possible. For local GSOs this funding was significant:

We ended up being able to get our first grant from Health Canada. We pursued it with the provincial government, who ignored us until the election. And just before the election was called [they] gave us a grant for...maybe \$50,000 or something. After the same government won the election they were prepared to meet with us and to give us some funds because basically they didn't want to deal with it themselves. So they were prepared to give us a grant. And certainly that was the influence of some of the senior infectious disease doctors at the STD clinic, who were very supportive of us and were our advocates. And probably because of their influence the government decided to give us some money to reach out to the gay population and other undesirable groups within the community that they didn't want to deal with directly.

(interview, December 1999)

One respondent went so far as to say, "It started out at someone's house with a box of files and that type of thing and eventually they applied for funding several years later and started to turn into a real organization" (interview, March 2000). GSO groups were only able to expand their services with incorporation and government money:

And then we moved on into the incorporation phase in 1985 and then in '86, once we got our first notice that the federal government was prepared to start providing some money, then we started pulling together a multi-year proposal and at that time looking at us as an organization looking at who would run the organization and how we would staff it and that sort of stuff.

(interview, November 1999)

This shows a fairly good working relationship with the government--or at least that the government was willing to rely on expertise developed within the local organization and provide resources to back this up. The history of funding since 1985-6 has varied for different organizations, with some faring better than others.<sup>2</sup> The level of funding available to groups was not dependent on the services that they offered or related to the perceived need in any given area.

I think there just wasn't as much [funding] there. It wasn't very up and down but certainly a lot more tenuous and certainly there wasn't sufficient funding throughout [the province] to meet the need given, the numbers of people who test positive in [the province] versus other areas of Canada. It was quite a disparate level of funding compared to epidemiology if you even look at Ontario or even the East coast...I have to say that there was a lot of lobbying and advocacy that went on with the groups [provincially] and at a time when the push came on when the NDP government got elected here as a majority provincially. And I think [the government] didn't come willingly. Real advocacy had to happen with the groups and the government. They finally came on in 1995 with a fairly decent amount of funding.

(interview, December 1999)

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<sup>2</sup> Funding is not even across the board. One activist highlighted the problems that came with the unequal distribution of services: this is perhaps a downside of the fact that CAS is not more centralized and has no real control over how money is farmed out to local groups, which is a deliberate choice in line with the ideology of the organization.

While this took place under phase II of the National AIDS Strategy, significant change can be attributed to phase III and the federal commitment to provide fairly substantial ongoing moneys to AIDS work in Canada. One group member noted this explicitly:

In terms of the whole funding thing. There was certainly a lot of concern about the federal government not renewing the AIDS strategy and that sort of thing. So the organization was geared up to downsize to four people from 12 or 13. That didn't happen because it was renewed and the province has not only continued their support but they've increased their funding now for a couple of years.

(interview, January 2000)

But the financial situation is not positive for all groups and two of the GSOs that I researched faced cutbacks and attendant problems including increased competition between member organizations:

So there has been a sense of competition that has developed. Part of that has come out of practical concerns like shrinking resources and other ASOs competing for a piece of our pie. We have the most funding to provide services in our jurisdiction, in this area so other like organizations that would like to provide those services I know have approached our funders--looking for the possibility of funding. We might lose our funding.

(interview, November 1999)

No respondent chose to go into detail on competition between organizations and it may not have existed between GSOs. Perhaps it was a problem within cities or across Provinces, depending on the source of ASO funding. In one instance a GSO has faced severe government cutbacks:

From our perspective there was some real discrepancy from what we were being told and what actually happened. Certainly our impression was that we would put in our proposal and if there were questions or whatever then they would come back to us and the impression we had was that we should put in for what we wanted and they would come back with a lesser amount or they would come back with questions or clarification or whatever and what happened in fact is that they just said, No, there's not enough funding--you won't get anything. And they didn't come back with any questions or anything at all. So there was different

messages coming. And that's just government stuff. I don't know what the cause of that is.

(interview, January 2000)

The funding of these GSOs was similar, insofar as government support underpinned the finances of most groups and had a big impact on the services that they provided, for better or worse. In some cases groups have suffered in recent years. Often federally funded positions are limited in their mandate.<sup>3</sup>

We have different funders. Our main funding comes from the Ministry of Health. And then we also get funding from a program called ACAP, which is AIDS Community Action Programme, which is a federally funded programme. Now, for the two positions that are the federally funded agencies, the ACAP agencies, their mandates are pretty defined. They are funded to do something very specific. For example, one of them is the man-to-man project and their mandate is to offer prevention strategies for men who are having sex with men and they go out to the community and do different things. They go into the bathhouses, the parks, the bars, those things--where they can spread that kind of word. And the other thing that's funded by ACAP is the women's project and again the objective is to reduce the rate of HIV infection for women. Again through education, advocacy, health promotion. That particular programme is less hands on than the Man-to-Man project is, which works directly with clients. The women's project works more with community organizations that can make links with their clientele. So they'll go out and train and do in that sense but its very specific. So for example the women's project coordinator couldn't go into parks and do direct intervention and outreach in the parks. That's not in her mandate as defined by the federal government. It's to do training, to network with other community organizations so they can do that. So there's a certain amount of limits that are in place by the funders. There's an opportunity every four years to renegotiate the terms of the contract with the funders.

(interview, March 2000)

This raises questions as to the huge impact that changes in government or policy had (and could have) on GSOs or CAS itself, a problem that some groups have already had to face or are now facing. Groups would not be able to continue in their current form if there were to be significant changes in funding structures, although it is possible that they could

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<sup>3</sup> Funding for specific positions or limited projects was also prevalent at CAS.

increase reliance on private funding, as is the case with the AIDS Committee of Toronto (ACT), which has deliberately sought less money from the government in more recent years.

In their history of ACT, Anderson and Bébout note that "in the past few years ACT has--necessarily--worked to reduce its dependence on government funds (from about 75% of its budget in 1991-92 to just under 52% in 1995/6" (1996:11). They go on to discuss the struggle to get and retain government grants:

Early on it had to work hard to get any government money at all. The first grants were not even health-related: they came from a joint federal-provincial job-creation programme...ACT nearly faced its demise in the autumn of 1986, still having to fight for government commitments to secure funding. These battles eventually led to the creation of the provincial AIDS Bureau and the federal AIDS Community Action Program (ACAP) - sources of money later (if not still) taken for granted by scores of community-based AIDS groups. (Anderson and Bébout, 1996:11)

Clearly there were early government funding difficulties and ACT was one of the key groups to play a role in policy developments to overcome this. However, the more recent moves away from government funding can be attributed to ACT's ideology and desire for independence from government control:

ACT advocates then for so many other things--not only money--it's good if you're not beholden to them for everything, although that didn't stop us. At times we experienced veiled threats around funding but pursued the advocacy anyway. And persisted, persevered, what have you. But the events have definitely been the big place where private funding has come from. And its really only been the later years, really the last two, that ACT has been able to increase the resources coming in, from other sources, like planned giving started and direct mail is a larger piece.  
(interview with Joan Anderson, April 2000)

Private moneys are needed not only for independence but also to respond to community needs. Grants have remained static or declined and money is needed to respond to greater complexity and increased demands. This direction of looking again to the community for

more funding may be the way that other ASOs will have to go in the coming years, particularly if there is some drastic change in federal funding after phase III of the National AIDS Strategy. It should also be noted that smaller, more specialized ASOs probably do not have the security in funding of these larger groups. Local ASOs would not have received as much funding without government support, which was critical in groups providing ongoing services within their communities. ACT takes a percentage of special funds from special events and gives it to smaller ASOs through its Community Partners Fund. For the most part outcomes of this relationship with government have been good, and funding is indicative of government acceptance of these ASOs as legitimate.

#### Organizational Structure and Goal Setting

The important questions here are who held decision-making power within organizations, and to what extent was this located within the local communities from which these organizations come? This is tied to ideology, which I discuss in the next chapter, and highlights similarities and differences between organizations. Further this is related to goals and their effect on outcomes, also discussed in chapter 6. I have shown that CAS emphasized decentralization and each local member organization remained autonomous. How this is borne out for local organizations and the benefits and drawbacks of this are also discussed in the next chapter, alongside the inevitable unevenness in response because of differences between GSOs across the country. In general, GSOs have very similar structures with board, staff, volunteers and clients having an impact on the goals and make-up of the organizations under discussion.

Goal-setting appears, in many cases, to have been a dynamic process within organizations. As a localized activity, however, it had different degrees of success.

That's something that the organization has not done extremely well to be quite honest. In the time that I've been here for example we initiated a strategic planning process in 1996, I believe and in '97 published a strategic document, although very little of that has actually been implemented. So I would say that many of our goals are stated there in a general way in terms of where the organization was planning to go and certainly of its priorities. Now how those actually get translated into the actual work and programs and services is another question.

And I think that's where we haven't done a good job of looking at what our goals are as an organization and actually translating those practically in terms of our programs and services. The strategic planning was a consultative process so it did involve stakeholders. It involved PLWHIV and AIDS, caregivers, significant community partners, women's communities, members of the gay, lesbian, bisexual and transgendered communities. So it was a process that involved stakeholders. And those people certainly were involved in shaping the goals of the organization. However, again, that hasn't been an ongoing dynamic process. It was for the most part a closed process after that point only because it wasn't really effectively implemented and there weren't other opportunities for people to be involved in terms of planning and shaping the goals of the organization. Certainly there have always been challenges, as is the case with many ASOs. Some of that is just organizational development stuff in that we're a fairly new organization dealing with a social issue that is fairly new as well. So I think a lot of that change and turmoil is understandable but I think that in many respects before the last few years we had stronger partnerships with our communities. We involved members of those communities to a much greater extent. Through opportunities such as steering committees we involved those people in strategic planning and to some extent in organization and program evaluation as well. So yes I would say those people were better connected and had more respect for the agency at that point.  
(interview, November 1999)

In this instance the respondent argues that the process was not dynamic (at least not from beginning to end), although it did involve a wide range of interested parties. This was a somewhat complicated process in which the focus on those for whom the services exist got lost. Other groups more successfully involved the wider community in planning.

Planning and community consultation approaches have been used. This is how I would describe it. As you know, Organizations are really organic and not mechanical in that way. So regardless of whether people think we need to have a



plan every year or for a four year period or do an annual thing or do this and do that, what really happens is its a really organic process and we have had recently for example, three years ago or so, we had an extensive community consultation that came up with a range of suggestions about what we should be doing and it helped fuel our reorganization so that we now have three programming areas and we have a greater emphasis on communication and program evaluation and all that came out of that consultation.

And there were other consultations in the past too. I wasn't around for some of the earlier ones but I understand that some of the AGMs were really hot affairs in terms of people challenging the board and whatnot. And some of the board meetings were like something out a spy novel or something. There was a lot of different factions battling over things. But what generally happens is that the staff under the leadership of the management comes up with plans and they go to the board. And the board looks at them and connects and it goes back and forth. And it seems that every two or three years there's more of a consultation with the community than there would be normally. So the question would be, How are we doing? What do you think? in a more official way rather than the ongoing comments about whether we're doing the right thing or the wrong thing, which we're always absorbing. But any larger consultation is more on a two to three year basis.

(interview, January 2000)

In another organization this affected staff and the workplace dynamic:

I've seen people that have been so consumed by the politics of the organization and the changes that are going on and their opposition to the change or their position in the change--they are so consumed by those things that they can hardly get to their work. And so my own philosophy as an executive director has been if I see any staff person, and of course I'm limiting this to staff people mostly--but if any staff person is more interested in politics than they are in getting their job done then I expect them to change their orientation and start looking at their job first. Because they are not being hired to come here to immediately politic, to change this and change that and overthrow this thing and do whatever. And occasionally, especially it seems in the AIDS movement or in smaller organizations or whatever there seems to be that dynamic.

(interview, January 2000)

Individuals clearly influenced organizations. I have already discussed personality and its role, in earlier chapters. Although this was confronted by the executive director in the above instance, this was not always the case. Once again, this was a result of the lack of systematic organizational policy across the board.

Part of the GSO format is that there is a board, which is involved in the decision-making process in organizations. This is probably best summed up in the following description:

[The board is] responsible for hiring the executive director and then the ED is responsible for hiring the staff. And that's certainly where the problem comes in. After I was hired we were looking at hiring some other positions to get--and our bylaws stated in fact--that a PHA needed to be on the hiring committee and a staff person and a board member so it was a broad representation.

(interview, January 2000)

The board, therefore, plays a central role. However, a difficult dynamic can develop among board members, staff and clients, which different groups, including ACT, have had to face:

And then we moved from that board structure where everyone was elected at the AGM rather than having some people elected at the AGM and program committee appointing their representatives to the board. So that was a structural change. And then I think as the staff, as the funding developed, as the programmes developed and there were more staff then there were issues of it being staff driven... One of the things that I used to try and talk about when I was chair of ACT was trying to develop a team approach and a certain amount of balance around power. Because the folks who were opposing me, it was kind of like, the staff are servants. Which isn't a healthy model. But it then moved to a place where the staff were driving it and there wasn't a respect for the role of the board and that's not healthy either. So you need to work to that thing where there's mutual respect.

(interview with Joan Anderson, April 2000)

The ACT organizational tree for 1996 shows a board above an executive director with a number of education and support services, administrative positions, and fundraising and development staff. Compared to other organizations ACT had more staff but the structure, if not the dynamic, appears to be similar to other organizations. This can be seen in the following description of a smaller group:

We have 11 staff and volunteers...it changes--probably around a hundred. The board definitely sets the general tone, that's for sure. As any non-profit agency, the board members are all volunteer. So it depends on who is willing to come forward

and volunteer and what kind of experience those volunteers have. So what is there and what kind of leadership they can give to the association. There have been some rocky periods but right now we are in a very good position.  
(interview, February 2000)

The emphasis on volunteers is also important and is stressed in the CAS Omnibus Survey (Canadian AIDS Society, 1996). For 1994/5 volunteers saved CAS an estimated \$11 million and the survey states that "the use of volunteers is a tremendous resource for AIDS groups" (1996:5).

It seems that both the advantages and the disadvantages come from the fact that organizing is determined locally and there is no central trans-Canadian GSO policy (as with groups like the Canadian Cancer Society) dictated by CAS or any other group. This decentralization brought rocky periods, depending on the composition of the board or the personal outlook of Executive Directors (discussed in greater depth in relation to CAS in the next chapter). At certain points in history individuals within ASOs have wielded a great deal of power. Personality had a crucial effect on ASO organizing and, to some degree, character: this had an impact on association with other community organizations, and is discussed in this chapter.

### Services

All of the organizations I discuss provide a range of services (as the term GSO suggests). Common services point to shared characteristics of organizations and they affect the way organizations interact or are useful to one another in terms of providing information on how to tackle different problems, resources, etc. The broader the range of

services provided the wider the range of organizations to which one would expect an organization to be useful.

In the Omnibus Survey (Canadian AIDS Society, 1996) it is clear that the range of services offered across ASOs is broad. 45 different programs and services were available in the organizations surveyed. As ACT is something of an ideal type--larger than other organizations but with similar organizational structure--I begin by highlighting the range of services offered by ACT in the period under study. Many of these were available to some degree in smaller organizations. Like many of the other GSOs, ACT started with a few staff, who performed a number of general tasks. Specialization developed at a later stage. Education, linked to advocacy (from another GSO: "my particular position is leader of education and advocacy"--February, 2000) for ACT includes referral services (putting clients in contact with other agencies, social work, etc.), a library,<sup>4</sup> health promotion among gay men, outreach to women, health promotion among those who are HIV+, a training and communication officer and a phoneline. Of the other groups on which I have information, all provided some form of education service. The Hamilton AIDS Network (HANDS) distributes materials, holds talks, has a phoneline and provides support services. As early as 1988 the AIDS Network of Edmonton (ANE) provided educational services through a phoneline, a speakers bureau, forums and workshops with healthcare professionals, publications and a library. AIDS Vancouver Island (AVI, 1992) also had a phone line, a speakers bureau (including PWA speakers), a resource library and a media file for educational purposes. The AIDS Committee of Ottawa (ACO) provided a

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<sup>4</sup> A resource I used in my research and witnessed several people from smaller organizations using.

phoneline, counseling and other services. The Comité Sida Aide Montréal (C-SAM) provided a similar range of services to other GSOs (Morrison, 1991).

Support services are also offered by ACT, including volunteer services, first contact services, counseling services, practical assistance programs and a support group program. HANDS also provides one-on-one support through staff support group programs and a range of support services through a health center. ANE had support groups, a befriending program in which "volunteers assist people with AIDS with day-to-day activities" (AIDS Network of Edmonton, 1988), the Ross Armstrong fund (moneys to assist people living with AIDS) and referral services. AVI offered a wide range of services: crisis intervention, intake for newly diagnosed PWAs, one-to-one counseling, support groups and an emergency financial assistance fund, referral, buddy support, a therapist, rural outreach and prison visitation. ACO also offered counseling, a buddy programme, support groups and emergency financial assistance. The AIDS Committee of London (ACL) had support groups, counseling and practical assistance services. These are the main services offered by the groups under study. Thus GSOs offer a common range of services.<sup>5</sup>

A number of interviewees discussed services offered by their organizations, which in many cases are tied to the ideology of the groups. The broad goal behind the services offered was and still is to combat HIV/AIDS and its social impact:

A large part of our job is to go out into the community and make people aware of AIDS and how it is transmitted and the life experience of people who have contracted AIDS. I run the speakers bureau, which is composed of volunteers.

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<sup>5</sup> The CAS Omnibus Survey (530) shows the whole range of services offered by ASOs across Canada.

Now the whole program has grown over time: how it is done and the links that are made in the community to allow us to do those things cooperatively.  
(interview, February 2000)

The broad range of services offered seems to have been present from the earliest stages for some organizations: "I was hired [in 1986, with the first influx of government money] with the mandate to pull together a social services programme, an education programme and a fundraising programme" (interview, November, 1999). These services still exist in this organization in a much developed form. Education, with prevention, once again was a core service offered by different groups.

...we also had a very strong prevention side of our programming which we continued to put out to the wide community and we had a project for men who had sex with men. We also had projects for youth and we had projects for schools and that kind of thing.

(interview, January 2000)

While the information here is drawn from several years activity, it shows that there is an emphasis on educational services with a number of different forms of support services common to all of these organizations, highlighting some common goals across groups (tied to ideology in chapter 6). This also shows that there are at least informal networks of activity: some common models were developed among the organizations under study in the early years of ASO activity in Canada prior to and immediately following the formation of CAS as a formal organization.

#### Ties with other organizations

Cain (1993) highlights the "variations [which] mean that AIDS educators have to contend with differences in the numbers of people they need to reach and in the geographic spread of their potential audience" (p.5). These variations might be expected to affect whether or not organizations established links with other groups in their

communities. Because these GSOs are from larger population centers there may be less reliance on other organizations, in comparison to more rural groups. Strong links to other organizations would show a network or coalition effect, which might be tied to CAS membership. However, in certain instances this might also show groups working independently of CAS in order to create their own provincial or local networks. Smaller organizations might be more likely to network but the greater number of members in larger organizations means more potential links. I deal with this in the next chapter, looking at member GSO connections with CAS.

Some groups were formed as a result of ACT activity:

Some [groups flowed out of ACT] but certainly not all of them...some of the ethnocultural groups like Black Cap; one of the counselors at ACT, Doug Stewart was one of the founding members of Black Cap. And a gay Asian group where ACT could help at times. So for example the city would flow money through ACT to these fledgling groups that weren't in a position to be eligible for money. So ACT could play that kind of role...because all of these groups can't duplicate--and it wouldn't make sense to--all of the services that ACT has.

(interview with Joan Anderson, April 2000)

While this is a unique form of relationship between local organizations (existing with some variation in less populated parts of Canada) a more common experience was for groups to network through the Ontario AIDS Network (OAN) and the Pacific AIDS Network (PAN), which is still only a few years old: "PAN has played a pivotal role in connecting other rural groups to each other, in building networks among staff and among Executive Directors so that we can pick the phone up and call someone and say, What's going on?" (interview, December 1999). This larger organization in the network played a role in supporting other ASOs in the area with information and, in some instances, resources.

Networking was an important feature for other organizations, which perhaps fell outside of the more formalized provincial networks:

One of the key mandates that I had was to do networking and we knew that our strength would be in getting all the groups together to sing from the same songsheet in order to do lobbying. And early on we and another GSO took the role of forming a Community Council on AIDS and bringing groups within the larger city into a council where we met and did our networking, shared resources, did training and also lobbied as one voice the provincial government. That was one reason, in fact, why we were able to maintain our funding. We weren't going to be played one group against the other, because the Province wanted to fund some groups and not fund others. So we insisted they would fund all of us or none of us.  
(interview, November 1999)

Other networks were built as different organizations attempted to avoid duplication of services. Groups made themselves aware of what other organizations were doing and worked closely alongside them.

Yeah, there aren't a lot of other agencies around that specifically deal with AIDS. There are other organizations which deal with HIV-infected persons but its not in the same sense. They offer help for housing. So they don't offer the same services that we do. There are other organizations that deal a lot with sexual health issues, which is the public health department. So we work in close proximity with that department. However, again we do not offer the same services. They don't offer drop-in, they don't offer counseling, they don't offer outreach programmes--we do those things. So they offer the actual medical support and the in-school training --those types of things. So we are in cooperation with those groups. There's a lot of women's organizations that may deal with abuse or cultural women's organizations that have different problems themselves in the transmission of the information because of the language and the social barriers that are there.

We network a lot with those organizations so that we can transmit the information to the people that are running those organizations so they in their own social environment can pass the information down. So there's those types of organizations that we deal with. We network with other groups like the youth services bureau--which obviously deals with youth in the area. Things like the other community organizations--there's telephone hotlines that we will in turn refer people to specific services that we don't offer. The needle exchange programme--we would certainly do co-operative efforts with them. Detox centers, the YMCA. There are not a lot of the organizations that deal specifically with HIV and AIDS. There are anonymous testing centers -- we will refer them there. There's a whole range from basic community organizations to government



organizations. And aside from that like the sexual health clinic. There's very many levels of people that we network with to be able to offer all the services and to be able to refer people to where they need to go. And we do have a legal aid clinic that is from the University. It is part of their training, their placement--so they are here for a certain period of time and they come here one day a week on site and then they take care of different cases individually.

(interview, March 1999)

While these quotations show some more formal networking within cities and throughout rural networks, there were also groups that had only faint connections to other organizations. They were aware of the work others did but tended not to share many resources. Some groups, for example, got together with other ASOs for training sessions or forums but, it appears, for little more. And, while some groups were able to confront the threat of competition successfully, this is not true of all (see chapter 3):

I think that competition has come about as a result of political differences, as a result of scrambling to provide services that [we] in my opinion should have been providing. What ended up happening was that people moved in and attempted to provide those services and that would be seen as competition. So there has been a sense of competition that has developed. Part of that has come out of practical concerns like shrinking resources and other ASOs competing for a piece of our pie.

(interview, November 1999)

Another organization did take a role in distributing resources that came down through government funders:

But through our local coalition we supported and also paid their facilitators through the local organizations and part of those dollars are seen as coming through [Provincial] Health but they came through [us] and they are considered [our] operational dollars so we actually paid their facilitators for a couple of years. And the same thing with the self healing. We paid for their facilitator through the health coalition. And also we gave money to the peer support group. Each year if we could. And also supported them being funded through the Health Coalition as well. And there's been overall good relations with all of them.

(interview, January 2000)

A lack of centralized coordination may have played a part in this but generally the ideology of cooperation, which was behind the formation of CAS, seems to have been upheld at the local level, even where groups did not share resources evenly or lost out to government cutbacks. Most groups seem to have embraced collective work, if not ongoing organization, and this might be tied to their membership in CAS to the extent that it also places a strong emphasis on coalition work, which one would expect to continue among organizations involved in its formation. There was some degree of local cooperation in all of the organizations discussed. Beyond a common value placed on collective work, however, it is not clear how much of this can be related back to membership in CAS, as CAS was not acting as an umbrella organization in that it was not directing organizations in establishing links with one another.

## CONCLUSION

Many similarities exist among the organizations I discuss (and between these groups and CAS in all the areas noted). GSO autonomy is evident in the foundation and development of these groups. Individual organizations direct (similar) programmes and services with little recourse to CAS, or any other group, as a central organization. While some networking characteristics are displayed this was a fairly loose coalition. In the next chapter I return to the concepts of chapter 4 for these member organizations: gay identity, which can be related largely to the roots of the organizations I discuss; ideology, which is reflected in my discussion of organization and services; and outcomes. These highlight the relationship between CAS and GSOs, returning to the issue of the organizational structure of the Canadian AIDS Society as a network, coalition and umbrella organization. In the

case of the groups I discuss CAS operated only as a very loose network. There was little experience among groups of CAS as an umbrella structure, apart from the oft-cited example of the phases of the National AIDS Strategy (I discuss umbrella and coalition work in more detail in chapter 6). The main result of this is that there is a certain inequality amongst the organizations. Some are underfunded or do not receive as much ongoing support. This chapter shows an evolution of organization at the local level beginning around kitchen tables in the gay community and growing to become sophisticated General Service Organizations providing complex, coordinated services to their wider communities. This is part of what I argue to be the necessary formalization of organizations which seek to continue to be effective. The groups discussed in this chapter have remained important service providers within their communities. They have achieved positive outcomes, providing and developing services. Most of the groups have ongoing funding, showing acceptance at the government level, an important measure of outcomes. These issues are further explored in the next chapter.

## **CHAPTER SIX**

### **LOCAL GSOs AND CAS: IDENTITY, MOTIVATION, IDEOLOGY AND OUTCOMES**

In the previous chapter I discuss the roots of General Service Organizations (GSO), their formation, development, funding structure, services and ties to other organizations. In this chapter I focus on ties between GSOs and CAS as a network, coalition, and umbrella structure in different circumstances. I then look at GSOs in light of some of the theoretical issues which inform my understanding of CAS as an organization: the identity of member GSOs and the extent to which this has fluctuated over time; motivation behind membership in CAS; ideology and ethos behind the work that local organizations do. I then discuss the relationship with CAS in terms of outcomes for local GSOs specifically as drawbacks and benefits which come from CAS.

Throughout I show the extent and closeness of the ties between GSOs and CAS. As in previous chapters, I focus on why the relationship with CAS evolved as it did and on the consequences of the evolution of organizational structure. If the constructs used throughout “fit” with the discussion in chapters 3 and 4 this might point to, if not the potential for a closer working relationship, at least to an umbrella structure over these organizations with the “fit” making it more likely that member GSOs would be willing to allow CAS to work on their behalf. The greater the disparity in these core concepts the looser the affiliation, or potential affiliation, between organizations. While in practice loose affiliation would not affect CAS’s ability to work as an umbrella structure it would have an impact on it as a network or a coalition and on its ability to present a united front against AIDS in Canada now or in the future.

### Ties to the Canadian AIDS Society

The questions in this section are about the nature of the relationships that GSOs have to CAS and the closeness of the ties between CAS and these member organizations. Given the importance of GSOs to CAS's formation and development, one would expect closer ties to these organizations than between CAS and other member AIDS Service Organizations (ASOs).<sup>1</sup> Less frequent contact might point to a general distance between ASOs and CAS; however, it is also possible that GSOs, coming from larger population centers and receiving direct provincial and federal funding, now have less need for support and information from a centralized organization. My discussions with respondents focused on whether or not the relationship with CAS was one way (i.e., did CAS only provide information to member organizations or was it also informed about the work of these groups and developments undertaken by them?). The answer to this question indicates how structured the relationships were and points to the nature of CAS as an organization and the consequences of this.

Respondents spoke at length about the relationship between their organizations and CAS, and for the most part they told a story of decreasing contact. As one respondent said, "The relationship with CAS has changed in as much as I don't call them as frequently unless something really heavy is coming down...[then] I can call them and deal with it" (interview with longtime local organizer and former CAS board member, March 1999) . This might be attributed to CAS's development from a network to a more complex

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<sup>1</sup> ASOs do not provide the same range of services as GSOs. They focus on specific populations or provide specific services not offered by other groups.

coalition (discussed in chapter 3). Several respondents highlighted the fact that their organization decreased contact with CAS over the years.

I think that CAS, it seemed to me, was more active in advocacy campaigns and in providing leadership at a national level and helped us to sort through complex issues related to living with HIV and AIDS. For example things like the whole issue around criminalizing sexual acts without informing a partner that you're HIV+. So in those sorts of things it plays an important critical role. However, it doesn't seem to me over the last few years that there's been a whole lot of work between [us] and CAS. It just doesn't seem to me that there's a strong connection between the CAS and [us] and I'm not sure if that's true of other ASOs and that might be more reflective of our approach to the CAS than the CAS approach to local ASOs. In any case it seems like a fairly distant relationship currently and personally I would like to see that change because its obviously mutually beneficial for both of us to be in more contact with each other.

(interview, November 1999)

This respondent is very clear that CAS more recently did not fulfill a role that it had played previously. From a long term perspective, the connection had weakened. This respondent also highlighted the importance of collaborative work. Another interviewee, involved in local level organizational work since the early eighties, attributes the changing relationship to CAS's growth and the necessary formalization of relations that were a part of this:

Well certainly as time went on with more groups and with staff changes it wasn't the same little network of the original founders, who all knew each other quite well. Certainly it had to become more formal. It did become more formal. And sometimes there were struggles between whether CAS became a larger office doing all of the development and doing all of the interfacing between governments and our other national partners.

(interview, November 1999)

This is important in relation to my argument in chapters 3 and 4 about the impact of formalization and bureaucratization on CAS as a collection of organizations. Other interviewees also characterized the relationship as fairly formal but made it clear that it was easy to call someone if one-to-one contact was desired, at least with the current CAS Executive Director.

I suppose its all really formal. It's just different types of formal communication. There's times when I'll write a letter or stuff like that but there's also times I'll pick the phone up and talk to the ED of CAS, Sharon, and that works real well. I don't feel like I necessarily have to put everything in writing. I can just have a conversation with her.

(interview, December 1999)

While this points to positive personal interaction and good links between CAS and member organizations, another interviewee pointed to the difficulties that come with bureaucratic aspects of CAS and the fact that the force of personality can have a negative impact. Personal ties are frequently cited as a benefit or drawback and seem to be an important factor.

I've been on both sides as a staff person, a volunteer and a client of the ASOs —both my partner and I have been hellraisers in some situations and there's just nowhere to go...if you call the funders and say, Look, I'm not getting this service...[t]hey say, there really isn't anything we can do about it we're just the funders. If you call the OAN or CAS they say the same thing. So there's really nowhere to go if you get deadlocked at the ED level or the board level depending on which is the stronger. And that's a real problem.

(interview, January 2000)<sup>2</sup>

This shows a situation where CAS is not able to be effective and hints at a desire for its more centralized involvement, which a number of respondents discuss in this chapter. Ultimately this respondent argued that the relationship with CAS would benefit from being more centralized, regimented and controlled, thereby allowing CAS to dictate solutions to certain problems. Another respondent was even more critical of CAS and the politicized aspects of the organization as well as the negative impact of clashing personalities.

I feel guarded because I feel that the CAS [has] become so political and politicized that I wonder how they can get anything done. I don't know what their board is about. I don't know what their board accomplishes. I don't know what the tone of their work is. I know that we've had a CAS board rep that lives [here]...who has been so consistently problematic and negative with our organization that at one point we just gave up. Completely gave up on having any kind of a normal link to CAS through that individual. And I've been interviewed before by people that have

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<sup>2</sup> Difficulties in terms of bureaucracy, which I discuss in chapter 2 surface again in this chapter.

said, What makes a strong relationships and connections and I've said, For God's sakes its the representatives--the board reps. If they can't communicate and if they won't communicate or if they begin to play personal politics on an ongoing basis then what they've done is they've jeopardized a whole segment of the membership and its relationship .

(interview, January 2000)

These quotations clash but both respondents agree that a tighter bureaucratic structure with less room for personality conflicts would be beneficial. There appear to have been some cracks in the ideology of decentralization which was so forcefully put forward (see Chapter 4). One might expect this to be a problem for local and more rural ASOs struggling to provide services in smaller communities.

Like other organizations ACT fully supported CAS from an early stage:

...several of us went to the May conference in 1985 in Montreal. One of the first staff people at ACT was Kevin Orr and we put him forward for the steering committee. So he was a member of the initial steering committee. We felt it was important to support a national coalition. Basically we felt it was important to support community organizing. We saw that was important in itself. The other thing is that we were getting a lot of calls from communities and groups who were starting up, who were looking for advice, help, whatever, and we had a hell of a lot to deal with right in Toronto. So we saw this is beneficial to support coalition development to support people being able to have these organizations in their own areas. It would take some of the pressure off of ACT and it would enable people to be supported from their own communities. So definitely right from the beginning. And then once Stephen Manning became the ED and they had the actual AGM in Toronto with the first elected board then we felt it was very important that we support the national coalition and basically gave them Stephen. He was an incredibly valuable asset.

(interview with Joan Anderson, April 2000)

This shows a unique motivation behind support for CAS's formation and development as a coalition with an impact nationally and within local communities. However, the relationship between ACT and CAS was uneven over time and affected by a number of different factors.

It kind of went in and out over the years...sometimes it resided more in the ED than it did in the board level. But support around the board level kind of fluctuated depending on who was around the table at the time. And I think there were a



number of years certainly where I as the chair of CAS and all the community persons felt that ACT had become more insular, more Toronto focused. And to some degree that was necessary. It was like they were relating more to the city government structure and to the provincial government structure than the federal. I mean a shift happened where they were getting much more of their funding from the province and the city than they were from the federal government. So it became less important and I think it became a little bit more like, Well CAS'll do that. And so again I think the more recent boards of the last few years who have Charles as ED--there's been a bit more reconnection with CAS, as well kind of more organizational commitment to what goes on nationally. But it's kind of fluctuated over the years.

(interview with Joan Anderson, April 2000)

In this instance the dynamic at the local level impacted the relationship with CAS more than environmental factors or difficulties within CAS related to action taken around given issues. Internal divisions in ACT had a negative impact. Although not much explored within this dissertation, the dynamic of individual organizations affected their place within the collection of member organizations and CAS's effectiveness as a representative coalition of ASOs. The impact of personality is again important here in that with different executive directors the relationship to CAS (and therefore the potential for networking and coalition building) changed: this was at least a part of the fluctuation and points to a lack of centralized organization. ACT's goal was to have CAS work as a national organization, allowing the Toronto group to focus on their immediate environment. Had CAS maintained more control over member organizations, a standardized relationship could have been established across groups along with services, structures and unified contact systems. Personality would then have had less impact. But there would have been different outcomes. Given the way the AIDS movement evolved in Canada, from a grassroots base, a more deliberately centralizing CAS policy would not have been effective. Nor would it have attracted as many member organizations, conflicting with the

prevalent ideology within the gay community. CAS's claim to representativeness and action as a coalition and umbrella organization would not have been as effective.

Interviewees see CAS as having been most effective in taking care of policy work beyond the scope or scale on which local groups were able to organize. A number of interviewees highlighted this and CAS's ability work on things with which local organizations might not have been able to deal.

I think there's a benefit in having a national organization. That's clear. There are some benefits that come in terms of their expertise and they can focus on certain pockets and areas of concern and that kind of thing and do some of the leadwork that we can't do. Then we can link with them and get some help around issues.  
(interview, January 2000)<sup>3</sup>

Essentially, CAS's activity on the larger scale saves many organizations from this work. This relates to Staggenborg's (1986) argument that coalition work is more likely where a task is beyond the resources of an individual organization. The difference in this case is that CAS is willing to give organizations a free ride (beyond the membership fee of 0.2% of a group's funding)

Well, I think that there's any number of vehicles that we have contact with--from a department level to a programming level to as a member of CAS. [We are] a founding member of CAS so we're pretty supportive of CAS. We have staff on various committees of theirs...we get their INFOCAS bulletins and their policy bulletins and that's really useful for us because we don't have to duplicate coming up with policy. Don't have to do all that research for ourselves. Its right there.  
(interview, December 1999)

This is echoed again and again in interviews:

We receive a lot of material. They will give us overall information. Either changes in policies or specific things that we may need to advocate on--information on specific things that have come out about HIV and AIDS that we need to pass on. Information about conferences...so it did help us with networking...we work

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<sup>3</sup> This respondent is one of the ones, however, who went on to talk about lateness of materials getting to ASOs and of the need to be self-reliant in the face of CAS's disorganization.

with CAS more in terms of national programmes. CAS can certainly be seen to give direction to work at the national level."

(interview, March 2000)

Again, in another interview, the national direction that CAS gives was highlighted.

Well they've been doing some really good stuff with providing resources and ... Spearheading national fundraising events like the walk. Spearheading national advocacy and discussion issues and providing resources that can be used at the local level. So in those three things they're doing a really good job. It makes perfect sense that they spearhead the walk so that its standardized across the country--that there's national advertising, national partnerships with the larger companies like Molson and so on. That makes perfect sense and they do that well and its very helpful. The national advocacy--again, we don't have the manpower at the local level and they do a good job--they'll send down papers to us and say what do you think, we'll put our input in and we'll send it back and they'll finalize it and take it all and they have the person power to really meet with the government and do some advocacy and so on.

(interview, January 2000)

This sort of work on the part of CAS extends to "renewing the National AIDS Strategy and those sorts of things" (interview, December 1999), which could be argued to have been CAS's most effective and far-reaching success at the national level. For the most part GSOs agree that CAS acted as an effective national voice, providing representation for ASOs at a national level, spearheading campaigns and coordinating and distributing the information that ASOs needed. This was good for local organizations and is work that they would have been unable to do otherwise.

However, a number of interviewees also highlighted the fact that some essential information and materials had been slow to reach them and that this rendered them useless in cases where they were late.

I think that the biggest challenge with CAS is they're a national group and they provide coordination work for a lot of the regions. When that coordination work breaks down that becomes the biggest challenge. Ok because it has an impact not just on us at a local level, although it does have an impact, its at a local level across the country and that's problematic...the awareness week this year was atrociously

done. We still--its what, three weeks after awareness week--have not received our AIDS awareness week material

(interview, December 1999)

I don't know what slows it up but I'm telling you it must make the small organizations crazy. We don't depend on them at all for that [AIDS awareness week materials] because its just ridiculous. So [what] that has caused is that we develop our own AIDS awareness week materials.

(interview, January 2000)

Although slowness to distribute important materials may affect other aspects of CAS's work most of the groups represented here appear to be satisfied with the general organizing on a national scale although not with all of the specifics. Through INFOCAS, the organization newsletter, and other publications member groups are aware of CAS activity. However, there is little feedback or information on successes and struggles, or sustained input from GSOs to CAS on policy developments. Basically little of this is systematized.<sup>4</sup> In most cases, interviewees said that there was no flow of information from them to CAS. Joan Anderson says that varied, depending on who was the executive director of ACT at the time. Another interviewee said that most staff were not even privy to information coming from CAS:

If it does it doesn't trickle down necessarily and I think feeds my feeling of this distance because there isn't a great deal of communication or if there is it somehow misses me and other people in the organization as well. So I'm not sure what the problems are there but they're not effective communication channels.

(interview, November 1999)

This shows that there are no systematic communication channels beyond the newsletter and that information does not "trickle down" to GSO staff. This is perhaps because of hierarchies within local organizations and because most information from CAS went through ASO Executive Directors. One respondent noted that, "we don't have all that

much personal contact" (interview, March 2000). Even when information reached local organizations, which should then have been in a position to comment, there was conflict between the pressures and time constraints at the local level and responding to CAS demands, even in terms of information:

They'll usually send out draft stuff for us to comment on. Again the difficulty with that is just workload. Generally, I was the contact for CAS. They would send stuff down to me and I would try and make sure that I sent it out in our client mailout or sent it to the support group or had at least some people respond to it. But it took a bit of time and a bit of work and if I didn't do it--if I was swamped and just didn't get a certain paper circulated or whatever it just didn't happen. And so there was no feedback from the local level. And even when we were providing feedback on what the third stage of the National AIDS Strategy should be. After the fact, when we reviewed and talked about it at the provincial and federal level, very few organizations did a concerted effort of going out and talking to clients and bringing it back in. I don't know exactly what the reasons were. Workload was part of it. But there was no requirement to do it. There was no follow-up to say, We need this input to powerfully advocate for you and understand the issues. So on a lot of stuff there's very little local feedback. And I'm not sure what CAS can do to improve that or if they can. I think its a fault at the local level but I'm not sure how to address it.

(interview, January 2000)

There was a lack of information going out from local organizations to CAS, even for such important developments as the National AIDS Strategy. This interviewee sums up a lot of the problems in terms of feeding back information to CAS and shows the complex nature of the relationship, given demands of time and effort it takes to get back to the central organization. Despite attempts to operate as a coalition, seeking information from local groups, without the systematic requirement that groups get back to CAS (or seek information from their clients, etc.) there was no way to gather information broadly and CAS operated in reality with more of an umbrella structure, acting on behalf of local groups without necessarily having input from them. This ties to comments from one

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<sup>4</sup> This again can be seen as a drawback coming from the lack of more centralized control--services could be completely lacking in certain areas and it seems that CAS would be unaware of this or, at least, unable

correspondent who trusts “in my heart and in my gut that they’re acting on my behalf and on their behalf but I don’t know what they do” (interview with long time local organizer, April 1999). There seems to have been conflict between local and national interests but this is not something that respondents elaborated on when they were asked about it directly. One organization pointed out that their group had “...contributed to their regional updates that they do” (interview, December 1999) but this does not show a dynamic contribution on the part of groups (assuming that this is the extent of others’ involvement). Rather, information on decisions already made was sent by the local groups to CAS.

Among the GSOs studied here, CAS had a different relationship with different groups, dependent on personality and geography and on CAS’s structure. The structure became more bureaucratized and this had an impact on the relationship with groups and on difficulties in getting materials to organizations in time for them to be used effectively. Differences among groups also account for distinct relationships with CAS and could be the cause of flux in some ongoing relationships. Although it maintained a very decentralized structure, CAS served an umbrella function of sorts, particularly in managing the flow of information and in the national level presence it had independent of local groups. The desire on the part of some GSOs for centralization points to further differences among GSOs in their relationship with CAS. The presence of a coalition is evident in member group support for CAS national actions and in the quotations showing organizations presenting a united front with CAS in lobbying and other actions.

### Identity

As with many modern SMOs, multiple identities were at play in CAS (cf. Stoecker, 1995), particularly with the broadening demographic of those affected by AIDS. At the local level, all GSOs which granted interviews were formed in and out of the gay community and one would, therefore, expect gay identity to have been important in their early stages of activity (just as it was for CAS) and in their ongoing relationship with a centralized organization countering homophobia and heterosexism. I discuss the extent to which there was a development away from this identity, the importance of AIDS itself in shaping the identity of groups, the importance of PLWHIV/AIDS, injection drug users and other affected populations. The disparity between local and national group identity is also highlighted in my discussion of the effects this had on CAS as a coalition and the consequences for local organizations.

As expected, the GSOs all locate their foundation in the early eighties in gay identity. The picture in the later eighties and throughout the nineties was more complex. Different identities as well as clashes over the distinction between AIDS organizations and gay organizations came to the fore. One respondent summed up this complexity and the historical importance of the group's gay identity as well as the important role of PLWHIV/AIDS:

It was certainly present historically. It still plays a role. Both gay identity and PHA involvement. They are the two that ASOs tend to flip flop. A lot of the time what I have seen is an ASO will focus very much on the gay community and gay services so to speak and having people on staff and so on. Then there'll be some community complaint because they're not addressing other community issues and then they'll swing back the other way and completely ignore and not provide services for the gay community and change the identity completely again. And then it'll be too far the other way. Its very difficult to find that balance but its definitely there.

(interview, January 2000)

There is a pendulum swing back and forth here in terms of perception of the organization within the gay and wider communities. This was noted by another interviewee, whose group was accused of turning its back on the gay community as more and more straight people came onto the staff.

So symbolically, the signal was given that this organization is being run by someone who is straight, who comes from the straight world and can maneuver in the straight world and can be accepted by the straight world etc. etc. Then the rest of the tussle was around what was the complexion of the staff. Some of the gay people that have worked here...have left angry and certainly haven't described this to me but the ones that have left contented with their contribution and feeling ok about leaving the organization and letting it get on with its business have talked...they've observed gay and lesbian individuals coming to [us] and working for pay in responsible situations and being completely out--whatever that means--and being respected and all those things which are so powerful. Very very powerful for people that come from communities that are largely marginalized in various ways and/or discriminated against in a silent way or a more vocal way...until last year, you could be forced out for being gay and it was perfectly legal. So I as a gay man first working for the government and later for some large hospitals, this kind of thing--I could never say to anyone, I'm gay. Because my boss could have fired me and I would have had no legal recourse whatsoever. And its shameful actually. So you could have people that were openly gay in an environment with other gay people all being paid to do semi-professional or professional work and that in itself was so liberating for individuals that they will probably never forget their years here, ever.

(interview, January 2000)

The good and the bad also comes out here with some gay men finding a place in an organization they felt represented them and others not, although the interviewee finally goes on to note that, "in terms of identity people found their own personal identities strengthened here by the organization despite the fact that there were straight people running it." This echoes comments made by another respondent about CAS being the first place that he could be openly gay and not fearful, but part of a healthy environment (see chapter 2).

The swing of the pendulum can also be related to the fact that it is possible to emphasize or de-emphasize gay identity (something CAS confronted in its early pursuit of



funding described in chapter 2).<sup>5</sup> This was also a question for ACT and the role of the Executive Director and the contribution of personality was again critical here:

So you have a thing where an organization born out of gay political life--people who were not only gay but sophisticated politically--you had that combination with gay men who were responding to AIDS and who didn't have a sense of political nuances and the political organizing--those kinds of things. So that was one of the tensions in that storming piece too. So you'd have some of the guys would be really clear that it wasn't a gay organization--it was an AIDS organization. And certainly when I was chair I didn't deny the gayness so quickly. And I'm probably being a bit too hard on them. It wasn't so much that they wanted to deny that gay folks were there but they felt that for the organization to be accepted and to get funding...whatever...and again I didn't think that was a good strategy. What you need to do is say, Yeah most of the people involved are gay and we've come out of the gay community and we're proud of that.

(interview with Joan Anderson, April 2000)

The executive director, or in this case Joan Anderson, then an ACT board member, had a big impact on the direction of the organization and emphasis on identity. The critical difference between AIDS and gay organizations is highlighted. This was also the case in another interview, where the struggle to make the distinction between the two types of organization was clear.<sup>6</sup>

It wasn't even considered that [we] would want to go into the straight bars because its a gay organization...or on an ongoing basis we would get calls from the media whenever there was any issue around gay rights, gay this gay that gay whatever, they would call [us] for comment. And it really started irritating us. Our local gay and lesbian community services association has been strengthening its position in the community for several years now and I'm really pleased to see it and they've appointed a media spokesperson and now the media has gotten the message. I really spoke with them and I said to a couple of their board members, please designate a media spokesperson and get their name out to all the media outlets so that they stop calling us about gay issues. And they have stopped calling us about gay issues and that only happened about the last year to two years. Now the media calls us on HIV and AIDS if there's anything they want comment on and [the other group] gets called for gay and lesbian related issues.

(interview, January 2000)

<sup>5</sup> Lehr (1994) discusses this issue explicitly.

<sup>6</sup> This has also been a struggle for ACT UP and other groups and was a tricky area because groups did not want to distance themselves from the gay community, while not being seen as exclusively gay.

An important distinction was therefore made by this organization: identifying itself as a group concerned with AIDS was key, whereas identifying with the gay community and having board members who were gay was important but secondary (this is the same organization that had straight executive directors for a number of years). This shows a more complex relationship between organizations and the issues that they deal with in that, while opposed to homophobia and heterosexism, they clearly did not want to be identified as gay because this could be seen as exclusionary. But while it may have been politic for groups to de-emphasize gayness at certain points in time, respondents reported that “the majority of our clients are gay men” (interview, March 2000). This is the group to whom the bulk of outreach still seems to be directed, as was discussed in the previous chapter.<sup>7</sup>

The part played by PLWHIV/AIDS fluctuated over the years. Organizations made more room for this group at certain points in their history than at others. As I discuss in chapter 2, some PLWHIV/AIDS, who felt that they were not represented in more mainstream groups, started their own organizations. While CAS struggled to correct this problem and addressed it in its membership guidelines (Canadian AIDS Society, 1992), some groups have not made room for either PLWHIV/AIDS or gay men:

...the staff are very aware that there are no gay men on staff. There are no men providing frontline service and there are no PHAs on staff. And that is definitely a factor for the comfort level of clients and the approachability... Now that can be true for other communities as well but ideally you’ve got somebody providing frontline service that would supposedly be a gay man and someone else (or that person) who can have some connections with and good understandings of street communities, some history with street communities, IDUs and other communities in the geographic area.

(interview, January 2000)

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<sup>7</sup> A good example of this is the Gay Men’s Survey administered by AIDS Calgary in 1994, which reached out to CAS’s main client base and focus of outreach.

This suggests that there may be any number of groups who are either underrepresented in an organization or not represented at all. There was a fluctuation, depending on a number of factors. Several groups faced the issue of representation.

And so I think that part of that has also been a lack of effective outreach to other communities so there has certainly been those political struggles and I think that has been exacerbated to some extent by the fact that we live in a city where there isn't a very well defined visible gay and lesbian community, such as Toronto. So I think that there isn't as much support for that and also it is our mandate to serve the diversity of communities that require HIV services so we are certainly charged with that responsibility and have not taken any other stand than that but its sometimes perceived that we are just a gay agency so that has been an ongoing political struggle...we don't have a strong representation of PHAs in our organization although that has been the case to a greater extent in the past it isn't currently. So I would say that in many respects the organization doesn't have a stronger identity as an AIDS organization than it does as a gay organization.

(interview, November 1999)

In this quotation it is apparent that there are a number of groups, including PHAs, who were not well represented in the organization. Other identities were at play. The question as a whole for PHAs is dealt with effectively by Roy (1995) but there has been no real research on the other groups affected by AIDS and apparently left out of the organizational structures that I discuss. There is no other single identity that could compete with gay identity or the identity of PLWHIV/AIDS. Many of the populations who are clients of these organizations are not part of organized communities in the way that gay men were (e.g. Injection Drug Users (IDUs) and prostitutes do not form a large network out of which competing organizations could be built but these groups are represented on some ASO boards across Canada and there are organizations which reach out specifically to these populations, who are members of CAS (eg. Prostitute's Safer Sex Group and Main Line Needle Exchange)).

For the most part there has been little conflict between local identity and CAS's position as a national organization. However, one respondent emphasized that tensions had arisen between local and national levels:

So I think that here...we get very clearly the connections between local, regional and I would say national and that the one impacts the other. At the same time I think there are also moments where at a local level people wish--because its always the ED and the board chair that does those other pieces at the regional level and the national level--that it would be easier sometimes if we could just be here doing our work rather than out there doing stuff. But I think most people here get that there's a connection. That we're out there doing that work because it will impact our work here.

(interview, December 1999)

Some conflict occurred even as the organization and the community of which it is a part recognized that the organization needed to have a connection to the national and provincial levels. The importance of the roles of the executive director and board chair are also interesting to note in that the organization generally was not much involved in what happened at the national level. Identity with the local community is discussed further in the section on ideology.

Gay identity for local groups initially played an important part, but seems to have decreased (or at least fluctuated) in importance and recently has not been strongly emphasized. In hiring staff, many organizations moved away from the gay community as a second, more professionalized, generation of HIV/AIDS workers replaced the first. This is reflected not only directly in my research but also in the unfolding of the research itself, with access to interviewees getting harder the further I moved from the first generation of activists and organizers. The effect of the relationship between GSOs and CAS on outcomes is obscure for the most recent period but was clearly important for the formation of the network and ongoing opposition to homophobia. Identity also had an

impact on the ability to reach out to certain populations, which in part explains decreasing emphasis on gay identity by local organizations in the most recent period under study.

### Motivation

Motivation is related to the mobilization of local groups and of CAS more than to the evolution of the organization or its outcomes. However, motivation also helps to explain continued CAS membership and, therefore, the outcomes for local groups and for the organization as a whole, which attracts an impressive number of member organizations. Most of the GSOs under study were founding members and so the motivation for membership is largely contained in the discussion in chapter 4 looking at why CAS was founded. Beyond this, motivation is rooted in the need for a national representative voice.

As far as the GSO staff members interviewed were concerned, CAS was able to work at a national level, taking on the government in advocacy, developing national policy documents, and twice securing the renewal of the National AIDS Strategy. This provided motivation for continued membership in the organization, together with the fact that many of the outcomes for GSOs were positive in terms of funding and having a representative voice with a seat at the table. Where CAS failed to meet these needs, organizations fell further outside the coalition, taking the initiative for more activity themselves--something which may be attributed to conflict between local and national programmes.

The work they did in lobbying for the National AIDS Strategy--that's the kind of work that I think they are good at. So they have done critical critical work at the national level and all power to them is what I say. But where they start getting mucked up around, almost getting in the way of organizations getting their stuff done then I think its not helpful. I'm sure you've got it in your theory, in your literature--its that whole struggle between centralization and regionalization. And as you know there's a real move towards regionalization happening...So what

we've got are regional organizations that have sprung up and are becoming increasingly empowered. So does a national organization sit there and try and control everything and centralize, centralize, keep everything centralized or do they adapt and say, What is our role given the increasing growth and strength in regional organizations? Maybe our role is different. And I haven't seen that. What I've seen is them just acting in that same centralizing manner and maybe its not going to be effective in this decade.

(interview, January 1999)

Thus local activists conveyed some satisfaction with what the organization does at a national level.

This can be related to the different theoretical aspects of motivation outlined in chapter 1: organizations are motivated internally to remain effective, allowing them to focus on work at a local level; external incentives are the need for funding and legitimacy, which came from association with the Canadian AIDS Society; expectancy of success is seen in the idea that organizations are more likely to achieve their long term goals in coalition with other organizations: "I think that just in terms of creating coalitions and having collaborative partnerships it makes a good deal of sense and I think that CAS has an important place...because it is obviously mutually beneficial for both of us to be in more contact with each other" (interview, November 1999).

These aspects of motivation indicate that the benefits accruing from membership outweighed any costs (such as conflicts and difficulties in communication, the membership fee) and this was a strong enough motivation for long-term membership and a useful predictor of whether or not CAS will continue as a collection of organizations. The membership dues are not heavy and time and effort spent on involvement in CAS has always been optional because of the decentralized structure. There is, therefore, nothing to be gained from leaving or lost by staying, in spite of the frustrations that might go with CAS's ineffectiveness in certain limited areas because of its structure.

### Ideology

Ideology is tied to the goals that an organization sets or chooses to pursue and to its (hidden) motivation for certain actions. Ideology also may provide another reason for uniting with other organizations or with CAS. Organizational structure is also impacted by egalitarian ideology (in the case of the Canadian AIDS Society, pursuing a decentralized organizational structure). One would not expect organizations promoting rigid hierarchy to be involved with CAS.

A number of the GSOs studied presented only a very loose ideology with regard to their involvement in their communities or with CAS. Most broadly, ideology was expressed as an emphasis on community, which can be tied to the CAS ethos of decentralization. This was most fully expressed in the following, which clearly lays out community goals and broader social justice concerns:

We certainly are a community based organization--so that really informs a great deal of the work that we do in terms of the involvement of stakeholders and the way that power is distributed across the agency. That is certainly a part of our ethos and also being a health promotion organization a lot of the principles of health promotion inform the work we do, things like calling meetings, capacity building and community development. Those are certainly important principles in the work we do. Also the fact that we're a social justice agency definitely has an impact on the kinds of work we do and how we do that. The sorts of community partnerships we form or go seeking. So yeah, I would stress the social justice orientation. Our nature as a health promotion organization, certainly our community based perspective.

(interview, November 1999)

It is also expressed in the idea of the whole community, rather than one specific group, owning an organization:

The whole community. The citizens own this organization. Its almost as though, if there's any sort of ethos that went on through the whole thing it was simply that people felt very passionate about the organization. Felt a strong sense of ownership and what's actually happened is that the organization through one way or another has continued to be supported and has continued to be relatively stable over that whole period of time of the ups and downs and different client groups

and splits on the board and the gay community saying, You've abandoned us or you haven't and all that sort of stuff. There's a resiliency there that I think comes from a basic community support that just exists and maybe part of it is the actual funding.

(interview, January 2000)

This shows breadth of identity in relation to what might drive the organization (fostering a sense of ownership throughout the whole community of which the organization is a part).

Another respondent, when asked about the ideology behind their organization said,

"Basically it's to prevent the transmission of HIV and AIDS and to improve the quality of life of those who are living with HIV and AIDS. It doesn't get much more complicated than that" (interview, March 2000). This sentiment is held by all ASOs across Canada<sup>8</sup> and it is possible to see it driving specific actions on the part of different organizations.

To extend the community aspect, "client need" was closely tied to an ideology of community for one respondent:

I think the fact that we're very much driven by client need. Our programs are developed in response to community need. In response to what clients are wanting and needing to see happen. I think that that's very true. There are philosophies that we all share. That's evidenced by our joint membership at such agencies as CAS. There's a philosophy of empowerment and access to services that I think runs throughout the agencies that belong to that organization.

(interview, December 1999)

This shows an inclusivity in a philosophy of empowerment. Another respondent discussed ideology in relation to identity in a somewhat inclusive tone: "In the early years it probably was easier because we had more common enemies in the sense that the struggle was better defined... There was less a focus that we were a gay organization and more that we were a community organization" (interview, November, 1999). This again shows the community emphasis and the fact that ideology tends to be more inclusive. This is actually very similar

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<sup>8</sup> This also ties to ACT UP's goal, which is, simply stated, to "end AIDS."



to what others expressed, with only one respondent pointing to a certain amount of exclusivity in the ideology:

Its pretty easy for a new person to come in and say we're going to switch this around and this around and they just have to notify the government, the funders, that that's what they're going to do. So there's no consistency and there's no accountability beyond that. So the standard missions for them are basically all the same--public education and support for PHAs. Some of them have advocacy as a component.

(interview, January 2000)

Some broad goals are expressed in "education and support for PHAs" but there is also some dissatisfaction with the lack of centralization or control exercised by CAS. In this case there is also a lack of accountability to the local community.

The emphasis at ACT was always on decentralization, partnership and community, what Joan Anderson refers to as "health from below," just as Michael Sobota did in discussing CAS's own ideology (see chapter 2).<sup>9</sup> ACT's own emphasis on community aspects is drawn out and emphasized in Anderson and Bébout's history of the group, which quotes from one ACT annual report:

We're convinced that the most effective responses to AIDS are the ones built and controlled by the very people most affected by AIDS. In our partnership work we do not simply teach people about AIDS. We teach--and learn--self-empowerment, self-help and skills for genuine community development.  
(Anderson and Bébout, 1996:4-5)

Again, there is an emphasis on community and on the empowerment not only of ACT but also of its clients, as well as the central importance of working in partnership with others.

Overall, perhaps unsurprisingly, there is a strong emphasis on community (or on the fact that it has broken down) throughout, showing largely decentralized organizations with ideologies broadly congruent with one another. Decentralization points away from umbrella organization structures and towards more egalitarian coalition at all levels.

CAS's decentralized role is clear throughout this, for better and worse, with autonomy being held by local groups or, in some cases it would seem, specific members of those groups (see my earlier discussion of personality). Certainly not all of the interviewees saw this as best; some expressed frustration at lack of centralization.

### Outcomes

The basic question regarding outcomes, which can be tied to questions of motivation, is what effect membership in CAS has on these GSOs. Informants were asked, "What are the benefits of membership in CAS?" and "What, if any, are the drawbacks?" A number of the outcomes of CAS membership are discussed throughout this chapter, including a representative voice at the table in government meetings, distribution of information, organization of large-scale and trans-Canadian events, and renewal through three phases of the National AIDS Strategy (with pressure on the government), which was referred to only in passing in interviews. Membership in CAS clearly brings benefits although in some cases these benefits also extend to non-members. CAS member organizations do exclusively benefit from the information distributed in INFOCAS.

First, CAS was a resource to member organizations, providing information that they might not otherwise have gained access to (this is not a universal benefit but is specific to member organizations):

I think, ideally being a resource for an organization like [us] that doesn't have the resources and perhaps the expertise to develop positions on controversial issues related to living with HIV and AIDS. I think there's all kinds of things that we...get from CAS in terms of policy development and certain political positions. Also, participation in advocacy campaigns could have a direct impact on our clients and our work we do here locally. Those kinds of things would be important at the CAS. Also organizing national events like the AIDS walk, increasing

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<sup>9</sup> The ideology is fully laid out in Homophobia, Heterosexism and AIDS (Canadian AIDS Society, 1989).

awareness nationally and providing opportunities to local ASOs to participate in national HIV awareness. Those sorts of things I would regard as important to the CAS. I'm a strong believer in networks and collaborative partnerships and sharing resources and all those sorts of things so I can only see it as a benefit from that perspective.

(interview, November 1999)

A number of interviewees noted that CAS did things that they were not able to organize locally:

The national advocacy--again, we don't have the manpower at the local level and they do a good job--they'll send down papers to us and say what do you think? We'll put our input in and we'll send it back and they'll finalize it and take it all and they have the person power to really meet with the government and do some advocacy and so on.

(interview, January 2000)

I have already quoted another interviewee on the benefits of a national organization "in terms of their expertise and they can focus on certain pockets and areas of concern"

(interview, January 2000) but this interviewee also went on to speak of the slowness of CAS to get certain materials out to groups for specific actions. While this is not necessarily a drawback it is at least an inconvenience.

One interviewee went so far as to say that CAS had shaped the organization in which s/he was involved:

...they certainly provided a series of meetings. Apart from the annual general meetings they were involved with a number of training seminars and facilitating [payroll] policy, which we were able to use. They sponsored all kinds of meetings between Health Canada and the regional offices of Health Canada and ourselves and CAS certainly led the development of the gay men's education stuff. Yeah they were very much involved on a policy level and on a developmental level across the country. And given their limited resources and our limited resources, I think very few parallel movements have done any better.

(interview, November 1999)

This highlights specific benefits and links into government networks on a local and national scale, which might not otherwise have been possible or so speedy. However,

CAS's failure to effectively coordinate work on some fronts, even as the benefits of their national work are highlighted, is also noted:

I would say that coordination of national campaigns, although I'll be blunt--they need to improve on some of those areas. But for instance, the national walk. The coordination of the national walk last year was superb and we could never afford (well we have and we just couldn't do it again) all the print materials, sharing of resources for that event. You know the coordination of that, getting those national sponsors on board. We wouldn't have access to those types of funders. Corporate stuff, not a chance. We don't have a large corporate base here so having access to CAS gives us the open door to other places.

(interview, December 1999)

Benefits seem to far outweigh any disadvantages at this level and coordination between local GSOs and CAS is generally efficient and effective:

We're doing a project that's in relation with CAS this year. It gives us the opportunity to be more visible in our own community...So in that sense it helps us because it is a major item that we couldn't otherwise get our hands on or afford to bring in. So they'll present those kinds of resources and information sessions and around at that point. It also gives us the opportunity to do a little fundraising around something that is so visible.

(interview, March 1999)

The same positive comments come up again and again in interviews.

A possible exception to the way that the relationship between GSOs and CAS worked is the AIDS Committee of Toronto, which had more impact on CAS at certain points in their histories than vice versa.

...the '86 - '87 year when ACT was doing some federal lobbying because CAS was still in formation. And then as CAS got an Ottawa office and an ED and could work directly on the Ottawa scene you know there were battles going on with the provincial public health and stuff going on in the city that really demanded all the energy and attention. But there was somebody to let it go to, which was important.

(interview with Joan Anderson, April 2000)

As I show in the previous chapter, ACT had taken something of a national role on behalf of ASOs, in many ways paving the way for CAS; but this was a position that the Toronto

group was able to step back from once the national organization came into its own, having received core funding.

The positive outcomes relate to benefits, which came from having a nationally representative voice in Ottawa to air ASO concerns at the top of the political hierarchy and having the staff to coordinate national actions and annual events. However, it is already apparent that CAS was not always well coordinated with regard to specific actions, particularly in recent years, which some member organizations experience as a drawback of membership, having to coordinate their own campaigns or not being able to hold events at all. In some instances there is not enough follow up with local groups: "But there was no requirement to do it. There was no follow-up to say, We need this input to powerfully advocate for you and understand the issues. So on a lot of stuff there's very little local feedback" (interview, January 2000). This may be a disadvantage of decentralized organization and is related to previous quotations on the inefficiency of national campaigns, although it perhaps only applies to one year where activities were poorly coordinated. One respondent (quoted above) said that the national coordination is an area where CAS could improve its record.

For the most part, however, organizations are happy with benefits that far outweigh the drawbacks. Many of these may reach far beyond the member organizations of CAS but the information that goes out from the central organization only reaches member groups. Benefits come to member groups with very little demanded of them in return.

## CONCLUSION

Throughout this chapter I have shown that CAS performed some coalition and representative functions for groups at a national level. It did not attempt to control or direct member organizations, nor did it always seek information from them beyond initial questions. CAS, therefore, worked less as a network as it evolved. Groups were not tied closely together, certainly not evenly across the country. This is demonstrably not the case with GSOs. The networking aspect was more apparent in early CAS coordination in the late eighties, shown in interviews earlier in this dissertation. The Canadian AIDS Society was a coalition to the extent that groups presented a united front on a number of issues, including the AIDS awareness week. It was at least loosely connected through a common, if unformulated, ideology and identity. Organizations were motivated to continue as members because of good outcomes at the local level. Some umbrella structure features are also apparent in representation around the National AIDS Strategy, which was formulated independent of input from local member groups (though CAS did try and solicit information from members). The organizational features (network, coalition and umbrella organization) discussed in chapters 1, 3 and 4 were present to some degree but none appears to have been dominant in CAS as a collection of GSOs.

A number of coalition features from the literature are prominent in CAS's history. Member GSOs do have a common ideology (Curtis and Zurcher, 1973), which is important for the formation and maintenance of coalitions (Staggenborg, 1986). The organizational diversity among member organizations was not a barrier to collective action (Feree and Hess, 1994). Nor was the tension between building a movement for long term change and seeking more immediate results (Kleidman, 1993). Rather, CAS established itself as a long-term, decentralized coalition representative of diverse member groups. The

GSOs surveyed in chapters 5 and 6 have been member organizations, for the most part, from the beginning and have benefitted from membership in CAS in funding, the services that they were able to provide and especially from CAS's ability to represent groups' concerns in Ottawa without significantly drawing on their resources. Oliver and Furman (1989) write that "political realities almost "force" organizations addressing national issues into creating a professionalized staff" (174) and this was indeed the case with CAS. However, diverging from Oliver and Furman, I would argue that member organizations are not just paper members but "real" members involved in some national level activity. Like the American movement organizations that Oliver and Furman discuss, CAS has no way of compelling members to follow certain courses of action. Only in the National AIDS Strategy negotiations did CAS act "on behalf of the entire set of constituent organizations" (Laumann et al., 1978:474), that is, as an umbrella organization representative of member groups. The outcomes of this form of organization were, however, positive. CAS managed to achieve renewal of the Strategy and its funding, allowing groups to continue providing services in local communities. In all other aspects, member organizations have experienced CAS as a network and coalition. All features are differently present at stages in CAS's evolution, with attendant outcomes, as I discuss in my dissertation conclusion.

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## **CHAPTER SEVEN**

### **CONCLUSION**

In this dissertation I have discussed the mobilization and development of the Canadian AIDS Society (CAS) over a fourteen year period. The focus of my work has been on how a collection of organizations evolved and the outcomes of this (i.e. the consequences of adopting particular organizational forms). I use the concepts *network*, *coalition* and *umbrella organization* to discuss organizational growth. Staggenborg (1998) argues that a 'fluid' conception of social movements after mobilization is needed. I attempt to provide this through the use of these concepts and a discussion of several other issues from the social movements literature.

The Canadian AIDS Society developed out of a series of meetings between representatives of 16 local AIDS Service Organizations (ASOs) from 1984 to 1986. CAS was formed through networking among individuals and continued to develop exclusively as a network of organizations between 1986 and 1988 (that is, as a collection of organizations sharing information and some resources). While CAS was relatively unsophisticated politically, with little access to government, it began to develop bureaucratically, meeting "at the good graces of the federal government" (interview with Michael Sobota, March 1999). Using short term federal grants the board visited member organizations across Canada, thus strengthening the network.

In 1988 CAS became incorporated. The organization was able, with more substantial federal moneys, to rent office space in Ottawa and hire the first full-time staff.

This was the beginning of a period of accelerated formalization. CAS became more politically sophisticated, lobbying and holding meetings with members of the federal government. As a central organization, CAS grew as a representative of an increasing number of local member organizations. CAS was a coalition of organizations at this time, with some ongoing network features in relation to member groups. Also in this period, beginning in 1989, CAS was involved as one of several stakeholder organizations in negotiations towards the development of a Canadian National AIDS Strategy. The stakeholders were national organizations responding in some capacity to AIDS. CAS worked on the National AIDS Strategy throughout the period under study.

In the nineties, CAS stabilized as the leading national AIDS organization (Roy, 1995) with membership increasing to over 120 groups. This was a period of further formalization in which CAS overcame internal divisions and increasingly displayed some umbrella organization features. This was particularly evident in ongoing negotiations around phases of the National AIDS Strategy. From 1995 onwards, with the renewal of the Strategy in doubt, CAS campaigned for ongoing government support, acting on behalf of member organizations throughout 1998 with little input from ASOs. CAS and the other stakeholders secured renewal of the third phase of the strategy with ongoing funding from the government for AIDS work.

By this later stage of CAS's development the organization was displaying network, coalition and umbrella organization characteristics as a complex collection of organizations. While CAS sought input from member groups, this was not always forthcoming. CAS became a bureaucratic organization representing a diverse array of member groups. The member organizations that I focus on are General Service

Organizations (GSOs) providing a range of services in cities of more than 200,000 people. These all had roots in the gay community and mobilized in response to the effects of AIDS in their local communities. Groups grew out of informal meetings (often around kitchen tables). However, parallel to the formalization of CAS, these organizations became increasingly sophisticated. Most quickly received government funding, supplemented with a little income from their own fundraising activities (e.g. AIDS Walks). The relationship with CAS grew more distant as the central organization became less aware of and received less input from member groups. However, this resulted in only sporadic tension and for the most part member organizations have been satisfied with CAS's national level work, including ongoing distribution of information and educational materials.

While CAS's formation and evolution as a collection of organizations was unique, shaped by the peculiarities of the Canadian context, my analysis of the organization's characteristics and discussion of the issues of *insider and outsider status, identity, frames and ideology, motivation and outcomes* situates CAS and its relationship with member organizations in the larger context of social movements literature. My study of the organizational evolution of CAS and of the outcomes of this may contribute to an understanding of other networks, coalitions and umbrella organizations.

The main focus of my research is on the evolution of CAS through various organizational forms and the consequences of this development over time. I use three core concepts from the literature. A *network* is a loose formal or informal grouping of organizations united largely for the purposes of information sharing but also to support one another in a variety of ways and is characterized by face to face contact between individuals. This form is advantageous in allowing groups with shared ideology to link up

with one another and work towards shared goals. This form, at least in this study, was not enough to allow a growing number of groups to present a united front at the national level. *Coalitions* may involve networks but also have unique characteristics. In a coalition the relationship between organizations is more structured, allowing for shared resources. Ideology and goals are more clearly stated than in a network. This organizational form allowed CAS to develop a representative voice, maintaining contact with local groups while negotiating on their behalf with the government. An *umbrella organization* is centralized and formalized, acting on behalf of member organizations and coordinating actions. Umbrella organizations develop themes for groups to follow, require members to cede autonomy, and perform a management and coordinating function. This may all take place within a democratic environment. CAS did develop some umbrella features, which allowed it to negotiate with the government around the National AIDS Strategy, particularly in Phase III, when negotiations required a quick response to certain proposals. It was difficult, however, for CAS to maintain contact with members as it became increasingly formalized and the form of umbrella structure conflicted with CAS ideology.

Within the literature these concepts are dealt with separately but clear distinctions are not made between them. In this dissertation I more clearly discern differences between the concepts and use them to show CAS's development. CAS began as a loose network and underwent various stages of formalization becoming a coalition-network and eventually displaying some features of an umbrella organization. This evolution was the necessary response of CAS to the need for sophisticated negotiation with government and representation of an increasing number of member organizations spread across the country. CAS developed its organizational structure to become and remain effective in

Ottawa, in contact with the government and able to distribute information and benefits to member organizations (cf. Staggenborg, 1988). Member groups highlighted this as a vital function of CAS working at the national level. Local group representatives acknowledged that this was not something they were capable of with their own resources. Only through use of the three concepts is it possible to look at the development of the organization as a whole and to trace the outcomes of this.

I agree that networking is crucial for mobilization (Carroll and Ratner, 1992) and can be of ongoing importance for movement longevity and continued effectiveness (Diani, 1995). However, I go beyond this to argue that other organizational forms can usefully be developed alongside networking by an organization in pursuit of wider goals, particularly when it is beneficial to have a central organization able to represent constituents. A number of points from the literature on coalitions can be used to highlight this development. CAS increasingly acted as a "mesomobilization actor" (Gerhards and Rucht, 1992) working to build connections between groups in the provision of information and common goals and pursuits (e.g. in lobbying MPs on common issues). The low demands of member organizations and CAS's stance as a national organization, not involved in the nitty gritty day to day running of member groups, meant that the organization avoided conflict between the local and national levels (Kleidman, 1993). The professionalization and formalization of CAS allowed it to develop and carry out work as a coalition (Staggenborg, 1986). CAS evolved as a broad-based, formal, decentralized coalition of organizations with a concern for AIDS, which shared goals and at least a loose ideology. This is very much in line with the literature on coalitions, which I discuss in chapter 1. I would emphasize, however, that CAS overcame a number of problems

through the fact that it is not completely centralized. The fact that CAS is involved in only a few actions at the local level (e.g. The AIDS Walk, Advocacy Packs on how to meet with an MP, etc.) positively impacts its ability to work on behalf of a broad range of organizations at the national level. CAS does not focus time and resources on organizing services within diverse communities and is thus able to act as decentralized representative at the national level. Because of this, coming out of organizational ideology, CAS did not become exclusively an umbrella organization. It took on some umbrella structure features, however, in pursuit of effective negotiation with the government developing themes as the basis for action (Stathusen, 1991) and having the prerogative to represent member organizations and act on their behalf without necessarily consulting them (Laumann et al., 1978). The looseness of this concept in the literature is problematic for its application but I show that CAS does have some umbrella features displayed most prominently in the recent National AIDS Strategy negotiations. I understand an umbrella organization to be a centralized organization able to act on behalf of member groups without consulting them (thus separating the concept from *coalition*) but that member organizations do not necessarily cede autonomy (cf. Hansen, 1986; Vickers et al., 1993).

CAS's accomplishments grew out of the organization's ability to represent member groups and negotiate effectively with the government and other national level organizations over the course of the nineties. This success allowed CAS to attract new member organizations and to work for the adoption of the National AIDS Strategy with ongoing funding.

As well as organizational forms, I also discuss a number of issues which impact outcomes for the organization. CAS's position as an insider, with access to government

and other elites (Morris, 1984) more than an outsider (although for most of the period under study the organization walked a line between the two) had an important affect on outcomes (Gamson, 1975) and organizational structure. CAS developed coalition and more formalized umbrella features in order to be able to negotiate with the government and target policy-making effectively as an insider. The motivation (Pinard, 1983) of the organization, towards acting as a representative, national, unified voice, had a similar impact on goals and outcomes. I argue that it was necessary for CAS to develop as it did in order to work towards its particular organizational goals, especially around mobilization and at other significant points in its formalization. The identity (Stoecker, 1995; Lehr, 1994) of the organization, initially rooted in the gay community, impacted early mobilization, allowing geographically diverse groups to network and eventually to form a central organization. By not emphasizing identity in certain situations, CAS could act as an insider, negotiating with the government. This had an ongoing effect on goals and action (see Bernstein (1997) on the "celebration and suppression" of identity in interaction between the gay and lesbian movement and other actors) . CAS continued to reach out to gay men and counter homophobia, which were goals that came from organizational ideology. CAS ideology (Oliver and Johnstone, 2000; Staggenborg, 1986) also emphasized decentralization (see also Handelman, 1989, on another decentralized AIDS organization) in the relationship with member groups. Some member groups felt that this had a negative impact: ASOs do not provide an even service across the country.<sup>1</sup> This ideology also impacted organizational structure, in that while some umbrella features were

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<sup>1</sup> I would further hypothesize that this would most affect ASOs in smaller population centres, which were not included in this study. These groups would be more reliant on external funding and information than in the larger centres studied here.

developed CAS retained coalition aspects with limited networking. Framing (McAdam, 1996) was not formalized but is apparent in the actions that CAS took.

All these issues impacted outcomes at the national level in relation to government and to member organizations. They also affected the organizational form that CAS took and it is for this reason that I have included them in my discussion. The particular aspects of each issue discussed here and the way that each issue was dealt with allowed CAS to develop in the way that it did. Each issue is tied to organizational evolution, increasing understanding of why CAS developed as it did and useful for the study of other organizations.

My dissertation contributes to the AIDS literature at two levels. First, it adds to the Canadian literature on AIDS (Cain, 1997; 1993; Kinsman, 1997; Rayside and Lindquist, 1992a, 1992b) presenting a history of an important national level Canadian AIDS Organization and touching on a number of issues already raised in that literature from a new angle (see also Roy, 1995). Second, I add to the wider literature on the importance of coalitions for AIDS work (Schneider, 1992), the role of identity (Lehr, 1993) and the part played by activists and social movement organizations in making advances against AIDS in North America (Sheperd, 1997; Epstein, 1996; Wachter, 1991; Handelman, 1990).

Following Curtis and Zurcher (1973), I agree that interorganizational relations are crucial for social movement organization success. Without the support of (and ability to represent) member organizations CAS would not have been able to act as effectively at government levels or remain a relevant national voice. Working on the National AIDS Strategy as one of ten stakeholders (by 1998) and effectively negotiating with those



groups was an important part of the success of the renewal of stage III of the Strategy, though not explored in depth in my dissertation. That CAS was able to establish itself as an effective coalition had a significant impact on outcomes for the development of local organizations and (to an extent that is difficult to measure) on the National AIDS Strategy negotiations as well as CAS's ability to distribute information to member organizations. This is tied to Burstein et al.'s (1995) argument that interaction among SMOs and with their targets is important for outcomes (see also Schneider, 1992; Steedly and Foley, 1979). The relationship both with government and member organizations are important topics for future research, given limits in the present study both in access to ASOs and the exclusion of the provincial and federal government perspective on CAS organizing.

I contribute a broader understanding of the concepts *network*, *coalition* and *umbrella organization* used throughout this dissertation. Each ideal type is present in some form along a continuum of formalization after initial appearance. Use of the three concepts together in analyzing the development of a social movement over time, and the outcomes of this, gives a richness to the research that would be lacking in an examination of one point in time. CAS is the central organization in a broad-based, decentralized coalition of organizations across Canada concerned with AIDS. Given the positive outcomes that the Canadian AIDS Society has gained in working with elites, while maintaining contact and (sometimes limited) input from member organizations, this study of CAS is a useful model for the formalization of grassroots collections of organizations displaying network, coalition, and umbrella structure features, developing relationships with government and member organizations.

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