NEW YORK CITY'S NEEDLE EXCHANGE POLICY AND THE INTERSECTION OF SCIENCE, ACTIVISM, AND POLITICS: A CASE STUDY OF ACTIVIST RESEARCH AND SOCIAL CHANGE

by

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Abstract

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by

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An extensive body of literature has been concerned with the problem of the nonuse or misuse of social science in policy making, and the basic disconnect between what we know about social problems and how they are dealt with through governmental action. Most research on the intersection of social science and policy has limited its analysis to one particular type of audience: policy makers. As a result, the role of activism as a critical source of political change, as an audience and consumer of social science research, and as a valid and important role for social scientists to engage in, has been greatly neglected. Taking, as a case study, the political struggle over needle exchange policy in New York City, this research examined the multiple roles social science and activism played in promoting policy change. Data for the case study came from three sources: 1) *published material*, including academic publications, newspaper articles, and newsletters from academic, advocacy and activist organizations; 2) *interviews* with individuals who played a central

role in this history, including researchers, activists, and policy makers and government officials; and 3) *archival documents* accessed from the private records of individuals interviewed, including private correspondences, internal documents of organizations, court transcripts, photographs, and video documentaries. The results of this study provide strong evidence that activism, the overlap between activist, social scientist, and policy networks, as well as social science knowledge itself, all played a key role in the success of the needle exchange movement. The results also support the idea that empirical evidence, while playing an important, and perhaps necessary role, is often not enough to promote policy change. These findings challenge the science-advocacy dichotomy, pointing to activist and advocates as vital sources of social change, and therefore, key beneficiaries of the resources that social science can provide. Some of the disconnects and tensions between social scientists and activists are discussed and recommendations for how to better support activism, social movements, and broader policy struggles through the methods and discourses of social science are made.

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Chapter One: Theoretical Framework

The gap between empirical evidence and policy has been one of the most discussed themes in the social sciences. Examples of this persistent and extensive gap abound: the use of capital punishment, despite overwhelming evidence of its ineffectiveness as a deterrent on crime (Haney & Logan, 1994), the ban on funding for needle exchange programs to reduce the transmission of HIV among intravenous drug users in the face of compelling evidence of the effectiveness of these programs (The U.S. Department of Health and Human Services, 1998), and policies that discriminate against gay and lesbian parents (in terms of foster care and adoption issues, and in custody and visitation disputes in the context of divorce), even though virtually all of the evidence demonstrates that parental sexual orientation has no negative impact on children's development (Patterson & Redding, 1996). On many issues, the research is clear, with firm consensus about what works, and what does not; but policy stands in glaring contradiction.

Policies that ignore empirically-grounded solutions have far-reaching and often devastating consequences for people. Tens of thousands of people have needlessly contracted HIV because of a ban on federal funding for

needle exchange programs[1]. This ban is in place despite the fact that a strong and consistent body of research supports the efficacy of such programs at reducing the transmission of the virus, while not finding any evidence to support the criticism that giving out clean needles promotes drug use (Lurie, Reingold, Bowser et al., 1993; Bayer, 1997; Lurie & Drucker, 1997; Goldstein, 1998). Roughly 500,000 people are incarcerated for drug-related offences, despite overwhelming research demonstrating the efficacy of drug treatment for substance abusers (Caulkins, 1997), and the clear inability of deterrent and incapacitation-based policies to have any sustained impact on the reduction of drug use nationally (Mauer, 1999; Parenti, 1999).

Literally thousands of publications have documented or commented on the gap between social science research and policy. The general conclusion (agreed to varying degrees) is that the social science research is rarely or poorly utilized in policy decision-making (Lindbloom and Cohen, 1979; Elms, 1975; Backer, 1990; Rosenberg and Limber, 1996; Morin & Collins, 2000), a reality that has been referred to as the "crisis" within the social sciences (Saxe, 1985). This is not to say that social science does not get used by policy makers, because it does. The types of research that make

[1] "Using a very conservative model, a *Lancet* article estimates that 4,400 to 10,000 HIV infections among U.S. intravenous drug users $500 million in health care costs. Action taken in early 1997 could have prevented an additional 11,000 infections by the year 2000, saving over $600 million" (Lurie & Drucker 1997, cited in Coffin, 1997).

their way into the policy-making arena are typically those that fit the dominant discourse surrounding policy issues and support the agendas of policy makers, independent of the scientific merits of the research (Weiss, 1977; Larson, 1980; Rich, 1991). By definition, research that supports progressive change challenges the status quo, and is often rejected, discredited, or "politicized," even in cases when the research is robust and strongly supported. The greater the challenge research poses to established interests, the more strongly it will be rejected. And on many of society's most pressing social issues, progressive policies are supported by an overwhelming majority of the research that has studied the issue. Therefore, on many policy issues it is the majority of research which is being marginalized.

This research aims to provide a better understanding of how social science can be more effectively translated into policy change. The study of social policy, however, is quite complex. It entails examining a multitude of historical, political, and social factor that can not be reduced, in any meaningful way, to a set of variables that are modeled statistically. Therefore, any study that aims to truly capture the interaction among these different dimensions must examine each in-depth, calling for the case study methodology. This research will utilize the case study methodology in order to examine the intersection of science, policy, and activism within a

particular political struggle where research played an important role. Rather than looking at what doesn't work (e.g., how science is misused), this project hopes to further our understanding of what does work—what methods and strategies of social science utilization can have a positive impact on policy. This study is about the role of social science, its relationship to activism, and how it can best capitalize on and help carve out opportunities for social change.

The Case of Needle Exchange Policy in New York City

The policy chosen as the focus of this case study is the political struggle over the practice of needle exchange (NE)—a policy of distributing clean needles and syringes to injection drug users (IDUs) in order to reduce the transmission of HIV and AIDS—in New York City, during the height of the AIDS epidemic, the period between the early 1980s and 1992. As a policy that was supported by broad scientific consensus, yet shrouded in controversy from the very beginning, this history provides an ideal opportunity to understand what happens when social science enters the complex and contentious world of politics.

New York City was the first municipal government in the U.S. to attempt to institute NE as a model of HIV prevention for IDUs. It arose as a policy issue in 1985 when the city's health commissioner proposed making needles and

syringes more accessible to IDUs. This would have entailed either overturning or circumventing state law which made it illegal to possess drug injection paraphernalia without a prescription, a law that was intended to discourage drug use and therefore legislate abstinence. The unintended consequence of this law, however, was to encourage the sharing of used needles and syringes by IDUs (since it was so difficult and expensive to obtain clean ones) and therefore, contribute to the spread of HIV/AIDS among the general population[2].

Before reviewing this history in detail (which takes place in chapter three), this chapter will review the debate within the social sciences regarding the relationship between science and political decision making. Several different bodies of literature are reviewed here, some representing the mainstream or conventional view, espousing the separation of science from political concerns, and others that represent a challenge to this position, such as critical theory, feminist-standpoint theory, and post-modern theories. Other bodies of literature reviewed here come from the fields of community psychology, the sociology of knowledge, and the social movements literature. The second chapter will outline the methodology of the case study, which entailed extensive archival data on

[2] HIV/AIDS until the mid to late 1980s had been largely confined to gay men, but injection drug use increasingly led to infected IDUs, their non-using partners, and eventually to the children of infected partners.

the history of NE in New York City and interviews of a sample of principal actors of this history. Chapter three is an historical review of NE policy in New York City from the early 1980s to 1992. Chapter four will discuss the analysis and results of the research, which is largely qualitative, but does include some quantitative data. Chapter five will summarize the findings and discuss the implications for an activist research model of social science practice.

Parameters and Assumptions

Social science vs. physical and medical sciences

Up to this point, I have used the term "social science" rather than the more general term "science." In many ways, much of the discussion here may be equally relevant to both of these labels. At the same time, there may also be some important differences as well. It could be, for example, that the relationship between the physical sciences and policy making is different, in some ways, then the relationship between social science and policy (perhaps because of the subject matter or because of nature of the methods). These types of questions lie beyond the scope of this study. However, there are several historical examples that suggest that the ways in which the physical sciences are used in policy making are very similar to the ways in which the social sciences are used. For example, in their book, "the Betrayal of Science and Reason: How Anti-Environmental Rhetoric

Threatens our Future," Paul and Anne Ehrlich (1996) demonstrate how prominent critics of environmental science and conservative media outlets (such as the Wall Street Journal) have attempted to "undermine the findings of decades of research on the dramatic deterioration of the natural world." A review of the book in the Washington Post (Lee, 1996), summarizes the conclusions of the book the following way: "The Ehrlichs characterize the recent barrage of attacks against scientific conclusions about pesticides, declining biodiversity and other ecological woes as a distinct movement, launched by a disparate group of corporate lobbies, pundits, propagandists and researchers. They even give the movement a name: the brownlash." This pattern of use and misuse of research from the physical sciences seems to parallel the use of social scientific data. Because examples like this suggest that the patterns of use of social science and physical science are similar in political decision making, a distinction is not made in this study. Furthermore, it seem reasonable to assume that any discourse, scientific or otherwise, that conflicts with the discourses of dominant group interests will follow similar patterns of misuse and marginalization. Therefore, in this study, the terms "science" and "social science" will be used interchangeably.

Categories used to group scientific discourses

The debate within the sciences regarding the role social science does and should play in policy and political decision making forms the theoretical framework for this study. Before this literature is reviewed, it is necessary to reflect on this debate, specifically, how well the two positions articulated here accurately reflects the actual diversity of views within the social science community. Two contrasting world-views are discussed here—conventional or mainstream perspectives on the relationship between science, activism, and policy, and theories that challenge the fundamental tenets this view. They are two competing world-views or discourses for conceptualizing reality and its relationship to language, theories, knowledge and other constructs for knowing the world. Theories from the mainstream of the social sciences are based on modernist views regarding reality and knowledge, where "good" science produces constructs that adequately represents that world as it is. Challenges to this view are diverse, but focus on the central role of power in the construction of reality, including knowledge produced by the scientific method. The two most powerful challenges to mainstream perspectives have come from Marxist-inspired or neo-Marxist standpoints (e.g., critical theory, queer theory, critical-race theory, and feminist-standpoint theory) and post-modern standpoints. However, because these two perspectives are at odds with each other on many central points, their grouping together is

based more on the rejection of modernist principles rather than on the specifics of how they are rejected. Again, power, albeit conceptualized differently, is the theme that links these frameworks together and provides the key point at which they differ from mainstream perspectives.

Epistemological Stance

To a large extent, the motivation behind the questions raised here, how they've been framed, as well as the data and analytical procedures chosen, all reflect an epistemological stance critical of modernist notions of science (the stance of dispassionate scrutiny) and conventional views of an open democratic political system. The most powerful of these biases is the practical consideration that motivated this project: the dissatisfaction with traditional methods of using social science to promote change (disseminating research to policy makers) and skepticism with regard to the openness of the current political system to scientific data. A core value underlying this research is the acknowledgement that the world-views of researchers frame the process of their research from beginning to end. Because of this acknowledgement, much consideration for the current study has been geared toward attempting to represent both world views reviewed here on the relationship between science and policy, fairly.

A priority of this study is to include, as much as possible, competing frameworks, sources of data, analytical styles and interpretations. Several steps have been taken to ensure this objective, including collecting data that crosses the political spectrum and including data and analytical codes that have the potential of support the principles of the various perspectives reviewed here. Because of this, there is no hypothesis about which theoretical perspective will be supported by the data. This research is more inductive than deductive. The current study does hypothesize, however, that, despite the failure of science to change federal policy around the funding of needle exchange programs, it did have a significant impact in many other ways, and that impact occurred through multiple routes, audiences, and discourses of science. These hypothesized findings leave open the issue of process, which lies at core of this research. The questions are: what were the different ways in which science impacted needle exchange movement and what were the processes through which science impacted change? The goal is to collect data in the most open manner possible, from which a better understanding of the questions posed here can emerge. In other words, while one bias of this study is its critical-realist epistemology, a counter-veiling value is the belief that no theory has a monopoly on useful knowledge.

The problem is not *if* social science is used, but rather *how* it is used

The problem I seek to understand is the *relationship* between social science and policy, not necessarily that science per se is not utilized enough in the policy making process. Science does get used, and many have written about these cases (Lazarsfeld & Reitz, 1975; Aronowitz, 1997). Central to the current view, the large majority of applied research has not been geared toward social change, but has rather been conducted "in the service of the status quo and the establishment" (Oskamp, 1984). Caplan, Morrison, and Stambaugh's (1975) seminal study on the use of social science by federal decision makers supports this view. They interviewed 204 high-level office holders. Looking at their awareness and self-reported use of relevant research, the authors found 61 percent of the respondents reported two to four examples of use, and 13 percent reported five or more examples. The types of science reported used by policy makers, however, revolved largely around internal government issues (e.g., training of employees, organizational management), where the "dominate purpose of knowledge utilization is to improve bureaucratic efficiency" (p. 373). Therefore, it is clear that the science that was reported by decision makers as influential was utilized in the service of "what is" rather than "what could be."

Policy makers often cite scientific research to support their policy positions, however, it is often done in a self-serving and partisan manner (in many cases, the relationship between science and policy is in blatant disregard of the espoused principles of the scientific method). Some of the largest policy initiatives have been founded on social science research. The Manhattan Institute, for example, a conservative think-tank made up of researchers (in the social sciences as well as other disciplines), as well as policy-makers, develops ideas and gets them into mainstream circulation. Scott (1997) attributes the efforts of the Institute to helping change the course of New York social policy, and notes how it has been very successful as a networking structure for conservatives (and moderates, in some cases). The result has lead to many issues being placed on the public agenda which were not previously, and in some cases, accumulating enough influence to "enable politicians and much of the public to agree on a profound shift in direction." The direction of the reform was always toward the political right and in the interest of those with political and economic influence.

One of the conservative researchers funded by the Manhattan Institute was Charles Murray, who helped push supply-side economics theories by writing the influential book *Losing Ground*, which many agree contributed to welfare reform and promoted theories about crime and public disorder

that later influenced policy in this area. Similarly, the conservative theorists James Q. Wilson and George Kelling's (1982) "broken windows" theory of crime prevention is cited as the theoretical centerpiece for New York City's crime policy, which focuses on zero-tolerance for low-level quality-of-life crimes. Some key components of the broken windows theory have been translated into policy—those that support enforcement, control, and surveillance, rather than progressive reform, despite the fact much more research and empirical evidence, supports progressive reforms rather than tough-on-crime practices. A perfect example of this is the well-known RAND study, which demonstrates that treatment is seven times more cost-effective at addressing addiction and drug abuse than incarceration (Caulkins, et al., 1997). In fact, the strength of the modern-day conservative movement is largely attributed to the utilization of conservative think-tanks such as the Heritage Foundation and the American Enterprise Institute, acting as "a comprehensive ideological apparatus of an insurgent movement which includes scholars from the social sciences as well as the humanities" (Aronowitz, 1997). The problem, then, is not necessarily that social science is underutilized in policy making; the problem is how it is utilized. The focus of the analysis should therefore be on the *process* by which knowledge is used (or not used), rather than the *content* or orientation of the research. This point leads to the next assumption, the idea of narrative fit—the degree to which social science

findings, theories, and discourses are consistent with dominant social narratives and ideologies.

Because science does in fact get used in much of policy making in this selective manner, the term, science-policy gap, is somewhat misleading. However, the selective use of science, which is based on narrative fit rather than on the merits of the science itself, will be considered as an example of the gap between science and policy rather than an example of use. The "science" side of the science-policy gap term, refers to a body of science as a whole, not a particular set of studies. Therefore, this research is concerned with the challenge of how do to bridge what we know about a social problem (i.e., the best available scientific knowledge) with what is done about them through policy? Since selective use of science is usually not based on providing the best available knowledge, it is not considered an example of appropriate use.

What types of Policy does this Study Address

The fact that the term policy means so many different things requires a clarification of the types of social policy that this study is addressing. Besides differing on the governing body which is responsible for various types of policies (federal, state, and local government), policies also differ on content (e.g., criminal justice, education, health) and on political

salience (the level of importance stakeholders attach to the policy). It is this last point that is critical for specifying the types of policies this research is addressing. Simply stated, this research addresses policy issues that are highly controversial and contentious, and that threaten the interests of stakeholders with political influence.

This brings us back to the issue of narrative fit. One of the most widely agreed upon observations and empirical findings is that the single most important factor determining patterns of social science use is the narrative fit between research findings and dominant belief systems (Gamson, 1998). For those scientific discourses with good narrative fit—those that are not characterized as being highly controversial or contentious—the factors determining its impact on policy are much more likely to be empirical and rational in nature (such as research that supports the need for greater money for child care for low income mothers, which few would argue is not a good policy). So on many policy issues were there is narrative fit, the relationship between social science and policy making may indeed appear rational and pragmatic to a substantial degree. It is situations where social science clashes with the dominant discourse that this study is focused on. The less the fit, the less patterns of knowledge use reflect instrumental rationality and the more they reflect patterns of power and ideology.

Conventional Theories on the Relationship Science-Policy Relationship

Theories from mainstream social sciences have been premised on the what Stone (1997) refers to as the "rational ideal," the belief that policy making is a rational process, and gaps between policy and knowledge are therefore attributed, in large part, to limitations in the knowledge itself or in the ability to communicate it to policy makers in a timely and usable manner. The position articulated from the mainstream of the social sciences, including most of social psychology, reflects widely shared beliefs about the potential of instrumental knowledge and conventional democratic routes to bring about social change. From this perspective, the principal strategy for utilizing social science to promote social change is to maximize the objectivity, reliability, and general scientific soundness of the research, and to find the most effective means of communicating and disseminating the findings to decision makers (Rich, 1980; Weis, 1979). Theories have examined the role of social science in political decision making, outlining the predictors of and the "barriers" to the utilization of social science knowledge (e.g., the limitations of social science to meet the informational needs of policy makers, such the need to have information quickly and with clear cut solutions). The most effective ways of influencing policy have been to produce more and better (i.e., more methodologically rigorous) research and finding ways of effectively communicating it. Central to the objective of ensuring the validity and

reliability of research is the tenet of separating politics from the scientific process. Researchers produce and disseminate knowledge, and should not use it in any from of political action or should not let political concerns enter into any aspect of the research process.

The audiences of the research are those sitting at the top of the power hierarchy (policy makers), those working to influence them (advocacy and policy organizations), and sometimes public opinion. The assumption is that with enough knowledge, social change will occur, or that this approach, however limited, is the best option available, since fusing science with advocacy would only corrupt the research, rendering it unreliable, and therefore, ineffective as a tool for social change. This belief reflects and depends on the ideals of democratic pluralism, where "democracy is maintained: (1) through the competition of organized groups and political parties, and (2) by the adherence of our leaders, at all levels, to democratic values" (Young, 1973, p. 385).

The field of study referred to as "knowledge utilization[3]" is a good example of theories that reflect many of the principles of the rational ideal. It has produced an extensive body of work looking at the barriers that limit the

[3] The knowledge utilization field was much more prominent in the 1970s and 1980s, and published much of its studies in the journal, "Knowledge: Creation, Utilization, and Dissemination." Although the field has gone through various "waves," it is much less active and organized as it was.

use of social science in public and private decision making. Various types of "problems" that occur at the intersection of science and policy have been identified, such as *bureaucratic barriers* (political, administrative, and procedural problems), *communicational barriers* (different intellectual and professional orientations between researchers and policy makers), and *problems in technology transfer or dissemination*. These problems have been grouped into three theoretical perspectives: 1) knowledge-specific theories, 2) "two-communities" theories; and 3) policy-maker constraint theories (Oskamp, 1984).

Knowledge-specific theories point to the limitations of the research as responsible for the science-policy gap, such as a lack of consensus, limitations in study designs, irrelevance of findings, or as a result of the prejudices and biases of researchers themselves. Policy-maker constraint theories look at conditions that limit the ability of decision makers to utilize research, such as time constraints (i.e., having to vote on policies before the research results are conclusive) and political feasibility (where the policy implications of research may be too costly to be adopted). It has been the two-communities theory, however, which has been the most influential. This theory states that conflicts in orientation (differences in intellectual styles and schemas for understanding the world, institutional incentives, rewards, and constraints) between policy makers and

researchers pose the most serious problems for knowledge utilization (Rich, 1991, Backer, 1990).

Some of the research within the knowledge utilization is more critical of the limitations of knowledge, by itself, to impact policy. Barabba (1985) argues that besides many of the technical issues often discussed in the literature, perhaps the most intransigent of obstacles includes the litany of political dynamics that compete with research. "When research threatens entrenched systems that are satisfied with the way things are going, factors such as timeliness and objectivity of knowledge, communication patterns are all of little importance" (p. 281, Rich, 1991). Weiss and. Buculvalas (1977) similarly argue that the more information challenges dominant beliefs, the less likely it is to have an impact, independent of its scientific merits.

Despite the recognition of science's limited ability to compete against entrenched political interests, the response by social scientists is often to produce more research. This raises the question of why a field would keep on producing more research and pouring more resources into disseminating it when there is strong doubt that policy makers will consider it in their decision making. Some logical speculations can be made about this contradiction. For example, it seems like many hold a type of

"threshold theory" of impact where research does not have an impact until it reaches a certain, and very high, degree of robustness and exposure. Alternatively, researchers may be working under the assumption that their data will lead to social change once the socio-political conditions or zeitgeist shifts in their favor. Researchers may also be working under the assumption that they are doing all that is possible given the realities of the political system, where "political issues are resolved through a process of conflict and coalition rather than through the rational use of information, despite the fact that the latter process is more comfortable to researchers" (Oskamp, 1984). The next section reviews in greater detail the grounding assumptions of mainstream social science regarding the role of research in social change.

Strategies for change: The Discourse of Objectivity

One of the tenets of mainstream social sciences is that it requires dispassionate scrutiny (Harding, 1992; Marshal, 1992; Scarr, 1995). Researchers have to maintain an appropriate level of distance from political concerns in order to insure the highest degree of objectivity possible. "Advocacy, even for the perceived public interest, is an uncomfortable companion to science, because it may pit social change against research findings" (Scarr, 1995, p. 164).

Mainstream social sciences' response to improving the efficacy of their research in influencing policy is to move closer to the ideals of abstract empiricism, where the lines between politics (or advocacy) and science should be made as distinct as possible. Harding (1992) refers to this as the "ideal of neutrality" (p. 569). Advocacy and (good) sciences are mutually exclusive. This ideal is strongly promoted by one of the most influential liberal policy centers, The Urban Institute, in a series titled, "The Future of the Public Sector: A series on the Long-Term Influences Affecting Social Policy." A piece in this series by Galster (1997) reaffirms the corrupting influence of advocacy on science. "Legitimate social science can and should provide higher standards of objectivity and methodological soundness than those of advocacy research. Advocacy research attempts to mimic certain features of social science, such as the use of theory and statistical techniques, but fails to be genuinely objective."

Galster offers three recommendations for a stronger, more effective social science policy research: a greater reliance by policy makers on blue-ribbon panels of respected social scientists to produce concise, readable, state-of-the-art briefs on topics of forthcoming legislation, greater use of evaluation research for new governmental programs, and more rigorous review of research proposals to evaluate such programs. In short, he calls for a reification of the basic tenants of the liberal-rational

framework, greater objectivity, more research, and better forms of communication and dissemination. The assumptions, again, is that the political system is sufficiently open to change through conventional democratic routes.

Alternative Perspectives on the Science-Policy Relationship

Many researchers working toward progressive social change have articulated deeply-held critiques regarding the extent to which democracy has fallen short of the rational ideal articulated or assumed in mainstream social science theories regarding knowledge utilization. Policy is not seen as the product of democratic, pragmatic or scientific processes, but rather as means through which groups justify the inequity of societal resources and privileges. As Piven and Cloward (1992) argue, "rule making is a strategy of power" (p. 302).

An example of this type of rule making is discussed by critical race theorists, Derrick Bell (1992). Bell argues that the agenda driving the call for "color blind" social policies, where race is not a consideration (such as an eradication of affirmative action policies within higher education), is motivated by an attempt to undermine policies that compensate for deep, persistent, and long-standing racial inequities. In contrast, Bell powerfully demonstrates how racism is very much alive and strong. He notes that

"when whites perceive that it will be profitable or at least cost-free to serve, hire, admit, or otherwise deal with blacks on a nondiscriminatory basis, they do so. When they fear—accurately or not—that there may be loss, or inconvenience, or upset to themselves or other whites, discriminatory conduct usually follows" (p. 7).

In light of this portrayal of social policy, the basic critique of the rational ideal is that access to political and economic power is fundamentally unequal, restricted, and concentrated. As a result, the illusion of an open political system masks a political system dependent on social and economic relations of exploitation, (Etzkowitz & Glassman, 1985). One of the bedrock assumptions guiding social change efforts is that "the fundamental conflicts of human life are not between competing ideas, one true and the others false-but rather between those who have power and use it to oppress others and those who are oppressed by power and seek to free themselves from it (Sarason, 1981, p. 831)." Instrumental forms of knowledge are insufficient in a system that is not open to change, and social change, therefore, often does not occur in the absence of intense struggle. From this perspective, influencing policy requires much more than overcoming informational barriers. It requires political struggle, and (most often) needs to include the primary "intended" stakeholders of

policies (the groups that are the subjects of the research, for whom th;pe data is speaking for) to one degree or another.

The call is for radically different forms of knowledge use and radically different conceptualizations of the scientific enterprise (Lewin, 1947; Lather, 1986; Park, Brydon-Miller, Hall & Jackson, 1993; Martin-Baro, cited in Aron and Corn, 1994; Fine et al., 2001; Steinitz, & Mishler, 2001; Fine & Barreras, 2001). For many working from this framework, the overarching phenomenon of interest is the status quo and strategies that challenge it (Seidman, 1988). This is exemplified by Serrano-Garcia's (1984) description of the field of community psychology as "a discipline with a sense of urgency and a belief in change" (p. 174). Lather (1986), writes about "what it means to do empirical research in an unjust world" (p. 257). She views, as do others from this perspective, "prevailing scientific norms as inherently supportive of the status quo," and calls for an "emancipatory social science," committed to bringing about a more just society by empowering the disenfranchised segments through critical knowledge of their oppressive conditions and of their potential for change. This bottom-up vision of social change has a strong tradition within the social sciences, grounded largely in Marxist-inspired social thought, such as critical, feminist, and queer theories. Patti Lather (1986) has referred to this theoretical, epistemological, and ethical orientation as

critical-praxis-oriented research, building on a rich tradition of activists researchers committed to progressive social change before here, such as Ignacio Martin-Baro (1984) and Paulo Freire (1970). Strategies for influencing policy through research have focused on supporting grass-roots and advocacy organizations and creating alliances with groups struggling for change. It is not that top-down strategies are not utilized, but rather that they are not relied upon. Change requires multiple points of entry, not just disseminating findings to policy makers.

In terms of understanding the opportunities for influencing policy through research, theorists form this perspective argue that the acceptability of policies, interventions or discourses offered by the social sciences rapidly diminishes to the extent that they require a change in the nature of relationships of power and privilege (Fairweather, 1972). Those working outside the mainstream argue that science must compete with these lenses and frames of marginalization, and that under these conditions the factors that influence policy are political as well as instrumental, (Cook & Shadish; 1986, cited in Rigor, 1989, p. 381). In other words, "the issue is not imperfect information, it is power" (Rigor, p. 382), and power is realized in relationships between groups.

Others have argued that because of this dynamic, the potential for change in most instances comes not from traditional democratic routes, but form the actions of marginalized groups. They argue that change often requires collective action that places pressure on decision makers. Often, this will even require those vying for change to "violate rules and disrupt the workings of an institution on which important groups depend" (Piven, 1991, p. 319). What distinguishes mainstream social sciences from its challenges, is that, from the mainstream view, participation in these political struggles contaminates the scientific process, while participation goes hand-in-hand with knowledge production within non-mainstream standpoints.

The other side of the science-advocacy debate

Within the "scientific posture" assumed within mainstream science, political and value-laden presuppositions are often "smuggled in the form of dispassionate interpretations" (Furstenberg, Jr., 1999). In other words, there is always a bit (or a great deal) of advocacy in science. Harding (1992) argues that it is through the claim of neutrality that dominant scientific paradigms marginalize competing perspectives. She talks about the "normalizing" procedures embedded within mainstream scientific practice, where "supporting and following the prevailing rules of scientific institutions and their intellectual traditions"... "defines the objections of its victims and

any criticisms of its institutions, practices, or conceptual world as agitation by special interests that threatens to damage the neutrality of science" (p. 569). She notes how the stance of neutrality has justified and led to "trivialization and even demonization of feminist approaches to history" (573).

Objectivity: A critical view

The notion that good science can only be objective science is seriously challenged within the many perspectives critical of mainstream social science: "In science, the notion of an objective reality is an interesting hypothesis, but it is not necessary to carry out scientific work" (Kvale, 1995, p.19). The knowledge that comes from scientific research is useful to the extent that it poses the ability to perform effective actions. Similarly, Foucault argues "discourses might be tested in terms of how they can actually intervene in local struggles" (p. 35). Some have argued that the alleged activism-science dichotomy has prevented the social sciences from developing a theory of social change or intervention (Seidman, 1988).

Many, wanting to retain some aspects of the notion of objectivity have redefined objectivity away from its positivist roots. Wagner (1995) argues that objectivity can still be a useful concept to retain in a science that

wants to contribute knowledge. He argues that the "classical rationalist pretense of absolute objectivity must be given up in favor of a relative objectivity, based on the characteristics of one's own culture." Relative objectivity is obtained to the extent that one realizes the ways in which one's culture filters one's comprehension of the world, determining what we can and cannot comprehend. Similarly, Harding makes the distinction between objectivism and strong objectivity, where the former reflects modernist assumptions of the ability of knowledge to represent reality, and the latter involves an ideal that can be moved toward by adopting a set of procedures that systematically detect for distorting assumptions privileging some paradigms and perspectives over others. Central to this process is the requirement of theorizing from the standpoint of marginal lives, which provides the "crucial first steps in gaining less partial and distorted accounts of the entire social order" (p. 583). The fairness of a discourse's representation of the world "must include multiple voices, be contextualized in its various cultures and their ideologies, be conflictual, negotiated, ambivalent, tentative, emergent, and continual (Clifford & Marcus, 1986, cited in Watkins, 1994)." Good science is "objective" or fair in its execution, that is, it is not predetermined in its conclusions and open to conflicting data and interpretations, leading to a process where advocacy and sound science are not incompatible.

Study Objectives

With regard to the objectives of this study, three points about the science-policy literature need to be highlighted. First, a vast amount of theory and data, from both mainstream and non-mainstream perspectives, undeniably demonstrates that the gap between science and policy is extensive and pervasive. Second, different world-views, that probably overlap to a considerable degree, provide different accounts of the troubles in the science-policy relationship and the relationship between social science and political change. Third, while the large majority of research has provided evidence for the existence of the gap or has provided theory for understanding its causes, few have focused on understanding how to reduce the gap and make social science more influential in policy making. As a result, our understanding of what *does* work—how social science can be effectively used to promote social policies—is dramatically limited in comparison. For those wanting to use social science (researchers, activists, or advocates) to promote progressive social change, there is very little theory or data to work from. This understanding needs to move beyond mainstream frameworks that focus almost exclusively on top-down methods of attempting to influence decision makers with compelling data and beyond understanding the predictors and barriers related to the impact of social science on policy.

This understanding also needs to find ways of translating critical social science discourses (those that critique the legitimacy and fairness of existing social conditions) into programs of social change. While critique is important it is also often not enough. Hill (2000) captures the spirit of this study best in his questioning of what political commitment to social justice means among progressive social scientists (his comments are directed at progressive criminologists, but are just as relevant to the rest of the social sciences). Hill argues that the demands of progressive criminologists "read more like ideological chants rather than operational manifestoes." "Perhaps if progressive criminologists are to become more than ideological complainants or Dickensian chroniclers," writes Hill, "they need to consider ways of translating their works from 'intellectual skepticism' into a *tangible* form of political action" (p. 10). Hill goes on to argue that progressive criminologists should begin to tell each other (and the rest of us) how to go about 'structural' or 'institutional' change. The research proposed here aims to further exactly this kind of understanding.

Focus on Activism and Activist Research

This research hypothesizes that "translating research" into "tangible forms of political action" requires multiple methods of using science—multiple audiences and consumers of research, multiple scientific discourses and voices, and multiple roles that researchers engage in. Because of this,

there needs to be a broader, and more inclusive understanding of the full spectrum of scientific practice, specifically those on the margins. As discussed in this chapter, the fusing of science and advocacy has been marginalized within mainstream social science discourses (by, for example, institutional incentives such as the need to publish research in peer review journals, and concerns from institutional review boards). Because of this, the focus of theories on the science-policy relationship has been on the role of the research itself—data, theories and studies, rather than on researchers themselves. The principal question has been: why doesn't social science research play a greater role in the policy making process, and conversely, how can social science research be *utilized* more effectively? The term "utilization" here portrays the social scientist as passive in the policy making process, at least after the data has been produced, as if someone else is going is going to use the data. The extent of their participation is commonly understood as presenting findings at a venue that may include the decision makers themselves.

As a result, the focus in the literature has been on the data itself, specifically on the use, nonuse, and misuse of data. There is very little literature, however, on role of researchers themselves, what they do, the different roles they play, the different audiences they work with and target, and most importantly, the extent and ways in which they engage the

political process. While there is literature on the role of expertise and of experts, the focus is still on what they know, about data, theories and studies, rather than on what they do. From conventional theories and accounts of the social science-policy relationship, one would have to conclude that social scientists are not involved in this process at all. And in fact, that is the mainstream position: the separation of the practice of social science from any type of political consideration.

The other limitation of the literature on the science-policy relationship to highlight here is the focus on policy makers as the audience of data. The ubiquitous term, the "science-policy relationship" reflects this focus. This focus has led to a neglect for studying and operationalizing the "black box" of policy making, and the idea that is that any particular social policy is the end product of an enormously complex set of social dynamics, and is the last stage of an often long and contentious process. From this perspective, it is more useful to think of science impacting the policy process, not policy itself. The science-policy relationship is therefore often indirect and diffuse. The point to stress here is that literature has neglected the policy making process, the set of complex social and political realities (ideologically driven debates, the domination of corporate and market interests) that, in fact, determine policy. It is argued here that process box represents the black box of policy. It this black box that this research will

attempt to provide a better understanding of. It is hypothesized that social science and activism represent two crucial aspects of the policy making process, and by understanding how they impact policy, you can have a better understanding of the conditions that need to be met in order to for progressive policy change to occur, i.e., a better understanding the black box of policy making.

Chapter Two: Methodology

Why a Case Study of Needle Exchange Policy?

The political struggle around the establishment and funding of needle exchange programs in New York City, from the early 1980s to 1992, served as a case study to understand nexus of science, activism, and policy change. The policy issue selected for the case study was determined on the following criteria: 1) the body of research had to have a strong degree of consensus and has to be highly robust; and 2) social science had to have had played a significant role in impacting policy related changes. The NE issue was selected because the literature, as a whole, strongly demonstrates that each of these criteria has been met. Furthermore, it is an issue familiar to the researcher, and this familiarity provides a firm 'jumping-off' point from which to conceptualize the types of data to collect (significant events, and particular sites to begin to examine) and where to collect it (what publications, databases, and archives to search through and which individuals to speak to). With regard to the second criteria on policy related change, it is important to point out that science has failed to persuade policy makers with regard to the most important policy change, the ban on federal funding for needle exchange programs . However, there have been many other successes that have led to other types of policy-related changes. Highlighting these impacts will be a key objective of this study.

As a case study for understanding the dynamics that occur at the intersection of science, politics, and social movements, needle exchange is ideal. Most importantly, the practice of needle exchange, and the scientific consensus which supports its efficacy, clashes violently with conventional wisdom regarding how "addicts" should be "dealt with," and with a deeply-held belief that drug use should not be tolerated in society, much less "encouraged." This observation needs to be broken down further however. One part of it is that the science is robust and compelling. The other is that discourse of drug use is extremely politicized and intimately attached to the political careers of policy makers (i.e., appearing "soft on drugs" is seen as akin to political suicide). In other words, it is an example where, because the ideological and political resistance against the science and practice of needle exchange s is so great, political wins by needle exchange advocates are all the more significant. This is the case even if the wins are small and scattered, and even if the primary policy objective has not yet been achieved. It is within this context that the impact of science on policy needs to be understood. From a review of the history of NE, several interesting examples stand out where social science may have played a critical in role shaping the political landscape (e.g., minimizing the level of resistance to NE and converting former opponents into supporters) and even impacting key policy decisions at all levels of government.

At the national level, while the research has not been effective at lifting the ban on funding of needle exchange programs (arguably the most important objective), other, very important political battles where researchers potentially played a significant roles. The most important of these was the defeat of a bill pushed by congressional opponents of NE, which attempted to prohibit state and local governments receiving federal funding, from operating needle exchanges, even if they were privately funded (Goldberg, 2001). In other words, this bill would have gone much beyond just banning funding for needle exchanges, it would have effectively led to the closing of virtually all existing programs nationwide. As a result, 130 needle exchange programs that were in operation around the country were allowed to remain open. While this is still quite a small number of needle exchanges as compared to other countries, these programs, none-the-less, have prevented tens of thousands of new HIV cases (Lurie & Drucker 1997). Furthermore, while about half of these programs have had to operate illegally, many have had "tacit" approval by the local authorities (Lurie, 1993). It seems plausible that this tacit approval toward needle exchanges by local authorities might have not been possible if the research had not effectively addressed the concerns of communities that such programs encourage drug use.

At the state level, in 1992, New York legalized the over-the-counter sales of syringes, which essentially gave pharmacies the ability to sell syringes without prescriptions (Warner, 1993). This represents a significant shift in policy, and passed despite considerable resistance. At the local level, in New York City, NE advocates have had a much more difficult time establishing programs, despite having the highest rate of HIV and AIDS in the Country. However, research has been implicated in some important political battles there as well. For example, in 1992 Mayor Dinkins, who was an opponent of NE, and even closed the only legally running program when he got into office (an issue he initially ran on during his election campaign), reversed his position. He cites research from an evaluation of the New Haven needle exchange along with the increasing problem of HIV within communities of color as the primary factors in his reversal of opinion (Navarro, 1991).

It seems likely that as the research delves deeper into the history of the needle exchange, more 'small wins" will be discovered. Therefore, an analysis of the history of needle exchange policy can not focus on any one event or piece of legislation. The goal is to understand the multiple and diverse arenas where political struggles are fought and the manner in which research is used to lesson the gap between policy and science.

While some aspects of relevant federal policy have been included in the case study, it has largely focused on state and local level policy. The principal analytical strategy was to map out the different groups involved in the struggle and tease apart the role that social science played. Particular emphasis was placed on representing all the interests involved (e.g., community, public safety, harm reduction advocates).

Data Collection

The basic framework for the analysis was to examine key events or outcomes (e.g., legislation passed or debated, funding allocations for needle exchanges, the decision by a community to allow the opening of a needle exchanges) in order to understand the role that social science played in each event. Because the study takes a systems perspective, the outcomes included in the analysis occur at multiple levels. For example, one set of outcomes involves the events that occurred at the federal level. Here it could be said that social science has failed, to date, to influence policy. However, many conservative policy makers have introduced bills to make it even more difficult, if not impossible, for needle exchanges to exist. This can be seen as a type of outcome. Furthermore, while there is a ban on Federal funding for needle exchanges, states have handled the issue quite differently. There is even more variability within states, with some communities allowing and even funding needle exchanges and

neighboring communities banning them. It is for this reasons that the state and local level-analyses are so critical.

Archival Data Collection

The case study was based on two types of data: archival records and interviews of key individuals involved in the struggle over NE in New York City. The first stage of data collection was solely based on archival data, in which a comprehensive review of published records of the NE was conducted. Documents were located through relevant database, which included Lexus Nexus, Sociological Abstracts, Psych Info, and Medline. The data collected during this stage served two functions. First, it provided an understanding of the socio, historical, and political landscape of the issue: who the different interest groups are, their arguments, key individuals, a time-line of key events (e.g., legislation introduced and voted on) and the general direction of these events (e.g., greater amount of support or opposition for a particular policy position). This descriptive information served as the basis for chapter three, which essentially outlines the timeframe and history of this issue, laying the groundwork for chapter four, which takes a more analytical look at the data, extracting themes and patterns with the data.

The second function of the archival data was methodological, specifically with regard to the sampling procedure and to the construction of the data collection instrument. In terms of the sampling procedure, the archival data provided the understanding needed to determine who were the key groups and individuals involved. For example, many of the key individuals representing the various interest groups became apparent only once the literature was review. In terms of the data collection instrument, the archival data provided and understanding of the questions to ask and how to ask them.

Interviews and Interview Protocol

The second stage of data collection entailed interviews of key individuals, which was determined from the literature review and archival data collection. The interview data provided an "insiders" account of the events reviewed in the archival data and complimented the archival data in at least two key ways. First, because much of the archival data was superficial in nature—newspaper articles often glossed over important points—the interview data allowed a deeper analysis of these key issues. Second, the interviews in most cases substantiated and complicated the accounts found in the archival data. In fact, the interview protocol was developed in order to: 1) substantiate claims made in the archival data; 2) address discrepancies; and 3) probe deeper into key issues.

The interviews were semi-structured. An interview protocol provided the overall structure for the interviews, and contained a few open-ended questions, and various specific probes, regarding various issues key to the study. For the most part, participants covered many of the key issues when addressing the first question of the interview, which simply asked participants to discuss their first involvement with the needle exchange issue. This question usually prompted interviews to discuss the history of their involvement, from beginning to end. This was in fact the intention of this question. As the interviewer, my objective was to guide the discussion to the conversation on key topics, which included three key points in the NE history: 1) the events that led up to the opening of the pilot program in 1988; 2) the events surrounding the closing of the program by a new Mayor; and 3) the events surrounding the movement to push for legal needle exchange programs in the city, which included the underground (illegal needle exchange activities). Since the focus of the study is on the role of social science and activism, both were probed for throughout the interviews. The protocol therefore, contains a set of probes, some of which are quite general, asking them to discuss, for example, the role of activism and advocacy in the pilot program. Other's are quite specific, and ask about such things as the needle exchange trials and about some key studies that were published. Most participants had much more knowledge about and experience with some events rather than others. For

example, some participants knew very little about the policy issues but a great deal about the role of activism. Therefore, the content and structure of the interviews varied considerably.

Sampling

The sampling strategy was fairly straight-forward. The goal was twofold: to interview a subset of the individuals who played key roles in the history, and to interview members from the various interest groups, which included: policy makers at the city and state level, researchers, activists, and members of community groups both for and against needle exchange. The final sample (table 2) included fourteen people, included members from each of these groups. Most importantly, those included in the sample were typically those who played the greatest role in this history. Because of this, the sample contained many of the key individuals. Because of the focus of the study was on social science, researchers were overrepresented in the sample. The final sample consisted of one former Mayor, two former city health commissioners, one under Mayor Koch and one under Mayor Dinkins, seven researchers, three activists (although some of the researchers also identified themselves as activists and did engage in activism), one representative of the federal government (the Centers for Disease Control), one representative from the drug treatment community (the former President and CEO of Beth Israel Medical Center), and the

director the Black Leadership Commission of AIDS, the principal group opposed to NE.

Concurrent Collection of Follow-up Archival Data

During the time that the interviews were conducted, additional archival data were collected. The types of data collected at this stage were different from those described in the previous section. Because many of the interview participants had been so involved in needle exchange, they had collected various records, some of which were quite extensive. In most instances, the participants actually offered to let me use the data without me asking. For example, one of the activist interviewed had boxes of literature with records that were very relevant to this study. This included such things as the transcripts of the needle exchange trial, notes and internal memos from ACT UP, a video, and correspondence between ACT UP members and researchers, health officials, lawyers. Because of my association with one of the interview participants—Dr. Ernest Drucker, who the head of the Epidemiology Department at Montefiore Medical Center, I also had access to several boxes of records. Again, this included his testimony at the needle exchange trials, a comprehensive collection of newspaper articles, and correspondence between himself and health officials, including the health commissioner of New York and elected officials involved in the issue.

Data Categories

Data was collected on several aspects of the NE history, including data on the state of the research, the history and socio-political context, and on knowledge utilization strategies (how research was used to create change). These are discussed in detail below.

Social Science Research

One of the first stages of data collection was a review of the scientific and literature. Particular emphasis was placed on locating all of the major studies and representing debates about findings fairly and accurately. This entailed reviewing meta-analytical studies as will as the majors studies that existed. The question addressed by the data was: What solutions did the research support and how strong or conclusive was the research in terms of the conventional criteria of reliability, validity, and robustness (i.e., effect size) as well as the degree of consensus that surrounded the conclusions and recommendations? As is the case with just about all other policy issues, there was not a total consensus on the findings of the research with regard to NE. As pointed out earlier, this section is largely descriptive and therefore mostly reviewed the positions of experts in the field regarding the research.

History of Policy Issue & Socio-political context

The component of the analysis is an historical account of the policy issue. The primary questions addressed here were: when did the problem first become defined as a problem and by whom and what were the different sides of the issue or the different "interests" (Stone, 1998) involved? In other words, who was the target of the policy and who were the stakeholders? What solutions and interventions were proposed and implemented? Who stood to benefit from the proposed policy and who stood to lose from it? To a large extent, this section was an ideological analysis of socio-political context. For example, data was collected in order to understand what the dominant discourses regarding the policy issue were, how dominant they were, and when, if at all, competing discourses prevailed? That is, to what extent did the dominant discourse marginalize competing discourses? In terms of needle exchange, the dominant discourse was the abstinence rhetoric and the law enforcement approach to illicit drug use at the expense of harm reduction and public health approaches. In sum, the objective at this point was to represent the various arguments made for and against funding for needle exchanges (moral, empirical, political, practical), and who the interests were (political, economic, ideological, and practical).

Knowledge Utilization, Advocacy and Activism

Data on the socio-political landscape and on the social science research as just discussed provided the context needed to understand the a central objective of this study; the efforts to promote change by advocacy and activist groups, and specifically, the role that social science played in this process. Therefore, this layer of data made up the core of the study and addressed the following question: At what points during the life of the policy issue, from the time it was first framed as a problem, did social science impact the political landscape and course of the issue? Furthermore, what were the processes or pathways through which impact occurred? For example, did the impact of social science occur through conventional "enlightenment" routes, where knowledge by itself leads to change? When did it occur through more political routes, such as by mobilizing grass-roots groups or by influencing the make-up of coalitions among policy makers? Theses questions are essentially concerned with process, and revolve around five central *interrelated* issues that characterize the use of social science in social change projects: places/people, products, roles, discourse, and method. They are discussed further in the Analysis section that follows.

Analysis: Thematic Analysis, Data Coding and Categorization

Content analysis was the primary analytical procedure utilized. The analysis

of the data was guided initially by a priori codes, helping to synthesize data into themes and categories. It was anticipated before actual data collection that these codes would develop and change as a result of the data, and this is, in fact, what happened. The shape of the final structure of the analysis was as influenced as much by the a priori codes was by emergent codes. One difference in particular that should be noted is the greater focus on the role of activism than initially conceived. In fact, it is fair to say that the focus of the analysis ended up being roughly equally dedicated to both social science and activism, which was not anticipated before data collection.

There were no codes or specific analytical procedure for chapter three, which was essentially a descriptive history of the NE history in New York City, from the early 1980s to 1992. For chapter, which synthesizes the various streams of data into a single narrative structure, the a priori codes for extracting patterns were: 1) places/people; 2) products; 3) role; and 4) discourse. The first code, *Places* and *people*, refers to the site at which political change is targeted (sub-codes: public opinion, social-networks, advocacy groups, grass-roots and community groups, criminal justice agencies). It refers to the audience of the research and how, if at all they where included in both the research and social change process. *Products* refer to either the physical manifestation related to a research-related

project (published study, a pamphlet summarizing empirical findings, an amicus brief or other form of testimony, a community needs assessment) or to an activity (providing technical assistance to community groups, using research to build coalitions). Most importantly, products differ in the degree to which action is attached to the research (e.g., from the least active method of knowledge production and dissemination to the most active where researchers allay themselves with particular groups struggling for change). Codes will distinguish between different levels of direct and indirect political action. *Role* has to do with the types of activities that researchers engage in (e.g., advocate, expert, technical assistance provider). It has to do with methods utilized and actions taken to promote change. *Discourse* refers to the voice that researchers employ, which could be one that critiques existing social conditions or one that works within existing institutions or working "within the system."

As stated previously, the five superordinate codes in this section are interrelated. The overlap between discourse, and the final set of codes, *method*, is a good example of this: the discourse researchers adopt is very much related to the method through which they are working toward political change. With regard to the types of knowledge produced by the social sciences, the theory is that instrumental forms of knowledge are often necessary but not sufficient for change, and that such types of

knowledge need to be produced and disseminated. However, on many issues, change will only occur from political struggle, where other forms of social science knowledge (i.e., critical and political) and other forms of social science use (i.e., bottom up) are required. Furthermore, and at the heart of this study, is the question of how these different levels of change and different social scientific discourses benefit and depend on each other for change. For example, does political mobilization at the grass-roots level depend on the political legitimacy of policy positions come from mainstream research that explicitly distances itself from advocacy efforts? It is this interplay between the different discourses of science and various levels of change that is at the heart of the current study.

A great deal of effort was dedicated to ensuring that multiple perspectives were allowed to enter into the data analysis. In general, evidence for mainstream and marginal theories of the science-policy relationship were sought with equal vigor.

Chapter Three: Social, Political, and Historical Context

AIDS and Injection Drug Use in New York City (1981-1985)

During the mid 1980s, the number of Americans infected with HIV was more than an estimated million and growing. It was also during this time that a shift occurred in the patterns of risk and transmission of the disease. Epidemiologists began tracking AIDS in 1981, when the first test for HIV was created. At that time, 80 percent of all cases were among homosexual men, and the remainder among injection or intravenous drug users (Drucker, 1986). Therefore, in the earlier years of the epidemic, AIDS was primarily seen as a disease affecting homosexual men. Beginning in the mid 80s, another group emerged as the primary risk group: IDUs. Data from the Centers for Disease Control (Altman, 1985) showed an increase of 500% in the rate of HIV infection among IDUs in New York City between 1978 (estimated at 12%) and 1984 (estimated 60%). This increase in the rate of infection represented a circumscribed population where more than half the people were infected. In New York City, which had the highest concentration of intravenous drug use in the country, with the IDU population estimated at the time to be 200,000 (Hardy, 1985), there was also one of the highest rates of HIV and AIDS in the nation. New York City, therefore, was the epicenter of both the AIDS epidemic and of injection drug use.

The fact that the prevalence of AIDS among IDUs surpassed that of gay men has as much to do with prevention efforts among the latter as it does with transmission patterns among the former. Injection drug use introduces multiple risk opportunities for exposure to the virus among drug users and the general population. First, needle sharing itself places new and younger injection drug users at risk. Second, sexual practices among the addict population lead to infection among the non-injecting or drug-using heterosexual population. As Drucker (1986) notes, "...the population of intravenous drug abusers is by –and large heterosexual and of an age range in which most are sexually active." Many IDUs transmitted HIV to their non-drug using partners through heterosexual contact. One study (Drucker 1986) found that as many as 40 percent of the partners of addicted AIDS patients (who themselves were not injection drug users) were HIV-positive themselves. Heterosexual transmission also occurred through prostitution. "With around 30 to 40 percent of all addicted IDUs being women, as much as 50 percent of them turned to prostitution to support their addiction, and the frequency of sexual contact is often in the thousands per year, which represents a substantial bridge from the infected addict population to a new risk group of heterosexuals—i.e., those who frequent prostitutes (p. 171)."

Despite these startling figures, AIDS for the first few years of this period was still largely thought of as a disease of gay white men. At the time, for every study on AIDS and addiction published in professional scientific journals, there were 10 on AIDS and homosexuality (450 vs. 45 between 1981 and 1986) (Drucker, 1986). As Drucker notes, the first article on AIDS and drug abuse did not appear in the New York Times until October of 1985. In the public mind, and among policy makers and some researchers, the connection between injection drug use and the rapid spread of AIDS was not made until the late 1980s, several years after studies had actually demonstrated the connection.

Race, Class, Stigma and Government's Inadequate Response to AIDS

While the impact of the AIDS epidemic was devastating to both the drug-injecting population and to the gay male population, the experiences of these two groups, vis-à-vis the resources they were able to mobilize for treatment and prevention, were radically different. While gay men had the stigma of homosexuality attached to them, a large proportion of them were college educated and with at least middle-class incomes or higher. This translates into a community with a substantial amount of political capital, who knew how to educate themselves about the disease, and how to mobilize political action.

In contrast, the population of IDUs are largely black and Latino, poor, and with little post high-school education. At the time, AIDS was the leading cause of death among black men and women ages 25 to 44 (Drucker, 1986). Of the 700 babies born HIV-positive in 1987, an overwhelming percentage of them were born to black or Latino mothers. It was projected at the time that by 1991, of all the 90,000 AIDS cases in New York, 52 percent of them would be black and 32 percent would be Latino.

In addition to most IDUs being marginalized economically and politically, they were also one of the most stigmatized groups, often referred to as "dope fiends," and "junkies." The image of ravenous drug addicts shooting up heroin all day long in a "shooting gallery," bathroom stall, or in alley ways, looking lifeless, and with "track marks" on their arms, and doing whatever they had to—rob from friends, families, or anyone else, or prostituting themselves—was the ubiquitous portrayal of IDUs in popular media. A Newsday article described public sentiment about injection drug users as follows: "The average American's sympathy for heroin dependency could fit on the tip of a hypodermic needle and there'd still be room left for, oh, a small airport" (Newsday, 1988). Although much more recent, a comment made by one of America's most popular television judges, "Judge Judy" Sheindlin, underscores the harshness of this stigma. Sheindlin, in front of an audience in Brisbane, Australia,

commented that there was no point talking about how best to approach the problem of AIDS among IDUs, since the "solution is simple, give 'em dirty needles and let 'em die," taking the point further by stating "I don't understand why we think it's important to keep them alive" (ACT UP, 1999). Sheindlin's remarks, calling proponents of needle exchanges "liberal morons", also illustrate how important policy issues become politicized, were public and private discourse is grounded in ideologically-laced rhetoric as opposed to reason and pragmatism. Sheindlin's remarks typify the marginalization of certain points of view--even if supported by scientific consensus— that successfully make them the target of ridicule rather than of objective examination.

These social dynamics explain why injection drug users, as a group, were not only unheard, but also why there were few willing to advocate on their own behalf. They were essentially a voiceless group, seen only through the lens of stigma and moral denigration. As a result, they did not garner the sympathy or attention that gay (largely white) men did, who, although battling their own set of societal stigmas, had many more resources—socially, economically, and politically—to do so, and were much closer to mainstream society than were IDUs. In fact, many of those in the gay rights movement, who also made up much of the AIDS movement, did not want to take on the needle exchange issue, because

they felt that supporting injection drug users would be a poor move politically. This helps explain why the needle exchange movement was not very effective in the first few years, at least until the gay community did take on their cause. To a large extent, it was the intersection of the gay community and the IDU community that ultimately resulted in the emergence of an actual needle exchange movement.

The Inception of the Needle Exchange Movement: Nationally and Abroad

Discussions about NE in New York City began in 1985, when the acting Health Commissioner under Mayor Ed Koch, David Sencer, proposed a plan to ease the restrictions on the sales of hypodermic needles as a means of curbing the spread of AIDS among IDUs. Koch was skeptical of the idea, and publicly stated his doubt about the program. However, he said he would cautiously endorse it if law enforcement officials and the city district attorneys gave their support. But they did not. In fact, they were strongly opposed to the idea (Gillman, 1989). The principal argument was that by distributing needles to drug addicts, government would appear to condone drug use. The city law enforcement officials attacked the plan, and a New York Times editorial wrote the following: "How can cities ravaged by heroin condone its use?" (Editorial, 1985) A candidate for mayor politicized the issue by attributing it to Koch, calling it "one of the most hare-brained ideas I've heard from city government." Shortly after,

the Koch administration rejected the commissioner's recommendation (Purnick, 1985). During a conference, the mayor said in response to the proposal that the idea of giving out needles to injection drug users as a means of preventing AIDS is one "whose time has not come and, based upon responses, will never come."

Existing Research & Scientific Consensus: Early 1980s to 1986

Existing Research. When making needles accessible to IDUs was first proposed in 1985, there had been only one program in operation, and that was in Europe. In the summer of 1984, an advocacy group for drug users in the Netherlands, called the Rotterdam Junkiebond (the Junkies' Union), began exchanging needles and syringes with support from the Municipal Health Service. The group became concerned when local pharmacists who proposed banning the sales of syringes to injection drug users, which members of the Junkiebond feared would lead to a hepatitis outbreak (Lurie, 1993). In the U.S., researchers and health officials learned about the program through international conferences where, via mostly anecdotal information, the Amsterdam program was reported.

In 1986 there was a new Health Commissioner for New York City, Stephen Joseph, who, following the lead of his predecessor, proposed a program to actively distribute needles and syringes to IDUs. During this time, there was

little or no research on the efficacy of needle exchange as a prevention measure for HIV/AIDS. The empirical data that did exist was basically on three lines of research. The first was on the behavioral characteristics of injection drug users. In April of 1985, Don Des Jarlais, Coordinator of AIDS research at the New York State Division of Substance Abuse, cited research conducted by former addicts who interviewed street sellers—those who sold needles and syringes on the black market—and found an increased concern among IDUs about buying clean needles to avoid contracting the AIDS virus. Researchers reported that the street sellers, aware of the risks of using dirty needles, chanted the line "Get the good needles. Don't get the bad AIDS" (Altman, 1985). The demand for clean injection equipment became so great that an underground market developed. In some cases, used needles and syringes were rinsed and repackaged so they would appear to be sterile, and then were sold on the street to unsuspecting customers (Altman, 1985).

This type of data was important because opponents of NE based their opposition, in part, on several myths about drug users, such as the belief expressed by Sterling Johnson (Special Narcotics Prosecutor in the Manhattan District Attorney's office) to Mayor Edward Koch:

> Drug addicts, in the frenzied and desperate minutes before injecting a needle into their veins, could care less about contamination." Johnson went on to argue, "...experience has taught us that slaves

> of addiction do not change their daily habits," (Letter to Ed Koch, October, 1984 (Purnick, 1985).

The second important line of research at the time was on the prevalence of HIV among IDUs. As Des Jarlais (personal interview, November 7, 2003) noted, "...there were data indicating the problem was huge." He and his colleagues, in particular Samuel Friedman, at the National Development and Research Institute (NDRI) came up with the first seroprevalence estimates for IDUs, which showed that 50 percent of this group were infected with the virus.

The third line of research came from a comparative study of two cities, one that had new restrictions placed on syringes, and one without any restrictions. In Edinburgh, Scotland, city officials implemented a crackdown on drug paraphernalia that had forced the city's addicts to share dirty needles. After that, the city recorded the highest infection rate in Britain, which was largely among drug users. In contrast, Glasgow, with no similar needle restrictions, had nearly twice as many drug users but far fewer AIDS cases.

Scientific Consensus. By many accounts, the consensus regarding needle exchange began to emerge by the mid 80s. Warwick-Anderson (1991) notes that among health professionals, a consensus regarding the efficacy of needle exchanges as a means of preventing HIV/AIDS began to

emerge in 1986, two years after the Amsterdam program had been in operation. By this time, there were also needle exchange programs in London, Sydney, and other parts of Australia, but there had still not been any data produced. Because there was very little data at the time, "In the middle of the 1980s there was consensus that things like syringe exchange should be tried" (D. Des Jarlais, personal interview, November 7, 2003), but not necessarily that NE was effective or that it wouldn't have any negative consequences.

In 1986, there were at least two important conferences that acknowledged the importance of NE and similar initiatives in worldwide prevention efforts to combat HIV/AIDS (Warwick-Anderson, 1991). One was an international conference on AIDS sponsored by the World Health Organization, and the other was a conference sponsored by New York State Health Department and the Milbank Memorial Fund. During the conference, a member of Australia's national AIDS task force discussed how injection equipment in Sydney was freely available to IDUs and that there was no indication that drug addiction had increased. The other important event regarding the scientific community, and reflecting this consensus, was a report by the National Academy of Science's Institute of Medicine titled, "Confronting AIDS." This was the first major report that discussed the role of needle exchange as an HIV prevention measure.

> The epidemiology of AIDS clearly demonstrates that unprotected sexual intercourse (receptive anal or vaginal intercourse), the use of shared needles and syringes, and the transfusion of blood products contaminated by HIV represent the greatest danger of transmission of the virus.

One of the principal recommendations of the report was to:

> Begin experimenting with public policies to encourage the use of sterile needles and syringes by removing legal and administrative barriers to their possession and use...
> Curbing the spread of HIV infection will entail many actions, one of which was to experiment with making clean needles and syringes more freely available to reduce sharing of contaminated equipment.

Competing Ideologies: Abstinence vs. Harm Reduction

U.S. drug policy has been dominated by the abstinence ideology, the belief that (illicit) drug use is fundamentally immoral and a threat to the social fabric, a belief system that is put into practice through social policy. This policy aims to deter drug use through punishment (i.e., arrest and incarceration), fear ("deterrence"), and the stigmatizing of users. Abstinence-based laws discourage drug use by attaching stiff criminal penalties to it, and by creating an atmosphere of enforcement and surveillance, exemplified by zero-tolerance and mandatory minimum sentencing laws. As with most ideological systems, the power of the discourse of abstinence is its common sense appeal: most people see it as the only way of dealing with the issue of drug use. For most of society, it is the only approach imaginable. To even consider a society where drug use

is not a criminal act runs counter to the most basic expectations of conventional social mores, and stirs up images of rampant drug abuse, crime, social chaos, and moral breakdown. Furthermore, competing ideologies inconsistent with the discourse of abstinence are marginalized and shunned. In this sense, the abstinence ideology is a hegemonic belief system (Gramsci, 1971).

Recent social policy regarding drug use, affecting almost all aspects of public and private life—grade school and universities, the workplace, welfare, and in particular, the criminal justice system—has been created from the mold of abstinence. In the 1980s and 90s, the principal drug prevention strategy in schools has been the "just say no to drugs" campaign and zero-tolerance approaches for drug use. Some schools have even gone as far as requiring urine samples from students to test for drug and alcohol as a requirement to attend the senior prom. During the time when this study was being written, a high school in a middle-class community in South Carolina conducted a drug raid on the student body, which the principal organized with the local police department. The raid was conducted early in the morning, with military style execution: police dogs, guns drawn, and searches of students, backpacks, and lockers. The raid turned up no drugs. In colleges and universities, students are denied student loans if they have ever been convicted of drug misdemeanor. In

public housing, entire families are evicted because of the drug use of one family member (Shapiro & Schwartz, 2001). Abstinence models have also held a virtual monopoly on drug treatment in the United States.

Regarding injection drug use, abstinence-based laws have been particularly severe and punitive. In some states, it is illegal to not only possess the drugs that are injected, but also to possess the equipment needed to inject them (e.g., needles and syringes). All states have regulations on the sale of injection equipment, but when the debate over needle exchange in New York was occurring, eleven states had "paraphernalia laws," making it a crime to possess or distribute drug paraphernalia "known to be used to introduce illicit drugs into the body. Paraphernalia laws make the manufacture, possession, or distribution of drug paraphernalia a misdemeanor or felony offense" (Gostin, 1991). During the time period discussed here, New York was one of the eleven states that had paraphernalia laws.

Many segments of society have been extremely critical of the abstinence and criminal justice approach to drug use, arguing that it has led to much more harm—to individuals, families, and communities—than actual drug use itself. They cite the fundamentally inadequate (and some would say broken) system of drug treatment in this country. During the period under

discussion here, there were 40,000 drug treatment "slots" available for the estimated 200,000 IDUs (Drucker, 1989). Thus, for those who wanted to enter treatment, the barriers were substantial: waiting lists to get into treatment programs were common and it was extremely difficult or even impossible (depending on the time of day) for someone to gain access to a detoxification program because available slots would fill up before midday. Harm reduction advocates argued further that for those in treatment, relapse is common, and full recovery is a goal that often takes many years. However, many programs punish relapse—reflecting the abstinence model—which helps to undermine the recovery process itself. Some individuals, however, are simply unable or unwilling to quit. These individuals do not cease drug use because of the legal penalties attached to them. For many, the pain experienced from withdrawal, and the profound craving symptomatic of chemical addiction, overshadows the rational evaluation of consequences.

Needle exchange represents a radically different approach to the problems associated with injection drug use. While treatment is certainly offered, it is not aggressively forced on IDUs. Advocates argue that needle exchanges work to reduce behaviors that place IDUs at risk of acquiring HIV and other harms, and refer them to treatment and other support services. However, the goal of these programs is not to require abstinence,

but to reduce the harms associated with drug use. This clash between the ideologies of abstinence and harm reduction lies at the core of the history of needle exchange in New York City, as well as in the U.S. generally.

National Politics

At the national level of government policy making, rather than perceiving needle exchange as an HIV prevention issue, opponents viewed it largely as a drug use issue, and more specifically, as immoral. At the core of the opposition to needle exchange was the perspective that allowing drug injection equipment to be distributed to drug users sends a moral message condoning and even encouraging drug use. For example, Rep. Todd Tiahrt, a Republican of Kansas, argued that tax dollars should not be used to enable addicts to continue their drug use, claiming "we owe it to our children to send an unambiguous 'no-use' message, and if they should become ensnared in drugs, we must offer them a way out, not a means to continue this addictive behavior" (AIDS Policy and Law, 1998). Interestingly, Barry McCaffrey, the nation's Drug Czar under President Clinton, employed the same rhetorical strategy of invoking images of children, stating similarly that "we owe our children an unambiguous 'no use' message. (AIDS Policy and Law, 1998b)." Rep. Sue Myrick's, R-N.C., statements not only condemn NE, but condemn the harm reduction approach entirely: "In a time when drug use is again on the rise, we simply should not send a

message of tolerance in any form, because we need to discourage drug use, not try to make it safer." This statement clearly demonstrates the prevailing tendency to marginalize public health concerns regarding drug use by moral issues.

One of the most important factors that shaped the response to the AIDS epidemic was national leadership at the highest levels of government. AIDS emerged as a health issue during the Reagan presidency. That this [the AIDS epidemic] happened when Reagan was president was very important. As Ernest Ducker, a leading expert on the history and epidemiology of AIDS noted:

> This is a man that did not say the word AIDS in a public address until 1987, when there were 40,000 cases. Remember, he's elected in 1982. This is exactly the year that AIDS begins. So the whole early stage of the epidemic is dominated from the top by the attitude of Reagan, whose principal advisor on health was a guy named James Mason, who was a Mormon, and who had nothing but discomfort about all of this [referring to homosexuality and drug use]. And that mattered for New York politics. It gave comfort to those people who thought it didn't make sense to help drug addicts use drugs. So AIDS—the response to it, the moral message, in regards to drugs, early on, is associated with national leadership and the moral agenda. (E. Drucker, personal interview, April 15, 2003).

The "power of this Reagan revolution" contributed greatly to the ideological context of the needle exchange debate. Importantly, however, it also had direct and powerful implications for drug policy in New York City. For example, Mitchell Rosenthal, the director of Phoenix

House, one of the nation's largest drug treatment programs, and the largest in the city, was hand picked by Nancy Reagan (E. Drucker, personal interview, April 15, 2003). Phoenix House represented treatment through the lens of the moral agenda. Phoenix House, like the vast majority of treatment programs, was abstinence-based, and therefore inherently at odds with harm reduction approaches such as needle exchange. Rosenthal would later go on to be a vocal opponent of needle exchange in New York City.

State Level Politics

At the state level, efforts had been under way early on in the debate to repeal the state's paraphernalia laws, which were some of the strictest in the country. Within government, this movement was spearheaded by State Assembly member Richard Gottfried who introduced a bill making legal over-the-counter sales of syringes and needles by pharmacies and drug treatment facilities (Gillman, 1999). Significantly, Democrats held the majority in the State Assembly and Democrats have generally been more open to prevention and treatment-oriented policies compared to Republicans, who, on average, have tended to push harder for sanction-based approaches. Similarly, and perhaps more important, was the fact that both the governor and the mayor were Democrats. This was crucial on two fronts. First, and most importantly, it was the city's health

commissioners under Mayor Edward Koch who were among the first to push for needle exchange. Secondly, it was the state's health commissioner who had the power to authorize a needle exchange program, not the assembly. However, it is important to note that most Democrats were not openly in favor of needle exchange, which represented a very dangerous issue for which to take a stand.

New York City Politics

In New York City, the idea of NE had been under attack from the outset. Resistance, often fierce, came from many segments of New York City. The leaders of black communities felt that distributing needles to drug addicts in their communities was akin to genocide (Cohen, 1999). Their fears stemmed from very real past abuses of science and highly unethical experiments with black men and women, such as the notorious research conducted in Tuskegee, Alabama (Jones, 1993). Charles Rangel (D-NY), who represented many black communities, introduced a bill in Congress that would prohibit the use of the federal funds to support need exchanges (Editorial, 1989). Interestingly, the Latino commission on AIDS was, from the beginning, much more open to the idea of needle exchange. Their position, however, played a much less significant role than the black community's opposition did. The other major source of opposition to NE came from law enforcement. Both the police and the

District Attorney's office were vehemently opposed to NE, and they would come to represent one of the greatest obstacles for the movement. Finally, the treatment community was also against NE.

Early Advocacy and Activism (1986)

Before the needle exchange debate even started, activists were concerned with the health risks of needle sharing, and addressed these risks through "teach and bleach," the practice of distributing bleach kits to IDUs and instructing them on ways of cleaning their injection equipment (Gillman, 1989). The only group providing this service at the time—and the only group advocating for drug users themselves—was the Association for Drug Abuse Prevention and Treatment (ADAPT). Since at least the mid-1980s, ADAPT has been distributing bleach to shooting galleries (Gillman, 1989). Because of this, the city had refused funding to the agency for several years. Eventually however, ADAPT was able to secure funding from the city, and would later go on to become one of the most influential interest groups pushing for needle exchange in the city.

First Needle Exchange Program in the Country Proposed in New York City

When Stephen Joseph became health commissioner in 1986, he recalled how early the NE issue came up from reporters when he gave his first press conferences:

> It came up right a way. I came to it with not much of a bias either way...I became very convinced, very early, that we were looking down the gun barrel of an explosive infection between women and their kids in the modality of their partners IV drug use or their own drug use, so it started to gather steam, and it was presented to me very early (S. Joseph, personal interview, August 26, 2003).

As discussed earlier, there were virtually no data at the time on the efficacy of NE itself (although there were other lines of research that were relevant), and Joseph acknowledged not even being aware of the Amsterdam project. For him, "it was a common sense argument," meaning that "the potential for significant benefit was obvious and the potential for harm could well be controlled."

> It just made enormous intuitive, biological, epidemiological, and clinical sense, and it seemed to me that to make the counter argument would be so difficult, that it was an Occam's Razor kind of thing.

Joseph was aware of the difficulty this proposal would face. He recalled how there were many epidemiologists within the state health department who didn't even feel that the threat of an epidemic among IDUs was that great, and was also aware that there would be many political barriers to deal with, particularly resistance from the state Health Department, and its commissioner, David Axelrod. Joseph (2003) recounted:

> It was clear from the very beginning that the opposition would be enormous. I talked to the Mayor about it early on, and there were three things we had to do. We had to have the Mayor at least not oppose it. We had to have some level of a buffer against media opinion, which we knew would be negative, and some way to try to

> talk to the community on this. And third and in a practical sense, we had to get by Dave Axelrod on board.

Furthermore, NE was an issue about which the Mayor was weary and had even opposed politically just a year before. However, after just a short while, Joseph became convinced that NE was a policy that needed implementation. Both Joseph and Koch's willingness to take on a controversial political issue is an important factor to highlight. As Joseph recalled:

> He [Koch] trusted his commissioners. He gave you an enormous amount of latitude. I never had to clear any of my speeches or public comments with City Hall, never. The rule was, go, and if you go too far, and get beyond the point where I can't support you, whether for political reasons or content reasons, you're gone, and everybody knew that.

So Joseph, and to a lesser extent Sencer (since he put the issue on the agenda), and Koch (since he was willing to put himself at risk politically), deserve credit for making NE a viable public policy issue. His first proposal to the state Health Department was to distribute needles and syringes to a small group of IDUs; he used a group of several hundred addicts on a waiting list for a methadone maintenance program (which often took several months) as a control group. At the time the proposal was submitted, it was not even clear if the city could get the necessary approval from the state, since the health commissioner there, David Axelrod, as well as the Governor, Mario Cuomo, had been opposed to the

idea of distributing needles. However, after two years of opposition to NE, Axelrod was prompted by a National Academy of Sciences report outlining the relationship between AIDS and injection drug use to reexamine the issue (Associated Press, 1986; Sullivan, 1986). The report said that government's response to the AIDS epidemic was "inadequate" and that the country faced the possibility of a 'medical catastrophe' unless the spread of AIDS is halted." Axelrod responded by saying, "I think it's worthwhile to consider, as the National Academy has suggested, limited trials that can be controlled to determine whether or not there is any effect on the transmission of the AIDS virus in the intravenous drug population is worth pursuing." However, Axelrod merely offered to consider the issue, which would continue to face opposition from state health officials, including Axelrod himself.

Although Axelrod decided to reconsider the city's proposal, officials from the state Health Department said they weren't satisfied with the methodological aspects of the proposal, which, they argued, would not include enough participants to provide the necessary statistical rigor (Sullivan, 1987). Joseph later submitted a revised proposal with an increased sample size but state officials responded with skepticism. Dr. Lloyd Novick, the director of the state's Center for Community Health, said it "...would be exceedingly difficult for the city to submit a plan that would

meet the sample size requirements" (Sullivan, 1987). In reality, it is questionable that the issue was really one of scientific rigor. Joseph himself acknowledged that the "study was an attempt to balance opposition to needle exchange programs and the need to curb the high rate of AIDS among New York City's injection drug users (Sullivan, 1987b).

Activism and Defiance to Current Policies Grows

While city and state officials debated, activists, many of who were highly critical of government, did not sit and wait for a decision. Serrano, along with other board members, was frustrated by the state blocking the city's efforts to distribute needles to IDUs and prevent further cases of HIV. In January of 1988 Yolanda Serrano, the executive director of ADAPT, announced plans to distribute clean needles despite the state's paraphernalia laws. ADAPT considered this an act of civil disobedience, and hoped it would force the issue forward. The activists argued that they were willing to face prosecution and the loss of city funds and tax-exempt status in order "to protect the public and save lives" (Lambert, 1988). Serrano argued, "We believe it's too late for research," referring to the ongoing debate between the city and the state over methodological issues (attached to notions of scientific validity) of the pilot program. She argued further, "Something has to be done now. Someone has to take the initiative to challenge the state in the name of public health." Following

this, the city's Department of Health froze ADAPT's operating budget and shut down their office for 48 hours.

Gillman (1988) notes: "The media response was overwhelming. Representatives of ADAPT were interviewed on radio, television news and talk shows (among them the "Today" show, and "20/20"). The issue was covered on the nightly news for two weeks. Metropolitan newspapers published editorials on the topic. ADAPT sent a telegram to the Governor, threatening to defy state law by distributing sterile needles on its own (p. 16). Importantly, however, ADAPT, and Serrano in particular, had a good reputation in the city and beyond. The month before, she had testified before the President's commission on AIDS about the spread of the disease among IDUs. Joseph responded to the plan with a great deal of respect for the group, stating "I can't condone or support an illegal action in this area," acknowledging at the same time that ADAPT is "a group that clearly has a great deal of expertise, the most credible community action group on drug abuse in New York City, a very responsible group" (Lambert, 1988).

That same month, both Axelrod and the Governor, Mario Cuomo, switched their positions and decided to support the city's effort to distribute clean needles. Axelrod said he based his decision on recent

data collected by his department on the extent of the disease, showing that one in every 61 babies born in New York City carried HIV antibodies. The infection rate was highest in poor neighborhoods where injection drug use was most prevalent. . Axel rod's response to this was, "Frankly, I'd be willing to do just about anything to try to stop this disease" (Schmalz, 1988)). Axelrod was also presented data on needle exchanges in Europe and Australia, which showed that the program did demonstrated preventive outcomes, and most importantly, in the eyes of state officials, that there was no evidence that NE led to increases in drug use (Kerr, 1988).

Regarding the Governor, NE presented a "politically dangerous choice," with the possibility of being perceived as either "soft on drugs or being seen as slow and ineffective in combating AIDS" (Kerr, 1988). A New York Times article argued: "In the end, officials said new data on AIDS made it clear to the Cuomo Administration that, whatever the other dangers, it must now try new strategies to fight the disease. As a result, the State Health Commissioner, Dr. David Axelrod, reversed two years of opposition to the experiment" (Kerr, 1988). In response, the State Assembly's Republican minority (the 56 Republicans of the 150 member assembly) approved a resolution calling for the issue to be submitted to the Legislature, contrary to how it was actually handled, administratively through the State Health Commissioner himself (Associated Press, 1988).

Vehement opposition was voiced among many other city groups, such as by Sterling Johnson, who argued that the "Health Commissioner can designate whoever he wants to have needles, but you cannot authorize somebody to take a legal instrument and use it for an illegal purpose" (Barron, 1988). Gillman (1989) speculated about other factors that may have played a role in the Governor's policy switch. While recognizing the important role that ADAPT's threat played, she also took into consideration the fact that the Governor had recently abandoned his efforts to run for President on the Democratic ticket. As a result, she argues that Cuomo was "freed of the political liability associated with approving such a controversial program" (p. 17).

After Three Years of Political Struggle, Needle Exchange Opens

Finally, on November 11, 1988, after three year of negotiation, Mayor Edward Koch opened the first government-sponsored, experimental NE in a large city (Navarro, 1991). The fact that it was framed as an experimental program (with an actual control group and with an adequate sample size) was the turning point for the city's district attorneys, who argued all along that it would be unlawful to distribute equipment used for illegal purposes. Framing it as an experiment gave the program a certain degree of legitimacy in the eyes of prosecutors. Warwick-Anderson (1991) argues that, "the only politically acceptable (and practically

efficacious) way to distribute clean needles in New York City was by representing the intervention as a controlled clinical trial, and setting aside considerations of any potential ethical infraction" (p. 1507). Because the idea of distributing clean needles to IDUs was seen as "political anathema," he argues that the cover of a clinical trial was use of a "restrictive research process to organize public policy."

Among advocates of NE, there was a substantial debate about whether the experimental program actually moved the issue forward, or slowed--or even stalled--the movement to provide clean needles on a large scale. To be clear, very few, if anyone, actually had anything favorable to say of the program with the exception that it might be a stepping stone to larger change. The experimental program was, on all accounts, extremely limited in scope, particularly in comparison to the program ADAPT originally lobbied for, involving 6,000 participants. In a city that had an estimated 200,000 IDUs, with an infection rate estimated at 50 – 60 percent, it was clear that a program with 400 participants (only 200 of which would actually be receiving needles) would have no real impact on seroprevalence rates. Furthermore, the project would take 18 months before any data would be available, and in a period when HIV was on the rise, the prospect for change was not very hopeful.

There was also an enormous amount of skepticism about how the program was actually structured, which seemed as if it was doomed to fail. What was once crafted as a "clinical trial," was at the opening of the program, called a "pilot study," and "seemed less consequential than ever" (Warwick-Anderson, 1991). The number of conditions and caveats placed on participation were substantial, and most felt, overwhelming. First, in order for injection drug users to participate, they had to register at the headquarters in downtown Manhattan, in the same building as the city's courthouse (not a place that injection drug users, who are often the target of arrest or harassment by the police, feel particularly comfortable in). There, they would "be interviewed and examined by doctors, sign consent forms, and be tested for tuberculosis, sexually transmitted diseases, and HIV infection. These tests were to be repeated regularly throughout the trial. Only drug users who had applied to a drug rehabilitation program and been turned away because it was full were eligible for the study. When they came in to register they had to show a letter of referral from the program" (Warwick-Anderson, 1991, p. 1511). Furthermore, to prevent others from getting clean needles, all participants were required to have a photo ID and the researchers planned to check the blood on the needles to make sure it matched the blood type of the participants.

In light of the conditions to which program participants were subjected, it is easy to understand why so many needle exchange advocates were so critical of the program. One group that was critical was the AIDS Coalition to Unleash Power, more commonly known as ACT UP. ACT UP was started in 1987 by a group of individuals whose lives were deeply and personally touched by the ongoing AIDS epidemic, and specifically, to the government's inadequate response to it. When ACT UP began however, its focus was on gay rights rather than drug use. It wasn't until later that ACT UP would take on the issue of users' rights. Richard Elovich, a member of ACT UP, who would later go on to be a leading activist in the needle exchange movement, recalled deliberating at an ACT UP meeting on whether or not the organization should support the city, and whether it was actually a move in the right direction. At the time, Elovich argued they shouldn't support it, because besides its limited scope, there was the very legitimate question of, "why would drug addicts come downtown, right inside of the criminal court building? It was just such an unlikely place, so it just seemed like a token." (R. Elovich, personal interview, April 28, 2003)

ADAPT, on the other hand, while viewing the program as "doomed to failure" argued it was the "beginning for policy change (Bodin, 1988)." Despite the fact that disagreement existed within ADAPT with regard to the social change value of this program, ADAPT worked hard to help the

program succeed: "She [Serrano] was literally taking the people she was doing outreach with there, actually taking them out in vans. She felt that if you could show that this works, then we can take it to the next step" (R. Elovich, personal interview, April 28, 2003).

Scientific Evidence: 1988-1989

The data available at that time, while not overwhelmingly robust, was clear and consistent. Des Jarlais (personal interview, November 7, 2003) characterized the consensus during this period as the following:

> By the late 80s, there was consensus that as a preventive measure, syringe exchange, along with other services, could prevent epidemics... there was data showing that if you implemented large scale syringe exchange or distribution, you could keep HIV prevalence rates very low, under five percent. There was data indicating that as a preventive measure, you can avoid an HIV epidemic if you had large scale syringe exchange.

By 1988 there was data from needle exchange programs abroad that, although preliminary, was positive. Data from Amsterdam at the time even suggested a decrease in the rate of injecting by some drug users and an increase in the demand for drug treatment and counseling (Warwick-Anderson, 1991), and these findings were further supported by preliminary studies from various programs in existence at the time in England, Australia, Holland, and Scandinavia. The early data showed that while there were no indications of increased drug use, the rate of seroprevalence had been slowed (Gillman, 1989). In fact, during that time,

the director from the exchange in Liverpool, England consulted with national and local health officials, including officials from New York City, in a two-week visit to the U.S. (Lohr, 1988). Following this visit, representatives of the program were asked to come back a few months after to meet with "highly placed government agency heads," who were interested in the program. They "privately expressed their support for Liverpool's program, but at the same time, refused to publicly come out in favor of advocating a similar program in this country" (Parry & Fazey, 1988, cited in Gillman, 1989).

Warwick-Anderson notes that by late 1988, evidence of positive outcomes was frequently cited, and characterizes it as a "time of rapidly improving understanding of the subject" (1507). The data from needle exchanges in Europe and Australia provided promising evidence that was being disseminated worldwide. Des Jarlais presented data from these programs at the Fourth International Conference on Acquired Immune Deficiency Syndrome in Stockholm and made the following points (Lambert, 1988):

- Studies in Amsterdam-where 700,000 needles were given out last year-show no rise in drug use as measured by such indicators as drug overdose or applicants for drug treatment. Despite fear that free needles would promote drug use, no such indications have been reported in other sites-Liverpool, England; Sydney, Australia; Edinburgh, and Lund, Sweden- where they have been made available.

- In another study in the Netherlands, drug injections actually decreased among addicts who received needles. Out of 180

addicts, 87 percent injected at least daily before joining the needle program. But after receiving needles, only 48 percent injected daily. Dr. Des Jarlais attributed this shift to "increasing health consciousness" instilled by the fear of AIDS, even though the clean needles end the AIDS threat. In Britain, anecdotal reports indicate that free needles help build a bridge of trust with drug counselors that leads some addicts to enter treatment programs.

- It is still unproven that the needle exchanges have succeeded in slowing AIDS infection. Judging from the time it took prevention programs among homosexual men to result in slower infection rates, Dr. Des Jarlais said, it may take a couple of years to obtain data for drug users.

Controversy Persists

Although the new program was officially legal, it was still a source of tremendous controversy. The most prominent source of opposition—that which had the greatest bearing on policy makers—came from the citywide drug prosecutor at the time, Sterling Johnson, who "all but pledged to sabotage it (perhaps by busting people as they leave the program or simply by staging drug agents in the area to intimidate)" (Barron, 1988). Some of the city's treatment providers, particularly Phoenix House, were also vocal in their critiques. Mitchell Rosenthal, the director of Phoenix House, was one the strongest opponents of NE, arguing that NE was merely a band-aid approach to drug addiction, and what was really needed was expanded drug treatment.

Some of the loudest resistance came from the African American community. As many have noted, one of the reasons they were so angry

was that they felt as if they were not consulted about how NE would impact their community and about how they thought they could make it work. However, they also felt strongly that the Department of Health had neglected to adequately address social and health problems caused by drug use in the poor and communities of color (Lurie, 1993). At least in part then, the challenge to the idea of NE reflected a:

> tactic to try to make points about the larger racial relation issue, at the expense of public health, because the black community didn't see AIDS as the danger it represented. Their entire framework was, 'we're dying of everything anyways.' For them, drug use was the plague. (E. Drucker, personal interview, April 15, 2003)

Another crucial aspect of the black community's negative reaction to NE is the broader socio-political context in New York City, specifically, the historically poor relations between the black community and the Koch administration. As Drucker notes, "In the black community, the genocide argument was invoked because of the hostility that existed between Koch and the black community who were very distrustful of him." All these factors combined to create a deep-seated mistrust of NE by the black community, which eventually played a critical role in the demise of the pilot program.

Pilot Program Shut Down by New Mayor

During the time the experimental needle exchange was in operation, the Mayoral election was going on in the city, and David Dinkins, a black

candidate running against Koch, vowed, as a campaign promise, to close down the NE if he were elected, because he believed it sent the wrong message to communities impacted by drug use. Mayor Dinkins won the election for Mayor and, as promised, shut down the program in 1990. In an interview, Dinkins stated that providing needles to addicts "is to surrender" to drug abuse. He stated further," I think we need to go at fighting drug addiction in the first instance and I don't want to give people the paraphernalia to continue using drugs" (Purdom, 1990). Aides to the Mayor said that the decision was made in collaboration with his new health commissioner, Dr. Woodrow Myers.

When the decision was made by Dinkins, with firm backing from Myers, several groups met with the Health Commissioner to attempt to convince him of the importance of the program and to discuss the data supporting its positive effects. One of these meetings was between Myers and Des Jarlais, who argued, "The case is not scientifically proven, but the evidence is surprisingly clear and consistent" (Hilts, 1991). However, Myers did not shift his position. Elovich (personal interview, April 28, 2003) recounts a story that illustrates how Myers' stance on NE was impervious to empirically based challenges:

> The first health commissioner under Dinkins was Woody Myers, and I and a number of other people from ACT UP met with him, and he basically said he was ideologically opposed to needle exchange. And as soon as he said ideologically opposed, we got up and

> walked out of the meeting, and we basically said, so you're not here as a scientist...and you're essentially saying that no evidence would sway you, so why are we meeting?

In February of 1990, Mayor Dinkins kept his campaign promise and closed the pilot program. In a telephone interview, Dinkins said that providing clean needles to addicts is "to surrender" to drug abuse (Purdom, 1990). He furthermore said the scientific study of the pilot program, despite its positive, yet preliminary findings, did not change his mind. The pilot program was open for 10 months and served 260 participants. Over half of them were HIV-positive (demonstrating the need to prevent them from sharing their needles with other IDUs) and more than half entered treatment as a result of the program. Dinkins and his health commissioner, Woodrow Myers, argued that the study was not reliable because of the small sample size. Stephen Joseph responded by saying, "My strong conviction is that the program has proved itself worthwhile" and furthermore "the small numbers were a reflection of the constraints placed upon the program, so it's kind of circular reasoning to say it didn't draw many participants" (64). At the time, there were two other legal needle exchange programs in the country: one in Portland, Oregon, and the other in Tacoma, Washington.

Immediately after Dinkins closed the pilot NE, both ACT UP and members from the AIDS Brigade, the group started by Jon Parker, began publicly

distributing clean needles in the Lower East Side of Manhattan and in the Bronx. Although ACT UP was, in private, critical of the pilot program, it did not publicly condemn it, because there were still those who were trying to make it work. When Dinkins closed the program, however, they felt it was the time for them to distribute needles to those requiring them in a way that would actually reach people:

> As soon as Joseph's program was closed down by Dinkins, my argument was, we should do it. We should do it the way it really should be done. As soon as the city's program was stopped, that's when we stepped in, and that's when we started doing it illegally (R. Elovich, personal interview, April 28, 2003).

They distributed needles illegally for little less than a year before they were arrested in March of 1990. In April, the trial of the eight activists began.

The New York City Needle Exchange Trial

Two of the most ironic aspects of NE history in New York City are related to the trial. One of these was the judge--the same judge who found ACT UP members guilty of illegally entering Stephen Joseph's offices. The other ironic aspect was the fact that one of the key expert witnesses called by the defense was Stephen Joseph.

Lawyers for the activists put forth the necessity defense, which argued that the act of distributing needles was necessary, and therefore lawful, in order to attempt to avert a medical or public health emergency, as their

strategy for the trial (Drager, 1991). The role of scientific evidence was a critical aspect of the defense's strategy to meet the criteria required by the necessity defense argument. Two criteria, in particular, posed the greatest challenge for the defense. The first was that "the defendant acted under a reasonable belief, supported by *medical evidence* [emphasis added], that his or her actions are necessary as an emergency measure to avert an imminent public or private injury." The second criterion was whether or not distributing clean needles was an effective method of ameliorating this emergency.

Several expert witnesses were called to testify on behalf of the defendants (Drager, 1991). This included Stephen Joseph and some of the "leading experts on AIDS," including Dr. Ernest Drucker and Dr. Don Des Jarlais. The research they presented specifically addressed the necessity defense criteria. For the first of these, the defense had to demonstrate that AIDS presented a medical and public heath emergency. Researchers presented data on the increase of the epidemic in the city, and in particular, prevalence rates on the shift of the epidemic to "poverty and minority communities." Ernest Drucker testified that, "In the poorer neighborhoods, it is estimated that 10-20% of the all men between the ages of 25 to 45 and 3-6% of the women are HIV infected." The dramatic increase in the rate of infection among women and babies was also

highlighted. Another line of data that supported the public health emergency claim was presented by Stephen Joseph, who testified on the unavailability of drug treatment slots, citing the ratio of 40,000 treatment slots for the estimated 200,000 addicts.

For the second criterion—that the defendants' actions were an effective strategy to deal with the emergency—the witness for the defense discussed data on existing needle exchanges, both in the U.S. and abroad, and the data demonstrating their efficacy at preventing HIV. As the court transcripts noted, citing data presented by Des Jarlais and Drucker, "According to several defense witnesses, studies of needle exchange programs reveal that these programs reduce the sharing of needles among addicts without increasing drug among existing users or potential new users (Drager, 1991)." Researchers argued that there was "complete consistency" between the data from the European programs and those in the United States. Data from the Netherlands needle exchange program showed that 75 – 80% of all drug users had been reached, and that these data were similar to the studies of "less formal, self-selected programs."

One highlighted study in particular was of a "reverse" needle exchange program in Edinborough, Scotland. In 1982, there were no reported cases of HIV infection among drug users. However, after the city changed their

law to make needles inaccessible to drug users, 75% of drug users were infected by 1986 (Drucker, cited in Drager, 1991). Joseph discussed data from New York City's pilot program, and cited interview data that suggested program participants had ceased to share used needles, which was not substantiated by the data on returned needles, possibly because of the small sample size. However, the data did indicate that drug use did not increase, and the program did act as a bridge to treatment, with 78% of participants entering treatment.

Another point supported by the empirical evidence, which although not addressing the criteria for the necessity defense, was nevertheless important: to make the idea of needle exchange palatable in light of the powerful abstinence ideology to which the court was certainly not immune. By showing that needle exchange acted as a "bridge to treatment and services," it was easier for the court to consider needle exchange as a valid intervention, and not just a "band aid," which the state was arguing. Relying on the data from the New York City's pilot program, Stephen Joseph testified (Drager, 1991:

> Clearly the availability of clean injection equipment is a way of stopping the transmission of the virus from person to person. That availability of clean injection equipment is also a way to bring people, whether they are infected or not, into a stream of health care and public health preventive efforts that are equally important in this epidemic.

The state put forward the testimony of only one expert witness, Dr. Lawrence Brown, an endocrinologist affiliated with Harlem Hospital and a Senior Vice President of Addiction Research and Treatment Corp. Dr. Brown testified that in his view:

> Further studies are needed to determine the safety and efficacy of needle exchange programs. Due to the diversity of drug using behavior, particularly in New York City, the state does not believe the exiting study adequately answers these questions.

Dr. Brown also argued that needle exchange programs are a band-aid approach to drug problems avoiding the root causes of addiction. The court's ruling on the necessity defense was the following: "this court finds it was reasonable for the defendants to believe their action necessary as an emergency measure to avert an imminent crisis in New York City." Judge Drager cited the scientific evidence as influential on various points. One point was on the efficacy of needle exchange programs as a prevention measure:

> There is no dispute that use of clean needles by addicts prevents the spread of HIV infection. The defendants presented significant expert medical and public health witnesses who testified that needle exchange programs have been proven successful as a means of providing addicts with clean needles witch addicts will use.

Second, Judge Drager pointed to the data on drug users' behavior as an important factor in her decision:

> The witnesses further testified that addicts are either aware of or can be educated to the fact that needle sharing spreads the virus. Although studies in this area are limited, defense witnesses claimed

> the available evidence suggests addicts will not continue to share needles if they knew they have a source of clean ones.

Third, she addressed the argument put forward by opponents of needle exchange, including Dr. Brown, the state's expert witness, that needle exchange encourages drug use: "Moreover, the witnesses testified that there is no reason to believe needle exchange programs encourage people to use drugs (cited in Drager, 1991."

Finally, the Judge discussed the role of needle exchange as a bridge to treatment:

> Most significantly, when coupled with AIDS education and counseling, a needle exchange program serves as a means for convincing addicts to avoid other risk-related behavior, to get medical care and ultimately to discontinue the use of drugs."

The judge also addressed the rationale behind the state's paraphernalia law and rebutted it with the scientific data as well:

> The crime of possessing a hypodermic needle was enacted as a weapon in the war on drugs. Although law enforcement officials believe the statute essential in this fight, available evidence suggests it has had limited success. As the testimony revealed, only eleven states have statutes similar to New York's law. Despite these statutes, these states—and New York in particular –have among the highest rates of addiction, and there are sill plenty of dirty needles available (p. 25).

Three months later, in June, the activists were acquitted. Judge Laura Drager invoked the necessity justification in the state penal law, which states that "conduct which would otherwise constitute an offense is

justifiable and not criminal when such conduct is necessary as an emergency measure to avoid an imminent public or private injury" (Drager, 1991). While the trial was occurring, ACT UP continued to distribute needles illegally, and they said they would continue to do so after the trial.

Scientific Evidence: 1990 -1991

When Dinkins closed the pilot program in 1990 there were various lines of research providing data that supported NE to some extent. However, each of these studies had its flaws and significant limitations. Most studies had been conducted by the needle exchange programs themselves (as opposed to independent evaluators) and none of them was a controlled study with pre- and post- measures of behavioral change (S. Jones, personal interview, October 12, 2003). Because of this, there was a minority of pro-needle exchange individuals with a different take on the state of the research (R. Heimer, personal interview, September 11, 2003; P. Lurie, personal interview, September, 2003; S. Jones, personal interview, October 12, 2003,). Stephen Jones, who headed HIV prevention programs for drug users at the Centers for Disease Control, and who many (P. Lurie, personal interview, September 12, 2003; E. Drucker, personal interview, April 15, 2003) have regarded as one of the most important individuals at the Federal level advocating for needle exchange argued the following:

> One of the frequent statements was that the science proves it, and references are made to the federal studies. I think that the actual

> scientific proof of the effectiveness for HIV prevention is pretty slim, and I'm not saying this because I'm against needle exchange, I think it's a wonderful part of what ought to be a much larger approach to HIV prevention (S. Jones, personal interview, October 12, 2003).

Similarly, Edward Kaplan (personal communication, September 14, 2003), one of the principal investigators of the evaluation of the New Haven needle exchange (discussed in the next section), stated:

> I think there were four main problems with the data that existed at the time. First, most of the studies were conducted by the same people who ran the programs. Whether accurate or not, there was a perceived conflict of interest.
>
> Second, most of the studies were based upon changes in self-reported data by participants in the programs. Again, the data could well have been accurate (and certainly the reported results suggested that needle sharing dropped as a result of needle exchange participation). But still there was a credibility problem.
>
> Third, none of the prior studies showed an OPERATIONAL link between needle exchange and the program outcomes. How did whatever results seen depend on program characteristics such as the number of needles exchanged, for example?

And fourth (and perhaps most importantly), what were the consequences for HIV prevention? How many infections was needle exchange really capable of preventing?

Kaplan was skeptical that a consensus did exist in the broader scientific community, but did acknowledge that consensus existed among "HIV public health types." Furthermore, he acknowledged that at the very least, "There certainly was a body of data suggesting that needle exchange

should work." In sum, while the large majority of proponents of needle exchange believed the data was strong enough to provide a consensus, not all those favoring needle exchange perceived the data the same way. Des Jarlais (personal interview, November 7, 2003) characterized the nature of the consensus well:

> I think the overwhelming public health opinion was that syringe exchanges do work or can work if implemented correctly, the big factors being their size, the bigger the better, and user friendliness.

It's important to make clear, however, that even though there were some within the public health community that did not feel that data on needle exchange had reached the "gold standard" of scientific validity, there was wide spread consensus that the data, overall, strongly supported the value of NE. Des Jarlais acknowledged that although each of the studies had significant limitations, as a whole, the conclusions were very sound:

> It was not just the research but it was the consistency showing the syringe exchange programs almost always work." (D. Des Jarlais, personal interview, November 7, 2003)

The Yale-New Haven Study-In August of 1991, Yale University researchers working with the New Haven Health Department released a report on its findings from the evaluation of an eight month needle exchange program. The key finding of the study was that "under the conditions of the New Haven program, we were able to estimate a 33% reduction in the rate of new HIV infections" (E. Kaplan, personal communication, September 14,

2003). Just as important as the findings was the methodology. Just about all of the data before the New Haven study had relied on self-report methods. Researchers at Yale, however, developed a method of tracking the presence of HIV antibodies on the syringes themselves when they were returned back to the program. This method, combined with sophisticated mathematical modeling, provided the most robust data on the efficacy of NE to date.

Dinkins Changes His Position on Needle Exchange

Late in 1991, Mayor Dinkins announced he had been prompted by two sets of events to reconsider his position on needle exchange. One event was the steadily increasing rate of HIV infection, particularly in communities of color. The second was the Yale-New Haven study.

During this time, Woodrow Myers, Dinkins' Health Commissioner, had left his position and was replaced by Margaret Hamburg as the acting Health Commissioner. Dinkins asked Hamburg to examine the research on NE, and she put together a committee of influential government officials to help her draft a report. Hamburg, an African American, was more open to needle exchange than her predecessor, and many needle exchange activists were optimistic once again.

> When she took her position as commissioner, everybody was confident that she would bring back needle exchange, and she did! He [the mayor] trusted her, he trusted her credentials. She made it her business to do her homework and got the data and brought the

> people down from New Haven to meet Dinkins (A. Clear, personal interview, June, 6 2003).

Hamburg cited the "growing body of evidence" as a primary factor for her decision to endorse NE in the report she produced for the Mayor (Navarro, 1991). In addition, the Yale study was also said to have changed the positions of other New York City officials, including Ruth Messenger, the Manhattan Borough President. In November, Dinkins announced that he would allow needle exchange to operate in New York City.

Chapter Summary: Needle Exchange as a Successful Social Movement

The extent to which the needle exchange movement in New York City was successful is certainly a debatable issue in many ways. On one hand, it took almost seven years, from 1985 to 1992, for a needle exchange program to be approved and funded in New York City. This does not take into account other significant events that occurred within this time-period, the 1988 experimental needle exchange program in downtown Manhattan, and the running of illegal needle exchanges by activists. Because of the excessive limitations placed on the '88 program, it cannot be argued here with a reasonable amount of confidence that it was a successful program for the needle exchange movement. At best, it may be considered a stepping stone on the way to larger, more significant policy change. This is a belief shared by a few interviewees, one of whom

felt it paved the wave for the New Haven NE program, which eventually ended up influencing Dinkins' policy reversal in favor of NE (S. Joseph, personal interview, August 26, 2003). Many, while being very critical of the program, felt it was an important step for the movement. As Jones (personal interview, October 12, 2003) argued: "It was a joke, but it was necessary, it was a politically crafted public health program." At worst, however, it can be considered an inadequate compromise that stood in the way of real change and diverted attention from what was really needed, or as others have referred to it, " red herring" (S. Friedman, personal interview, May 10, 2003).

However, the extent to which needle exchange was a successful movement must be understood within the context of powerful ideological forces diametrically opposed to harm reduction approaches. From this perspective, it is the milieu of zero tolerance and moral condemnation for drug use, and in particular, injection drug use and addiction, that is a significant piece of this story. Almost all the activism and much of the research that went on during this period was basically conducted in an attempt to overcome the intense degree of ideological opposition to any policy that, even on the face of it, did not conform to the dominant discourse of abstinence, and zero-tolerance. The fact that this struggle occurred during one of the worst drug epidemics—crack—in recent history,

associated with crime sprees in the inner cities, and deprived images of drug users in the popular media, is highly significant. Just as important is the fact that this occurred during the moralistic Reagan revolution, with his refusal to even utter the word AIDS until late in the epidemic (E. Drucker, personal interview, April 15, 2003) and his "just say no to drugs" campaign as the answer to skyrocketing rates of drug use.

It is under these societal conditions—when social science "threatens the natural order" addresses some "politicized issue," and when "sentiments are mobilized"—that social science is most likely to be marginalized and political (Epstein, 1996, p. 5). Epstein argues that AIDS research, because it's marked by all these characteristics, has been surrounded by volatility and controversy. The fact is that research on needle exchange not only falls into this category, but has the added burden of carrying the ideological baggage associated with injection drug addiction. Therefore, according to these criteria, NE as a harm reduction approach to HIV/AIDS prevention lies at the very margins of acceptable ideas and discourses.

These are the social conditions under which a few individuals and groups in New York City, concerned with a segment of society that nobody else cared about (injection drug users), attempted to make it safer for them to continue to use drugs—the very practice that society despised. In light of

this, I argue that the needle exchange movement was successful and accomplished what it could given the constraints of a society apathetic and even hostile to its cause. From an ideal standpoint, it's easy to critique the system for taking so long for change to occur. However, in reality, if it weren't for the actions of a few, it seems quite possible that New York City, which was at the time of the crisis the epicenter of intravenous drug use and HIV/AIDS in the world, may not have had needle exchange until several years later. This possibility seems all the more likely given the fact that Rudolph Giuliani, stridently opposed to NE, became Mayor in 1994, and was in office until 2002.

Chapter Four: The Intersection of Science, Activism, and Politics

In the previous chapter, it was argued that the needle exchange movement, while certainly not a total success, did bring about significant accomplishments. While the previous chapter took a more descriptive approach, this chapter is more analytical; the objective is to examine in detail: 1) the various roles that social science and activism played; 2) the different ways in which they impacted the political processes; and 3) the overall process of policy change.

The history of NE in New York City is punctuated by a series of key events which are the focal points of the analysis. The first focal point was the first attempt to make needles accessible to IDUs, proposed in 1985 by David Sencer. This movement eventually turned into the "watered-down" and much criticized "pilot" program, which was nevertheless politically significant (although in what direction is debatable). The second focal point was the closing of this program by Mayor Dinkins, which highlights the continued degree of political resistance to NE during this period as well as the marginalization of science under such politically and ideologically-charged social conditions. Finally, the third focal point was various events that coincided with Dinkins' policy reversal on NE. This includes a new health commissioner who was more sympathetic to NE, the release of the Yale-New Haven data, and the reaction by activists to the

city's opposition, which translated into an organized, illegal, and underground program to distribute needles to IDUs, which was in part direct (social service) in the face of a growing epidemic, and in part civil disobedience. This culminated in the arrest, trial, and acquittal of some of those involved in these underground activities, and occurred (and is related to) the build up of a critical mass of support for a needle exchange programs, resulting in a state sponsored and fully-funded needle exchange program in New York City.

The backdrop of these events was the ongoing research. Throughout this period, the research continued increasing, and the consensus within the public health community became solidified. By most accounts a consensus within the public health community was present by the late 1980s. To be clear, however, consensus regarding the *potential of NE* as an effective HIV prevention strategy likely occurred before the conservative standards for scientific rigor had been met. In fact, because of the nature of much of the data on NE, often without an adequate control group or without a control group at all, and because much of the data was self-reported from IDUs, some say this criterion has never been met (S. Jones, personal interview, October 12, 2003; R. Heimer, personal interview, September 11, 2003)). However, by this time, there were programs in several cities around Europe and Australia showing positive effects and

numerous studies demonstrating that NE did not lead to increased drug use and, in fact, increased the chance that IDUs entered into treatment. The international nature of AIDS—the cross-fertilization that frequently occurred between researchers and activists from different countries—is an important part of this story. Finally, another important point is the diversity of the research at the time. There were researchers who were activist-oriented, and there were those whose research was more traditional.

While one of the goals of this section, and of this study, is to understand the various roles that both social science and activism played in the political process, the goal is not to analyze which factors had the greatest impact. The nature of the issue (the complexity of the phenomenon and the enormous confounding of factors) makes these kinds of scientific causality goals unrealistic. This would in fact be a spurious objective since, in many regards, activism and research merged to such an extent that it would be artificial to try to separate them. It is this merging of activism and social science which lies at the heart of the political struggle over needle exchange in New York City, and which is a principal finding of this study. In light of these objectives, the questions driving this chapter are as follows:

- *What were the political impacts of both science and activism?*

- *To what extent and in what ways did activism and social science overlap and work together, and to what extent and in what ways did they clash and work at odds with each other?*
- *What were the barriers to change, and how where they overcome or circumvented?*
- *What where the pathways through which social science and activism impacted the political context?*

As discussed previously, one of the contributions this research hopes to provide is a more comprehensive and systematic understanding of the factors involved in shaping social policy, considering all the important factors of the system (e.g., interest groups, empirical data, public opinion) together rather than only focusing on one or two. However, the complexity involved in understanding such phenomena from a systems perspective introduces the challenge of how to, on one hand, understand the individual components and their interactions with other factors of the system, and the other, understand the crucial dynamics of the system as a whole.

In order to structure the narrative of the analysis in a way that maximizes this objective, a diagram was created from both a priori theory and from analysis of the data itself, which represents the broader policy making context or system and the individual parts (Chart A). The sections of the narrative for the remainder of this chapter coincide with the different

components of the diagram. Thus this diagram provides the analytical framework for this chapter. It represents the theory that preceded and structured data collection and analysis, and as well, the relationships and patterns that emerged from analyzing the data, which supported, complicated, and even challenged the a priori theory.

The focus of the diagram is the role of both social science and activism. It represents their multiple roles and the types of resulting outcomes on the political process. The diagram therefore contains three sets of factors: "Sources of Change," "Roles," and "Policy-related Outcomes."

The circle in the diagram labeled, "Advocacy and Activist Networks" includes the AIDS activism movement, the user movement, and the needle exchange movement. The circle "Science and Research Networks" includes the public health community, researchers interested in the study of drug use and abuse, and researchers working on HIV and AIDS. Each of the four arrows represents the connections between these different groups of factors, and the four sections in this chapter coincide with these arrows or pathways. For example, the first path (arrow 1), represents "Advocacy and Activist Networks" engaged in four different 'methods" of social change work. Therefore, the first section of this chapter addresses the various roles of activists and advocates.. The second (path 2) discusses the

various roles of the research community. The third section (path 3) discusses the interconnections between activism and social science. Finally, the fourth and final section (path 4) will examine the pathways through which social science and activism impacted the political process.

The Role of Social Movements, Activism, and Advocacy

Needle exchange, first and foremost, is a practice that arose from activists (who were often drug users) whose risk for contracting blood-borne diseases was worsened by governmental policies (often supported by the treatment and research communities) that placed a greater priority on forcing abstinence from drugs than on saving lives from AIDS. Therefore, the story of NE begins with "user" movements, traced back to the Netherlands in the mid 1970s, where the Junkiebond was already distributing sterile syringes in response to concerns about the transmission of hepatitis. The relevance of this history to New York City should be emphasized, since it was the first model of NE. However, it was also an important model for understanding how to organize users and how activists can impact the policies that impacted their lives. Quite importantly, the Junkiebond—Amsterdam's user movement—has been credited with doing exactly this.

> In this capacity, Nico [founder of the Rotterdam Junkiebond] played an indispensable role in changing the face and character of Dutch drug policy. Under his charismatic leadership, in the early 1980s, at

> the height of the Dutch heroin epidemic, the Dutch drug user movement was able to push the discourse of the slowly developing local and national drug policies away from "compulsory treatment" and "verelendungs philosophies" towards "acceptance," "pragmatism" and "normalization" (Grund, 1997).

The other critical piece that should be emphasized in order to understand needle exchange activism in New York City is the much larger and more powerful collective response to AIDS by private individuals and groups critical of government and science policies regarding AIDS treatment and prevention. As Epstein (1996) writes, "perhaps the most striking feature of the landscape of AIDS politics is the development of an 'AIDS movement' that is more than just a 'disease constituency." Epstein discusses how the AIDS movement pressured government for more funding, impacted governmental decisions and policies, and influenced research practice and priorities.

As well, the gay and lesbian rights movement should be mentioned in this context. The AIDS movement, as Epstein argues, "was a beneficiary of 'social movement spillover.' Because of the gay and lesbian movement of the 1970s and 1980s, there were was a preexisting network of individuals and organizations that were experienced politically and had significant resources, because the movement was dominated by white, middle-class groups with a high degree of 'political capital.' In a similar way, the NE

movement was a beneficiary of social movement spillover from the AIDS movement.

An important part of the story with regard to the role of activism is that needle exchange did not fully benefit from the organizations and networks that were formed to address AIDS until several years after the policy was introduced in New York by Health Commissioner Sencer in 1985. This is because the two principal AIDS activist groups, ACT UP and the Gay Men's Health Crisis Center (GMHC), were reluctant to take up the injection drug use issue for fear that it would marginalize them further from the political process. As one of the researchers interviewed stated, "There had been a fight in ACT UP, a gay activist organization. The core of GHMC did not want to take on the drug issue, because they thought it would discredit the gay issue" (E. Drucker, personal interview, April 15, 2003). Eventually, because of the shared impact of HIV/AIDS experienced by IDUs and the gay community, and importantly, because some key ACT UP members were also injection drug users, ACT UP would later go on to play a key role in the needle exchange movement.

The role of activism was, however, multifaceted, and extended beyond conventional notions of what activists do. Besides challenging the system from the outside, through pressure tactics, activist were also engaged in direct social service—distributing needles illegally to IDUs—when the

government refused to take on this service itself and even made it criminal to do so. This was critical to the movement. As Elovich wrote in an ACT UP Newsletter:

> Who says activism can't work on a number of fronts at once? ACT UP's needle exchange, which for two years has blurred the line between direct action politics and lifesaving AIDS services is now reaching addicts at five sites in the Bronx, Harlem, Brooklyn and the Lower East Side (Elovich, 1992).

Activists were working on a number of other fronts as well. They were linked with policy making networks both directly and indirectly through their connections with the public health network of researchers and physicians. They were also engaged in direct social service, legal reform, and in producing knowledge that challenged that of traditional experts. This section outlines the various roles activists played in the needle exchange struggle. *It is argued here that NE would not have been a reality in New York City were it not for the level and intensity of activism that existed.* What follows is a description of the different ways in which activists worked for change.

Direct Service Delivery: Direct Social Action

Because government has always been resistant to adopting the practice of needle exchange, activists have been the first group to provide this service to drug users. This is what happened in the Netherlands and it is what happened in most cities in the U.S., such as with David Purchase in

Tacoma and Prevention Point in San Francisco. In New York City, however, because NE was being pushed through the state bureaucracy, an underground exchange didn't develop until later. Early on, however, activists were the only ones providing services for drug users. The only form of prevention of blood-borne diseases among IDUs was the practice of "bleach and teach." This is most likely because of the paraphernalia laws that existed and were enforced in the city, and also, because at the time, the only real group advocating for and addressing the needs of drug users was ADAPT, whose funding came primarily from the city's health department. ADAPT was advocating for the rights of drug addicts and providing direct services to them several years before ACT UP and GMHC became involved in the issue. Therefore, to a significant degree, ADAPT is responsible for making the health of IDUs a more salient policy and public issue.

When the pilot program was closed in 1990, it was ACT UP, and to a lesser extent Jon Parker (who was arrested over 40 times in the course of his activism) and the AIDS Brigade that filled the service gap. At that time, activists were the only ones engaged in needle exchange programs in New York City, and they often had to do it behind the backs of law enforcement. They were, whether they realized it at the time or not (and at least one activist interviewed did not realize he was doing this), providing

social services to one of the most difficult populations to reach. As this activist recounted:

> "I never really thought of it as social services. It was really about helping people right there and then. No one was knocking on the doors of shooting galleries (A. Clear, personal interview, June, 6 2003).

Although this was ACT UP's longest standing act of civil disobedience, they were not trying to get arrested, at least not in the beginning. They knew more and more people would become infected with HIV because of dirty needles; that was their immediate focus. ACT UP members would have regular spots and would give out needles. They did everything they could to reach this very –hard to reach population. They would outreach, go into shooting galleries, offer other services, and struggle to find financial support for their work. In some important ways, they looked very much like a social service agency, with one notable exception: they had to do this illegally, with the threat of arrest and the harassment of law enforcement.

Working Outside the System- Protest and Contentious Politics

It is important to note that activists and advocates were diverse in terms of how they worked toward social change, some working "within" the system, or from conventional or more socially accepted forms of politics (lobbying government officials, receiving support from mainstream or governmental institutions to provide some service), and some working "outside" the

system (practicing tactics of social disruption and challenging the very legitimacy of governmental institutions). This section focuses on the latter strategy, what McAdam, Tarrow, and Tilly (2001) refer to as "contentious politics." They define contention as "a socially constructed set of adversarial relationships that is embedded in a legal/institutional system that effectively constrains the strategic options available to all contenders" (p. 25). Contentious politics are fundamentally "strategic," and can "activate and empower nonviolent social movements." Much of the influence that ACT UP had on struggle over needle exchange can be attributed to tactics that were contentious in nature, and which brought about change through pressure rather than through legislative reform.

Although the focus of this section is contentious politics, it's important to point out that many of the activists and advocates in the NE history actually engaged in both standard and contentious politics. This is true for both ADAPT and ACT UP, although the former worked significantly more within the system and the latter more outside it. This section discusses how both these groups worked to promote social change by challenging and protesting the system and working against or in conflict with government. The next section will discuss how these groups worked within the system and in collaboration with government.

Although, for the most part, ADAPT worked in collaboration with government and had some important connections to it, it sometimes worked on the margins of what was socially acceptable by government. The practice of "bleach and teach" is a good example of this. When they first began this practice, they were denied funding from the city because of it. However, they would later go on to secure funding from the city's health department, which actually helped support "bleach and teach". So their stance on the margins was effective at changing what government was willing to condone and even support.

When ADAPT felt that the state had been "dragging its feet" on approving the city's request for the pilot program, it moved outside the margins, and stepped out of its role as institutionalized organization, and threatened to give out needles illegally. In doing so, it was in direct conflict with government, and even temporarily lost its funding because of it. Gillman (1989) discussed the city's response to this action:

> In response, the Department of Health froze ADAPT's operating money and shut down ADAPT's offices for 48 hours. Mayor Koch called ADAPT's threat "cheap talk" and declared that any ADAPT member distributing needles would be arrested. The city did not reimburse ADAPT for any expenditures for over three months.

In doing so, however, ADAPT, was instrumental in overcoming opposition to the pilot program. It does not seem merely coincidental that shortly after Yolanda Serrano threatened to distribute needles in defiance of the slow

pace at which the state was reviewing the NE proposal, that then Governor Cuomo along with David Axelrod, the state Health Commissioner, finally gave their approval for the program. The fact that this event was covered for two weeks on nationally syndicated news outlets may have played an important role in placing pressure on elected officials to not appear negligent in how they dealt with a national health epidemic. The fact that this was an outcome that was totally consistent with its stated mission is also significant:

> ADAPT seeks to build an agenda by producing a social movement aimed at publicizing the plight of intravenous drug addicts in the AIDS epidemic. ADAPT's goal is to dramatize the needs of its constituency, making it visible. By mobilizing public opinion on the epidemic among IDUs, ADAPT seeks to activate governmental response to the health crisis its clients are experiencing (Gillman, 1989).

With the exception of this example, ADAPT, for the most part, can be said to be an organization that worked within the system, since it had institutionalized ties to government, with restrictions on what it could and could not do. In contrast, one of the best examples of activism outside of the system, placing pressure on it to change rather than working through legislative avenues, is ACT UP. Elovich (personal interview, April 28, 2003) discussed the different roles that ACT UP and ADAPT occupied, given their relationship to city government:

> The 501C3 Yolanda has means she has a contract she has to keep up and the moment she becomes too political, she losses her contract; the moment a researcher seems biased, he loses his

> authority. We were doing civil disobedience. That's what ACT UP was about. We were trying to demonstrate that there was a crisis, and part of the crisis was that government was indifferent, and wasn't responding, and didn't care about the people that were affected by AIDS.

The hallmark of ACT UP is its "in your face" tactics. ACT UP members were driven by anger and distrust of the system, as illustrated by their motto, "Silence = Death". One of the more powerful and common themes to arise from the interviews with activists was how emotionally vested they were in the issue because of how closely and deeply it had impacted their lives. One of the activists interviewed discussed his entry into the needle exchange movement (A. Clear, personal interview, June, 6 2003):

> In around 87, I started working at a restaurant, where most of the people that worked there had AIDS, and I was going to AA and NA meetings in the Village, so virtually everyone I knew had HIV. People were dying regularly.
>
> [At one of the restaurants] there was a wall of lockers with a bunch of locks on them, and the head waiters told me those belonged to other waiters that were dead and they never took the locks off. So this was a real scene of devastation, and having this going on around me, I couldn't not do something.
>
> "One of the waiters I worked with had been going to ACT UP meetings, which was really a gay organization, and I thought, how I would fit in there. Would I be welcome? But I really liked everything I saw about what ACT UP was doing, about using media and outrage to create change. Because when I was growing up in England and being 16 in 1976, that's what punk rock was all about. I was very much drawn to what ACT UP was doing. The impetus was being in AA meetings and literally hearing every other person saying, 'I got sober, then I found out I got AIDS.

Another ACT UP member interviewed had a similar experience:

> I got involved with ACT UP in 88, largely because so many friends of mine were dying...ACT UP started in 87. At that time there was very little organizing around drug users, it was about [gay rights]. ACT UP wasn't about drugs at all. I was going to AA meetings, and I was seeing more and more people symptomatic with AIDS...and at that time, people weren't living with AIDS, they were dying of it.
>
> I went to a gay-pride parade right after a good friend of mine died of AIDS, and I saw these people [ACT UP members] who very angry, and I connected with that.

This observation is supported by the comments of one of the researchers interviewed. He discussed the strength of the needle exchange movement and the driving force for the activists:

> They had zeal. They were fueled by the fact that there was this epidemic that was raging, and increasingly involving drug users, that drug users were being ignored. They were fueled by anger, and anger is a powerful motivator and certainly operated here. People were plenty pissed off (P. Lurie, personal interview, September 12, 2003).

ACT UP members would conduct "sit-ins" in the Health Department, attend almost every public meeting the commissioner had with signs and posters, heckling, and raising their watches (signifying that time was running out and people were dying of AIDS). Elovich (personal interview, April 28, 2003) discussed one specific incident that illustrates their approach:

> We stopped the Stock Exchange from opening, eight of us. We blew fog horns and released a banner 'Boroughs Welcome, Make AZT Available' because AZT was so expensive that people couldn't buy it. And the judge dismissed the case against us on the grounds that 'whatever damage we did that day at the Stock Exchange, the greater harm was that AZT was prohibitively expensive, and people were dying of AIDS.

On more than one occasion ACT UP members broke into the Health Department's executive office, demanding to meet with the commissioner. One of these times Stephen Joseph was there, and after a confrontation that involved at least some degree of physical contact, Joseph has them arrested and they were eventually charged with unlawful entry. In his book, Joseph discussed, in detail, his confrontations with ACT UP:

> It began largely along rhetorical lines. Posters and stickers were pasted on lampposts and mailboxes around the city, proclaiming that 'the AIDS Estimates are a Lethal Lie,' and 'Stephen Joseph Has Blood on His Hands' (superimposed on a crimson hand print); in another version the bloody hand was identified as Ed Koch's). A chanting demonstration in front of the Health Department labeled me as a murder and urged that I resign (Joseph, 1992, p. 164)

Joseph also described his incident when ACT UP members broke into his office for the second time (p. 165):

> My silence in the face of their screaming and invective seemed to infuriate them further, especially one mustached and sun glassed young man wearing a red dress and high heels, who later sent me an inscribed photograph of the two of us sitting at the end of my conference table. The inscription said: "Stevie Dearest—Thanks for hanging out with us this day; it was just too much fun!!! Let's do it again soon, huh?!? Ever, Spree.

The fact that ACT UP members engaged in such contentious politics would lead one to believe that they would have little or no opportunity to attempt to influence policy through mainstream routes, such as working with and advising policy makers. However, one of the striking findings of

this study is that ACT UP did play a role in internal policy decisions, both at the state and local level.

Activist Involved in the Policy-Making Process: Working within the System

As discussed previously, one of the central findings of this study was the rich network of connections between activists, researchers, and individuals in government. These connections proved to be a valuable asset for activists, and because of them, ACT UP was able to help shape, in very important ways, key aspects of the 1992 needle exchange program. An example of this was a collective called the Lower East Side AIDS Strategy Group (LESASG), which played a key role in working with the state in crafting specific aspects of the program. This group was made up of members of ACT UP, including Allan Clear, who would later become the co-director of the Lower East Side Needle Exchange, along with other community groups, such as the Lower East Side Family Union and the Ryan Nena Community Health Center.

One member of the LESASG had connections to a staff member in the New York City Department of Health, Raquel Algarin, who was from the Lower East Side, identified with the issues the community was facing, and was very sympathetic to their cause (A. Clear, personal interview, June, 6 2003):

> There was a guy who worked for the Lower East Side Family Union, who introduced us to Raquel Algarin and she was working at the Health Department and was from the lower east side, and she came out to join us and asked me to talk at this task force [from a local city organized task force], and brought the community on board, including the social service workers.

So Algarin brought important representatives from the state Health Department to visit this *illegal* needle exchange, and they meet with ACT UP and the coalition. From that point on, the LESASG worked closely with the State AIDS Institute in crafting the state waiver applications (in order to make it legal, given the state paraphernalia laws) and developing specific aspects of the program. "What we didn't want were regulations put on the program," recounts Clear. One point they negotiated (or perhaps more accurately argued) with the state was the issue of drug treatment. The state wanted to emphasize treatment within the NE, and do everything they could to encourage or "push" treatment on needle exchange clients. The LESASG, however, felt it was crucial to keep NE, first and foremost, as a harm reduction center. They wanted to make it as user friendly as possible in order not to discourage IDUs from accessing it. This did not mean they would not offer treatment or referrals to treatment, but rather that it was not going to be pushed on clients:

> The state wanted everyone to be offered drug treatment, and we wouldn't allow it. There were vehement arguments about that. 'You can't even put drug treatment first on the list of referrals.' We offered lots of referrals, housing, food, drug treatment. We don't want emphasis put on this [drug treatment]. And we would fight quite vehemently. But

> it was a process where the state received and asked input from us (A. Clear, personal interview, June, 6 2003).

Importantly, the LESASG was successful in its demands, and therefore had a significant impact on the requirements placed on needle exchange programs by the state.

Another example of how ACT UP members were involved in policy concerns involved Richard Elovich, who was one of ACT UP's key members. Elovich would later become the Chair of the Ryan White Planning Council and an advisor to the state on drug prevention. In this capacity, he met with different constituencies around the city, one of which was the black community. He discussed a story that took place during a crucial point in this history when Mayor Dinkins was considering changing his position on NE, but one of his greatest concerns was the reaction from representatives of the black community. There was a meeting held between members of the National Black Leadership Commission on AIDS, which had been one of the greatest opponents of NE, and treatment providers. Elovich, a white male, recounted how the other "expert" brought in to speak was an African American representing the "drug free position." However, Elovich was successful in "bridging the gap" between their two positions when they discussed their shared experience of witnessing so many people in AA and NA (narcotics anonymous) die of AIDS:

> And I said to him, most of those people aren't going to make it to drug treatment. They're going to die before that, so syringe exchange isn't in opposition to drug treatment. I said, if you want people to go into treatment, they have to be alive. And he got it, and he got the logic of that. So when Dinkins did his press conference in the blue room [announcing his new policy on needle exchange], we were standing behind him. And Caleel [the other expert] said, 'I can't support this, because I don't think it's enough, but we will not oppose it. We do not have the right to oppose anything that offers help.'

This was a critical moment. The presence of a member of ACT UP negotiating with key constituents, then standing behind the Mayor when he announces that he will allow needle

exchanges to operate is a powerful testament to the role of activism.

ADAPT also played an important role at the policy level in New York City. From the beginning ADAPT was the principal group advocating for needle exchange, laying the groundwork through such programs as "bleach and teach." Importantly, their mode of work involved working within the system, having institutional ties to city government, and being connected to leading research centers, such as NDRI. These connections were important when approval was being sought by the city for the pilot program. Gillman (1989) did a case study of ADAPT, and in particular its "role in gaining government approval to establish the city's experimental program amid the controversy that needle exchange generated" (p. 3). Gillman argues

that ADAPT was successful at "getting on the government agenda" and in validating a "competing ideology." She argues further that:

> ADAPT accomplished an important goal by getting needle exchange recognized as a 'systematic agenda' issue, worthy of public attention and involving matters within legitimate jurisdiction of governmental authority (p. 34).

Besides being crucial at making AIDS among IDUs a legitimate social problem and getting needle exchange to be a viable public policy issue, ADAPT also played a role in making the pilot program work, or at least work as well as it could, given enormous constraints:

> At some point Yolanda Serrano came to ACT UP and talked about the city's syringe exchange, the one that Koch opened up. And she was trying to make it work. She had a very credible street outreach. She was directing people to go to the program on Worth Street. The reasons she was doing this is that she and ADAPT had precipitated Koch taking action.

Activism and Knowledge Production: The Role of Vernacular Knowledge

One of the greatest sources of disagreement between activists and the science community within the history of AIDS has been competing versions of valid knowledge. Much of this debate centered on standard arguments within the science community regarding issues of scientific validity. However, another debate was occurring in the margins of scientific practice regarding the question of who can be considered an expert and what forms of knowledge are validated and which forms are marginalized.

The conflict over whose understanding of the world has greater validity is a primary reason ACT UP was created.

> Gay men were ill and dying and the earliest voices of warning, such as that of New York playwright, Larry Kramer [founder of ACT UP], were loud in their claims that medicine, science, and government were criminally ignoring the growing problem, and that the gay community had to organize not only for its own defense, but also to force an adequate response from the rest of society (Joseph, 1992, p. 95)

ACT UP's critique of mainstream science is further illustrated by their mission statement:

> One of the reasons ACT UP was founded was because health officials, government researchers, medical bureaucrats, doctors and pharmaceutical company executives were believed to be "AIDS experts" and held all the power over people living with AIDS. Here in the affected communities, our points-of-view were made invisible and our real-world knowledge about the changes that needed to be made to end the crisis was ignored. Living with AIDS, as we all are in New York City, one of the epicenters of the AIDS pandemic in this country, we are the experts! (ACT UP, 2003)

An example of the manner in which data from above (science and government) looks different from data from below (marginalized communities) is the early estimates of AIDS, and how, as ACT UP argued, science and government significantly undercounted the extent of the epidemic and the groups at risk. Elovich (personal interview, April 28, 2003) discussed the early years of the HIV/AIDS epidemic, and how in the early 80s, the first report from the CDC's Morbidity Mortality Weekly Report came

from clinical reports from doctors observing symptoms among homosexual men, and "how the CDC definition of AIDS was crafted around men."

You could argue that IDUs and poor women didn't have access to health care and weren't appearing on the radar screen, but were dying. It was this data that led to the city's undercounting of HIV/AIDS cases. Ed Koch was downplaying the AIDS epidemic. He was saying it was only a crisis. So both infected drug users and women were dying in the early 80s. How come it took so long for the CDC definition to reflect that?

Elovich, who is academically trained in Public Health, discussed the marginalization of knowledge that does not come from designated "experts." Borrowing language from Barbara Jordan, he differentiated between authoritative knowledge—that which comes from those in socially designated roles of "expertise"—and vernacular knowledge, "what people know on the street and in programs." Because authoritative knowledge has a monopoly on what's considered valid understanding, vernacular knowledge is marginalized, and therefore, policy makers as well as many researchers don't see the inherent value of vernacular knowledge. Similarly, Epstein (1996) discusses the process of credibility struggles, where scientific "credibility" refers to the "capacity of claims-makers to enroll supporters behind their arguments, legitimate those arguments as authoritative knowledge, and present themselves as the sort

of people who can voice the truth" (p. 3). He goes on further to argue that the science of AIDS "cannot be analyzed 'from the top down.' Rather, it demands attention to what Michel Foucault calls the 'microphysics of power'," where "the propagation of knowledge, practices, meanings, and identities out of the deployment of power" are made (p. 4).

One result of this marginalization of vernacular forms of knowledge, for ACT UP, was that the understanding they had gained about how to make NE work, and about its effectiveness at getting to difficult populations, was never utilized (this is discussed further in the conclusion chapter). Despite this, in many ways, the "deployment of power" by those on the bottom, such as ACT UP and other activists, did have a critical impact on many aspects of the debate: about AIDS, injection drug users, and about the needle exchange.

II. The Role of Social Science: Researcher Networks, Activist Research, and Data

Another key finding of this study concerns the multiple roles that researchers played. In fact, conventional notions of what researchers do—producing data and providing knowledge—actually made up only a modest portion of what the social science community actually did within the NE history. As discussed in Chapter 3, there was no actual research

conducted on the effects of needle exchange in the U.S. until the early 90s. Most of the research during the first few years was to understand prevalence rates, risk patterns, and the prevention of HIV/AIDS. For the most part, this is because there were no needle exchange programs. However, another important reason for this was the Federal ban on research on needle exchange, which successfully prevented the examination of a policy the government officially opposed. This resistance on the part of mainstream institutions may help explain a key finding of this study: the extent to which many (but certainly not all) researchers were engaged in various forms of political activism, either indirectly through their research, or directly, by helping promote and lobby for needle exchange by working within the system, and working outside of the system, through involvement in the illegal exchange.

In discussing the research community, it is important to highlight the variability that existed in both the range of ideological positions and degree of political involvement among researchers. The ideological divide reflected the clash between the harm reduction and abstinence positions, keeping in mind the actual term harm reduction did not appear until the late 1980s or early 1990s. Ideologically, most of the public health community was open to the idea of NE. However, some were more adamant in the belief that NE should be separate from treatment.

Therefore, many in the public health community shared beliefs from both the harm reduction and abstinence positions. Furthermore, and quite importantly, there were those within the social science community ideologically opposed to NE, and who were vested in the abstinence position.

Politically, there was an enormous amount of variability with regard to the degree and nature of researchers' activism. On one hand, many of those interviewed commented on the responsibility that the social science community bares for its *inaction,* such as by having their research agendas influenced by what government agencies, such as the National Institute of Drug Abuse (NIDA), was supporting, and therefore promoting, ideologically and politically. They also criticized the inaction regarding the ban on research on NE, antithetical to democratic notions of an open society, guided by principles of reason and pragmatism, and antithetical to the very core scientific objectivity, that should not be constrained to only examine political questions that support the status quo. On the other hand, there was a core group in the social science community that did engage the system politically and did work toward promoting and strengthening the NE movement. Many of these described themselves as activists as much as they did researchers. Following is a discussion of the different roles researchers engaged in and the different ways in which

both social science data and social science activism engaged the political system.

The Role of Empirical Data and Knowledge of Problem Dimensions and Solutions

It is critical to discuss the role of knowledge, in the context of providing an understanding of the nature of social problems.. As one of the interviewees succinctly stated, "Knowledge is knowledge: if I don't know anything about AIDS, how can I do anything about it?" (S. Friedman, personal interview, May 10, 2003). Basic knowledge of the prevalence of HIV/AIDS, demonstrating its epidemic levels and its shifting epidemiological patterns, is crucial. For example, the enormity of AIDS was certainly a factor that convinced Commissioners Sencer and Joseph to push for a controversial and politically dangerous policy. The data on AIDS was also said to have played an important role in overcoming opposition to NE on the part of key government officials--Governor Cuomo and his Commissioner of Health, David Axelrod. When they both changed their positions, Joseph commented (Kerr, 1988):

> In the last few weeks we have had some very dramatic demonstrations of the rates of infection of women and children. I think David Axelrod was hit by those numbers...When he and the Governor saw those numbers in black and white, it must have had an effect. Intravenous drug use is the key to the epidemic.

On other hand, it is also important to point out that neither Sencer nor Joseph needed research to tell them that NE was an idea worth pursuing (since there was no data at that time demonstrating this). Furthermore, the data on the AIDS epidemic was not compelling enough to convince many others, including both Mayor Dinkins in 1990 and his first health commissioner, Woodrow Myers.

Therefore, while it's safe to say that the basic knowledge of AIDS was critical—helping to make the issue salient and important—it was only the first step in defining risk among IDUs as a social problem. In general, however, the relationship between social scientific evidence and social policy was inconsistent and weak. For only one event series is there a correspondence between empirical evidence and policy. During the first series of events, the opening of the pilot program, which began in 1985, there was little or no evidence that NE was effective or that it did not lead to increased drug use, yet two commissioners of health and eventually the Mayor supported it, and it was ultimately pushed through state resistance. By the time there was a strong body of data supporting NE, and a strong consensus within the public health community, the pilot program was shut down in 1990. It wasn't until the third series of events—when Mayor Dinkins was said to have been influenced by, among other things, the New Haven study—that a relationship between science and policy began to appear.

Furthermore, it should be emphasized that the New Haven study was just one of many studies that supported the efficacy of needle exchanges. In particular, there were two studies that have been cited as influential during this period. One was the Federally funded report compiled by the National Commission of AIDS, "The Twin Epidemics of Substance Abuse and AIDS." As Des Jarlais (personal interview, November 7, 2003), one of the authors of the study, noted:

> In 1991 the report on the twin epidemics came out, which came out at the same time as the first reports from New Haven came out, almost to the same day, and they served to reinforce each other.

The other study cited as influential was one showing lower rates of HIV infection among diabetic IDUs, because they had access to clean syringes. Noted Kaplan (personal communication, September 14, 2003), one of the principal investigators of the New Haven study:

> Mayor Dinkins (or at least his staff) cited our study as one of the major reasons for reversing his policy. The Baltimore ALIVE study showing differential HIV prevalence among diabetic and non-diabetic IDUs was also cited (HIV prevalence among diabetic IDUs was much lower than among non-diabetic IDUs in the ALIVE cohort, presumably because diabetic IDUs have regular access to new needles).

Finally, there was preliminary data from the Tacoma syringe exchange, the first legal syringe exchange in the nation, which showed that needle exchanges were effective and didn't lead to increased drug use (Lurie,

1993). For several reasons, however, it was the New Haven study credited with the greatest impact on the political process during this period. This is due in part to the methodological soundness of the study. In this regard, three points have been raised in the literature and among interview participants. First, the New Haven Study was the first study at the time not to rely on self-reported data, but rather collected the used syringes of program participants. From this, the researchers modeled how many new HIV cases had been prevented. It was perceived at the time as the most rigorous study of needle exchange.

> Our study was clearly the first to suggest an answer: under the conditions of the New Haven program; we were able to estimate a 33% reduction in the rate of new HIV infections from our data via a coherent mathematical model (E. Kaplan, personal communication, September 14, 2003).

Second is the fact that it was done by independent evaluators:

> Our evaluation team (Rob Heimer, Kaveh Khoshnood and myself) were all affiliated
> with Yale, we did not receive any financial support from the City of New Haven, and we submitted our work independently to peer-reviewed journals (E. Kaplan, personal communication, September 14, 2003).

Third, they provided a viable theory for how needle distribution actually led to large-scale declines in new HIV cases.

> No one could really say what the role of specific program features was on the data observed. The "circulation theory" that we developed filled this gap -- we argued that needle exchange

> reduces the circulation time of needles; that the shorter the circulation times, the less likely needles were to become infected (since needles would "share fewer people"), and thus the lower the likelihood that an IDU injecting with a needle would do so with an infectious needle. The rate of needle exchange determines the needle circulation times, so we had a clear link (E. Kaplan, personal communication, September 14, 20032003).

Many non-scientific reasons were raised for why the New Haven Study was so important. First, it was well situated politically to have an impact, much of which had to do with race. From many accounts, the racial tone of the issue had dominated the fate of needle exchange in New York City. Part of the impact of the New Haven Study should be understood within this context, not just within the context of the practical impact of scientific evidence on people's beliefs about the value of NE. As one interviewee stated,

> The New Haven study simply cut the rug out from under that argument [the racial argument], because it was done by a black mayor in a black administration. One of the important points of the New Haven study is that it tilted that equation (S. Friedman, personal interview, May 10, 2003).

Others voiced this sentiment as well:

> New Haven was convenient: it was nearby, it was another city, there was a black mayor at the time, and the black neighbors knew each other (E. Drucker, personal interview, April 15, 2003).

> New Haven served to defuse the race issue, that it was not this horrible thing done by white officials to the black community. That was critical (D. Des Jarlais, personal interview, November 7, 2003).

Second, it was closer to New York and it was easier, politically and perhaps logically, to draw the relevance of a needle exchange program in an urban center just two hours away from New York City. Third is the fact that it was conducted at a prestigious university, thereby adding to the "objective" and "credible" appearance of the study. Hamburg (personal interview, August 8, 2003) argued that this was clearly an important factor influencing Dinkins' policy change:

> If it had been a study from Podunk University, I don't think he would have felt as compelled to look at it. But being from Yale University made it more compelling.

What these patterns of knowledge use emphasize is the degree to which the impact and use of empirical data occurs within a political context, and is framed by political considerations. In other words, how data supported or challenged the agendas of different constituencies was as important, if not more so, than the actual scientific value of the data itself. The idea that research was "crafted around political objectives" was one commonly voiced by several of those interviewed:

> People like Don [Des Jarlais] knew that needle exchange worked. So he was beyond the "if" statement. He was playing the role in terms of, what evidence do I have to produce to move the political...Don was crafting the research around three different lines. One was, that if addicts are given access to clean syringes, will they use them? Will it lead to behavior change? The second was, is it a bridge to treatment? And remember, this is what the city's program was called, "a bridge to treatment." That's how they got it through. The third piece was that needle exchange does not increase drug use. Those were the three points, and literally, that's what Don set out to

> show, that's what Don testified on (R. Elovich, personal interview, April 28, 2003).

The fact that the pilot program had to be framed as a bridge to treatment further supports the finding that research and empirical evidence was so often used as a political tool rather than as a means of understanding a social problem. As Elovich stated,

> It was really about what kind of research you need to do, it's no longer about epistemology, it's about what kind of research you need to do to convince politicians. It was ideological, it wasn't scientific.

In sum, there are a few key points regarding the role of empirically based knowledge. First, at one level, the belief that "science doesn't matter," is not justified by the data of this study. Some key examples illustrate how empirical data impacted the political context in important ways. First, it mobilized those who were sympathetic to, or at least not ideologically opposed to the idea of NE. Second, it lessened the level of opposition and resistance to NE. There were several occasions where empirical data was credited with impacting the policy positions of government officials. However, it is not known whether their actual attitudes toward NE changed or whether the political consequences for not endorsing NE changed. Most interviewed, however felt that the impact of data was largely political rather than informational:

> To a politician, the data mostly provided cover, and that's what our report did, and that's what Ed Kaplan's report in New Haven did.

> Somebody like him [speaking about Mayor Dinkins] looks at the data in a political context. I think it provided cover, I don't think it led to an honest to goodness conversion based on the data (P. Lurie, personal interview, September 12, 2003).
>
> I don't think information mattered, then or ever. It's totally a political and impassioned thing (S. Jones, personal interview, October 12, 2003).

However, Margaret Hamburg, the one person who worked most closely with Dinkins on the NE issue, had a different perception (personal interview, August 8, 2003):

> I really think from spending time with him on this issue that there was an emotional reality to his feelings. It was more than just politics. He was really uncomfortable with the concept of needle exchange, partly because he was surrounded by colleagues and friends that were very anti needle exchange. But I also think that it also was true as he saw more and more the devastation of HIV and AIDS in black communities and other communities that he felt that if something really did reduce HIV transmission, one had to step up to the plate.

Regardless of the causal mechanism, the fact is that research was related to changes in policy positions, even if it was in the form of political cover, which is still a form of impact. On the other hand, however, there is another point regarding the role of empirical data. Despite the above important examples, there was still a large gap between the research and the policy regarding NE. Even the impact of the New Haven Study must be understood within the context of several other non-scientific factors, such as race. Furthermore, it was the other roles in which some members of the

research community engaged that deserves as much attention as does the empirical data. These are reviewed next.

Social Science Engaged and Supporting Activism

The previous section discussed the role of empirical data. This section and the two that follow focus on the role of researchers themselves: what they did to promote NE, what roles they occupied, and what audiences they targeted. The theme that runs through these sections is the extent to which a core group of researchers worked, sometimes in their capacities as "experts" lobbying government officials; other times as activists working with grass-roots groups, to increase the support for NE. This section discusses their activist work, which was quite varied. For some, research and activism were totally separate activities. Their activism had nothing to do with their research; this, in part, reflected the belief that research was impotent at creating any real change (Curtis, 2003). Others tried to fuse their activist and research agendas, in an attempt to support activism through the methods of science. As one researcher stated:

> I do feel that role [activism] when I go and testify to the state legislature on a variety of other situations when called upon to do so. It probably crosses the line a little bit, but it's based on the data. I try not to go beyond what the data allow me to conclude from a strict, bio-medical meaning of the word (R. Heimer, personal interview, September 11, 2003)).

Another example of researchers supporting activism through the practice of science involved a key connection ACT UP members had with experts in the public health community. Elovich (personal interview, April 28, 2003) recounts a story of the early days of the illegal exchange, when he and Rod Sorge (another key figure in ACT UP and in the needle exchange movement) met with Ernest Drucker, a leading AIDS and substance abuse researcher running a methadone program at Montefiore Hospital/Albert Einstein College in the Bronx. He remembers a discussion with Drucker, saying to him, "We know this is working, what we're doing. We know it. And Ernie said, you got to show it. So we brainstormed at lunch how we would show it, how can we do our own research." What they had to demonstrate was that the needles they were giving out were actually being returned, which would show that users were taking the responsibility seriously, that they were using clean needles, then returning them for more clean needles, which was exactly the way the program was supposed to work. So they came up with a plan whereby all of the needles would be marked, or color-coded by exchange site. So, for example, needles from the Lower East Side were marked with a red band, and needles from the Bronx were marked with a blue band.

Elovich credits Drucker for the fact that "he stepped out of his role [as a researcher], and lent his expertise to do this with us." He also recognized

that many other researchers weren't willing to do this, largely because the exchange was illegal, and there was therefore a risk of doing research that supported an illegal activity. Other researchers crucial to the NE movement would only do so within their traditional roles, such as providing affidavits when they needed one, testifying on their behalf, and writing letters of support.

Another similar example of this type of collaboration involved ACT UP members realizing the limited scope of their work, and wanting to find ways of reaching more people, which they did by tapping into the network of users to distribute needles and syringes more effectively--what they referred to as secondary distribution.

> We were on the streets, but only one day a week for a couple of hours in one site. You know, that's nothing. It's like distributing goulashes in the middle of a flood zone. We were well aware that what we were doing was very limited. So we would get certain people that showed up at the needle exchange site who showed up kind of regularly and then started to help out in some way, and those people would say to us sometimes, 'you know what, I live in this SRO [single room occupancy] and there are these people that are injecting drugs in the SRO. Can you give me twenty syringes and I'll bring them back to you next week.

So ACT UP, with crucial support from Ernest Drucker again, putting aside his traditional research hat, came up with a plan to collect this data, and they did. However, they could never do anything with it. This could have been very useful data on the "how" question, and they were counting on it, but

"no one made use of it." So even though ACT UP had this important data, they didn't have a "Ph.D. who was willing to adopt us." So without the legitimacy afforded by the role of an "expert," he argues that the data would not have been seen as valid.

The other mode of activism within the social science community was researchers switching roles completely, and doing direct activism. Within NDRI, the gap between social science and activism was bridged when it was clear to some of its employees that research, data, knowledge or pragmatism had no bearing on the actions of policy makers. It was when Dinkins closed the pilot program that ACT UP organized the illegal needle exchange. Motivated by the same reasons, some staff members at the National Development and Research Institute (NDRI), working on various HIV and substance abuse research and outreach projects, decided to become involved in the illegal exchange, and did so with the tacit approval, or at least the feigned ignorance of their supervisors, some of whom were quite high up in the organization. When one of these individuals was told about what was going on, he responded, "It's on their own time, it's not my business." So some staff of this research-based organization, funded largely by the federal government, were engaged in this illegal, underground needle-exchange with their supervisors providing

their support by turning a blind eye, and in some cases, by even providing emotional and financial support.

Some of these individuals actually became key figures in the underground movement. One, for example, was Richard Curtis, a researcher at NDRI at the time who became involved in the illegal exchange. Curtis (personal interview, May 16, 2003) characterized his role as an activist the following way:

> It was strictly advocacy and activism on my part. It wasn't about research. NDRI told me that if I got arrested at the time, I would lose my job (even though they liked what I was doing and benefited from it). NDRI was, as an organization, was not for needle exchange. I think they felt it would cost them too much politically. They get funding from OASAS, which does not support needle exchange.

Senior members of NDRI were also involved in their own form of advocacy and activism. They recognized the natural connection between themselves, as AIDS experts, and grass-roots activists starting up and running needle exchanges. The activists needed the expertise of researchers to document, empirically, the value of NE, and the researchers needed the data as the basis for their research agendas. Most importantly, however, both had the mutual goal of promoting NE, so the match was ideal. Friedman (personal interview, May 10, 2003) discussed, for example, how he was using data from existing needle exchanges, such as the one in Portland for advocacy at the local level in New York City:

> One of things we were doing with the data was helping their [the needle exchange sites'] position in the community. We're feeding to the community what they need to hear, that there's no data that it's doing damage, and that there is considerable data that it's doing good, and of course it's not definitive, but what is definitive?

Friedman also discussed how Don Des Jarlais and he were collaborating with David Purchase, one of the most important activists in the needle exchange history nationally, and how all the researchers and activists would get together at conferences: "...basically we were all friends, trying to push prevention ahead." In fact, it was the international conferences on AIDS that provided the forum for the extensive amount of networking that went on between activists and researchers, and to a lesser but significant extent, with public health officials.

It's important to recognize the value and limitations of the roles of activist and researcher . That is, when is it time for research, and when is it time for action? This underlines the concern that some researchers have with how the practice of research can actually have a negative impact on progressive social change efforts. As one researcher commented (P. Lurie, personal interview, September 12, 2003):

> I consider myself an activist, first and foremost, and did it through research for a while, and my allegiance was always to the people on the field, not to the researchers. By 1996, a lot of the role that science had on policy had come to an end. It was clear that the decisions on Federal funding would be made on non-scientific grounds. It became not about science, and I kind of felt, OK, you did your part at a moment when science mattered, which I think was

> that period between 1990 and 1996, and it doesn't matter anymore, so why do it?

Social Science Involved in Policy Making

The image depicted by the "rational ideal" as the role of discourse in social science in policy making is of policy makers relying on the knowledge of experts in the field and basing decisions on the best available evidence. As has been argued throughout these chapters, this scenario is the exception in the context of controversial political issues, and some would argue the rare exception. Of particular interest here, however, is an understanding of the extent to which this actually occurred in the history of New York City NE. As has been stated previously, a hypothesis of this study is that although the science-policy relationship model driving this research is one critical of mainstream models (reflecting the assumptions of the rational ideal), this does not mean all instances of the use of social science in policy making are non-rational. In fact, there were important examples of the rationality of the traditional model. This section reviews key examples of the role of researchers *directly* involved in the policy making process, which although not numerous, are nevertheless important.

The most common form of researchers' involvement in policy matters were the connections between the research and policy making communities. One of the most consistent observations by those interviewed was the

richness of the networks and how "everyone knew everyone." This connection was discussed by Drucker, who recounts having lunch with Nick Rango, the first director of the New York State AIDS Institute, directly under the leadership of Health Commissioner David Axelrod, and Yolanda Serrano, the president of ADAPT. Drucker (personal interview, April 15, 2003) recalled:

> They were allies... people in the AIDS institute of the state were always allies with the activists, and with all of us [referring to the public health research community as well]. We fed them information, we sought support from them. The AIDS institute was set up by activists."

Speaking of Steve Joseph, he said:

> I was connected to all these individuals professionally, as part of the progressive public health leadership group, so I had access to Joseph at this period, and I was presenting evidence to him all the time from overseas, and bringing people in.

From most accounts, the connection between researchers and health officials played a key role. One of the researchers with the greatest involvement with policy matters was Don Des Jarlais, who met with both David Sencer and Stephen Joseph on a regular basis, and advised them on crucial issues with regards to AIDS policy. After visiting the Amsterdam syringe exchange in the mid 1980s, he noted:

> I had gone to the Amsterdam syringe exchange and I had discussed it with Sencer and then with Joseph, and I worked with Joseph on the original pilot project. And I used to meet with Sencer monthly on AIDS issues.

When asked whether it was his role that led to Sencer's decision to propose making needles accessible to IDUs, he responded, "Yes, well, mine and other people. Within the small group of public health people working on it, there was consensus that something should be done."

The research community also worked to influence policy when Mayor Dinkins closed the pilot program. Don Des Jarlais and others meet with the new Health Commissioner, Woodrow Myers, who was strongly opposed to NE, to try to change his position. This was not successful, and when he left office, replaced by Margaret Hamburg as the acting Health Commissioner, key researchers mobilized to seize an opportunity for change. Eventually, researchers and empirical data did seem to play a role in Dinkins' new policy on needle exchange. As discussed in a previous section, the investigators of the New Haven Study were asked to come to New York to present their findings, which they did. Another critical point here is the report compiled by Margaret Hamburg outlining the state of the research on NE. It's significant that Dinkins, who was said to have been prompted by the New Haven Study, asked for the report to be compiled.

On the face of it, these events do appear to lend support to the mainstream model of knowledge use in policy making, where the route to policy change is through empirical data. However, one crucial point

should be addressed: the fact is that there were various other activities occurring at the same time leading to the same conclusion (the needle exchange trials and the acquittal of activist, the Lower East Side AIDS Strategy Group receiving funding from AMFAR to support NE, a new health commissioner, and the growing AIDS epidemic). Thus, it is not possible to know which of these factors were important and which were not. However, Edward Kaplan (E. Kaplan, personal communication, September 14, 2003) made a very compelling point regarding the role of the New Haven Study:

> Now, Peg Hamburg told me that the Dinkins administration was inclined towards reinstating needle exchange anyway, based on their own read of available data and the situation in New York at that time. Some (and I think this includes Peg) have interpreted this to mean that our study was not really that determinant because Dinkins had already decided upon what he wanted to do, but I think such reasoning misses a vital point: suppose that with exactly the same methodology, our results had come out reversed -- in other words, suppose that based upon syringe tracking and testing and our mathematical model, the results showed no benefits from needle exchange. Publication of such a result coming out of Yale would have made it extremely difficult if not impossible for Mayor Dinkins to reinstate needle exchange in New York, don't you think? Imagine a page one story in the New York Times that, instead of stating "Yale Study Reports Clean Needle Project Reduces AIDS Cases" (and this is word-for-word the headline on the page one story that appeared), said "Yale Study Reports Clean Needle Project Has No Effect on AIDS Cases."

Social Science Involved in Direct Services

Despite two important examples, there was much less evidence of researchers' involvement in direct social service. The two examples of this are the role of researchers in ADAPT and in the illegal needle exchange.

Both have been discussed in detail previously.. Involvement in the illegal exchange, as mentioned, was direct activism and protest. However, the illegal exchange spearheaded by ACT UP was as much an act of protest as an act of filling a service gap, and researchers did play an important role in this regard. ADAPT, while a social service agency, was an organization with a board comprised of a diverse group of individuals including members of the social science community who were very much involved in the way the organization worked toward social change. For example, Sam Friedman, who was also at NDRI at the time, and an expert on AIDS and on the behavior patterns of injection drug users, was crucial for ADAPT's work. His expertise on reaching and organizing IDUs with a focus on prevention measures was clearly critical to ADAPT's outreach efforts. It is likely that there are other examples of this type within this history that were not captured in this case study. However, because it is not the focus of this study, there was very little probing for this type of data, and the examples that did appear were unexpected, yet, nevertheless important to include here.

III. Interconnectedness of Activist, Social Science, and Policy Maker Networks

One of the most important themes or patterns to emerge from this case history is not the unique roles of social science and research, but how

much they looked alike and how much their work overlapped, a critical point depicted in Diagram 1. The last two sections have addressed many of the examples of this interconnectedness. However, because of its relevance, it should be discussed further. What the different lines of data strongly suggest is that one ingredient for the success of the movement seems to have been the political capital resulting from the collaboration between researchers, activists, and sympathetic government staff. As one activist recounted:

> From the beginning, there was this networking going on, it was always going on. I just don't see these hard and fast [categories], this person is a researcher, this person's an activist. It's more complicated than this. So Bruce and Joyce [researchers from NDRI] were out on the street with us, not as researchers, but as activists (R. Elovich, personal interview, April 28, 2003).

For activists, these connections proved to be an enormous resource. For example, ACT UP's connections to, not only researchers, but leading experts in the public health field who had important ties to government, was a crucial resource:

> What was powerful was that Don Des Jarlais was in the same room with us [ACT UP], knowing exactly what we were doing and that we were doing something illegal, and that he was on the President's AIDS Commission....When we needed an affidavit, he wrote it. He testified on our behalf. He wrote letters when we asked him to (R. Elovich, personal interview, April 28, 2003).

When ACT UP and other activists were arrested, several of the most prominent researchers testified on their behalf. Interestingly, Stephen

Joseph also testified on their behalf, even though ACT UP had basically done everything they could to run him out of office, because of other issues related to AIDS on which they clashed. NDRI is another example of these types of interconnections. While being well connected to research and policy at the Federal level, and in many ways being at the center of these networks, NDRI also had key connections to ADAPT, a group that deserves a good portion of the credit for NE in New York City. ADAPT's association with NDRI, and therefore its association with the legitimacy and objectivity of social science, likely played a role in its strong connections to city government. At the same time, Friedman did what he could, given his institutional role, to support NDRI staff who were involved in the underground exchange with ACT UP. There was also the important (informal) relationship between ACT UP members and public health researchers at Montefiore Medical Center/Albert Einstein College of Medicine. Finally, the yearly international conferences on AIDS where activists, health officials and researchers collaborated, strategized, and exchanged ideas played an important function in linking these different networks together. As was noted earlier, the international character of AIDS was quite significant, and led to ACT UP opening chapters in different countries.

The following is a summary of the different examples of interconnections discussed throughout this chapter:

- Researchers from NDRI engaged in and supported the underground exchange
- Researchers from NDRI were on the board of ADAPT and were heavily involved with the organization's mission and approach
- Researchers from Montefiore supported ACT UP'S underground exchange
- Researchers collaborated with ACT UP when they applied for funding from AMFAR, then conducted the evaluation component of the program
- Researchers lobbied government officials to get the pilot program approved
- Researchers and activists met at the yearly international conferences, strategized about gaining acceptance from communities and officials in cities around the country
- Researchers visited exchanges around the world to return with valuable information
- Researchers brought representatives form exchanges in other countries to New York to meet with health officials
- Researchers strategically compiled data that played a major role in the acquittal of activists arrested for distributing needles.
- Researchers from NDRI collaborated with the activists running exchanges in other cities, such as Tacoma and Portland

As one researcher interviewed described it, "it's clear that there are synergies" (R. Heimer, personal interview, September 11, 2003)). He described the roles of activism and research the following way:

> There is the necessary but not sufficient argument. The activists needed ammunition. We had ammunition. Without the activists pushing our data, it wouldn't have had much of an effect. It would have sat there in the American Journal of Medicine, the New England Journal of Medicine, or the American Journal of Public Health.

IV. Pathways of Policy Change: Knowledge and Direct Action

The previous section examined in detail the multiple roles of both social science and activism, focusing on the different ways in which they worked to support the movement to make clean needles and syringes accessible to IDUs. This section addresses the question of how these actions were related to the positions of policy makers. In doing so, it takes more of a macro or systemic perspective, examining how social policy regarding NE was related to: 1) the level and intensity of activism; and 2) the degree of scientific consensus. In other words, to what extent was there a correlation between the policy positions of key government officials and the amount of empirical support for NE, and to what extent did policy positions coincide with the level of activism? Did support for needle exchange increase as the body of scientific data supporting needle exchange increased, and did it increase in response to the actions of activists?

To address these questions, a final set of analyses was conducted utilizing archival data, with the objective of tracking: 1) the number of studies in support of needle exchange by year; 2) the level and intensity of activism

by year, as measured by the number of newspaper articles on ADAPT and ACT UP, and 3) the level of support for needle exchange among a small number of key government officials. By examining the patterns of support and opposition for NE across time, juxtaposed with the amount of empirical support and activism, it is possible to compare patterns and make inferences about the degree to which they may be related. This analysis, by itself, cannot support any causal conclusions (e.g., this study led to that policy). However, patterns can nevertheless be informative. At the most basic level, it would be helpful to know, for example, if support among policy makers increased as the empirical support for NE increased, or if support coincided with peak levels of activism. This layer of data also complements the more in-depth qualitative data comprising the bulk of this study.

Chart One illustrates the number of key articles supporting NE from 1985 to 1991. A thorough review of the literature yielded what is likely to be a large percentage of the key studies. Two types of studies were included here. One type was studies that collected data on the practice of NE. This excluded many published papers on NE that discussed its policy implications and in some cases contained other forms of data, such as data on patterns of HIV/AIDS or on risk factors for HIV, but did not actually include data on NE per se. Major reports released either by government or

by a major research or scientific institution (such as the National Academy of Sciences) comprised the only published reports included in the analysis that did not necessarily include data on NE. This was the second class of studies. While it is likely that the studies included here represent a large percentage of the total number of actual studies demonstrating the positive impact of NE, there were likely some studies that could not be located. Therefore, the sample included here is an underestimate or a conservative estimate of the actual studies supporting NE. Furthermore the chart does not include abstracts from conference presentations, because of both logistical reasons (many of the conference abstracts discuss data from the same needle exchange program, so it was difficult to determine the number of actual studies) and theoretical reasons (data presented at conferences is less likely to be influential to policy makers, since it is typically preliminary in nature).

Chart 2 illustrates the number of articles published in the New York Times, the New York Post and Newsday (the three principal New York City newspapers) on either ACT UP or ADAPT, by year (from 1985 to 1992). To be included in the analysis, the article had to make more than just a passing reference to these organizations and had to have at least a paragraph focusing on them. While this measure clearly has its limitations in terms of understanding the actual level and intensity of activism, it seems

reasonable to assume that the amount of coverage from the print media would reflect the importance of events. Given the controversy of NE in New York City, the chance that the print media would have covered these events seems quite likely. Nevertheless, this measure is also an underestimate of the level and intensity of activism, particularly since much of the illegal exchange was underground.

Chart 3 summarizes the degree of support for needle exchange, by year, for the four principal government officials at the city and state level: the Mayor, Governor, city Commissioner of Health, and state Commissioner of Health. Support for NE was marked with 1, opposition with -1, and neutrality with 0. The score for each year represents the sum of the four scores of the four officials. For example, in 1985, everyone was opposed to NE with the exception of the Health Commissioner at the time, David Sencer, so support was scored as -2 (-1, + -1 + -1 + 1). There are some limitations to this measure as well. The most serious one is that it is difficult to rank the degree of support or opposition, and a three-point scale certainly does not capture the actual range of positions on the issue. However, to some degree, it does capture the public stance that government officials were willing to take on the issue. As an elected official, indicating you were neutral on NE was very different from indicating you were for it, the latter being associated with a much greater degree of political liability.

Therefore, it is argued here that although it may not be a refined measure, it does capture the degree of publicly stated support and opposition over time.

Correspondence between the Empirical Support and Support for NE

Comparing the trajectories of the number of studies supporting NE (Chart 1) and the amount of support among decision makers (Chart 3) from 1985 to 1992, demonstrates that if it were not for the years 1990 and 91 in Chart 1, there would have been a strong correlation between the two. In other words, the amount of support increases each year, and so does the amount of support with the exception of 1990 and 1991. However, this is not a trivial exception; it's a major exception, especially when one considers that by 1990, there was strong consensus that NE was effective. Another important point is one that has been made previously: that there was very little empirical support for NE until a few years after the movement to implement it began in 1985, when there were actually no data available. Therefore, the first finding to highlight is the fact that at a time when there was virtually no research demonstrating the efficacy of NE, two commissioners of health and eventually the Mayor (who reversed his earlier opposition to NE in 1986) were willing to provide their support for the program. In contrast, however, in 1990, when there was an ample amount of data, support for NE declined. Thus, at one level, there appears to be, at

best, a modest correlation between the amount of empirical support and political support for NE.

On the other hand, two other points in Chart 3 should be highlighted which do suggest a correlation between these two variables. First, in the period between 1985 and 1986 (in Chart 3), there was an increase in support among policy makers. Both Axelrod and Cuomo moderated their resistance to NE, based on the National Academy of Science report which was released that year. Then, in the period between 1991 and 1992, there was an increase in support coinciding with the release of critical studies--most importantly, the New Haven Data and the "Twin Epidemics" reports. Thus, in some important ways, there was evidence of a relationship between the empirical data and political support for NE, and the qualitative data supports this interpretation. However, this relationship was inconsistent, represented by the decline in support in the years 1990 and 1991, when that pilot program was closed down and there was no legal needle exchange in the city. An examination of the level of activism provides another layer of data that, to some degree, better parallels the pattern of support for NE.

Correspondence Between the Level of Activism and Support for NE

In contrast with the modest relationship that empirical support for NE had with political support, the level and intensity of activism, as measured by the number of newspaper articles, strongly paralleled the amount of support among policy makers. In comparing Charts 2 and 3, it's apparent that every increase in political support coincides with an increase in activism (from 1985 to 1986; from 1987 to 1988; and from 1990 to 1991). Furthermore, the qualitative data explains two of these co-occurrences. Between 1987 and 1988 there was an increase in political support, which resulted from Commissioner Axelrod and Governor Cuomo softening their resistance to NE (therefore, their score in the analysis went from -1 to 0). This was the same time that Yolanda Serrano and ADAPT threatened to give out needles illegally because they were tired of waiting for the state to approve the city's pilot program, which explains the increase in the number of newspaper articles. Similarly, between 1990 and 1991 there was also an increase in both activism and political support for NE. On the activist side, this is explained by the acquittal of the ACT UP activists, and on the policy side, with the new Commissioner of Health, who supported NE, and ultimately, Mayor Dinkins, who switched his position. In sum, the increases in political support for NE coincided with the level and intensity of activism.

This analysis is not meant to be interpreted as a statistical test. The goal was simply to compare the patterns of different key variables. Therefore, the fact that there is a correlation between two variables can mean several things, one of which is that the relationship is spurious. However, when these patterns are triangulated with the qualitative data, another layer of understanding emerges. The one conclusion about the charts that seems most justified is that political support for NE seemed to be more closely related to activism than to empirical support. What cannot be determined from these data is the direction of this relationship. It could be that activism led to political changes or that political changes led to increased activism. Again, this could also be a spurious relationship. Regardless, activism tended to be more responsive to political situations than was the research community. This interpretation is also supported by the qualitative data. Many of those interviewed discussed the multiple incentives and constraints placed on researchers, some of whom were at odds with those in the needle exchange movement. Activists, however, were much less constrained to react against political decisions which they felt were unjust. This finding, therefore, adds support to one of the principal conclusions of this study, that activism is a critical role in policy matters, and that finding ways of fusing activism and research can be an important contribution to the study and practice of social change.

CHAPTER FIVE: CONCLUSION

Summary of Findings

This study speaks to one of the most significant realities faced by social scientists working toward social change, the so-called "gap between science and policy." It is useful to examine the language and terminology that has permeated this debate, which in general has reflected the assumptions of the "rational ideal." Typical phrases such as "policy-relevant research," 'bridging the gap," and "informing policy" conjure up images of experts and researchers actively shaping social policy, and governmental officials as non-partisan consumers of research findings.

Typically, the focus of these terms is on attributes of the research, of the audience (policy makers) or both. For example, the term "policy-relevant" research implies that what's important is making the research useful for policy makers, by, for example, making sure it adequately addresses the nature of the problem and provides practical solutions. Similarly, the term "bridging the gap" implies that what policy makers do and what social scientists know are not at odds with each other, but are simply separated by time and space, and that by connecting them or bringing them together, knowledge and action can merge.

An important consequence of this framing of the determinants of policy is that the notion of policy seems like something that develops in a social and political vacuum. In other words, it appears as if social policy results from the deliberations of policy makers, which may or may not include empirical evidence. However, the fact is that impact policy makers have received much less attention. The results of this study, in contrast, strongly suggest that these factors provide an understanding of the policymaking process. Although it is common for those studying these issues to acknowledge the role of social and political factors, few actually theorize them, or systematically take them into consideration in their models in any rigorous manner.

In sum, the dominant discourse regarding the role of social science in policy reflects the tenet of the rational ideal. Although many are critical of this view, the default approach to influencing policy still revolves around top-down approaches and those that discourage active political participation on the part of researchers. The default approach neglects and even ignores the critical role of activism and social movements as determinants of social policy. The result is that while models of policy research are taught, encouraged, and even supported financially (through foundations and fellowships), there is very little understanding and even less support for doing activist research. And while models for

influencing policy makers through science, such as those outlined by Don Campbell, in his now famous work, "The Experimenting Society" (Dunn & Ginsberg, 1998) are clearly central to making research matter, social change efforts need to move beyond *just* targeting decision makers. In contrast, the results of this study point to both activism and activist-oriented research as key determinants of social policy with regard to NE. The key findings regarding this conclusion are outlined below.

The Central Role of Activism and Social Movements

One of the principal findings of this study is that activism played a central role throughout the history of NE in New York City. Almost all those interviewed argued that if it were not for the level of activism, NE would never have happened. Although alternative explanations—that the science in NE would have eventually led to policy change—cannot be ruled out, there is much evidence suggesting that activism was indeed a necessary condition and a catalyst for change. When asked whether the NE movement would have been successful without the role of activists, two interviewees responded the following way:

> I don't think they would have been able to shut them down. Somehow they would have gained their legitimacy by doing their work, the way they ultimately did... I think the most important thing is simply that there was a group of people that were handing out syringes, and they were about to back down (S. Friedman, personal interview, May 10, 2003).

> It wouldn't have happened. I mean, it might have happened in 1997 and 1998, but actually, it wouldn't have, because we had Giuliani after that. So it wouldn't have happened then either. We were showing it was possible it could be done; the sky didn't fall down" (A. Clear, personal interview, June, 6 2003).
>
> Policy makers are not people whose minds changed. The fact that people decided to hand out needles in the streets, that's what changed the situation (R. Elovich, personal interview, April 28, 2003).

Another important point with regard to the role of activism, even though falling outside of the scope of this case study (i.e., New York City), is that NE around the country emerged largely from the actions of activists who created their own programs illegally (often dealing with police harassment and arrest), which eventually became legal. New York City, in this regard, is an exception, since the movement really began from health officials and the public health community. However, activists were key in initiating the movement and in maintaining it when the legally run program was shut down. Others commented on how an important aspect of the activism was simply that it was going on, whether elected officials liked or not: "he [Dinkins] could not resist it. It was going on, and there was no way cut it down. It was embarrassing" (S. Friedman, personal interview, May 10, 2003).

The Role of Empirical Data

At the same time, there is compelling evidence that empirical data also played a critical role as well. The same activist cited in the previous section

who felt that activism was a necessary condition also felt research was a necessary condition, at least in terms of the New Haven study:

> As far as I'm concerned it wasn't about the research. Well, if we didn't have the New Haven Study, we wouldn't have needle exchange. I mean it was a turning point, showing thirty-three percent reduction in HIV infection. That allowed Dinkins and Peggy Hamburg to let it happen" (A. Clear, personal interview, June, 6 2003).

There were a few important examples of the role of empirical data that emerged in this case study. For example, there is evidence to suggest that Mayor Dinkins was, at least in part, motivated by personal concerns regarding the impact of AIDS, and this concern led to a favorable reception of the New Haven Study. Furthermore, when the report from the American Academy of Science was released in 1986, it was credited with easing the opposition to NE by David Axelrod and Mario Cuomo. Finally, some of the researchers interviewed discussed how they were using data at the community level to highlight the need for NE and to demonstrate that it was not associated with the negative outcomes that its opponents had argued would occur. An example that falls outside of this time period of this case study, but is nevertheless relevant is a study that Lurie and Drucker (1997) conducted which estimated, via a mathematical model, how many lives could have been saved if NE had been implemented in cities that had not done so. They then used this model to create local estimates for various cities where needle exchange activists were trying to

gain approval from the city officials. Finally, the impact of the New Haven Study has been discussed with regard to the policy in New York City. However, this study was critical with regard to the state of needle exchange in the city of New Haven itself as well as at the state level:

> It played a huge role in the state opening up needle exchange, allowing the creation of five other legalized, state subsidized, programs. It played a huge role in the state changing its syringe possession laws and permitting pharmacies to sell without prescription (R. Heimer, personal interview, September 11, 2003)).

It has been argued here that the role of social science was a necessary condition for change. However, it's important to make clear that this was largely because of the political and ideological climate that determined how the issue was discussed and handled. In other words, data, and more importantly, the legitimacy of science, was needed to circumvent or navigate through political and ideological constraints that really had little to do with questions of pragmatism or rational problem solving. This interpretation is supported by the fact that the only way the 1988 program was able to overcome political obstacles was by couching it as an "experimental pilot" program.

The use of science as a means of dealing with political barriers was an observation voiced by virtually all those interviewed. For many, this was the primary role of social science. As one interviewee commented, "There's

nothing that says that research has to be done. They could have just done it" (S. Friedman, personal interview, May 10, 2003). In a less ideologically charged context, the idea of NE would have been received with much less hostility, and the grounded and vernacular knowledge of those that work with drug addicts, and most importantly, of drug addicts themselves, would have provided the knowledge necessary to justify the program to policy makers. In fact, the process of setting up needle exchanges in Europe and Australia in the early days of the movement looked much like this scenario[4]. Further support for the view that research was not necessary to justify the value of needle exchange, from a rational and pragmatic perspective, was the fact that both commissioners of health under Mayor Koch (first Sencer and then Joseph) endorsed the practice of distributing clean needles to IDUs, at the time when there were virtually no empirical data to support it. As public health experts, they both recognized, intuitively, that NE was a useful idea to pursue. It is likely that if they would have had things their way, they would have paved the way for a full-fledged program, including research evaluation, but they did not need research to tell them that NE was a good idea.

[4] Although controversy and political resistance was a factor, it was not nearly as strong as it was in the US. In many countries, needle exchange was seen as more of a public health issue rather than a political issue, so elected officials were much less involved. For example, in the Netherlands, needle exchange emerged from the Junkibond's activism which resulted in influencing health officials. Most importantly, at that time, there was virtually no data on the impact of needle exchange or on its critique that it promotes drug use.

However, the political realities were what they were, and neither researchers nor activists have the ability to instantly change these realities. Change is often slow and painful, and this was the case with needle exchange (it was painful most poignantly in fact that thousands of people needlessly contracted HIV, many of whom eventually died). The fact that science and politics were so intertwined further complicates the idea of separating politics from science. In fact, one of the most consistent themes voiced throughout the interviews, as well as from the archival data, was the tremendous resistance from many different groups with regard to needle exchange. As such, the relationship between instrumental knowledge (i.e., data) and social policy was guided, to an overwhelming extent, by ideological and political considerations. As one researcher argued,

> The principal resistance to NE is political, it's not public opposition, it's political opposition, and the higher up you go in the system, the more opposition there is. It's very typical to find that, in private, a congressman or is his aides will say, 'Well, we're really for this, but we'll get in trouble. It's politically too dangerous" (E. Drucker, personal interview, April 15, 2003).

He discussed NE in terms of the "third rail phenomenon," referring to a term used to symbolize the manner in which elected officials deal with drug policy in general, which they try to avoid as much as possible, since it's so controversial and politically dangerous. The term refers to the third rail of a subway track--the one rail of the three that has live electrical current running through it, and is therefore extremely dangerous. Therefore, one of

the most important points to keep in mind when analyzing the struggle over needle exchange in New York City is that the obstacles proponents had to overcome were, first and foremost, ideological and political, not empirical or knowledge-based obstacles (i.e., limitations in the knowledge required to understand the potential risks and benefits of NE).

For many of those familiar with the history of needle exchange, this reality may seem obvious, but many people working on the issue in the early days of the movement were quite confident that when the research adequately demonstrated that NE didn't lead to increased drug use and that it significantly reduced the transmission of HIV/AIDS, the city and state policy, and ultimately Federal policy, would change accordingly to allow the establishment and funding of needle exchange programs. As Drucker notes, "...the belief was that if you demonstrate that needle exchange wouldn't lead to more drug use, that then it would be a done deal. But of course that wasn't true." Those working on the movement in its early history believed that data would "circumvent the political process." However, the reality was that the NE debate often had little to do with "merit" or data, and everything to do with "moral arguments."

Therefore, the obstacles for advocates of needle exchange were to an overwhelming degree political, not empirical. Elected officials and many

of the key constituents (the city's prosecutors, law enforcement, much of the drug treatment community, and the black community) were opposed to NE on ideological grounds, even though their arguments were almost always (except for Woody Myers) framed factually ("our community needs more treatment, not needles") or empirically ("the research on needle exchange is not clear"). Thus, first and foremost, the needle exchange struggle in New York City was a political struggle. It was about *political positioning* (elected officials recognizing the life-saving value of needle exchange, although not willing to jeopardize their political standing because of the appearance of being "soft on drugs"), *power struggles* (Dinkins vowing to end needle exchange as a campaign promise to win over the black community), and *ideological battles* (the moral abstinence vs. pragmatic harm reduction rhetoric).

Because the nature of opposition to needle exchange had very little to do with pragmatic concerns about NE, there needed to be action that counteracted the opponents of NE. The opponents placed pressure on the elected officials not to support it; there were many examples of this. One was the letter that Sterling Johnson wrote to Koch when Sencer first proposed making needles accessible. In the letter, he pledged to do everything in his power to stop it. There needed to be a countervailing political force which also placed pressure on government, and this was the

role for which activism was best suited. Without it, it is quite plausible that NE would not have happened in 1992. As one researcher put it: "It's the stick and the carrots, both. And that's just the way it's going to be. It's the incentives and the disincentives" (E. Drucker, personal interview, April 15, 2003).

This portrayal of the policy making process, first and foremost, is guided by political and ideological concerns, and has important implications for the role of empirical data in policy struggles and its impact on the political system. At one level, the impact of empirical data can be said to be additive—there were several examples of key individuals changing their minds in response to the amount of data that supported NE. The fact that they reversed their positions implies that, at least for some decision makers, data can have an additive effect. At another level, however, the impact of data on the political process is much more idiosyncratic than additive. In other words, the impact of data is largely dependent on the social and political realities. For example, if Woodrow Myers had remained as Health Commissioner, the New Haven data would probably have been less influential.

The Central Role of Activist Research

The observation, on the part of many researchers, that the ability of data to change minds was limited, probably played a role in their activist orientation. Almost all the researchers interviewed characterized themselves as both activists and researchers. Some considered themselves as much activists as researchers. Others were researchers first, and did what they could, pushed many boundaries, and even put their careers at jeopardy to support an important enough cause. Still others looked like "objective researchers," and didn't have much involvement in activism, but nevertheless based their research on clear political objectives, and supported activists by advocating on their behalf through data and the legitimacy that science affords. Therefore, in this study, the boundary between science and activism was much too blurred to have significance. Most people, both researchers and activists alike, were as much at the margins as they were at the centers of these categories.

The overlap between the roles of science and activism, in fact, proved to be one of the greatest sources of strength for the movement. This finding is entirely consistent with the resource mobilization theory of social movements, which argues that resources play a critical role in the life and progress of a movement. In the needle exchange example, the resource

social scientists provided was legitimacy for the goals that activists were working toward and a sense of urgency of the importance of the issue.

Disconnects between Activism and Research

The previous chapter discussed several examples of important linkages between the research and activist communities, and it was argued that these linkages played an important role in the success of the movement. At the same time, however, there were also important examples of tensions and disconnects between these two communities, such as when their immediate objectives and interests were at odds with each other. Given the fact that there was an illegal syringe exchange going on (an incredible social experiment, that if it were legal, would have attracted plenty of attention from researchers) that nobody studied is very significant. So the absence of researchers willing to go in and help collect and analyze data in the underground exchange was a reality that may have limited the potential impact of activism. Elovich (personal interview, April 28, 2003) recounts the frustration some ACT UP members had with research, which was solely focused on the "if" questions, even though needle exchange was going on at the time, and the critical "how" questions were being neglected:

> These 'if' questions don't help needle exchanges. Needle exchange programs have their own set of questions about are we reaching the people we have to meet. Are there certain people we're not engaging?

Elovich discussed the example of the data he and other ACT Up members had been collecting on secondary distribution (having IDUs distribute needles to those in their networks and returning the used ones), and on the return rates of the needles that had been painted, which they felt could have provided powerful support for their work, and they were relying on someone to help them with this:

> No one made use of it. And that's the gap, because that's where you have individuals occupying this structure [meaning researchers], and they were playing the game. They were doing research that allowed them to get published, and that's what counts, getting published.

One of the issues explored in the interviews was the question of why, given the important nature of the issues ACT UP was dealing with, there were not more researchers willing to provide support. Elovich was clear about not necessarily locating the reasons for this in researchers themselves, and recognized the institutional constraints and incentives placed on them, primarily the need to be published and the need to acquire or protect funding sources, and how it was that engaging in this kind of research jeopardizes funding and perhaps even jobs. He also discussed the institutional incentives and disincentives placed by government agencies on the types of research that were funded and encouraged, and those that were discouraged and marginalized:

> What kind of research is funded by NIDA [National Institute on Drug Abuse]? My argument would be that NIDA largely funds drug war research. And this is why I won't get into talking about individual researchers; I would look at the system which is basically not allowing us to do epistemologically sound research.

Despite the fact that a core group of social scientists were working in various capacities to strengthen the NE movement, there was still a void left by a lack of research done on NE. In part this has to do, again, with the lack of needle exchange programs to research. However, this also had to do with the politicization of science, which led to a ban on certain types of research. Lurie (2003) was quite critical of how the research community responded to this:

> [Academics] were not as brave as they could have been. For example there was a ban on funding for needle exchange research for many years, and the public health community said nothing about it, and sat around and took it, and in retrospect, I think it's really quite shameful. And it can be justified by wanting to keep your research operation going, but frankly, that's not good enough as an excuse. So they were really not as strong as they should have been.

A good example of the politicization of science had to do with the Federal government's agenda setting practices and the internal politics within government research institutions:

> There was the infamous 1989 memo from Barry Brown, a senior person from NIDA [the National Institute of Drug Abuse] that told people they couldn't work with any community-based organization that was doing needle exchange even if the work they were doing with that organization was not related to needle exchange. So there was that kind of McCarthyite tactic going on. And that scared off a lot of researchers. They were watching which way the wind was

> blowing within the administration, watching your back kind of thing. And they were disappointing to us, because they were people with public health backgrounds who should have been following the data, but they weren't.

Another example comes from Stephen Jones (personal interview, October 12, 2003), who was at the CDC while the needle exchange movement was occurring in New York City:

> The CDC was made up of liberal public health advocates. The only thing was that you had this political problem: There was a strong conservative power within the Congress, and if the CDC was seen as being pro-needle exchange, it meant trouble. It meant you would be attacked, that senators and representatives would go after you. They had to be very careful about how they were perceived. There was a time when the three politically red hot issues for the CDC were guns, sex (in terms of condoms and abortion), and needles. You had to be extremely careful about how things were said and how they were presented. And for all the statements that science mattered, it was politics

Others felt that while the research did play an important role, the research community could have done more to strengthen and contribute to the movement:

> I do think the research [the needle exchange movement] gave them legitimacy. It gave them the kind of legitimacy that they need to argue in the world of bean counting rationalists who have to prove things on paper that something works. So it did help out their argument. They needed eventually to have that empirical evidence, not just the testimonials of a bunch of do-gooders. Yes, I do think it was useful. It's too bad there were not more of them earlier (Curtis, 2003).

> But by and large, the researchers didn't do as much as they could until much later, and then by the time that they were emboldened, the science was kind of irrelevant (P. Lurie, personal interview, September 12, 2003).

However, while the institutional incentives and constraints placed on researchers are powerful, there was an extensive level of diversity in how researchers resisted and acted against them. Many in the public health community were in fact slow to warm up to the idea of providing needles to injection drug users, and many more were unwilling to take on the issue politically, as evidenced by there being little reaction to the ban on research that investigated NE by the public health community. This still does not negate the important contributions made by those willing to push the margins of what was acceptable. However, there were still critical gaps between the worlds of research and activism which should be discussed.

Perhaps, in part, because of these gaps between the worlds of research and activists, there was a certain degree of tension expressed as a basic lack of trust that some activists had of the research community. This may also be explained by a basic lack of familiarity between these two groups. One activist noted:

> We didn't want this thing [referring to the research component that the state required of the new needle exchange] imposed on us, and we wanted to have input. I did actually propose that people should wear a sign around their necks that said, "I am a researcher." So I think we were very afraid of being misled by these researchers. In fact, one of the needle exchanges, the Bronx-Harlem exchange, refused to have the research component added to their project (A. Clear, personal interview, June, 6 2003).

Despite this tension, Clear felt that the researchers did ultimately gain the trust of the activists, and this was likely to due to their being committed to the cause:

> They did become a real force within the exchange. Not to denigrate us or me, but we were completely unsophisticated. We were unsophisticated, but we were intelligent. Clear noted, that ultimately, it was a "good partnership, and certainly the relations we built among all of us led to the success of the whole thing."

The heterogeneity of the research community should be mentioned. It was clear from the case study that many researchers were deeply committed and passionate about the issue, and very much identified with the human costs associated with the government's negligent and naïve stance on NE. At one extreme, there were researchers who became activists, and others who engaged and worked with activists directly, doing everything they could, even pushing the limits of their institutional constraints. There were other researchers who were important to the movement, but acted from a traditional science stance, producing data, testifying on behalf of the defendants, etc., but would not engage in anything that resembled activism.

At the other extreme, there were researchers who were probably driven mostly by funding concerns, which reflects the critique of activists who argued that researchers weren't willing to study the questions that the activists really could benefit from: "researchers were trying to bring money

into their research agencies. They weren't really ready to do pro-bono research" (R. Elovich, personal interview, April 28, 2003). As another researcher familiar with the politics of academia (as was the case with all the researchers interviewed), stated:

> I mean who are researchers but people with PhDs and MDs who need to get grants to put their kids through private school (E. Drucker, personal interview, April 15, 2003).

Because of these perceptions on the part of activists, many were skeptical of researchers because activists thought researchers were exploiting the issue to support their research agendas, for publishing and funding purposes. Their critique was that "that they are too slow," and that "we'll study it, instead of doing something about it." Activists were screaming out (often literally) that the problems impacting their communities demanded immediate attention, not research. This frustration was fueled by the realization on the part of activists, as well as on the part of many researchers, that needle exchange was effective, and that it wouldn't lead to increased drug use. Some interviewees even argued that the research "took the steam out of the activism," speaking specifically about the 1988 pilot program, because it gave the appearance the city was doing something about the issue. This view—that research can often be an obstacle to change—was voiced by many of the interviewees, regardless of whether they were researchers, activists, or government officials. One comment is particularly insightful:

> A classic technique of decompressing an issue is the study commission. By giving a research grant, you take all the potential troublemakers out of the picture and put them on the payroll. And also you commit them to a three year program of research, and 'we can't really do anything until the study is finished and we have the results'. That's all the politicians think about...Congress is two years at a time [meaning that calling for research is a strategy of not dealing with politically contentious issues, with the hope that the issue fades from the agenda]. The time-frame is so different" (E. Drucker, personal interview, April 15, 2003).

Generalizability: What Policy Domains Does his Research Speak To?

This research has aimed to provide a better understanding of how social science can best be used to promote progressive social change. Therefore, one of the tasks of this study is an attempt to extract the findings that are generalizable to other policy domains, and to identify the particulars of this case study which make it unique. As discussed in Chapter One, because the term 'policy' has various meanings, it is important to make clear which types of policy scenarios this research speaks to. In contrast to the case of needle exchange, there are certainly many examples where empirical evidence has informed policies in a practical and rational manner, and there are many examples where activism and activist research were not involved nor required for social change. However, when the policy issue at hand is ideologically charged and controversial, such as when the findings of social science clash with the beliefs and interests of policy makers and their constituents, then the

conditions for the non-use and misuse of research are set in motion. It is under these conditions that findings of this research speak most closely to.

As I have argued here, needle exchange was an ideal scenario for which to study the intersection of social science, activism, and policy because it represents the clash between a powerful ideological system and a discourse being pushed to counter it. This scenario is not unique to the political struggle over needle exchange; it is characteristic of many, if not most, of society's pressing policy issues. However, before reviewing some examples of this, it is necessary to highlight the dynamics specific to NE that make it unique and which should be taken into account when generalizing the findings of this study to other policy settings.

AIDS Exceptionalism and the Particulars of the Case of Needle Exchange

The characteristic that would make the NE example most unique has to do with the issue of AIDS and the enormous impact it had on people, policies, and institutions, a reality exemplified by the term "AIDS exceptionalism." This term highlights the fact that few diseases have ever changed the face of public health and of politics as has AIDS. It led to specialized Federal funding sources (Ryan White funds), national and state level commissions and policy entities, and to an enormous research industry. The human toll of AIDS is clearly a crucial part of this story, and because of this, so is race,

since minority communities have been impacted the most. As Heimer (2003) notes:

> "I think the burden of AIDS had grown so much that people were willing to do things, even bureaucrats were willing to do politically unpopular things because they felt the overwhelming need to do something.

Some important implications of the AIDS epidemic, therefore, should be brought to light. One of these is the notion that AIDS presented such an enormous social problem that the politics surrounding it may be unique. It has been argued here that policy positions are a reflection of two basic considerations—an assessment of the ratio of potential risks and benefits of supporting a particular policy, and beliefs about the actual value of a policy. The fact that the social consequences of AIDS were so enormous may have changed the relative contributions of both of these considerations. In other words, some policy makers may have been more willing to take on a controversial and therefore risky position on AIDS issues, such as NE, because of its impact. There is some evidence to suggest that this is what indeed happened, at least to some degree. During the 1986 conference sponsored by the New York State Health Department and Milbank Quarterly Fund, James Curran, the Director of the AIDS Program at the National Centers for Disease Control, gave his support for NE, saying "I would not discount anything in trying to combat this disease... the problem we face is bigger than politics" (Warwick Anderson, p. 1508). However,

there is also evidence that for many, the AIDS issue wasn't bigger than politics. In fact, AIDS had the effect of severely politicizing public health. Many of the interviewees discussed how they knew several policy makers that, in private, believed NE was a good idea and necessary, but would not publicly provide their support for it. Therefore, while important, the impact of AIDS on the decision of policy makers should not be overstated.

Another implication of AIDS exceptionalism is the level of political organization it had created among both the research and activist communities. Because NE was such as a politicized issue, by all sides and all parties involved, the level and energy of activism is by itself a factor quite different from most other policy issues. This is because NE represents the convergence of two of the later part of the twentieth century's most pressing social issues: AIDS and illicit drug use. The needle exchange movement itself benefited greatly from the AIDS movement, which was extremely vocal, radical and, at times, disruptive, but which was also quite strategic.

The drug policy movement, in particular, the harm reduction movement, is made up of a highly rich network of activists and researchers (and activist researchers) in many highly prestigious, well-funded, and well-connected institutions. This is particularly the case in New York City, the epicenter of

both AIDS and drug addiction. New York City is the home to some of the most important organizations dedicated to drug policy (e. g., the Open Society Institute, NDRI, the Drug Policy Alliance). The point is that needle exchange policy entailed a level of organized resistance to governmental policies difficult to match in other issues. This intense level of organization may, however, reflect both an advantage and a disadvantage. Clearly, the more organized a movement is, and the more resources it has and the greater its potential to promote change, which is the central premise of the resource mobilization theory of social movements (McCarthy & Zald, 1973; Gamson, 1968; Tilly, 1978). On the other hand, the more organized a movement is, the more it threatens governmental interests and ideological positions; therefore, the greater the mobilization of opponents and the backlash from government. This is the reason why some (E. Drucker, personal interview, April 15, 2003) have argued that social change was, in terms of NE, easier at the local level, where opponents were less organized (P. Lurie, personal interview, September 12, 2003) than it was and still is at the national level, where political barriers have been too great to overcome.

Generalizable Findings

Although the particulars of NE as a policy issue are important to understand in terms of an example of social change, the similarities this

issue has to other political struggles over social policy are greater than the differences. In many ways, the case of NE is very similar to many historical examples of political change, which are typically fraught with conflict and controversy. History teaches us that power is tenacious and the status quo is intransigent. While it's quite easy to think of examples where progressive change required intense levels of activism, protest, social disruption, and a genuine social movement (e.g., civil rights, gay-rights, the feminist movement, welfare rights, workers' rights and labor unions), it's much more difficult to think of examples where empirical data was the driving force behind political change.

Even if one examines one of the best, or at least most well-known, examples of the use of social science in policy, the Brown vs. Board of Education case, it occurred during one of the strongest social movements in the history of the United States, the civil rights movement. However, this is rarely mentioned in published articles on psychology regarding the history of the Brown vs. the Board of Ed case. Historical examples such as this, as well as the findings of this study, do not dismiss the importance of policy makers as a key audience for research. The point is that policy makers should not be the only audience, and that for many social policy issues, the catalysts for change is activism and social movements. In other words, there needs to be a much greater appreciation and understanding for

how the social context must change in order for policy to change. When, for example, is public opinion a necessary condition for change? Many advocacy groups target public opinion as a strategy for changing policy, but there are several examples of social policies that exist despite being unpopular by a majority of the electorate, such as the Rockefeller drug laws in New York State[5].

This study demonstrated how community groups and local grass-roots efforts can play a critical role in the social policies of city government. Groups such as this (community-based organizations, non-profits, and service providers) are often at the center of many policy struggles, typically have key connections to government, and poses grounded knowledge about the complexities of the populations they work with and the policies that affect them, a point supported by research. Freudenberg, Lee, and Silver (1989) found that the community groups that had previous experience with issues related to AIDS prevention, such as drug use and sex, were the one's most likely to be involved in local advocacy and activism. Because of this, the authors argue that groups with this type of grounded knowledge are a valuable resource for government officials in charge of or planning public health programs and policies. They, therefore,

[5] A 1999 Zogby International poll found that 69% of New Yorkers favored greater discretion over sentencing as opposed to state-mandated laws, such as the Rockefeller laws.

represent an ideal audience to engage in socially meaningful and politically important work

Recommendations and Future Research

A concern driving this research has been the basic lack of models available for doing activist research, for collaborating effectively with activists, or for understanding how empirical data can support progressive social change. It is hoped that the findings of this study, at the very least, help to promote a dialogue about these issues within the social science community. I argue that the discourse, methods, and theory of activist research needs to be brought into the mainstream of social scientific training and practice. In order to contribute to this goal, I propose a model of activist policy research. This model would provide a framework for linking the worlds of policy research and political activism, inform researchers about the ways in which they can collaborate with multiple audiences and consumers of research, and would provide a framework for understanding the necessary conditions for social change and ways in which the discourse of science can help to meet these conditions.

The findings of this study, along with the framework provided by the different bodies of literature reviewed in chapter one, provide a starting point for the development of this framework. Below, I summarize the

different ways in which empirical data helped to promote political change in the case of NE in New York City. Many on the list are related to others on the list, but they are considered distinct enough to discuss separately. Furthermore, this is not an exhaustive list of the types of impacts that scientific evidence and discourse have, but rather the types of impacts that were captured in this case study.

- Gives voice and legitimacy to marginalized positions and counter discourses: The single greatest obstacle that opponents of NE faced was the set of discourses, stigmas, and ideologies about drug use, and about drug users themselves. The needle exchange movement, in essence was attempting to chip away at the hegemony of the abstinence ideology, and provide legitimacy for a harm reduction approach. One of the most consistent observations about the role of scientific data was that it provided legitimacy to an otherwise marginalized group and discourse. Legitimacy was the word that many used to describe the advantage of having research supporting one's position, playing a role not only in terms of policy, but also at the community level, where the practice of NE was actually occurring.

- Provides political cover: Related to the notion of legitimacy is the finding that research provided "political cover" for policy makers supporting or wanting to support NE, from ideological attacks from political opponents. It was common to find policy makers sympathetic to NE, but unwilling to endorse it publicly. However, for those caught in this situation, the release of credible studies supporting NE made it "safe" for them to endorse the issue, and even actively lobby for it. The more studies there were, the more officials there were publicly supporting it.

- Challenges social myths: One of the ways in which scientific data provided legitimacy was by directly challenging social myths and stigmas. It did this, for example, by challenging beliefs about drug users. One of these myths was that injection drug users would not take the necessary precautions to reduce the risk of contracting HIV. The other was that NE would lead to increased drug use. To a large extent, the legitimacy of NE was dependent on the debunking both of these beliefs, which is what happened.

- Increases the perceived importance and visibility of a problem: Another way in which the welfare of IDUs was given voice was by demonstrating the magnitude of the problem of HIV/AIDS. In this

sense, prevalence data played a key role. There were several examples of policy makers that cited data on the prevalence of HIV/AIDS as the reason, or one of the reasons, for why they felt NE was a necessary policy, including some who initially opposed it, such as David Axelrod, the New York State Health Commissioner, and Mayor David Dinkins.

- Reframes how issues are discussed: As a result of these different types of impact—prevalence data showing the magnitude of the AIDS epidemic, a movement legitimized through the discourse of science, and a strong challenge to social myths about drug users—the debate about NE shifted from a discourse of abstinence to a discourse of harm reduction. In other words, in the early years of this history, the debate about needle exchange was dominated by concerns about increased drug use. As advocates loudly complained, opponents of NE were more concerned about people staying of drugs then they were about them dying of AIDS. This discourse, however, was ultimately overshadowed by the discourse of HIV prevention, which slowly made its way into policy circles, and eventually into policy itself.

- Mobilizes support: Data played an important role in mobilizing advocacy efforts, both within and outside of government. This was seen within the public health community as early as the mid 1980s. The more data there was in support of NE, the stronger the public health community mobilized. This was also true inside of government, where some individuals played a key role in connecting government to local community based organizations. Furthermore, the inaction on the part of policy makers, in the face of the growing evidence, was a mobilizing force in itself. However, it should be noted that along with mobilizing support for NE, it also mobilized opposition. The more evidence there was for NE, the more opponents of the program felt they had to discredit this evidence.

- Increases accountability for opposition to or inaction on a policy issue: Another impact of scientific data was to make policy makers more concerned about the backlash of not doing enough to prevent AIDS. Governor Cuomo was torn about whether to support NE, but in the end, stated that the problem of AIDS was just too great. While he may have actually felt this way, there was also the political reality that if hadn't given his support for NE, it could have hurt him politically. Therefore, data had the effect of making the governor

take a stand on the issue (which he had not taken), a stand, which was pro-needle exchange.

- Changes attitudes and policy positions: One type of impact that needs to be highlighted is the impact of data on attitudes and beliefs. This is the impact most people think of when they consider the ways in which science influences policy. However, within this case study, the extent to which this happened can only be speculated on. This is because it can not be known whether a change in policy position was the result of an 'honest to goodness conversion" (P. Lurie, personal interview, September 12, 2003) or a change in political strategy. However, some felt that this type of change in attitude did occur, such as the case with Margaret Hamburg's belief that Mayor Dinkins did, at least in part, change his mind on the value of NE and on its potential harms.

- Provides knowledge about the nature of problem and proposed interventions: Finally, scientific data was crucial in informing the practice of NE, its effectiveness, the conditions under which it works best, and its limitations and possible unintended consequences. This data played a crucial role in improving service delivery and increasing the size of the population served.

Note that the impact of the data occurs at multiple levels and among multiple audiences (on policy makers, activists and advocates, the scientific community, and on public opinion and social discourses). Impact also occurs through various means: by changing attitudes and beliefs, by impacting the risks and benefits of supporting or not supporting a particular issue (regardless of how one actually feels about it) and by overcoming the stigma that may prevent those who actually support a policy from doing so publicly. In other words, the impacts of scientific evidence are attitudinal, political, ideological, and cultural.

A final point to address has to do with an issue raised in chapter one regarding the accumulation of scientific evidence, and whether there is evidence of a "tipping point" or "threshold" theory of the impact of data. In other words, is the impact of research additive (i.e., threshold model) or is it idiosyncratic (dependent on political events)? Although there is some evidence that data did have an additive effect (policy makers moderating or reversing their opposition after key studies are released), it was ultimately idiosyncratic. It wasn't necessarily the number of studies that had an impact, but the characteristics of the studies, the researchers, the sponsoring institutions, and, most importantly, political circumstances. There were several studies showing that needle exchange was effective and was not associated with the negative outcomes its critics had

proposed. However, the ones that gained the most attention were those attached to major institutions, such as the National Academy of Sciences and Yale University. However, if the impact of data were truly additive, Mayor Dinkins would not have closed NE when he came into office, since there was a considerable amount of data supporting the policy and none criticizing it; his decision to do so was based on political concerns, not empirical ones. Furthermore, almost everyone interviewed agreed that if wasn't for the actions of activists, NE probably would have never been legally sanctioned, much less funded by the state of New York. In sum, there is evidence that data had additive effects, but these effects weren't enough, by themselves, to create policy change. Change was dependent on political circumstances. However, the fact the impact of data is, to a significant degree, dependant on political conditions suggests that researchers and social change agents (activist, advocates, policy makers) need a better understanding of the political requirements for social change. What is clear from this case study is that data is not a sufficient condition for change. Therefore, conducting more studies and producing more data will often not lead to change, and in fact, may slow down the pace of change, since "studying" the problem can take the place of actually doing something about it.

In the spirit of Kurt Lewin (1997), and his famous dictum, "nothing is as practical as a good theory," the model I propose here should be based on theory built on sound empirical data. At the same time, and in the spirit of progressive activist social researchers, such as Ignacio Martin-Baro and Paulo Friere, the model should also be tied to a praxis of change. A model of activist policy research builds on the call of many community psychologist (e.g., Rappaport, 1977; Sarason, 1981; Seidman, 1988) to develop a science of social change. In light of this, a first step in developing this model and furthering our understanding of and appreciation for social change can begin with academia. For graduate programs that have an explicit social justice emphasis, there needs to be courses that teach students how to merge there activist agendas with the methods of sounds science. There needs to be a much stronger appreciation for the political context under which research is produced, used, and misused, and for the multiple pathways for utilizing research (top-down vs. bottom up methods, working 'inside' vs. 'outside' the system), audiences to target, and voices to write in. There also needs to be an understanding of the conditions under which different research approaches are likely to have the greatest impact and when they are likely to be of marginal impact. In sum, graduate school training should include the politics of science and knowledge use as well as its methods

and theories. In order to develop a viable model of activist policy research, future research should address the following questions:

- What are the ways in which researchers can actually support the work of activists, besides just studying them? What types of data would activists benefit from and how can the skills (methods) and resources (connections to policy networks) of researchers be utilized to support social movements?

- How can researchers address the competing demands of securing funding and satisfying institutional requirement (e.g., publishing) while engaging in activist research that is often at odds with these incentives and may challenge the ideologies and agendas of funding sources?

- What are the circumstances when producing more research actually impedes the social change processes? When these circumstances are present, what role can the social science community play to best support social movements? In other words, there must be a better understanding of when conducting more research is an effective use of resources and when it is ineffective or even counter-productive.

- How can research explicitly tailored for social change projects achieve the dual goals of doing "good science" on the one hand, and on the other, doing politically useful research? There needs to be a stronger discourse that challenges the dominant narrative of "objective" science, and the belief that "good" science and advocacy are at odds with each other.

Table 1: Research Questions
History of Policy Issue
1) Problem Definitions: When did the problem become defined as a problem and by whom?
2) Interests: What are the different sides of the issue or the different "interests" involved? In other words, who is the target of the policy and who are the stakeholders, who stands to benefit from the proposed policy and who stands to lose from it?
3) Dominant Discourse(s): What is the dominant discourse, how dominant is it, and what are they dynamics of power both driving and resulting from these discourses
Social Science
4) Social Science Evidence: What solutions did the research support? How strong or conclusive was the research, in terms of the conventional criteria of reliability, validity, and robustness (i.e., effect size). Furthermore, how consensual were the findings?
5) Narrative Fit: To what extent does the science around the policy issue fall outside of the dominant discourse?
Opportunities, Barriers and Pathways of Political Change
6) Overall Impact: At what points during the life of the policy issue, from the time it is first framed as a problem until the present, did social science impact the political landscape and course of the issue?
7) Research Utilization Strategies: What research utilization strategies have the various interest groups utilized to further their political and social agenda, and how successful have these strategies been?
8) Typology of Impacts: What are the different types of impacts social science had on the policy making context (e.g., impacting attitudes and beliefs, mobilizing support and action, influencing the coalitions among policy makers)?
9) Impact Pathways: What were the processes or pathways through which impact occurred?
10) Working Within the System: Taking into account the inherent ideological disconnect between federally-funded studies on NE and the dominant discourse, what were the political dynamics involved in producing these research studies and in forming recommendations

Table 2: Interview Participants
Allan Clear—ACT UP; Co-Director of the Lower East Side Needle Exchange Program
Richard Curtis—National Development and Research Institute (NDRI); Activist involved in and organizing the underground needle exchange
Don Des Jarlais— Coordinator of AIDS research at the New York State Division of Substance Abuse; Member of the Presidential Commission on AIDS
Ernie Drucker— Professor of Epidemiology and Social Medicine, Director of the Drug Abuse Treatment Program, and Head of the Division of Community Health at Montefiore Medical Center/Albert Einstein College of Medicine
Richard Elovich—ACT UP, Defendant in the New York City needle exchange Trial; Chair of the Substance Abuse Work Group of the Ryan White Council; Director of HIV Prevention, Gay Men's Health Crisis
Sam Friedman—National Development and Research Institute; Member of ADAPT
Margaret Hamburg—New York City Commissioner of Health under Mayor David Dinkins
Robert Heimer—Yale University; Co-principal investigator of the evaluation of the New Haven needle exchange program.
Stephen Joseph—New York City Commissioner of Health under Mayor Edward Koch.
Steve Jones—Center for Disease Control, U.S. Federal Government
Edward Kaplan—Yale University; Co-principal investigator of the evaluation of the New Haven needle exchange program.
Peter Lurie—University of California, San Francisco—Principal investigator of the landmark 1993 study funded by the Centers for Disease Control
Bob Newman—President/CEO of Beth Israel Medical Center; Leading methadone researcher and advocate.

Timeline of Needle Exchange Policy in New York City

1981

- **Research: Epidemiologist began tracking AIDS.** At the time, 80% of all AIDS cases were among homosexual males, and 20% were among IDUs (51).

1984

- **International Context: First government-sponsored NE opens in Amsterdam.** Activists and government health officials collaborate in response to a Hepatitis epidemic among IDUs.

1985

- **Research: Study shows IDUs attempting to minimize risk of AIDS infection by using more clean needles.**

- **Research**: Study shows the rate of HIV infection among IDUs increased by 500% between 1978 and 1984.

- **Social Context: AIDS still thought of as a disease of gay men.** Despite the startling figures on the spread of AIDS among injection drug users, AIDS is still largely thought of as a disease of gay men.

October

- **Policy: Discussions about a NE begins in New York City in 1985:** The acting Health Commissioner under Mayor Ed Koch, David Sencer, proposes a plan to ease the restrictions on the sales of hypodermic needles as a means of curbing the spread of AIDS among IDUs, which is rejected by the Mayor.

1986

- **City Policy: New city Health Commissioner proposes first U.S. needle exchange, which Mayor Koch endorses, reversing his early opposition to the policy:**

November

- **Research: National Academy of Science Report is released**: Report criticizes government response to the AIDS epidemic and points to the possibility of a medical catastrophe if the disease is not halted, and recommends government-sponsored needle exchange.

- **State Policy: After two years of opposition to NE, State Commissioner of Health, David Axelrod, is prompted by a report from the National Academy of Sciences to reconsiders NE.**

- **National Context: First person to distribute drug injecting equipment publicly in New Haven and Boston is arrested.** Jon Parker, founder of the AIDS Brigade, a radical activist group, is arrested.

1987

- **Research: "The Great Epidemiological Shift: IDUs account for the greatest percentage of AIDS-related cases for the first time.**

- **Research: World Health Organization releases report:** "AIDS among Drug Users."

May

- **State Policy: State health officials reject the city's proposal for a NE program.** They argue the study did not have enough participants to allow for scientifically valid results.

December

- **City Policy: City submits another proposal to the state:** Although the proposal increased its sample size, state officials responded with skepticism.

1988

- **National Context: The first U.S., non-government-funded NE to provide comprehensive services was established in Tacoma, WA**

- **Research: Presidential Commission on AIDS recommends consideration of needle exchange programs**

January

- **<u>Activism</u>: In defiance of state laws, activists announce plans to distribute clean needles.** Fed up with bureaucratic stalling, ADAPT announces plans to distribute clean needles in order to move the issue forward.

- **Governor and State Health Commissioner change their position and decide to support the city's proposal.** Three weeks after ADAPT's protest, both Axelrod and the Governor, Mario Cuomo, switched their positions and decided to support the city's effort to distribute clean needles.

November 11

- **Experimental Needle Exchange Opens in New York City: First in the Nation.** Despite fierce political opposition from the city's most powerful groups, and after three years of negotiation, Mayor Edward Koch opens the first government-sponsored experimental NE in a Large city

- **Bill introduced in state senate to legalize sales of needles and syringes**: The state assembly's Health Committee Chairman, Assemb. Richard Gottfried (D-Manhattan), introduced a bill to legalize over-the –counter sales of syringes.

1989

<u>Federal Level</u>: Congress bans distribution of drug injecting paraphernalia

- **<u>Politics</u>: During Mayoral campaign, Dinkins, along with all other candidates, vows to close the NE.**

1990

- **<u>Policy</u>: Dinkins wins the Democratic primary and shuts down the pilot program.**

March

- **<u>Activism</u>: ACT UP's Needle Exchange Committee is formed & Illegal needle exchanges are set up.** It was "dedicated to decriminalizing needle possession, safer injection education and drug treatment on demand."

- **AMFAR releases RFP, to which the Lower East Side Coalition, in collaboration with ACT UP, applies**

- **Arrest of 10 needle exchange workers from ACT UP and the AIDS Brigade**

1991

- **February, 1991: NE Defendants are acquitted.** Judge agrees that the "Necessity Defense" applies to their case. The judge rules that the activists' actions are justified by the need to try to save the lives of people vulnerable to HIV infection.

- **Preliminary data from the New Haven Study is released**

- **Dinkins reexamines NE.** He asks a group of city commissioners, headed by the Health Commissioner, Margaret Hamburg, to look into it. She later endorses NE in a report.

- **State approves the program and provides funding.** The program to be set up would be run by the city's Minority Task Force on AIDS, and two NE that were until that point, operating illegally, the Bronx Harlem NE, and the Lower East Side NE. The program was funded by AMFAR and the New York State Department of Health (who funded most of the program)

Post-Script

1992

- Congress passes legislation prohibiting the use of federal funds to support needle exchanges until the surgeon general could certify that they did not encourage drug use and were effective in reducing the spread of HIV.

1997

- By this year several U.S. government-sponsored reports had certified the two criteria set up by the congressional legislations

February

- the Secretary of Health and Human Services reported to Congress that a review of scientific studies indicated that NE "can be an effective component of a comprehensive strategy to prevent HIV and other blood borne infectious diseases in communities that

choose to include them (Department of Health and Human Services, 1998, p.1).

1998

- On April 20th, 1998. the Administration announced that it would not lift the ban on the federal funding of NE
- Congress changed the criteria law, continuing to ban federal funding for NE, regardless of whether the criteria are met or not.

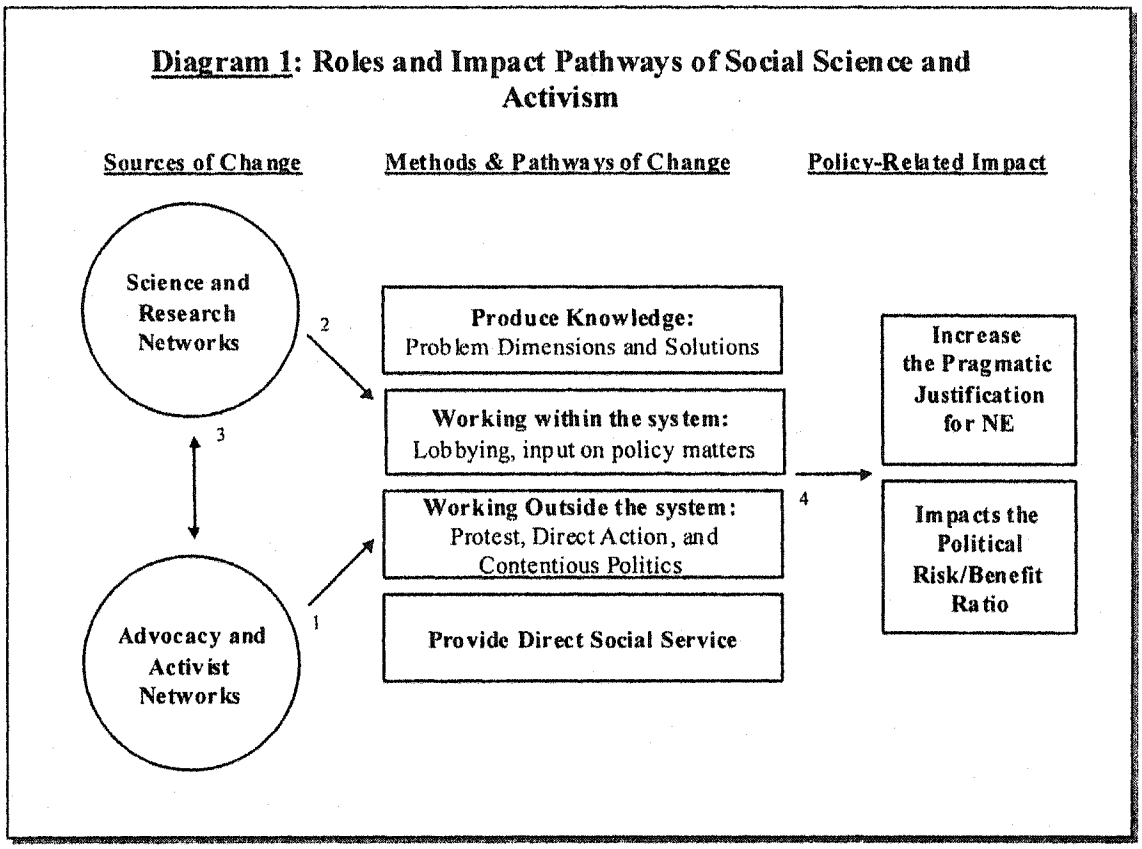
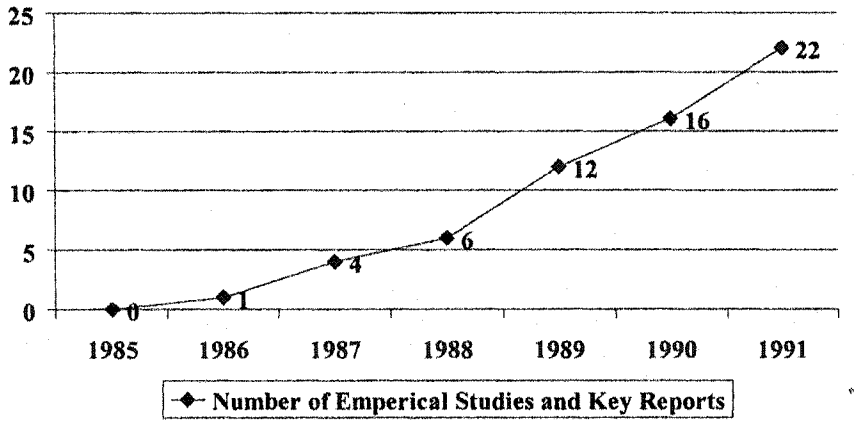
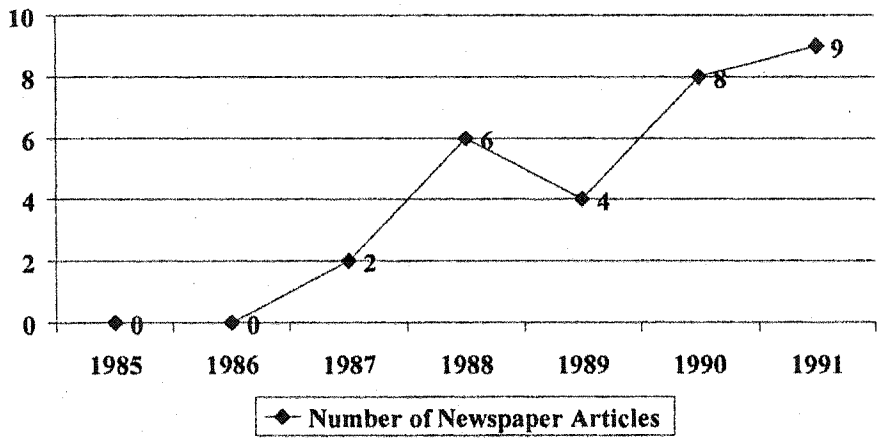


Chart 1: Key Studies Supporting Needle Exchange: 1985 - 1991



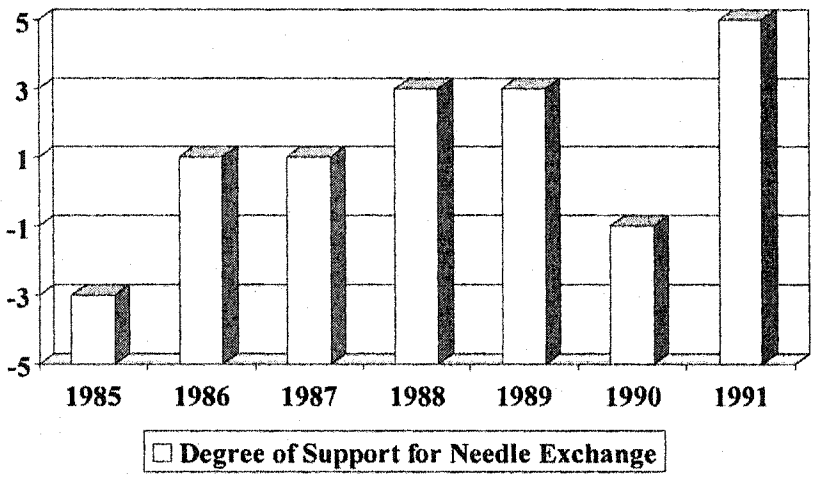
1986: 1) National Academy of Science
1987: 1) World Health Organization; 2) Waters; 3) Stimson et al.
1988: 1) Battjes & Pickens; 2) Tsa, et al.
1989: 1) Hart et al. 2) Hartgers et al. 3) Ingold et al. 4) Joseph; 5) Van de Hoek et al.; 6) Donoghoe et al.
1990: 1) Bardsley et al. 2) Christensson et al.; 3) Carvel, et al.; 4) Donoghoe et al.
1991 1) Buning; 2) Guydish et al. 3) Ljungberg; 4) National Commission on AIDS, 5) O'Keefe et al., 6) Nelson, et al. 7) Stimson et al.

Chart 2: Number of Newspaper Articles Mentioning ACT UP or ADAPT: 1985-1991



1987: 1) Bodovitz; 2) Sullivan,
1988: 1) Daley; 2) Lambert (a); 3) Lambert (b); 4) Lambert (c); 5) Marriot 1988; 6) Morgan,
1989: 1) DeParle; 2) Kolata; 3) Marriott; 4) Smith
1990: 1) Kolata; 2) Lambert (a); 3) Lambert (c); 4) Lambert (d); 5) Lambert (e); 6) Purdom (a); 7) Purdom (b)
1991: 1) Adams; 2) Editorial (a); 3) Editorial (b); 4) Navarro (a); 5) Navarro (c); 6) Navarro (d); 7) Nieves; 8) Sullivan; 9) Treaster,

Chart 3: Support for NE Among Four Key City and State Officials (1985 -1991)



Note: Scores were calcuated by summing the level of support for NE from each of the four principle government offials at the city and state level, where:-1 = Oppose; 0 = Neutral; 1 = Support. The range of support is from -5 to 5.

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