Responsibility and HIV/AIDS: A Sociological
Investigation

by

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DEDICATION

The inspiration for thesis comes from my father's announcement twelve years ago that he had AIDS. He died six years later. This thesis is my testimony to the painful but healing processes through which my father travelled and the continuation of that journey among his family and friends.

Respondemus, etsi mutabimur[1]

We respond, although we are changed.

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[1] This has been adapted from the work of Eugen Rosenstock-Huessy, as elaborated in (1969) 'Farewell to Descartes' Pp. 1-19 in *I Am an Impure Thinker* Norwich, Vermont: Argo Books.

Declaration

I declare that the material contained in this thesis is my own original work and has not been submitted for a degree at any other university. None of this work had been previously published. Excerpts from Chapter Four have since appeared in an article published in *Health* (2001) Vol. 6, No. 2. The title of the article was 'Messages of responsibility: HIV/AIDS prevention materials in England' and arose from research conducted for this thesis. The published article differs substantially from Chapter Four of this thesis.

Abstract

This thesis offers an analysis of how conceptions of responsibility have affected social responses to HIV/AIDS. The central premise of this work is that *how* responsibility for the disease is presumed has a determining impact upon policy and individual reactions to the epidemic. This in turn influence the spread of the disease. This thesis also addresses how AIDS and its associated meanings provides and necessitates new ways of understanding social relations of responsibility. I begin with a theoretical exploration of dominant perspectives on responsibility through the development of two analytical categories: *responsibility as freedom* and *responsibility as control*. The first of these represents those approaches to responsibility that regard it as the condition that makes individual freedom possible. The second views all notions of responsibility as an inherently restrictive means of individual self-disciplining which only serves to protect the status-quo. In the successive case studies on health promotion materials, HIV testing policy and the criminalisation of HIV transmission, I develop a detailed analysis of the embeddedness of individual responsibility as promoted by the *responsibility as freedom* model, and of the accompanying critiques of those individualised approaches that some from the *responsibility as control* model. I then explore and alternative form of apprehending responsibility that transcends this abrupt dichotomy between freedom and control. Using the example of the 13th International AIDS Conference at Durban, I elaborate an *intersubjective* model of *responsibility*. In this framework, I propose an understanding of responsibility founded on social relations and the interconnectedness of social actors. This position also acknowledges the political struggles inevitably involved in attempts to bring about change, struggles which involve individuals, civil society, organisations and states.

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ARVs	Anti-retrovirals
BMA	British Medical Association
BTS	Break The Silence
CBOs	Community Based Organisations
CDC	Centres for Disease Control (United States)
GMFA	Gay Men Fighting AIDS
GP	General Practitioner
GU	Genito-Urinary (or sexual health) clinic
HAArt	Highly Active Anti-Retroviral Therapy
HEA	Health Education Authority
HBM	Health Belief Model
HIV	Human Immune Deficiency Virus
IDUs	Intravenous Drug Users
MCT	Mother to Child Transmission
NGOs	Non Governmental Organisations
PHLS	Public Health Laboratories Service
TAC	Treatment Action Campaign
THT	Terrence Higgins Trust
TRIPs	Trade Related aspects of Intellectual Property
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session
VCT	Voluntary counselling and testing
WHO	World Health Organisation

CHAPTER ONE: THE RELATIONSHIP BETWEEN HIV/AIDS AND RESPONSIBILITY – AN INTRODUCTION

1.0 INTRODUCTION

This thesis offers an analysis of how conceptions of responsibility have affected social responses to HIV/AIDS. The central premise of this work is that *how* responsibility for the disease is presumed has a determining impact upon policy and individual reactions to the epidemic which in turn influence the increases and decreases in its spread. This thesis also allows us to think about how AIDS and its associated meanings have provided us with new ways of understanding social relations of responsibility. AIDS is not simply a medical or epidemiological phenomenon, it is also a social one and it has had a profound impact upon social experiences and understandings of the contemporary age. This is not only because of the staggering human suffering and loss that has been caused by the virus – some forty million current infections and twenty million deaths (UNAIDS 2002) – but also because it intersects with three themes important to contemporary identity: *health, sexuality* and *responsibility.* As the epidemic traverses these central cultural concepts, HIV/AIDS has prompted an interrogation of some of our most basic public institutions.

> Never before, even in the time of the great European plagues, has a
> health problem catalyzed such a broad rethinking of the health of
> individuals and society, and therefore also of our social and political
> systems. (Mann 1990: S247)

There has already been a significant amount of work carried out on the ways in which the HIV/AIDS epidemic impacts a variety of cultural constructions (Altman 2001a; Epstein 1996; World Health Organisation 1991). Such analyses explore how structural approaches to sexuality, health and marginalised groups have themselves been altered due to the epidemic itself. There has also been sociological investigation into how such constructions have been utilised to blame already stigmatised groups for the spread of the epidemic and how this has impacted upon prevention and treatment efforts (Bajos 1997; Bloor 1995; Brandt 1988; Musheno 1995).

Despite this research, perhaps the most crucial cultural construction within the discourse of HIV/AIDS – that of responsibility – remains relatively unexplored.

There has been some amount of research conducted on responsibility from within the disciplines of philosophy and social theory (Gillligan 1993; Honneth 1995; Levinas 1989; MacIntyre 1985; Taylor 1989; Wolfe 1989; Etzioni 1993) but often their applicability beyond the dusty realm of theory appears to be limited. Similarly, those accounts on the impact of HIV/AIDS mentioned above show little evidence of understanding how different theoretical understandings of responsibility will differently impact responses to the epidemic.

This thesis seeks to go beyond this divide. Not only is this important in order to understand the processes which combine responsibility, blame and stigma in their outcomes, but it also provides an opportunity to see how HIV/AIDS allows for a rejuvenation of theoretical approaches to responsibility. However, before moving on to an explanation of how this will be approached, I will first explain briefly how the transmission and spread of HIV/AIDS has come to take on meanings that are so laden with responsibility.

1.1 WHAT IS HIV/AIDS?[1]

In 1981, relatively rare conditions including Kaposi's Sarcoma and Pneumocycstis carinii pneumonia (PCP) were being identified primarily among sexually active gay men, haemophiliacs and intravenous drug users in North America and Western Europe[2]. These patients usually had a short period of acute morbidity followed by death. In the earliest years of the epidemic, the most visible response to the new phenomenon was mobilised among gay communities in urban centres (particularly in San Francisco and New York). This mobilisation began with efforts to relay as much information as possible about the new illness to gay men and was soon accompanied by a political movement that demanded action from governments and public health authorities who appeared to demonstrate a lack of discernible concern about the illness. The illness was given the title Acquired Immune Deficiency Syndrome

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[1] The term HIV/AIDS will generally be used in this thesis to denote the epidemic. Exclusive use of the acronym AIDS is not appropriate because it has the potential to diminish the fact that AIDS describes a cluster of diseases that are caused when HIV suppresses the body's natural immune response.

[2] It was also gradually recognised that the epidemic was killing people in Central Africa (particularly in Zaire) however because of different presenting illnesses, difficulties with centralised reporting and a bias toward the funding of research in high-income countries, it would be many years before the true scope of the pandemic in developing countries would be recognised both domestically and internationally.

(AIDS) and by 1984 the Human Immune Deficiency Virus (HIV) that caused it had been identified. A person infected with HIV could live months or years without any external symptoms of serious illness. However, in that time the virus would seriously diminish the CD4 cells in the blood that operate to co-ordinate the immune functions of the body. Consequently, the HIV positive person would be left with a severely depressed immune system leaving him or her vulnerable to a range of serious and ultimately fatal illnesses that someone with a fully functioning immune system would generally be able to resist. The term AIDS, therefore, was used to describe a range of characteristic infectious and cancerous diseases that would ultimately affect those living with HIV[3].

The virus was found to be transmitted when the bodily fluids such as the semen and blood of an infected (HIV positive) person are exchanged with another person. The most likely circumstances under which the process of sero-conversion (becoming infected with HIV) takes place are those where the bodily fluid of the infected individual has direct access to the bloodstream of the uninfected individual. Thus some practices involving the direct exchange of bodily fluids have a higher likelihood of transmission than others[4].

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[3] Since the discovery of HIV in 1984, international efforts to develop treatments have had positive results. While the first anti-retroviral (AZT) to be used demonstrated limited effectiveness accompanied by high rates of toxicity, new ranges of treatments, including protease inhibitors and their successors, have had much higher rates of success for large numbers of patients. However, these treatments also can have highly problematic side effects and it is not currently known how long such treatments will suppress reproduction of the virus within the individual. Additional advances include: specific treatments for opportunistic infections such as the development of aerosolised pentamidine which is now used successfully to treat PCP in its early stages; and post-exposure prophylaxis whereby a person who believes they may have been exposed to the virus undertakes a short course of anti-retroviral therapy with the aim that replication of the HIV virus inside the body will be halted before it has a chance to proliferate. As a result of all these advances, it is medically possible to substantially improve the immune system and treat the illnesses of many people living with HIV/AIDS so that they can live fulfilling and active lives. For this reason the rates of AIDS related deaths in the developed world have declined significantly in recent years.

[4] These include 'unprotected' (without condoms) anal and/or vaginal sex with an HIV positive partner; injecting drugs with a needle already used by someone with HIV; and the use of transfused blood and pooled blood products that have been donated by someone with HIV. In terms of the prevention of sexual transmission of HIV, the use of barrier methods (the female condom or lubricated male condom) during penetrative sex, or the adoption of sexual practices other than genital or genital-anal penetration have proven to be highly effective. In some countries, the establishment of needle exchange programmes have helped drug users to gain access to clean needles and ensures that their old equipment is not used by others or discarded in places where people may be exposed to an unintentional needle-stick injury. HIV can also be passed from infected mothers to their children through birth. The exact biological processes of this form of transmission has been the subject of scientific contestation. However, it has been demonstrated that the rates of mother to child transmission in these instances can be significantly reduced through specific practices including ante-retroviral treatment and delivering the child by caesarean section.

The epidemic recently passed its twentieth year. Despite the fact that a significant amount has been learned about HIV, its spread, and the broader effects of AIDS in that time, many millions of adults and children are currently living with HIV/AIDS. While some may still associate AIDS most readily with gay men and haemophiliacs, it is currently the case that about seventy-one percent of the infections world-wide are located in Sub-Saharan Africa among adults and children who were predominantly infected through heterosexual transmission and birth. Fewer than four percent of people now living with the disease live in high-income countries (UNAIDS 2002). While a significant proportion of these latter infections were transmitted through unprotected anal intercourse between men, current trends demonstrate that equal and sometimes higher numbers of new infections in high-income countries are occurring among men and women who have unprotected penetrative vaginal intercourse (European Centre for the Epidemiological Monitoring of AIDS 2002).

1.2 THE CONNECTION BETWEEN HIV/AIDS AND RESPONSIBILITY

The last quarter of the twentieth century witnessed an almost complete dismantling of the welfare state in the Western world as a result of global economic restructuring. Such events, combined with the blossoming of neo-liberal regimes throughout the developed world, gave rise to an emphasis upon the notion that the individual should be primarily responsible for his or her own well-being. Such an understanding became dominant across a wide range of social areas. Therefore we should view it as no coincidence that these changing ideologies should also coincide with the spread of a fatal disease which was significantly attributed to sexual behaviour. In keeping with the times, when HIV/AIDS first appeared among gay men, injecting drug users and sex workers, the popular response was to regard those who were infected as personally responsible due to their own 'immoral' practices (Shilts 1987). The disease's moral overtones were easily married with the neo-Conservative ideologies of the 1980s (Berridge 1996; Watney 1989) and AIDS became a symbol of the new era of individual responsibility.

This transformation of political and popular opinion was reinforced by popular press representations which differentiated between 'guilty' and 'innocent' 'AIDS

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victims'[5]. Activities such as injecting drug use, sex work and promiscuous sexuality (particularly homosexuality) were regarded as immoral activities by the many members of society. These activities now carried the risk of fatal illness with them and in the popular imagination previous moral associations were soon converted into causative reasoning. Thus the virus itself became confirmation of immoral behaviour. Such representations led to the conclusion that it was irresponsible people who engaged in such activities and incurable disease was the result of their irresponsibility. Among the most influential adherents to this approach were members of Reverend Jerry Falwell's Moral Majority in the US. In 1983, the executive vice-president of the group said: 'What I see is a commitment to spend our tax dollars on research to allow these diseased homosexuals to go back to their perverted practices without any standards of accountability' (Shilts 1987: 322).

As will be outlined in Chapter Three, many commentators have argued that this reactionary conservatism, which underlined the majority of the policy initiatives at the time[6], stigmatised the disease and exacerbated the spread of the epidemic because many people who privately feared that they had been at risk did everything possible to distance themselves from outward suspicion. As a result they were effectively blocked from receiving support and information that may have enabled HIV prevention. In brief, the social, political and scientific environment that dominated during the emergence of HIV/AIDS was not one that was conducive to disease prevention because the prevailing attitude among the establishment was that HIV positive people had brought the disease upon themselves.

The most vocal response to this kind of approach first emerged from urban gay communities. Rather than understanding the spread of the epidemic as a result of individuals' immoral and irresponsible behaviour, they argued that the disease had spread as a result of the stigmatisation of sexuality by conservatives and by the government inaction stemming from such attitudes. The ensuing years of HIV/AIDS have witnessed a mushrooming of community based organisations (CBOs) and

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[5] The innocent usually included HIV positive children and women, whereas those portrayed as guilty were often bisexual men with a 'hidden lifestyle' or promiscuous gay and heterosexual men.
[6] The influence of Moral Majority on White House decisions regarding AIDS was significant. It was the Moral Majority rather the Department of Health that was called in to consult on legislation to ban homosexual men from donating blood (Shilts 1987: 370).

community responses have had a significant impact on the development of the cultural images and meanings that are now closely associated with AIDS[7].

The above description of how HIV/AIDS has been related to responsibility and the ensuing rejection of such representations forms the basis of most academic explorations on this topic. While such approaches have made important contributions to the field, and provide valid and necessary critiques of generalised public responses that have resulted in the stigmatisation which permeates the epidemic, there are two reasons why I do not think academic investigation of the issue should stop there.

Firstly, there is much more analysis that remains to be conducted on the *specific* means through which the individualisation of responsibility for the epidemic has taken place. Too much of the critical academic work on AIDS in this regard has been on its representation in the media, and particularly the press (Colby and Cook 1991; deJongh 1986; Lupton 1999c; Watney 1989). To gain a fuller understanding of the role of responsibility in the epidemic requires an interrogation of the policies, practices and images that are put into effect by social institutions that govern both official and unofficial responses to the epidemic. Some of these factors have of course been the subject of academic analysis (Beardsell 1994; Brown 2000; Davies *et al.* 1993; Keogh 2001; Kinsman 1996; Moran 1997). However, most of these studies treat their topic in isolation rather than seeing the many different individualisations of responsibility as part of the same process. Thus we have studies of health promotion materials, or of policy documents that emphasise the role of individual responsibility yet they do not relate those developments to other similar trends in the AIDS sphere. One of the aims of this thesis is to provide examples of how the same process of the individualisation of responsibility occurs across many different realms in AIDS discourse and practice. This is achieved in Chapters Five, Six and Seven where I analyse the individualisation of responsibility with regard to health promotion material, testing policy and the criminalisation of HIV transmission.

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[7] For example, Stephen Epstein's *Impure Science*, 1996, provides an excellent exploration of the way that the previously closed scientific fraternity eventually had no option but to accept and utilise the expertise of self-taught treatment activists.

Secondly, in order to conduct such investigations, it is necessary to dismantle the traditional theoretical conceptualisations of responsibility that underlie such practices. From the start of the epidemic, responsibility has been a heavily contested topic. However, accounts that try to apportion blame for the epidemic do not problematise the notion of responsibility as it is currently understood. This necessitates the undertaking of a broader theoretical project that aims to ascertain the different ways in which responsibility itself is conceptualised, and this is accomplished in Chapter Two of this thesis.

1.3 THEORETICAL APPROACHES TO RESPONSIBILITY AND THEIR APPLICATION TO HIV/AIDS IN THIS THESIS

The idea of responsibility generally conjures up some sort of understanding of accountability; being called into question for behaviours that have somehow harmed the self or others. It establishes a tension between social participants and the demands of belonging to wider society, as it relates to the requirement that we must think outside of our own immediate needs. In Chapter Two I undertake a review of traditional theoretical approaches to responsibility, arguing that they can be broadly classified into two dominant approaches. First I discuss the position which I call *responsibility as freedom*. This involves those theorists who argue that individuals are required to act responsibly in order to ensure the social order that in turn will ultimately provide them with the conditions for freedom. This position covers such theories as liberal individualism, communitarianism and some versions of risk theory. The second position is one that I refer to as *responsibility as control*. This position, stemming mostly from a Foucauldian perspective, functions as a reaction to *responsibility as freedom*, and argues that responsibility is merely a technique of governance through processes of individual self-surveillance.

While I acknowledge that such classifications cover a wide variety of perspectives, I believe that they assist us in developing a clearer understanding of responsibility, by acknowledging that these two positions create an impasse. This occurs because they create a polarised image of the individual as either unfettered free agent or as dominated subject. In place of this dichotomy, I will argue in favour of a notion of *intersubjective responsibility*. Such a notion, as I outline it, is founded in the idea

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that responsibility is inherently relational – it is a socially negotiated concept that involves relations between individuals and between institutions. This approach places politics at its centre and seeks to develop an understanding of responsibility that rests within the networks of interdependence that exist across social strata and various organisational levels. This model of responsibility envisages social relations wherein actions are undertaken with the knowledge that how people, corporations and states conduct their own affairs will impact upon the existence of others. It is a model that I outline at the end of Chapter Two, and one that I also think, at various times, has begun to emerge within the response to AIDS and I outline these in Chapter Eight when I discuss the events at the 13th International AIDS conference in 2000 at Durban in South Africa.

Contemporary society has as its basis the neo-liberal ideology that has individual responsibility at its core. Through an analysis of the symbolic meanings of responsibility that have been attached to HIV/AIDS we are able to better understand the means through which this ideological shift has been supported. However, the ongoing spread of the epidemic is also a crisis, and one that cannot be solved by a further individualisation of responsibility. If we are to progress in preventing a further escalation of this crisis, individuals and institutions need to take more account of the intersubjective nature of responsibility.

1.4 THESIS STRUCTURE

In Chapter Two I will focus upon outlining the traditions of theorising responsibility that I have just mentioned – *responsibility as freedom* and *responsibility as control*, before proposing a conception of intersubjective responsibility as a viable alternative. Following this, there are four chapters that illustrate how the dichotomy transpires in different areas of discourse and practice. Firstly, in Chapter Three, I outline how responsibility has been discussed in the literature regarding health generally and AIDS more specifically. Then, in successive chapters, I provide three case studies of the individualisation of responsibility within AIDS practice. The areas analysed are health promotion (Chapter Five), testing policy (Chapter Six) and the criminalisation of HIV transmission (Chapter Seven). Chapter Eight discusses the history of International AIDS Conferences before concentrating on the 13th Conference at Durban in more detail. I argue that it was at this conference that earlier stirrings of

intersubjective responsibility that had been present in the AIDS world became crystallised and an effective effort against the epidemic seemed a realistic possibility. However, such optimism was partially faded by events following on from the Durban conference, and in the final chapter I discuss some of those developments and discuss the ramifications of these both for my notion of intersubjective responsibility and for progress against the epidemic.

CHAPTER TWO: RESPONSIBILITY AS A THEORETICAL CONCEPT

2.0 INTRODUCTION

In contemporary western society notions of responsibility underpin other central concepts such as citizenship, rights and community. How each of us interprets the notion of responsibility will influence how we interact with others and how we perceive ourselves within a social context. In order for the discipline to gain better insight into how people interact and respond in various social settings, it is imperative that sociologists undertake a fuller engagement with the topic of responsibility than in the past. In the introduction, I have outlined how this thesis is an exploration of various operationalisations of responsibility in responses to HIV/AIDS. It is thus a contribution towards that larger project whereby some social theorists and sociologists have gradually begun to grapple with notions of responsibility themselves. This chapter will explore aspects of that theoretical terrain before constructing an alternative to two dominant approaches within the area.

In this chapter I will review the work of some of the more recognisable figures in the field rather than providing a comprehensive overview. Using two paradigmatic representations of thought on responsibility - *responsibility as freedom* and *responsibility as control* - I will explore central aspects of academic debate on the topic. While some thinkers can be easily categorised as belonging to one side of the debate or the other, this is not the case for all. These two categories do not cover all of the available views, but they do form the basis of the struggle that has characterised modern understandings of responsibility. At the end of the chapter, I will discuss the limitations of operating within this dichotomy and suggest that it is necessary to incorporate social and political processes in any complete understanding of responsibility.

The central theme uniting those I have included in the *responsibility as freedom* category is that increased levels of responsibility and public duty will result in greater social and individual freedom supported by strengthened communities. Included within this category (but not constitutive of it) is a group of theorists who mourn a generalised loss of social responsibility and point to this as the reason for

modern crises in meaning and community-building[1]. I have characterised the second body of thought to be discussed as *responsibility as control*. From this perspective, the central argument is that responsibility is used in modern society to regulate individuals. Such theorists feel that far from promoting freedom, liberal operationalisations of responsibility are used as a means of maintaining boundaries which separate those types of behaviours and individuals that are acceptable and those that are not. The initial sections of this chapter will trace the development of these two strands of thought on responsibility through the works of contemporary social theorists, philosophers and cultural commentators. In the final section I will present an alternative, *intersubjective responsibility* which shifts the focus beyond the individual and looks to the struggles involved in interdependence.

2.1 RESPONSIBILITY AS FREEDOM

I shall begin the exploration of this position with a discussion of the intertwined notions of responsibility and rights. The reason to begin here is because these are the two features that are seen to maintain freedom. Mainstream interpretations of rights regard them as a means of social compensation for citizens who abide by a basic code of responsibility toward others. In this view, rights are a form of social currency received in exchange for individual responsibility. If we function in ways that do not harm others, then we are repaid with the protection of the state. In turn, it is within this protected and ordered social sphere that freedom is possible. Without social order of this type, it is argued that chaos reigns and opportunities for individual freedoms are unavailable (Hobbes 1985). In this way, the partnership of responsibility and rights are seen to lead to the establishment and maintenance of freedom through social order. After exploring the recent history of this partnership, this section will move on to look at socialisation as the means of reproducing a responsible citizenry. The *responsibility as freedom* position places a great deal of importance on the proper functioning of socialisation in order to ensure the reproduction of social stability through the bargain between rights and responsibility. Following recent social changes, a group of social theorists and cultural commentators have raised concerns about the failure of the contemporary socialisation process. This section will close with an exploration of these concerns,

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[1] See Beck 1992; Etzioni 1993; Jonas 1984; and Lasch 1979.

and the ways in which a more rigorous personal responsibility is put forward as the antidote to the perceived crisis.

2.1.1 Responsibility and rights

Much of the *responsibility as freedom* paradigm is derived from social contract theory, whereby individuals offer up responsible social engagement in exchange for the benefits bestowed on them by the state – most notably, individual rights. 'The social compact sets up among the citizens an equality of such a kind, that they all bind themselves to observe the same conditions and should therefore all enjoy the same rights' (Rousseau 1973: 206). As Cole summarised two centuries later in his introduction to Rousseau's *Social Contract*: 'there exists in every citizen who is a party to the Social Contract a recognition of his obligation so to act as to further the good of the society into which he has entered' (Cole 1973: xlv). Therefore, according to this approach, individual citizens expect to have their rights respected in exchange for personal resolve to keep the best interests of society at the centre of their actions. Respect for the other is balanced with a degree of tolerance and freedom so that all may prosper. Rousseau's notion of the social contract positioned the individual as the central social unit and solidified the notion of the free citizen protected by individual rights.

In the following century, individual rights and freedoms would become elevated to the point where Mill's *On Liberty* (1956) exclaimed that liberty was not to be limited unless it reached the point where the rights of others were being infringed. 'The only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others' (Mill 1956: 15). He went on to state that 'genius [could] only breathe freely in an atmosphere of freedom' (Mill 1956: 79). Thus, according to Mill, the structure of rights and responsibilities should operate in the distance in order to create a safe space for individual creativity to flourish. While he resisted the formal principles of a social contract, Mill did accept that those receiving the protection of society were in turn obliged to not injure the interests of other social members and to contribute to the overall productivity of the collective (Mill 1956: 80).

> It would be a great misunderstanding of this doctrine to suppose that it is one of selfish indifference which pretends that human beings have no business with each other's conduct in life, and that they should not

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concern themselves about the well-doing or well-being of one another, unless their own interest is involved. Instead of any diminution, there is need of a great increase of disinterested exertion to promote the good of others. (Mill 1956: 92)

Beginning with Rousseau's interpretation of the social contract, and heavily influenced by the individual liberties espoused by Mill – the modern West has thus inherited a philosophy of liberal democracy that depends upon the appropriate balance between individual rights and individual responsibilities enveloped within the gaze of the benevolent state. Thus 'it is only when the conception of the individual has been reached that the idea of responsibility begins, and with it both morality and the endeavour to obtain a personal salvation' (Sayce 1892: 305). These ideas have dominated the Western political horizon for the past two centuries[2].

Contemporary strains of moral philosophy attempt to codify moral obligation, and are thus the inheritors of this liberal legacy. Such work is largely constituted by a discussion about when an individual should rightly be held accountable for their action/inaction. A good deal of the literature in this area revolves around what are called Frankfurt-type cases to help determine whether or not an actor has alternative possibilities and free will, thus having the option to behave differently[3]. Some philosophers propose that a person should only be held responsible for an action when they regard themselves as responsible agents (Fischer and Ravizza 2000); and others hold this to be true irrespective of whether or not the actor has free will (Freeman 2000). Some argue that individuals can only be held responsible in relation to their actions affecting those within their social circle (Hazard 2000)[4]. The common element in all of these proposals is the image of the isolated rational individual. Such efforts attempt to systematise philosophical calculations that will allow actors to define the parameters of responsibility.

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[2] For example, prompt payment of taxes, attendance at jury duty and obedience of criminal laws are commonly understood to be important contributions toward the social good. Those who refuse to adhere to these norms will find their freedom curtailed by the state which will levy punishment through financial or penal means. This curtailment of freedom is widely held to be a necessary method of disciplining those who refuse to voluntarily meet their responsibilities as determined by the state. In return for responsible behaviour, citizens expect that they can enjoy rights such as the use of high quality publicly funded services, and the protection of living in a safe and just environment. Most domestic politics is dominated by refining the definition of these norms, and very rarely calls their existence into question.

[3] See (Fischer 1999) for a comprehensive discussion about the strengths and weaknesses inherent in this approach.

[4] This is also a theme found in Geras, 1998.

Aside from these moral philosophers who continue to work out the rules for ascription of responsibility, other late twentieth century advocates of the *responsibility as freedom* thesis frequently argue that the links that once united responsibility and rights have been lost. They hold that as a result of the disturbing effects brought on by rapid social change, we are left with a society where individuals demand rights, but have little awareness of the responsibilities they owe to the collective in return[5].

> Even if lawyers and judges realise among themselves that individual rights are limited by the rights of others and the needs of the community, as the language of rights penetrated into everyday discourse, the discourse becomes impoverished and confrontational...A return to the language of social virtues, interests, and, above all, social responsibilities will reduce contentiousness and enhance social co-operation. (Etzioni 1993: 7)

Etzioni is adamant on this point, insisting that a moratorium be declared on the granting of any new rights, until there has been a cultural shift toward increased individual responsibility (1993: 5). This lament is often raised in relation to the American paradigm of rights-based attitudes. For example, Taylor (1991) reflects on the way in which the culture of rights has lead to 'fragmentation' in that society. He argues that American political involvement has been reduced to single issues revolving around rights, and adds that this operates to divide rather than unite constituents along ideological lines.

> An unbalanced system such as this both reflects and entrenches fragmentation. Its spirit is an adversarial one in which citizen efficacy consists in being able to get your rights, whatever the consequences for the whole. Both judicial retrieval and single-issue politics operate from this stance and further strengthen it. (Taylor 1991: 117)

The recent critiques of rights referred to here do not question the validity of the notion itself. Instead they make the argument that the balance between rights and responsibility must once again be regained; presumably along the lines of theoretical models from the eighteenth and nineteenth centuries. Within this framework, concern about the impact of one's actions upon others in the community leads to the construction of a collective ethos; this is in turn supported by equal rights granted by the state. The *responsibility as freedom* position holds that the bedrock of equal

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[5] These arguments will be discussed in more detail below.

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rights opens the potential for human flourishing and freedom by those individuals who choose to take advantage of the opportunities that are open to them. Yet at the same time, they argue that overindulgence in the establishment of a rights-based culture disturbs the balance and causes individuals to abandon their own responsibilities. This delicate balance between rights and responsibilities requires a system of maintenance that initiates new social members into the liberal democratic framework. Those who take the *responsibility as freedom* position have broadly adopted the notion that socialisation provides this function, so it is to this topic that we now turn.

2.1.2 Socialisation as a means of maintaining social cohesion

Socialisation is often an implicit feature within the work of those who seek to continually reinforce the importance of responsibility in relation to the communal. It is regarded as the process that teaches individuals the value of responsibility toward others in maintaining social cohesion. Through socialisation, young members of society are taught the fundamentals about their responsibilities to the collective, as well as the benefits that will ensue because of responsible behaviour.

This notion of socialisation is largely dependent upon an image of children who are raised in an environment that is meant to constantly remind them of 'correct' actions and attitudes. These practices continually reinforce an understanding of the effects of one's actions upon others.

> From earliest youth the individual is trained in the constant restraint and foresight that he needs for adult functions. This self-restraint is engrained so deeply from an early age that, like a kind of relay station of social standards, an automatic self-supervision of his drives, a more differentiated and more stable 'super-ego' develops in him, and a part of the forgotten drive impulses and affect inclinations is no longer directly within reach of the level of consciousness at all. (Elias 1994: 452)

Elias' account of taming the anti-social nature of the child has the implication that a person who has not been socialised as a member of some community does not experience a feeling of responsibility. Theorists who support the *responsibility as freedom* thesis broadly agree that socialisation aims to develop of a member of society who will operate out of a sense of responsibility to socially determined values. Thus individuals will act out of concern for those who may not be physically

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present but remain internalised and inseparable from what we may call conscience (Elias 1994: 477). 'The realisation that one will or might be held to account, the passive side of responsibility, stimulates people to behave responsibly, the active side' (Bovens 1998: 39). This is a position that encourages conceptualisation of a uniform and 'correct' way of behaving. It leads on to a process of deduction whereby the individual who demonstrates what is perceived to be a lack of responsibility is assumed to have been unsuccessfully socialised (Etzioni 1993; Lasch 1979; Murray 1990; Parsons and Bales 1955) [6].

Freud's image of the super-ego underlies many such narratives of socialisation. In the Freudian model, responsibility is the external expression of the super-ego (Freud 1927). It refers to the needs and expectations of others built into our identity and reflected through our own actions. It also anticipates the requirement that we may be called to answer for our own behaviour, and can prepare excuses, defences or justifications for the things we do. In this construction, responsibility is intended to play a preventative function, potentially operating as a deterrent to those actions that would cause us to be called into question. Thus, the emergence of responsibility within ourselves occurs when we fully recognise that we are members of a wider social body that can question and constrain our actions. This straightforward presentation depicts a responsibility that is internalised by the individual who acknowledges the impact of his/her actions on other members of society. Rather than regularly being held accountable (and potentially punished) for acting in ways that harm others, this built-in responsibility mechanism encourages reflexivity which will in turn prevent us from doing deeds that would negatively impact either ourselves or members of the community. A key example of this account is found in Elias' *Civilising Process* (1994) which details the way in which responsibility develops as a part of broad social development whereby societies depend less on

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[6] Strong advocates of socialisation fail to take larger structural issues into consideration in their accounts. Thus the only source for accountability becomes the individual. Popular examples of this type of discourse would include: a) the properly socialised person who makes the 'wrong' decision when faced with a dilemma; or b) the inadequate parent who fails to raise his children with 'appropriate' social values. Subsequent sections of this chapter will explore the inadequacies of this highly problematic representation of social agency.

physical violence and more on normative rules in order to organise points of conflict[7].

These approaches have a generally pessimistic view of human nature, viewing us as interested only in our individual needs until taught otherwise. However, some accounts of the socialisation process have a different understanding of the basic drives of human beings. For example, Levinas' version describes responsibility as an inherent potential residing within each individual which is revealed as the self begins to recognise the needs of the Other. Thus it may be that we only fully become our*selves* when we take on responsibility for the well being of others (Levinas 1989). Here the core of the notion of responsibility is founded upon the assumption that we are called to protect and care for 'the Other' and our establishment of selfhood is only complete when this is fully recognised. Whereas previous approaches may have relied on a view of human nature that was rooted in original sin as manifested by Adam and Eve in the garden of Eden, Levinas' model does not take this view[8]. His account contends that instead of an ingrained disposition toward wrongdoing, humans are inwardly drawn toward the support and assistance of others. 'Responsibility for my neighbour dates from before my freedom in an immemorial past' (Levinas 1989: 84). This perspective is strongly supported by Bauman in *Modernity and the Holocaust* (1989).

In Levinas' account, socialisation is not a process whereby we must suppress our negative and destructive inner instincts. Instead he posits the idea that our selves come into being when we interact socially with others and come to recognise their needs. Once this act of recognition is made (although he does not satisfactorily explain what features of socialisation make this happen) the self who does the recognising is able to come into being[9]. Through responsibility the self is discovered and then can be free to flourish. It is at this point that Levinas also begins to

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[7] Also see Etzioni, 1993. Foucault ,1967, agrees that socialisation serves to reduce the need for coercive state intervention. However, in contradiction to Elias' and Etzioni's assertions that this will ultimately lead to greater social freedom, Foucault characterises this as an insidious internalisation of state control (see some elaboration of his views in section 2.2).

[8] Indeed, Levinas states that he believes in original goodness rather than original sin, 1989: 111.

[9] See Taylor, 1989, for yet another position on the role of recognition in the development of identity. From his perspective, it is only when the individual self attains positive recognition from another that it is able to reach out in acts of reciprocity and responsibility.

investigate the way in which we are each implicitly questioned by this primary duty to responsibility before we even come into being. He rightly makes the connection between being questioned and being blamed, prior to action or reaction: 'I have not done anything, and I have always been under accusation - persecuted' (Levinas 1989: 104). This important facet of responsibility is a topic in the subsequent section of this chapter on *responsibility as control*, and it is worth taking note that the blame Levinas identifies here, is that which is inflicted by the social pressures of responsibility.

Whether or not they regard socialisation as a taming of our negative instincts, or the nurturing of our positive ones, these theorists all contribute to a narrative of socialisation that reinforces the role of individual responsibility for others in a *free* society. However, many of these same thinkers write during a time that they would describe as being in crisis. Using the horrors of the holocaust, ecological devastation, the failure of the welfare state or the pervasive loss of social cohesion, they point to the failure of the modern individual to live up to her side of the social contract. They argue that in the bid to assert freedom, we have instead stripped rights of their meaning and transferred personal responsibilities to social institutions. They argue that due to a range of factors, the process of socialisation has failed and the only means of regaining social stability is to re-establish individual socialisation at the centre of the human project. They feel that in turn, this will revitalise individual responsibility, which will then bring increased overall cohesion.

2.1.3 The *crisis of responsibility* approach to social regeneration

Reflecting upon our current era as one of a '*crisis of responsibility*'[10], some argue that moral and ethical vocabularies no longer have any referent (Bauman 1989; Etzioni 1993; Horosz 1975; Jonas 1984; MacIntyre 1985; Taylor 1989)[11]. As MacIntyre puts it, 'we possess indeed a simulacra of morality, we continue to use many of the key expressions. But we have – very largely, if not entirely – lost our comprehension, both theoretical and practical, of morality' (MacIntyre 1985: 2). This *crisis of responsibility* thesis holds that as individuals, people have lost their

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[10] The term comes from Horosz , 1975.
[11] Not all of those whose work supports the *responsibility as freedom* perspective should automatically be assumed to hold the *crisis of responsibility* position.

relationship to the community. These relationships are seen to have broken down because of the collapse of morality, responsibility and ethics under the strain of changing social structures and competing systems of values. In reaction to these perceived threats to stability, this position relies heavily on the idea that increased individual responsibility will result in improved freedom and prosperity. A comprehensive overview of this type of approach is not the focus of this thesis. Instead, I intend to give a sample of this position by concentrating on a few important individuals who have worked in this area over the last few decades.

Through a variety of theoretical positions, prominent sociological figures such as Beck, Etzioni, Taylor and Bauman are at the forefront of this body of thinking which calls for a return to supportive community morality through strengthening the positive bonds of responsibility. They argue that one possible influence of postmodernism and the array of lifestyle and ethical choices that it brings is its ability to erode actions that consider the needs of others.

> It is as if one were acting while being personally absent. One acts physically, without acting morally or politically. The generalised other – the system – acts within and through oneself: this is the slave mentality of civilisation, in which people act personally and socially as if they were subject to a natural fate, the 'law of gravitation' of the system. (Beck 1992: 33)

Bauman's work (1989) supports this position yet goes on to develop a cure for this crisis through the adoption of Levinasian communities of reciprocal care (Levinas 1989). He argues that it is possible to discover our bonds to those individualised others if we allow ourselves to recognise our own vulnerability reflected through their actions[12]. Therefore, once we take up our individual responsibilities toward others, he argues that freedom and individual fulfilment will be attainable (also see Taylor 1989 and 1991).

Similar arguments were put forward in Lasch's influential *Culture of Narcississm* (1979) over twenty years ago[13]. He argued that dominant western culture had created a mass of individuals which in turn led to the eruption of a competitive 'war

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[12] As will be developed further below, there is a curious paradox in this logic, in that increased individualism is regarded as the source of the problem, yet it is only through individualised change that these theorists perceive a remedy for the *crisis of responsibility*.

[13] Other examples include Horosz, 1975 and Jonas, 1984.

of all against all' (Lasch 1979: 26). Alongside this narcissistic development, he adds that individuals' absorption with their own desires and interests has meant that they have transferred their responsibilities over to public institutions. Ultimately, this has meant that ordinary people can no longer meet their own basic requirements, because they have become so dependent on others to meet their needs.

> What appears to social scientists as a seamless web of "interdependence" represents in fact the dependence of the individual on the organisation, the citizen on the state, the worker on the manager, and the parent on the "helping professions". (Lasch 1979: 229)

Lasch believes that this lack of independence is proof that moral responsibility is completely eroded, because the individual can no longer even demonstrate responsibility for his own basic functions (as parent, as employee, as citizen). In his estimation, the first step toward the re-creation of a free society is to reinvigorate the notion of personal responsibility among individuals. This leads to the reinstatement of individual independence and no more over-reliance on social institutions. It is this individual independence that he characterises as freedom. His best-selling book provides a blueprint for the reconstruction of American society, giving practical pointers to individuals about developing increased responsibility in the realms of family, education, sex, old age, politics and sport.

There are many similarities between Lasch's work, and that of Amatai Etzioni sixteen years later in *The Spirit of Community* (1993). However, Etzioni simultaneously warns of the lessons learned from America's experience with extreme individualism. He argues that neither is swinging to the extreme of morally superior collectivism a possible solution and that we should rather embrace his 'middle road' ethic of communitarianism. This involves the increasing of social responsibility on both an individual and local community level. Reminiscent of Lasch, he argues that individuals have learned to crave rights while leaving the burdens of responsibility to the government (Etzioni 1993: 4) and his solution is to draw up a list of common values and duties to which everyone will agree to adhere for the betterment of society.

> What we must try to avoid is relying on the state to maintain social order, which can be achieved more humanely and at less cost by the voluntary observance of those values we all hold dear, such as driving without

endangering others and paying our share of the community's burdens.
(Etzioni 1993: 44)

His blueprint for action includes directions toward responsibility within the family, education, public health, politics and community institutions as well as increased state power to coerce responsibility from its less forthcoming citizens[14]. In reference to social pressures on the family (the core unit of his vision), he contends that all parents have a choice to make between their children and their consumer desires; decreased income simply makes those choices more limited (Etzioni 1993: 67). He argues that if we cannot convince people to make these kinds of difficult choices, then they will continue to claim individual rights regardless of the type of damage that this may cause to others – ultimately leading to environmental, political and social collapse.

Similar themes relating to the dangers of the *crisis of responsibility* are prominent in Alisdair MacIntyre's *After Virtue* (1985), a frequently cited text in discussions on responsibility. His work explores the notion that morality operated to bond communities together long before the notion of the individual was even possible. It is a narrative of caution, warning readers about the dangers of the 'emotivist' strain of theory which claims that there is no one morality beyond personal preference, a position that is now familiar as postmodernism. He argues that the emotivists have fallen in to the trap of claiming that there is no purpose to morality. According to MacIntyre, this makes them so distanced from the historical meanings and applications of the concept that they are no longer able make any statements about morality that do any justice to the term (MacIntyre 1985: Ch.2).

MacIntyre's overall project in *After Virtue* is to advocate a return to a version of Aristotelian *telos* as morality as outlined in the *Nicomachean Ethics*[15]. As MacIntyre describes it, Aristotle felt that when we exercise our intelligence in combination with a natural predisposition toward fulfilment then we arrive at virtue. This model best expresses itself in the shape of friendship; it is 'the sharing of all in the common project of creating and sustaining the life of a city, a sharing incorporated in the

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[14] Examples of Etzioni's recommendations in these areas include: elimination of freely provided health care and housing; mandatory notification of sexually transmitted infection to an individual's partners; and the drastic reduction of divorce through a change in legislation (Etzioni 1993).

immediacy of an individual's particular friendships' (MacIntyre 1985: 156). MacIntyre does acknowledge that Aristotle's theory relies upon a vision of humanity that is not disturbed by inequalities in power, but in the final chapters he relies heavily on Aristotle when he arrives at the notion that each individual is a narrative construction that has its own inevitable beginning, middle and end. In this way, he argues, if we create the circumstances whereby we can recognise our potential, then we are free to move in that direction. In the current environment which lacks responsibility and morality, we do not have the capacity to make this act of recognition.

Although the *crisis of responsibility* thesis is not necessarily new, in recent years it has been put forward with a great deal of collective force. There was a growing sense in the late 1990s that communitarianism and its off-shoots were a viable response to increased feelings of fear about disintegrating social values and practices[16]. However, as with many attractive social solutions, this is an approach that contains several critical flaws, which I shall just briefly outline here. Firstly, communitarianism contains similar pitfalls to the liberalism that it attempts to replace. 'The libertarian argument presupposes formal-legal rationality, just as the communitarian argument presupposes traditional rationality; both are types of legitimising domination as authority' (Rose 1996: 4). In addition, the notion of a '*crisis*' counterposes the present against a vision of a glorious past where individuals were able to strike a balance between rights and responsibilities and where the process of socialisation operated flawlessly as the means of reproducing harmonious society. We need to question this romantic vision: the best place that MacIntyre (1985) locates it is in the heroic myths of Scandinavian legend which seems a dubious example with which to compare twenty-first century global capitalism.

This leads us to the pervasive problem with not only the '*crisis of responsibility*' perspective, but the '*responsibility as freedom*' paradigm as a whole. Whether

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[15] For a critique of MacIntyre's reversion to Aristotle see Rose, 1996.

[16] Communitarian rhetoric was a consistent theme of Bill Clinton's Democratic Party in America during this time, and Clinton made specific reference to the importance of Etzioni's work in the re-establishment of the American dream (see opening pages of Etzioni, 1993). The work of the New Labour think-tank – Demos – is infused with communitarian themes which have clearly made their way into government planning from 'pro-family' policies that favour marriage (Freely 2000), to Blair's call for a 'new culture of responsibility' among welfare recipients (Etzioni 1997).

couched in libertarian or communitarian terms, the underlying themes of these modes of thought direct all responsibility and therefore all potential blame toward the individual. In reaction to the complaint that his theory does not adequately explicate the impact of inequality on the lives of individuals, Etzioni responds: 'Man and woman do not live by bread alone; it is unwise to believe that all we need is economic rehabilitation. We require that our daily acts be placed into a context of transcendent meaning and their moral import explicated' (1993: xii). With one gesture he sweeps the question of broader structural constraints to one side.

Similar sentiments are expressed by Giddens and his optimistic perspective on what he calls 'the double-edged character of modernity' (1990: 10). He argues that in the drive for progress, the disembedding mechanisms of globalisation have a tremendous potential to bring widespread upheaval and potential harm, while at the same time these processes allow the individual to engage in the process of constructing the self. With the help of increasingly complex expert knowledge and the malleability afforded by modern social structures, he feels that the reflexive individual has the potential to take responsibility for his or her own life trajectory in a way that has never before been possible (Giddens 1991). In this view, the modern individual can seize the opportunity to construct a responsible identity from the range of available options.

These are very safe positions from which to see the world for those who already possess some degree of power, because these ideas about individual potential do not threaten their own positions. Rather than problematising the structures that have granted them power and status, it is much easier to think that equality of opportunity exists for everyone, *if only they would be a bit more responsible*. Gillian Rose's analogy of three cities is particularly relevant here. She says that while the glories of ancient Athens and the new Jerusalem are hailed by those who imagine the newly liberated 'community', they may also harbour another reality.

> But what if they, unbeknownst to themselves, carry along in their souls
> *the third city* – the city of capitalist private property and modern legal
> status? The city that separates each individual into a private,
> autonomous, competitive person, a bounded ego. (Rose 1996: 21-22)

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Instead of recognising this danger, those who argue from the 'responsibility as freedom' perspective perpetuate it by attributing loss of freedom to those individuals who: a) have not achieved the appropriate balance between rights and responsibility; b) have not contributed adequately to the socialisation process; and c) have not made the correct 'hard' decision when facing material need. Such assumptions are apparent in the underclass thesis put forward by Charles Murray (1990). Following such rationalisations, blame rests with under-resourced parents who have failed; or those who become infected with HIV despite the fact that they 'should have known better'. From this type of over-simplified perspective there is no need to critically analyse the broader structural and social constraints that impact upon responsibility. Instead, solutions to the most troubling social ills are presented as those that are in the complete control of the individual: to develop stronger friendships; spend more time with the family and take the time to recognise to the needs of others.

For many these are attractive solutions – and we see their implementation all around us[17]. These ideas gain popular support because they appear to be accomplishing social reform, while in fact they require very little reflexivity from those who have the power to oversee the functioning of social structures. As a result, there is little hope fore the lasting change that might be effected by such reform, as a key source of the problem remains unchanged. Offering up simple blueprints for individual change may have some degree of resonance for the more privileged strata of society. However, for the majority this type of change is simply not so straightforward, because they are situated at a place in capitalist relations which affords them neither the resources (i.e. time/transportation) or the motivation (i.e. more pressing priorities) to take part.

Later in this chapter I will develop an idea of responsibility that can take into account these wider structural inequalities, but before doing so I want to turn to a group of thinkers whose ideas on responsibility invert the 'responsibility as freedom' paradigm.

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[17] One example of the implementation of such ideas is the recent introduction of a citizenship curriculum into schools in England and Wales. For a review and critique of the implementation of such ideas within Blair's New Labour see Levitas, 1998.

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2.2 RESPONSIBILITY AS CONTROL

Rather than regarding responsibility as a small price to pay for a harmonious society, some authors point to the isolation and powerlessness that is engendered when social ills are seen to result from the irresponsible choices made by individuals. Instead they call for recognition of the structural constraints on individual agency. In particular, they draw attention to the way in which responsibility is utilised as an ideological tool that continues to support such institutional structures. The most famous proponent of this position is Foucault, particularly through his reflections on the art of *governmentality* (1991). In his view, the state maintains order in societies comprised of self-governing citizens by impressing upon them the importance of individual responsibility.

> The 'common good' refers to a state of affairs where all the subjects without exception obey the laws, accomplish the tasks expected of them, practise the trade to which they are assigned, and respect the established order so far as this order conforms to the laws imposed by God on nature and men. (Foucault 1991: 95)

Foucault goes on to argue that this process dulls the individual's capacity to call broader relations of power into question. Because he or she is so taken up with the tasks of being a 'good citizen', there is no paradigmatic structure available that allows one to step back and take in a broader perspective on power. Thus the citizen is effectively blocked from being able to critique the broader institutional structure that creates and perpetuates inequality.

This perspective prompts us to explore how notions of responsibility are put to use within social structures to reinforce group norms through individual conformity. Along with Foucault and his followers, we will explore the ways in which theorists of risk and stigma such as Douglas and Goffman have examined the relationship between individualised responsibility and the maintenance of social norms[18].

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[18] Commentators on the social and historical progress of modern understandings of medicine, health and illness include Crawford 1994 and 1977; Brandt 1987 and 1988; Mort 2000; Weeks 1989; Gastaldo 1997; and Osborne 1997. This body of work has also made important contributions to this understanding of responsibility. Their work highlights the means through which the notion of health risk has progressively come to focus moral blame on the individual who becomes ill. Their work will be more fully explored in Chapter Three.

2.2.1 Revisiting the notion of democracy

In 1840 DeToqueville argued that, in modern democratic states, the individual becomes concerned only with the minimal duties that he or she owes to the state in order to maximise a repayment in terms of rights. This process results in what he called 'soft-despotism'- the state's ability to operate unhampered as citizens become consumed with their own affairs.

> A society in which people end up as the kind of individuals who are 'enclosed in their own hearts' is one where few will want to participate actively in self-government. They will prefer to stay at home and enjoy the satisfactions of private life. (DeToqueville cited in Taylor 1991: 9)

DeToqueville's concept of 'soft-despotism' refers to the paternalistic function of government which keeps citizens convinced that they have what they need. This leads to a situation where they are so caught up with issues of private comfort that they have no concern for other's needs or the desire to participate in political life. While Taylor (1991) employs DeToqueville's moral tales from *Democracy in America* to underline the need for increased personal responsibility to the collective through vigorous activity in political culture (reflecting a *responsibility as freedom* position), DeToqueville's own sensibilities appear to rest more comfortably with the notion of *responsibility as control*. He refers to modern democratic government as a novel 'species of oppression', operating in ways that gradually constrain individual agency. In reference to the way in which individual responsibility, and particularly individual rights, operate to silence opposition, he states: 'The principle of equality has prepared men [sic] for these things; it has predisposed men [sic] to endure them and often to look on them as benefits' (DeToqueville 1840: 337). DeToqueville points out that changing political leaders has no impact on the continued running of this type of political landscape. Instead, he marvels at the ingenuity of a system that 'does not tyrannise...[but]...stupefies a people, till each nation is reduced to nothing better than a flock of timid and industrious animals, of which the government is the shepherd' (DeToqueville 1840: 337).

We find that many of the themes raised by DeToqueville reappear in Foucault's exploration of the role of madness in modern civilisation. In *Madness and Civilisation* (1967), he analyses the means by which illness was used as a means of bolstering the power of the European state. He traces the development and

consolidation of this power through the establishment of two historically specific types of social exile: those categorised as lepers, and those determined to be insane. The process whereby certain individuals were singled out for expulsion is described by Foucault as a significant tool of broader social governance on the part of the state[19]. The significance of this role lay in its ability to keep citizens convinced that they must monitor themselves and each other for symptoms of deviance; rather than questioning the basis of social inequality itself. Thus the primary responsibility of the individual citizen becomes his capacity to monitor his own behaviour. With the decline of leprosy, Foucault argued that something was required to fulfil this same role in order for the valuable notion of 'confinement' to maintain its social usefulness as a signifier of deviance. 'Leprosy withdrew, leaving derelict these low places and these rites which were intended, not to suppress it, but to keep it at a sacred distance, to fix it in an inverse exaltation' (Foucault 1967: 6). As the economic structure shifted and increasing portions of the population found themselves entrenched in poverty, a significant new means of social exclusion emerged. If responsibility was characterised by productivity, then being idle came to signify madness in an individual, resulting in confinement by the state.

> It was in a certain experience of labour that the indissociably economic and moral demand for confinement was formulated. Between labour and idleness in the classical world ran a line of demarcation that replaced the exclusion of leprosy. The asylum was substituted for the lazar house, in the geography of haunted places as in the landscape of the moral universe. The old rites of excommunication were revived, but in the world of production and commerce. (Foucault 1967: 57)

Foucault understood the asylum to be the exemplary organiser of the masses. In order to avoid confinement, most people would try to be self-governing, 'good citizens'. This lifted the burden of discipline away from the state and left it instead with the responsible individual who constantly monitored his/her own behaviour and productivity. As the role of the asylum became more highly developed, it became the public organiser of guilt. '[It] substituted for the free terror of madness the stifling anguish of responsibility; fear no longer reigned on the other side of the prison gates; it now raged under the seals of conscience' (Foucault 1967: 247).

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[19] Douglas' analysis of the role of lepers confirms this view. She says that while other theorists have maintained: 'that the people of the period were confusing a real disease with imaginary sins. It is more likely that they were trying to cure a real social blight by isolating an imagined disease' (Douglas 1992: 97).

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Through the image of the asylum, the state had made its way into the mind of the citizen – designating behaviour and suppressing impulse.

2.2.2 Responsibility as blame: the uses of guilt, stigma and risk

The work of DeToqueville and Foucault draws to our attention the implicit means through which individuals become self-governing in modern democracies. This 'tyranny of the self' is largely achieved through a process of public norm demarcation. Those who violate central norms become the focus of public attention. It is said that such individuals have made irresponsible choices and negative consequences (often accompanied by a process of shaming) will result. This line of thinking reasons that negative consequences will result from behaviours judged to be immoral and irresponsible; therefore those caught up in bad events are seen to have done something to bring on their bad fortune[20]. Narratives of blame thus proliferate throughout the community so that it becomes widely known that X must have done something wrong in order for such events to befall her[21]. In turn, X internalises these accounts of her actions and feels guilt for what has happened; the social tool of responsibility makes it likely that she will blame herself for what she will regard as the negative consequences of her actions.

Foucault (1967) traced the institutionalised refinement of the social uses of blame, guilt and stigma from Middle Age leprosaria to the asylums and workhouses of the late nineteenth century. These notions operated as a means of isolation and punishment for individuals who were seen to have stepped beyond 'acceptable' limits and thus deemed to be irresponsible. As suggested above, the need for the physical presence of the asylum declined as the structures of guilt, blame and stigma began to take hold within the conscience of contemporary citizenry. Thus the concepts themselves become the functionaries of social control.

Goffman's (1963) renowned exploration of stigma pursues the ways in which blame and guilt impinge upon human agency. Those who do not match social expectations of normality (in terms of health, social behaviour, appearance, etc.) are subjected to

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[20] This theme will be raised again in the following chapter which provides a review of the literature linking morality, stigma and blame with disease and risk.

the judgement of members of that society. Such judgements will often involve an ascription of blame to the individual, which is a process that allows the judges to be disassociated from the deviation. In order to protect themselves, stigmatised individuals will often revert to safe social spaces or make attempts to conceal their stigmatising condition. This act of collusion between the stigmatised and the stigmatiser results in the illusion of normality that is inherently supported through the stigmatising process. Thus, the potential of the stigmatised individual to form relationships with others is continually flattened by the weight of stigma because it comes before all other considerations. Not only does the individual develop ambivalent feelings about him or her self, but it may also become difficult to form attachments with anyone else (Goffman 1963).

Douglas (1992) takes these notions of blame and stigma and traces their transmutation in the late twentieth century into the concept of risk. She argues that the notion of *danger* defines a society and that blame operates as central means of constructing ideological barriers against danger. 'Danger is defined to protect the public good and the incidence of blame is a by-product of arrangements for persuading fellow members to contribute to it' (Douglas 1992: 6). For all of its apparent objectivity, Douglas examines the role of risk analysis as a functionary of ideological boundary maintenance. She argues that in an increasingly individualised society, risk fits seamlessly into the institutionalised practice of self-governance. At the same time, it allows the powerful strata of society to relegate those on the margins to practical non-existence by labelling them as 'high-risk'. She says that risk is an ideal tool for global capitalism in this way because it operates to protect the deserving individual while simultaneously banishing the irresponsible one. 'Since it is inherently difficult to be aware of the liminal groups in a society organised under the principles of competitive individualism, it is easier to write them off as human derelicts' (Douglas 1992: 35). While Levinas constructed a notion of 'Other' that bounded us to responsible action, Douglas' position allows us to see responsibility as a means through which we can dissociate ourselves from the 'Other'. In this view,

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[21] The historical equation between immorality and illness provides the best example of this way of thinking. It is a topic that receives detailed review in section 3.1 of the following chapter.

'we' do not feel responsible to give aid because the 'Other' is perceived to be responsible for his own plight[22].

In direct contrast to Beck's (1992) much-celebrated theory of the universalisation of risk as a signal of modern 'reflexivity'[23], Douglas asserts that risk operates as a shorthand means of identifying deviants. She is interested in the micro-level impact of the individualisation of risk, rather than the aspects of risk that have been popularised by Beck (i.e. expert systems and calculation of catastrophic risk such as ecological or nuclear disaster). In *Risk and Blame* she explores the links between risk and taboo, coming to the conclusion that risk isolates the individual and 'disperses' solidarity (Douglas 1992: 30). Thus she finds that there is a great deal of symbolic power in expert discourse surrounding risk. What is particularly modern about contemporary risk discourse is its focus on the individual:

> Danger in the context of taboo is used in a rhetoric of accusation and retribution that ties the individual tightly into community bonds and scores on his mind the invisible fences and paths by which the community co-ordinates its life in common...It is part of the system of thought that upholds the type of individualist culture which sustains an expanding industrial system. (Douglas 1992: 27-28)

Blaming individuals for their lack of responsibility when confronting risks that should be 'known' to them has become a pervasive popular theme in contemporary culture[24]. Rather than bringing about solidarity, this is a discourse that separates individuals from one another because it replaces any impulse to help the weak with blame and ridicule and also contributes to fragmentation among those in the most vulnerable social positions. When its dispersal mechanism is most effective, this process renders those most exposed to risk non-existent – because then there will be no conflict with norms of self-sufficiency and individual responsibility.

This second approach thus criticises the *responsibility as freedom* position for not taking into consideration the ways in which unequal social relations act as a barrier to individuals' sense of self. It argues that the liberal neutrality assumed by the *responsibility as freedom* approach is a means of preventing individuals from recognising the needs of others. In turn, this lack of recognition develops into stigma

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[22] Also see: Arendt 1973; Stohl 1987; and Tester 1997.

[23] Beck's approach to risk will be discussed in more detail in Section 3.4 of the following chapter.

among the socially dispossessed. They have difficulty recognising not only their own worth, but also the value of those around them. In addition, those who are prosperous in liberal democracies are exposed to images of the dispossessed that socially construct them as responsible for their own plight. This makes it easy to exclude such groups from the individual's realm of concern. While these are the dominant scripts available to people living in such conditions, there are instances when individuals reject such scripts, and as a result evade internalised and externalised stigma and the damage it does to what may be regarded as 'responsible' practices (Wrong 1961). Yet we can also see how such forceful processes operate to constrain agency both among those who find themselves excluded, as well as those who are a part of mainstream society.

Our categorisation of people who are inside and outside of our realm of responsibility is largely determined by the material conditions which contextualise those social relations. As a result, the notion that individuals are freely able to choose their ethical framework is highly problematic. These structural constraints are not adequately addressed in the theories that belong to the *responsibility as freedom* position. This over-emphasis on human agency runs a high risk of assigning blame through the development of an 'objective' but nonetheless normative system of thought. Without a suitable framework in which we can understand the social foundations and implications of responsibility, we must question the utility of heavily rationalised formulations that attempt to calculate the existence of attribution, alternative choices, and free will.

The *responsibility as control* perspective thus highlights the weaknesses of the *responsibility as freedom* position and draws much-needed attention to institutional powers over the individual. However, the situation we are left in by this critique is one where the individual is paralysed by structural forces. Viewed from this approach, responsibility is an ideological tool that only serves to reinforce inequality and maintain social control. This situation is untenable because it provides no space for the existence of a responsibility apart from that which is imposed and

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[24] Drug use and unprotected sex are two common examples.

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constraining. This is not a position that I want to support in this thesis, because it would imply that there is never an appropriate time or place for responsibility.

While there clearly are times when responsibility is imposed and can be used as a mechanism of control, this is not the only way in which it should be understood to operate. Thus the *responsibility as control* paradigm cannot provide the final statement on the contemporary realities of responsibility. How can we allow for the existence of any human agency if we ascribe complete power over action to social structures? The existence of such a strong activist response to HIV/AIDS as well as many social movements that appear to utilise notions of responsibility fall into neither one of the dichotomous paradigms presented above. Their application of responsibility seems to me to be a much more complex phenomenon.

The two generalisable trends within social theorising on responsibility that I have outlined here both contain serious flaws. The theorists whom I have categorised as part of the *responsibility as freedom* school argue that social freedom emerges from individuals acting responsibly towards others in return for having their freedom protected by the state. However, such an understanding exaggerates human agency and does not take into account how this conceptualisation of responsibility can work to exacerbate inequality. This is corrected by the *responsibility as control* position but such an approach pays too much attention to our structural ties and results in a position where individuals are paralysed and unable to engage in responsible action. If any useful notion of responsibility is to be salvaged from this dichotomy we need an alternative understanding of responsibility. It is this alternative, *intersubjective*, conception that I shall outline in the final section of this chapter.

2.3 INTERSUBJECTIVE RESPONSIBILITY: AN ALTERNATIVE MODEL
Rather than accepting the outcome of this dichotomy, I will present an alternative conception of responsibility that places political and social processes at its centre. The assertion made here is that it is not feasible for us to dispense with the idea of responsibility simply because we have evidence that it can be (and is) mobilised for the purposes of controlling and excluding large segments of populations. Therefore I outline a view that rejects the idea that responsibility is *inherently* controlling because this is a view that disallows us from analysing the ways that responsibility

contributes to social cohesion and political motivation. While some strands of critical theory regard responsibility *exclusively* as a means of governance and institutional control, I believe that there *is* an important and purposeful place for responsibility in social being. The freedom and control dichotomy provides two static and unconvincing conceptions of responsibility. Responsibility is more complex than liberalism or its structural critique conceives. The alternative presented here offers an understanding of responsibility that is contingent upon social relations and is at the basis of collective efforts to use political power to effect social change.

This new perspective on responsibility is possible when we put to one side the assumptions concerning the centrality of the individual that form the basis of the two theoretical approaches already discussed. The first approach presumes a model of a rational, free-willed individual and the second centres on one that is structurally determined. Social theorising that uses the individual as its starting point prevents us from articulating theoretical approaches to responsibility that draw on the interrelations inherent in social existence (Barnes 2000). If we instead take a political perspective on responsibility that regards it as a process embedded in the relations between social actors, this allows us to take into account the struggle for power among those who have different priorities and points of view. This involves an acknowledgement that responsibility is inter-relational, and as a result it will involve conflict and struggle for those who use it as their means of engagement.

It is important here clarify the definition of intersubjectivity that forms the basis of this alternative notion of responsibility. It is not a perspective that dwells on issues such as the care and protection expected between family members, or between members of a religious community. Those are 'traditional' pre-modern responsibilities that were once characterised by 'blood, geography, ethnicity or political boundaries' (Wolfe 1989: 2), and they persist today in their own discursive frameworks. However, what interests me here are not the moral bonds of care that we have (or are meant to have) for those in our closest social circle. Rather, I am interested in the understanding of responsibility that impels us to reach out of that circle. This latter bond has developed with the increasing interdependence brought about by the social organisation of modernity.

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> Both the scope and the specificity of moral obligations change as
> societies become more modern. The sheer complexity of modern forms
> of social organisation creates an ever-widening circle of newer
> obligations beyond those of family and locality.
> (Wolfe 1989: 3)

It is because we have developed more complicated interdependent networks that our modern existence within capitalism demands an extension of responsibility beyond just the personal sphere. At the same time, however, capitalist social relations propel us into a situation that expects us to be concerned only for the welfare of our immediate social circle. This is what makes the type of responsibility I am interested in here – the type that encourages us to reach out of this circle – an important area of study. The ideas presented here rely on an understanding of the type of responsibility that resides in those spaces between more loosely affiliated social relationships and it is as a result of this that this type of responsibility is inevitably connected to the political. It is through an investigation of these spaces and what prompts responses within them that we will gain a view of a modern, intersubjective, responsibility that is politically and socially enabling and which does not serve to exclude the 'Other'. This includes investigations of relationships between individuals but also involves broader connections between people and institutions.

It is with this understanding of intersubjectivity that we can begin to argue that social frameworks of ethical bonds are the basis for an outlook which includes responsibility. This is not an idea of responsibility that is understood as a product of abstract rules removed from social relationships[25]. Enlightenment philosophers such as Kant attempted to develop universal moral codes which supersede power issues such as class, ethnicity and gender. Yet in contemporary society, it is much more useful to apprehend a type of responsibility that places these very issues at its centre; one that is not only communal but also contextual (Gilligan 1993).

While researching the development of responsibility Gilligan found that interviewees often demonstrated a strong awareness of the interdependence that is a requisite part of contemporary life[26]. Referring to a statement made by one participant, she wrote:

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[25] This is not a new idea, just a revived one. Honneth (1995: 14) points out that Hegel and Aristotle both made similar claims.

[26] Gilligan's project grew from her desire to demonstrate that moral constructions of responsibility were more diverse than the rationalised and masculinised versions that were over-represented in

> Tying morality to an awareness of power but equating responsibility with
> not hurting others, [the participant] considers responsibility to mean 'that
> you care about that other person, that you are sensitive to that other
> person's needs and you consider them as a part of your needs because
> you are dependent on other people'. (1993: 139)

This represents an understanding of the self that is bonded to society through a mutual sense of responsibility. It is a demonstration that responsibility can be understood as being much more complex than the equations of rights and responsibilities that dominate the *responsibility as freedom* position. Instead, this mutuality is accepted as necessary for the continuation of social order and the flourishing of the self within the conditions of life in a modern capitalist age. In addition to this, responsibility is bound up with a sense of self that is shaped by social features such as age, gender, class and ethnicity – it is highly particularised for people and groups *within* a local context while simultaneously having an effect that reaches outside of that local context.

The local context is of particular salience when we consider issues of power, stigma and esteem. Without recognition from other individuals and social institutions which supports one's worthiness as a rights-bearing member of society, it can be argued that an individual has difficulty developing self-worth (Honneth 1995). '[O]nly the feeling of having the particular nature of one's urges fundamentally recognised and affirmed can allow one to develop the degree of basic self-confidence that renders one capable of participating, with equal rights, in political will-formation' (Honneth 1995: 38). Thus we should be aware of the impact of social environments where groups and individuals are not afforded the basic elements required for the development of political identity. In such circumstances we can see how it may be

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previous studies of rational moral development, 1993: 18-19. In particular, she aimed to provide a direct critique of Kohlberg's work on moral stages. However, I do not see the utility in what has become the use of Gilligan's work to draw strongly gendered divisions between 'good' and 'bad' models of responsibility (for example, see Hekman, 1995). Gilligan herself warns against this type of simplification: 'The different voice I describe is characterised not by gender but theme. Its association with women is an empirical observation, and it is primarily through women's voices that I trace its development. But this association is not absolute, and the contrasts between male and female voices are presented here to highlight a distinction between two modes of thought and to focus a problem of interpretation rather than to represent a generalisation about either sex' (1993: 2). The strength in her work lies in its ability to articulate an alternative to the heavily rationalised and structured rubrics of morality that are characterised by the types of philosophical calculations meant to be universally applicable.

difficult (but not impossible) to recognise or sustain a sense of interdependent responsibility[27].

While the idea that self worth plays a role in the development of political will is valid, it is necessary to make a cautionary note about the notion that weak self-esteem is at the basis of failed responsibility as it has the potential to focus the entire discussion on the 'failures' of the individual. Honneth's work makes a significant contribution to a small body of theory examining the interaction between the individual and structural levels in the construction of responsibility, yet it also runs the risk of collapsing blame onto individual. Despite this, Honneth does try to develop a position that supports the incorporation of political struggle into a theory of intersubjective responsibility. This allows us to begin looking for those elements of responsibility that are inscribed into political being:

> A conception of ethical life in terms of a theory of recognition proceeds from the premise that the social integration of a political community can only fully succeed to the degree to which it is supported, on the part of members of society, by cultural customs that have to do with the way in which they deal with each other reciprocally. (Honneth 1995: 58-59)

With this idea of intersubjectivity we can begin to develop a model of responsibility based on the fundamental sociability of human beings. This kind of interdependence requires a degree of adherence to social concerns while at the same time it is what allows human sociability to flourish.

> The characteristic accomplishments of human beings are precisely the products of their lack of independence as responsible agents. Their cultures, institutions and forms of life; their inventions and innovations; their ability to generate and direct awesome concentrations of power; are all the result of their collective agency which derives in turn from ... mutual susceptibility. (Barnes 2000: 143)

It is not a model that relies only on the individual, rather it includes all forms of human organisation and activity in its scope, and regards human existence and behaviour as inherently social.

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[27] This leads on to his account of the development of social movements. He argues that excluded members of society must gain the cognitive understanding of what it is that is being withheld in order for them to feel the pain of exclusion. Once that hurt is felt, then it is possible to begin the fight for recognition through collective social action. See Honneth, 1995: Ch.6.

Following on from this understanding that responsibility exists as a vital component of social interaction, we can see how it plays a vital part in the struggle to shape others' visions and realities in an attempt to effect change for the benefit of society. In other words, it is political. As Rose asserts:

> Politics does not happen when you act on behalf of your own damaged good, but when you act, *without guarantees*, for the good of all. (Rose 1996: 62)

This vision offers a way of conceptualising a responsibility that is rooted in outwardly-directed action as the basis of social cohesion. It also includes the potential for conflict as a necessary element of political struggle.

Our consideration of the political aspects of responsibility also helps to diminish the centrality of individual responsibility as expressed in the *responsibility as freedom* paradigm. If responsibility did only operate within the self-contained unit of the individual, it would be impossible to explain the existence of the power that is exercised by groups (Barnes 2000; Honneth 1995).

> The manifest existence of *collectively oriented instrumental action* constitutes a fundamental problem, therefore, just so long as it is assumed that individuals operate independently and evaluate the consequences of their own individual actions separately in terms of the difference they make to the overall flow of events...And the existence of collective action implies that the postulate of such an individual, sufficient unto herself, unconnected to a larger context save only through expediency, is incorrect. Indeed it implies...that in order to understand the actions of an individual attention should be directed beyond her, toward her relations with others. (Barnes 2000: 57)

Our modern existence requires of us a mutuality that may not often be explicitly recognised, but is necessary nonetheless. Yet it is possible that the failure to recognise this interdependence comes about because responsibility is increasingly *attributed* to the individual while the real source of power derives more and more from institutional sources (Barnes 2000: 93-96). Thus the individual is blamed while decisions of consequence are made at higher structural levels. I have already analysed this at a theoretical level and in Chapters Four, Five and Six, I will provide empirical examples as to how this has occurred in official responses to HIV/AIDS.

So far I have established the need for an alternative understanding of responsibility because of the constraints of the individualised models of freedom and control, and

have discussed the requirements that such an alternative should place social context and social relations at its centre. This alternative understanding is inherently political.

I now want to turn to what I consider to be some of the most important elements of the political dimension of responsibility. In order to do this I intend to adapt elements of Weber's (1978) theory of politics as sketched out in his 1918 lecture, *Politics as a Vocation*. In this lecture, Weber outlines what he sees as the key characteristics of the 'good' politician. These are passion, a feeling of responsibility, and a sense of proportion (Weber 1978). His notion of responsibility is idiosyncratic and I will discuss it in more detail below. Before that, however, I want to turn to his notion of passion, wherein he refers to a feeling of commitment to a cause and a belief in a need for change. He did not elicit the sources of such passion, or provide an explanation of why some passions affect some and not others – rather he used it as his starting point for success in politics. Nonetheless, we should not take this to mean that passion is an inconsequential component of politics, when in fact it is essential.

It is not feasible here to explain all of the different possible motivations that lie behind specific decisions to become involved in political movements. However, in many of these instances passion springs from experiences of loss. As a result, we can gain insight from contemplating the way in which mourning plays a role in the absorption of loss in relation to intersubjective responsibility. This discussion will primarily be guided by Gillian Rose's (1996) discussion of the work of mourning after the holocaust of World War II and its implication in subsequent political projects and the development of responsibility. After mass death and the loss of millions of one's contemporaries, Rose argues that it is common to encounter 'pious' claims that the causes for such destruction are too vast to understand and that the responsibility for the deaths is too overwhelming to investigate or contemplate[28].

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[28] She referred to this specifically as *holocaust piety*, and discussed the way in which it inhibited political response. Rose argues that the refusal to mount a critical representation of such events amounts to an attempt 'to mystify something we dare not understand, because we fear that it may be all too understandable, all too continuous with what we are – human, all too human...What it is we do not *want* to understand?' (Rose 1996: 43). Although there is not the space here to elaborate much further on this concept, I think interesting analogies might be made through the idea of *AIDS piety*. That is, that in many

She explains this piety as coming from a refusal to engage in mourning, which amounts to a:

> refusal of entering into any experience which *comes to learn* that will, action, reflection and passivity have consequences for others and for oneself which may not be anticipated and can never be completely anticipated; which *comes to learn* its unintended complicity in the use and abuse of power. (Rose 1996: 122)

Rose presents a construction of mourning that overcomes this piety by using loss in order to stimulate investigations into the human condition. I believe that Rose's notion of mourning and its refusal can be usefully adapted to my purposes in developing a model of intersubjective responsibility. What I am talking about here extends well beyond the sadness and grief that we feel when we lose a person we love. Such emotions do not move us beyond the realm of the 'traditional' bonds with those in our closest social circles, as discussed in relation to 'blood and geographical ties' above. Instead, the understanding of mourning presented here relates to those events that bring about loss on a large scale and the affect it has on those who remain as well as their successors. The dead may include close friends and family but they also include those whom the mourner never knew. Such an experience has the potential to enable the mourners to apprehend the ways that the social structure of which they are a part has contributed to such loss. Therefore mourning is a means of coming into direct confrontation with our own human frailty and its enactment in the social structures of which we are a part.

The recognition of our own complicity in existing social structures that has been brought about through the difficult work of mourning can facilitate the more political, intersubjective responsibility under discussion here. In this way, we return to our discussion of the interrelationships between political impulse, passion and responsibility that Weber referred to as a requirement for success in politics, and which is necessary for an understanding of the way in which responsibility and politics combines in relation to HIV and AIDS.

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cases response to the epidemic has been halted by the sheer scale of infection, and the overwhelming moral imperative to act that it presents.

Within the arena of AIDS activism, there has been disagreement over the part that mourning plays. For example, writing about mass candlelight marches, Larry Kramer states:

> I am just slightly stunned when I witness so many electing to give such large amounts of energy, devotion, and caring to these morbid activities, rather than attempting to right the wrongs in a system that's made these activities necessary in the first place. (Kramer 1995: 264)

He regards such events as defeatist by nature because gay men who participate in them are accepting the hatred of homophobia as they bury their dead. He articulates an understanding of mourning that contradicts political passion because he says it merely involves the quiet acceptance of the deaths of numerous friends, acquaintances and strangers. Thus the atmosphere of respect that characterises such ceremonies is a symbol of defeat because it serves as a substitute for political action.

Kramer's position directly contradicts that which I am proposing here and is criticised in an essay entitled 'Mourning and Militancy' by Douglas Crimp (1989). Crimp describes mourning as a necessary element of AIDS activism because it figures as a means of responding to the world's silence about the epidemic. He characterises the first decade of the epidemic as a time when the press and public ignored the multitudes of deaths that urban gay men were experiencing all around them. Crimp describes this as a type of violence that interfered with the process of bereavement.

> The violence we encounter is relentless, the violence of silence and omission almost as impossible to endure as the violence of unleashed hatred and outright murder. Because this violence also desecrates the memories of our dead, we rise in anger to vindicate them. For many of us, mourning *becomes* militancy. (Crimp 1989: 8-9)

This anger erupted because those who mourned made the decision that they would no longer be complicit in the act of omission. Therefore the act of mourning for Crimp is the key to converting grief into action. This conversion requires that we 'confront ourselves' rather than living under the illusion that violence only comes from an external source (Crimp 1989: 17).

What we can take from the work of Rose and Crimp is an understanding that acts of mourning and loss are not apolitical. Instead, mourning is a social process of self

awareness that enables mourners to recognise not only the role of social structure in the losses they have suffered, but to simultaneously become aware of their own involvement in such structures. Once this process has begun, there exists the capacity to develop ethical bonds that reach out beyond one's personal sphere of family and friends. This is one process – one that I feel to be particularly important in relation to HIV and AIDS – which facilitates the formation of intersubjective responsibility.

This extension beyond the personal sphere is why I characterise this as a type of responsibility that is inherently political, and this returns us to Weber's political framework. While he emphasises the need for an 'ethics of intention' at the outset, he warns that the development of a politics based only on this passion will be ineffectual in challenging the status quo.

> The man who bases his ethics on intentions feels that he is 'responsible' only for seeing that the flame of pure intention, the flame of protest against the injustice of the social order, is not extinguished. The aim of his action, which, considered from the point of view of its possible consequences, is totally irrational, is to keep fanning this flame. (Weber 1978: 218)

Therefore to temper this passion, Weber states that successful political action also requires an *ethic of responsibility*. He describes the responsible person as the one who 'takes into account just those ordinary faults in men, he has...no right whatever to assume their goodness or perfection' (Weber 1978: 218).

This is a model of responsibility that directly relates to the ideas about mourning and its link to interdependent responsibility presented above. It is a responsibility that moves beyond the blinkered dreams of the passionate individual and takes account of the impact of action upon other individuals, communities and structures. It is also a model that reflects the interdependence of the modern world. Thus intersubjective responsibility cannot be enacted in a context where it is sheltered by the veil of naïve intention because 'the believer in an ethics of intention cannot accept the ethical irrationality of the world' (Weber 1978: 219). It is unrealistic and ineffective to enact a vision without the recognition that individuals and institutions with differing foci will present obstacles to what actors may regard as progressive social change. Politics is about ideology in conflict and success in politics requires a responsible

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account of the existence of struggle. This is how we can conceive of intersubjective responsibility having the political at its centre. It is a matter of taking account, not only of the others for whom there is concern to care and protect, but also the others who may use their power to assert alternative priorities.

Some have argued that the realisation of this power struggle in combination with the weight of responsibility prompts individual actors to believe that they can do nothing (Geras 1998; Tester 1997). Thus naïve idealism, where it exists, can come to an abrupt halt when it clashes with the paralysing sense that a problem is too overwhelming to resolve. While this may be the case for some, it does not explain those instances where intersubjective responsibility does occur – for example through the ideas expressed by the anti-globalisation movement; or in the international response to HIV/AIDS in the developing world. The third element of Weber's framework offers us a solution to this problem with the notion of *proportion*. He describes the individual or movement that finds a means of balancing conviction and pragmatics as one capable of influencing social change. Therefore the political strategy, the timing and selection of specific struggles forms a necessary component within this conceptualisation of responsibility. Those who can anticipate the needs and counter-arguments of their opponents and can then apply this knowledge to their planning have the most likelihood of success. It is with this kind of pragmatic approach, alongside passion and responsibility, that such efforts have the best opportunity to effect change.

This political process necessitates what we might call the *difficult understanding* that is required of responsibility (Arendt 1994). Engagement with the political involves a difficult undertaking – one in which uncomfortable realities will be confronted in the effort to determine how to act responsibly. I regard this as a project that will involve 'neither *ease* of understanding or *impossibility* of understanding but *difficulty* of understanding' (Fine 2000: 22). It is this need to confront the uncomfortable elements of politics, and hence the unfavourable elements of the self, that is required in order to realise responsibility. This amounts to an understanding of responsibility that is essentially political. Those who commit to this type of responsibility make an engagement with those outside of themselves. It is a declaration of the necessity of interdependence. However this is not an easy task. It requires realistic

acknowledgement that all of humanity does not abide by a universal system of ethics, therefore it is necessary to take into account the divergent principles and priorities of those who will stand in the way.

2.4 SUMMARY

This chapter has presented three different analytical approaches to responsibility contained within social theory. The approach that I call *responsibility as freedom* focuses on the requirement that individuals fulfil their responsibilities to others in order to enjoy the rights that are afforded to participants in orderly society. It is claimed by adherents to this approach that individual freedoms can only be enjoyed within a structure that is sheltered by such an agreed system of norms and values.

Following on from this, I presented an overview of the *responsibility as control* position which is critical of the individualism and assumed homogeneity that are implicit within the first approach. This latter body of work characterises responsibility as a means of establishing uniformity and self-surveillance among the least powerful groups of society, primarily by convincing individuals that they are to blame for their own misfortunes. While this second position accounts for social and structural context in discourses about responsibility, I have argued that it still does not provide a satisfactory means of interpreting constructive and political forms of responsibility beyond those that are employed for the purposes of control.

Therefore in the final section of this chapter I introduced the notion of *intersubjective responsibility* as an alternative to the prior views that are restricted by different shortcomings. Intersubjective responsibility involves an understanding that reciprocal bonds of care exist throughout modern society, well beyond a limited conception of the individual. This responsibility is actualised through political activity, and one of the motivations that I explored as an important source of political passion was the act of mourning. Through mourning we come to acknowledge the darker side of humanity, that in which we are complicit participants of destruction. It is with this kind of recognition that we are then able to return to the project of intersubjective responsibility with an understanding of imbalances in power and equality. This difficult knowledge is what gives this model its strength, because it has the added benefit of pragmatism in addition to passion. These are the reasons

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why an understanding of responsibility that is intersubjective can continue to be enacted in the face of inevitable conflict. 'The possible cannot be achieved without continually reaching out towards that which is impossible in this world' (Weber 1978: 225).

CHAPTER THREE: RESPONSIBILITY WITHIN DISCOURSES OF HEALTH, DISEASE AND HIV/AIDS

3.0 INTRODUCTION

In the previous chapter I outlined the ways in which responsibility has been discussed within philosophy and social theory. I characterised these approaches as *responsibility as freedom* and *responsibility as control* before arguing that if we are to move beyond the limitations of this dichotomy that we need to develop a notion of intersubjective responsibility. Of the two paradigms, it is the *responsibility as freedom* type of approach that has proved hegemonic and this has the effect of concentrating the notion of responsibility upon the head of the individual, in the fields of health and elsewhere. In the next three chapters, I will offer case studies of how this has occurred in three areas of HIV/AIDS policy: health promotion, testing and criminal law. Before that, however, I want to discuss how individualised notions of responsibility have developed within discourses of health and disease, and more specifically in discourses concerning HIV/AIDS. This discussion will also incorporate critics of such individualised notions, thus reflecting the dichotomy presented in the previous chapter. Following this, I shall discuss some contemporary ideas among those involved in the HIV epidemic who have begun to advocate a new type of action which closely resembles the model of intersubjective responsibility I have proposed.

I begin this chapter with a brief overview of writers whose work establishes the historical and sociological bonds between morality and disease. It has become a fairly common practice for those working in this area to trace the history of epidemic response as an antecedent of contemporary responses to HIV/AIDS. That history is not the focus of this thesis and thus what is summarised here represents only a brief review of their work[1].

Following this historical overview, I shall outline the increasing emphasis on the individual as the source of illness through a discussion about the emergence and

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[1] Those who have been most influential in establishing this area of research are: Brandt 1988b; Crawford 1994; Fee 1988; Fox and Karp 1988; Gilman 1987; Mort 2000; Musto 1988; Nelkin and Gilman 1988; Rushing 1995; Slack 1988; and Weeks 1989.

implementation of health promotion policy in the mid- to late twentieth century. This discussion will analyse specific models of health promotion with particular focus on the Health Belief Model (HBM) as it was reinforced in the 1980s due to the cultural phenomenon that had developed around AIDS.

As a part of this discussion about individual responsibility and health, I include the recent development and application of risk theory, including the impact that this potent construct has had on understandings of and critical reflections relating to HIV/AIDS. Risk permeates this discourse because of the close affiliation between individual responsibility and the avoidance of HIV risk in behaviourist approaches to prevention, and because the early establishment of 'risk groups' which allowed many people to dismiss the epidemic as something which was none of their concern. The final two sections of this chapter will review the ways in which the sociological literature dealing with HIV/AIDS has adapted over the course of the epidemic alongside contested understandings of individual and intersubjective responsibility. Before covering the specific case of HIV/AIDS however, there is a vast history to explore regarding the links between morality and the spread of disease.

3.1 INFECTIOUS DISEASE CONTROL THROUGH HISTORY

Socio-historians of health and illness have traced the moral elements of Western plague control through the centuries. Accounts of plague by the ancients, as well as the Judeo-Christians of the middle ages constructed versions of disease whereby those who were tempted by excess were then 'punished' by illness (Slack 1988). It followed that societies which collectively indulged in temptation would be stricken by plague or disaster, even if that meant that some 'innocents' were included among the 'punished'. Rhetoric surrounding illness and plague as punishment for sin is probably best traced through biblical references, particularly those in the Old Testament[2]. Although modern society is increasingly secularised, such metaphors

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[2] The Old Testament is littered with references to God's infliction of epidemic disease and pestilence upon those who have sinned against Him. A selection of these can be found in: Exodus 15: 24-26, Psalm 78: 50, Ezekiel 5:12, Amos 4:10, and in Jeremiah 14:12 when God says, 'When they fast, I will not hear their cry; and when they offer burnt offering and an oblation, I will not accept them: but I will consume them by the sword, and by the famine, and by the pestilence'; also 2nd Chronicle 21: 13-15 whereby prince Jehoram son of Jehoshaphat:

> made Judah and the inhabitants of Jerusalem to go a whoring, like to the whoredoms of
> the house of Ahab, and also hast slain thy brethren of thy father's house, which were
> better than thyself: Behold, with a great plague will the LORD smite thy people, and thy

have been sublimated in the popular imagination through new but related imagery (Gilman 1987; Sontag 1991).

Before Christianity overtook Europe, intellectual approaches to disease had been heavily influenced by the Hippocratic Corpus, with particular emphasis from Galen's work on humoral imbalance. The humoral approach focussed on disease which developed as a result of imbalances in the elemental substances of the individual body (Thomas 1997). Infectious disease and plague were understood to be caused by miasma, or foul air, caused by stagnant water, human exhalation and astrological influences (Rushing 1995; Thomas 1997). At this point, disease causation was located within the individual or through proximity to the sick but was not yet related to personal guilt or responsibility. However once Christian notions of sin and punishment mixed with these earlier understandings, the resulting explanations for illness combined all of these ideas. Therefore predisposition toward humoral imbalance could be regarded as an indication that individuals were engaged in sin, and plagues were blamed on prevalent wrongdoings of the day. As a result of these combined theories, those who associated with 'guilty' disease carriers were understood to also become both 'guilty' and 'infected' (Rushing 1995; Thomas 1997). Through this process 'miasma [becomes] an instrument of total rejection. The mere physical presence of the unwanted Other is dangerous' (Douglas 1992: 114-115). Location of disease causation within the blameworthy and immoral individual and the resulting social isolation would have a reverberating impact throughout the ensuing centuries (Nelkin and Gilman 1988; Sontag 1991).

Rather than leaving their lives in the hands of retributive destiny, those living in many early European societies fashioned responses to infectious disease that

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children, and thy wives, and all thy goods: And thou shalt have great sickness by
disease of thy bowels, until thy bowels fall out by reason of the sickness day by day.
In addition, there are also many instances where instructions are made to socially isolate the sick (particularly in the case of leprosy), as such individuals are the embodiment of God's disfavour: see Psalm 41: 7-8, Leviticus 13: 40-50 whereby strict instructions are given to the priest in order to determine the presence of leprosy, and to ensure that lepers are clearly identifiable and segregated. Further measures of segregation are also detailed in Numbers 5:2. Finally, biblical themes include those whereby the sinner pleads for divine intervention to relieve him of illness: see Psalm 38: 5&7 'My wounds stink and are corrupt because of my foolishness...my loins are filled with a loathsome disease', 2nd Samuel 24:15 where David pleads for forgiveness and the Lord offers him famine, plague or war as his three options of contrition. In the Bible's New Testament, accounts are given whereby Jesus heals the afflicted in Matthew 8:2, Luke 17:12 and Mark 1:40.

separated the infected from the uninfected, with the intention of separating the 'good' from the 'bad'[3]. Leper colonies were established thousands of years ago in the mistaken belief that any form of contact could lead to infection[4]. Thus long before the emergence of structured public health programmes, organised societies took measures to protect the health of the majority through quarantine and isolation[5].

First introduced for use among lepers and bubonic plague victims, quarantine and *cordons sanitaires* were common responses to disease in Europe for centuries. Moving forward to the Victorian era, it is possible to trace the ways that such measures were adapted for modern purposes. In the nineteenth century, efforts to contain cholera outbreaks in Europe and North America led to the institution of social hygiene programmes which further entrenched the already solid social boundaries between the activities of the civilised upper classes and the masses (Morone 1997; Mort 2000; Musto 1988; Rushing 1995; Weeks 1989). Owing to the strength of the popular imagery that condemned poor people and prostitutes as leading immoral and therefore inevitably disease-ridden lifestyles, it was these groups who were frequently targeted in control measures even when the same illnesses beset those in the middle classes. These social hygiene programmes saw the introduction of new forms of medical control through behavioural change but this did not completely bring an end to harsher means of segregation. As late as the first World War, more than 18 000 suspected female prostitutes in the United States were incarcerated in an effort to control venereal disease among soldiers (Brandt 1987).

While physical attempts to incarcerate female prostitutes in Victorian Britain were successfully defeated by early feminist campaigners (Mort 2000: 81), at the same

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[3] Slack, 1988 notes that Muslim societies often did not combat epidemics in this manner, as such events were regarded as deliverance.

[4] Musto, 1988 writes about the ceremonial segregation of the leper from the rest of society, representing the social death of that infected individual – and this is corroborated by Biblical references mentioned in footnote 2 above.

[5] Slack argues that response to plague had a role in the early development of the proto-nation state, as there emerged a need for an administrative body to protect the community against disease. He also points out that in some ways, we can witness the changing role of the Christian church by reviewing such developments. Gradually, more power became aggregated in the state as a form of protection against plague and disease through its ability to establish 'cordons sanitaires' around affected areas and cities, while all the church leaders could do was preach and pray. Not even the Pope seemed able to stop the Black Death despite the fact that he was meant to have divine powers of healing (Rushing 1995). The only thing that the church could do was to encourage charitable works for the poor and the sick. However, such measures led to a conflict between protecting the majority through complete

time moral and behaviour-based techniques of control became firmly embedded in the public psyche. The solution to social ills was increasingly sought through temperance and social hygiene. Mort argues that the development of a specific regime of sexuality and gender was crucial to the implementation of the medico-moral revolution that took place before the turn of the nineteenth century. Working class women's practices were placed under strict surveillance by the 'systematic forms of knowledge of sanitary science, social medicine, evangelical religion and philanthropy' imposed by organisations such as the Salvation Army, the Ladies' National Association, the Social Purity Alliance and the Quakers. This movement ultimately took on a nationalist flavour.

> The improvement of the physical and moral health of individuals was one
> of the prime duties of a Christian country, for the level of national health
> reflected the degree of civilisation attained by the state (2000: 52).

The remnants of this process whereby disease was moralised remain with us today and it will be argued below that metaphorical boundaries between 'us' and 'them' are today still reinforced through the use of individualised notions of responsibility. Rushing (1995) argues the transition between what he describes as earlier 'archaic' beliefs about disease toward modern 'metaphorical' and 'social deviance' models involves a process whereby religious beliefs have been supplanted by secular norms of morality (see also Brandt 1997; Mort 2000; Wellings 1990; Katz 1997). Sontag, who is often regarded as being among the first to draw attention to the metaphorical power of the long-established link between morality and health argues: 'The diseases around which the modern fantasies have gathered...are viewed as forms of self-judgement, of self-betrayal' (1991: 41). She points toward powerful remnants of the moral origin of disease within what many people would categorise as modern 'rational' societies[6]. In her analysis of the first mass health education campaign that took place in America, Tomes argues that the impact of such efforts firmly embedded the connection between morality and health in the mind of the average citizen:

> Because of its unprecedented scope and intensity, the turn-of-the-century
> crusade against TB [tuberculosis] had a profound impact on what might

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segregation and notions of Christian charity (Slack 1988). In this regard, the Church and state often had opposing views on the best way to deal with epidemics.

[6] The use of the term 'rational' here is indicative of the frequent conflation of rationality and responsibility as exemplified in the Health Belief Model and the Theory of Reasoned Action as discussed later in this section.

be termed public health morality, that is, the responsibilities that ordinary people assumed to guard themselves and others against infection. (Tomes 1997: 272)

3.2 SECULAR MORALITY[7]: HEALTH IN THE MODERN CONTEXT

Modern public health first emerged in mid-nineteenth century Britain and America as a means of protecting the well-being of the population against the harmful effects of industrial pollution, unmanaged sewage, contaminated water supplies and malnutrition (Ashton and Seymour 1988; Mort 2000). In this period, public health organisations began to consider their role within the context of a broader responsibility for the population on behalf of a nascent welfare state. As we have seen above, Christian social reform movements then encouraged the attentions of public health to focus on the behaviours of the individual. In the more recent secular age, the rhetoric has changed once again, this time revolving around notions of healthy 'lifestyle' choices. 'In the twentieth century concepts of morality are frequently translated into questions of lifestyle' (Nelkin and Gilman 1988). This is a perspective that maintains the nationalist overtones of its forebears through the implication that society is better off when citizens are well and that the individual is therefore responsible for the 'greater good'. A signpost of this international shift came in the form of Canada's 1974 Lalonde Report (Lalonde 1974)[8]. This report indicated a new stage in contemporary public health in that it emphasised prevention and took a keen interest in the lifestyles of individuals as a cause of illness. It introduced the 'health field concept', an approach taking human biology, environment, lifestyle and health care organisation into account as a unified means for government, communities and individuals to work towards improved health while at the same time saving costs.

Several key researchers in this field have also drawn attention to the role of John Knowles, President of the Rockefeller Foundation (now one of the leading funders of global AIDS research), in the promotion of an individualised notion of responsibility with regard to health (Brandt 1997; Crawford 1977; Nelkin and Gilman 1988). As the head of America's leading philanthropist organisation, his opinions carried a lot

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[7] This phrase is taken from the title of two essays, one by Leichter, 1997 and the other by Katz, 1997.

of influence within state policy development. Knowles' attitude may be illustrated by the following statement:

> The next major advances in the health of the American people will be determined by what the individual is willing to do for himself and for society-at-large... If he is unwilling to do these things, he should stop complaining about the steadily rising costs of medical care and the disproportionate share of the GNP that is consumed by health care. This is his primary critical choice: to change his personal bad habits or stop complaining. (Knowles 1977)

Here we have a prime example of rhetoric that places the onus of responsibility on the individual. As Knowles says in the same article: 'I believe the idea of a "right" to health should be replaced by the idea of an individual moral obligation to preserve one's own health - a public duty if you will' (Knowles 1977: 59)[9].

This perspective was intensified during this the 1970s for two main reasons. Firstly, there was a growing realisation that biomedicine could not put an end to all illness and disease, a chastening knowledge for a social order grounded in rational science. Thus the idea of 'good citizenship' was repeatedly reinforced by the production of government policy that deflected attention away from the imperfections of biomedical approaches (Crawford 1977). Secondly, there also exist strong socio-economic impulses behind the drive to the individualisation of health responsibility. Welfare states and large employers felt that they could no longer afford to provide high quality health care with its exponential rate of growth (Brandt 1997; Crawford 1977).

The shift towards the individualisation of health responsibility in the political and economic arenas was complemented by academic trends. Among health policy intellectuals, it was widely held that the means to improve public health was contained within the theoretical approaches to behaviour change that in turn led to the flourishing of new health promotion strategies. Taking early dominance in this field was Rosenstock's Health Belief Model (HBM). Although theoretical models

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[8] For commentary on the impact of this report, see Crawford 1977; Leichter 1980; and Bayer, 1989. Nelkin and Gilman, 1988 also draw attention to the release of the U.S. Surgeon General's document entitled *Healthy People* in 1979 that focussed on individual behaviour as the foremost cause of illness.
[9] The position outlined by Knowles has been dramatically challenged by the Treatment Action Campaign in South Africa which will be discussed in detail in Chapter Nine.

became more varied and diverse as the years progressed the HBM - with its central focus on the intake of health education by the individual and subsequent behaviour change – has continued to dominate many practical applications of health promotion[10]. Many current pieces of work continue to refer to Rosenstock's (1974) paper analysing the model's usefulness in predicting health behaviours and its application to health prevention through education[11]. He theorised that if individuals were provided with health information they would employ the tools of rational decision making in order to avoid illness. Rosenstock's original model operates on a series of interrelated principles. Firstly, the individual needs to perceive their own susceptibility to a health threat and they must regard that threat as something which is dangerous. The individual must also regard safeguards against that threat as effective and decide that the benefits offered by such safeguards outweigh any costs (Rosenstock 1974). The Health Belief Model is premised on an assumption that if individuals know about the existence of a risk and can apply it to their own situation, then they will change their behaviour[12]. However, Rosenstock did warn from the outset that the model would have limited applicability for those inhibited from health-seeking behaviour by socio-structural barriers and class-mediated attitudes and habits in relation to health.

> The Health Belief Model would seem to have greater applicability to middle class groups than to lower status groups since possession of the health beliefs implies an orientation toward the future, toward deliberate planning, toward deferment of immediate gratification in the interest of long-run goals. (Rosenstock 1974: 51)

While we may or may not agree with his characterisation of class difference, it does appear that Rosenstock takes some notice of external factors that constrain the individual[13]. There is, however, still a strong bias within Rosenstock's paper toward the ability of health promotion to persuade the target audience towards the goal of increased self-surveillance and behaviour change.

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[10] Tones (1990) points out that Becker (1984) later made significant amendments to the HBM. Bandura (1977) also modified the HBM by adding the notion of 'self-efficacy' (Naidoo 1994: 180).
[11] Rosenstock (1974: 32-33) clearly traces the development of the model from work conducted in the 1950s by Hochbaum and then more formally codified in 1966 by Kasl and Cobb.
[12] This is based on the concept of rational choice that has been widely criticised as a flawed means of framing human behaviour and decision making. It incorrectly presumes that all individuals are 'rational' and have the equal capacity to make informed judgements according to a uniform definition of rationality and neglects external power relations (Barnes 2000; Wolfe 1989).

The HBM is by no means the only model of behaviour change that has been applied to health promotion[14]. What follows is a brief overview of other models that have been influential in a range of health promotion contexts, but as yet have not proven to overtake the dominant role of HBM in its specific application to HIV/AIDS. Firstly, we might consider two predictive and process based models of behaviour change – that is, those that aim to help determine how rather than why people behave. The first is the Transtheoretical Model, often referred to as 'Stages of Change' introduced by Prochaska and DiClemente (1984). The authors represent behaviour change as a cyclical process, whereby individuals find themselves at different stages of ongoing decision making depending upon their own circumstances. Thus a person who is not yet ready to receive information would be (characterised by this model to be at the 'pre-contemplative' stage – a point where a small number of health interventions may be conceivable, yet others that are typified by most health education may not. At all stages in this cycle, such as the 'contemplative', 'decision', or 'action' stages – the individual is considered to be at the centre of decision making, while the health promoter is characterised simply as a facilitator. This model recognises the external social components that contribute to individual decision making as well as the fact that all people are not ready to receive health education all of the time. It also makes allowances for the need to maintain health behaviour changes, and that sometimes further decisions result in termination of change, factors that are not usually taken into account by other models.

In alignment with this approach is a more scaled-down version called the AIDS Risk Reduction Model, developed by Catania (1990). Here change is described in three stages: the first where behaviour is identified as problematic, the second when a decision is made to commit to change, and the final when action is taken. Again this is a model that takes personal and social factors of readiness into account but even more than in the Stages of Change model, there is little concrete provision here for health promoters who seek definitive content for their work. Instead, we find that

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[13] While the main criticism directed at Rosenstock is that he has neglected to consider social and structural contributions to health related behaviour, I would argue that this is mostly a result of neglectful research that has failed to consult the source document.

both of these cyclical models might support health promoters who are seeking to find a target audience who might be ready for health education, and in turn might allow them to tailor effective interventions for people who may be at different stages in the decision-making process. Aspects of these process-based models have been useful to the theoretical development of health promotion. However, the mass media campaigns that typify the most visible application of the field demonstrate that the only stage of readiness to which most interventions might apply would be the time immediately preceeding action when the individual is looking to gather information.

Other models focus less on decision making as a process, and instead concentrate on the reasons why individuals might change their behaviour, in much the same way as their predecessor, the HBM. The Theory of Reasoned Action developed by Ajzen and Fishbein (1980) demonstrated a shift towards considerations of factors residing outside of the interior terrain of the individual. Thus issues such as the perceived consequences of behaviour and expectations and responses from others in relation to individual decisions to change formed the basis of this approach. These exterior issues were understood to form the basis of intention, and Ajzen and Fishbein argued that intention was the main predictor of action. This model has been put into practice through health promotion campaigns which aim to develop normative frameworks that might encourage the individual to conform. Thus it is possible to see the ways in which celebrity spokespeople might contribute to the establishment of these types of norms, particularly when they are used to specifically target an ethnic or age-banded audience.

The Health Action Model as presented by Tones (1987) can be regarded as a model which combines process oriented features as well as internalised and externalised determinants of change[15]. In this model positive self-perception and esteem are regarded as key resources that lead to change[16]. Thus, an individual is not ready for change until it is possible to regard oneself as worthy and capable of gaining positive

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[14] Chapters Five and Six will explore the ways in which this model continues to assert itself in traditionally-based HIV/AIDS health promotion, as well as underlying many assumptions about the benefits of HIV testing.

[15] Also see Tones, Tilford and Keeley-Robinson 1990.

[16] Critics of this approach point to research which demonstrates that there is a weak relationship between an internal locus of control and healthy behaviours, as those with high degrees of confidence may be willing to take more risks (Naidoo and Wills 1994: 188).

control over external circumstances. Interventions which aim to boost self-efficacy among young people or marginalised groups may implement aspects of this model. Another approach which would be typified by this type of esteem-boosting, yet has a more complex theoretical underpinning is the Community Development model. Elaborated by people in the field such as Smithies and Adams (1990) and drawing on the work of liberationist philosophers such as Paulo Friere (1972) it is a model that comes from a completely different starting point than those described above. Rather than concentrating on the necessary processes to encourage individual change, the community development model conceptualises the way which shifts in power among social groups contribute to changes in health. This approach gained international significance when it was used as a key component of the World Health Organisation's central planning document, the Ottawa Charter for Health Promotion:

> Community development draws on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation in and direction of health matters. This requires full and continuous access to information, learning opportunities for health, as well as funding support. (WHO 1986: 4)

However, there are questions to be asked about the efficacy of implementing community development in a field that continues to be dominated by the individualised approaches that are typified by the Health Belief Model. 'Since CD [community development] is a political activity based on collective experience and action, it has remained at odds with the focus on personal behaviour which has dominated mainstream policy and practice' (Amos 2002: 63). Amos stresses the point that the majority of health promotion activity in the UK - and arguably across the developed world over the past several decades - has implemented individual-level theories of behaviour change, such as those discussed above. While community development approaches are apparent in some high-level policy guidance documents, there is a problem with the assumption that these two types of approaches can function properly alongside one another.

> Creating a framework which tries to create an all-embracing picture in which equal weight is given to each component may be offering an image of progressiveness while changing nothing. The risk is that this allows traditional practice (personal behaviour change) to simply continue under the guise of a more radical approach. (Amos 2002: 67)

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Leichter's (1997) analysis of health policy documents in the UK and elsewhere, supports the concerns raised by Amos, as he argues that the burden of change remains with the individual, no matter how the language appears to be couched differently.

I return now to the earlier discussion of policy change, preceding the spate of theoretical models that accompanied the drive for health promotion. With Leichter and Amos' concerns about the individualised undertones of health policy in mind, consider the case of the UK's 1992 *Health of the Nation* white paper. Although the Health Secretary's introduction spoke of balancing responsibilities between the government, other agencies and individuals, most specific strategies in the document were directed towards individual behavioural changes such as improved diet and safer sex (Department of Health 1992) [17]. New Labour's subsequent national health policy, *Our Healthier Nation* (1999), uses the notion of partnership to make arguments reminiscent of Canada's Lalonde report, twenty five years later: 'It is the Government's job to spell out the facts and quantify the risks on which individuals can make informed decisions' (Department of Health 1999: forward)[18]. Like the Lalonde report and *Health of the Nation*, it prescribes the role of government, communities and individuals on the assumption that these partners are operating on equal ground and that no conflicts exist between them. However, it is clear when looking at the sections outlining the roles allocated for these three partners, that the burden of responsibility rests with individual citizens. For example, the document opens with 'Ten Tips for Better Health' aimed at the individual, such as: don't smoke; reduce stress; exercise regularly[19]. The use of the term 'partnership' in *Our Healthier Nation* refers to partnership between government, communities and

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[17] An assessment of the success of this policy later found that it had little impact on public health in terms of policy implementation or outcomes, because it did not provide any framework regarding how local health trusts and local authorities were meant to use it (Department of Health 1998).
[18] This is a direct mirror of one of Mrs. Thatcher's rare quotes on AIDS: 'Governments cannot stop people from getting AIDS. They can give the information which enables them to prevent themselves getting it' (cited in McKie 1986).
[19] *Our Healthier Nation* excludes sexual health from its four main target areas, but says that a separate strategy for sexual health is under consultation. Poor statistics on teenage pregnancy and sexually transmitted infections in the UK alerted the government to deficiencies in this area giving great impetus to the development of a combined sexual health and HIV/AIDS policy. It is perhaps, however, a sign of the contradictory messages given by the government on the importance of sexual health that this topic is not at the centre of the national health strategy. The Government's long awaited Sexual Health Strategy was released in draft form for consultation in July 2001 and plans for its implementation were released in July 2002.

individuals and doubtless plays a necessary role in improving health. However, the idea of 'partnership' must be re-assessed in light of the state's own inactivity in restructuring the unequal social conditions of health. This partnership does not operate on the understanding that the most powerful and resourceful partner, the state, has the greatest responsibility for social change – beyond health reform rhetoric. The inverse is true in that the individuals who are most vulnerable and possess the least power have the greatest obligation to 'take responsibility' and change their 'lifestyles' in order to become healthier citizens[20].

3.3 CRITIQUES OF INDIVIDUALISED MODELS OF HEALTH

The increasing emphasis placed upon individuals to take active responsibility for their own health has been a focus for sociologists and anthropologists within the health field (Brandt 1997; Crawford 1977; Daykin and Naidoo 1995; Fee and Krieger 1993; Finerman and Bennett 1995; Gastaldo 1997; Leichter 1980; Moran 1988; Nelkin and Gilman 1988). In accordance with the *responsibility as control* arguments in the previous chapter, many have argued that this trend reinforces existing social divisions in classifying who is and who is not a 'good citizen'.

> The language of health came to signify those middle class persons who were responsible from those who were not, those who were respectable from those who were disreputable, those who were safe from those who were dangerous, and ultimately, those who had the right to rule from those who needed supervision, guidance, reform or incarceration. (Crawford 1994)

In their discussion of the American public health policy experience, Fee and Kreiger criticise the workings of health behaviour models that focus on the role of individual choice and behavioural change.

> Adopting the notion of the abstract individual from liberal political and economic theory, it considers individuals 'free' to 'choose' health behaviours. It treats people as consumers who make free choices in the marketplace of products and behaviours, and it generally ignores the role of industry, agribusiness, and government in structuring the array of risk factors that individuals are supposed to avoid. There is little place for understanding how behaviours are related to social conditions and

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[20] Not everyone agrees with this reading of the 'New Public Health'. For example, Ashton and Seymour argue that 'it seeks to avoid the trap of blaming the victim. Many contemporary health problems are therefore seen as being social rather than solely individual problems' (1988: 21). While *Our Healthier Nation* does appear to take social factors for illness into account, it still appears that the individual is given a tremendous burden of responsibility for behaviour change, with minimal outlines as to the public guidance or support which would enable such change.

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constraints of how communities shape individual's lives. From this perspective, populations and subgroups within populations – including 'risk groups' – consist merely of summed individuals who exist without culture or history. (Fee and Krieger 1993: 1481)

Criticisms of the historical and academic development of individualised approaches to health have been extremely popular among those researching the efficacy and impact of HIV/AIDS health promotion. While health promotion professionals have tended to argue that the primary way to prevent AIDS is to encourage individuals to change risky behaviour that can lead to HIV transmission, critics contend that isolating individual responsibility in this way serves to blame those who are most vulnerable to infection[21]. In the case of HIV/AIDS, the strongest criticism of the HBM has been that it disregards the intimate nature of sexual decision making and shared injection of drugs as these situations exist between real people.

> A model of behaviour like the HBM, which conceives of risk behaviour as a volitional individual act, seems quite inappropriate for the analysis of behaviour which self-evidently involves two parties not one individual and which is characterised by constraint, not free choice (Bloor 1995: 90).

This shall be discussed in more detail in the next chapter.

It is possible to argue that the appearance of HIV/AIDS in the 1980s contributed to the resurgence of focus on the relationship between individual responsibility and health. Yet at the same time we have already seen evidence that the connection was growing in popularity even before this point and we should divorce the responses to AIDS from wider neo-libertarian social developments at this time. The epidemic emerged when popular consciousness was already being directed toward the understanding that the individual has a grave responsibility to protect his or her own health[22]. In addition to the development of a new secular linkage between health and morality, Weeks argues that the disappearance of traditional social values also led to cultural obsessions with connections between sexuality and the creation of the self.

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[21] See (Brandt 1997; Crawford 1994; Daykin and Naidoo 1995; Frankenberg 1994; Keogh 2001; Sontag 1988; UNAIDS 1998a) as well as those referred to in further discussion on this issue in the last section of this chapter.

[22] A brief list of the central writers that have established the way in which the Anglo/American New Right resurgence established a moral ground upon which the widespread panic and ostracism that met AIDS flourished includes: Weeks 1989; Crawford 1994; Leichter 1997; Patton 1986; and Shilts 1987).

While also arguing that sexuality has never been far from the centre of hegemonic processes, he says that what is new in this instance 'is the way in which worries about changing sexual behaviour, and gender and sexual identities have become the explicit focus for debates about the current shape and desirable future of society' (Weeks 1995: 4-5). He goes on to argue that HIV/AIDS emerged at a point in history when issues of sexuality and health were simultaneously at the core of the citizenship project.

> If sex and the health, fitness and well-being of the body are principal
> elements of personal identity in the modern world, and if modern identity
> is in part at least based on an avoidance of death, then inevitably an
> epidemic which associates sexual activity (heterosexual as well as
> homosexual) with death is likely to have a profound existential impact.
> (Weeks 1995: 169)

Thus there is a strong relationship between changing social processes underway in the early 1980s and the emergence of AIDS at that time. For economic and ideological reasons, post-war faith in science and medicine could not maintain itself. Amidst all of the social change that took place in the latter decades of the twentieth century, key features anchoring the new sense of individual citizenship included strong notions of self-reliance relating to health. The new outlook revolved around the need for individuals to be responsible for the maintenance of personal well-being and, like other areas of individualised responsibility, this in turn served to reinforce entrenched social divisions. 'The new secular morality is only partly about health and a good deal about individual and collective social position, status, and image' (Leichter 1997).

It is this environment that contextualised the emergence of the new epidemic. AIDS reinforced the growing sense that science was fallible and, by affecting marginalised segments of society, operated as a mechanism which easily supported deepening divisions between the responsible and irresponsible, the well and the unwell. It supported and strengthened the distance between self and 'Other' that had begun to emerge through discourses about health in preceding years. AIDS also provided the sense of crisis that in turn made it easy for mainstream Western politicians, press and public figures to promote the need for moral systems to provide some stability in a changing world.

3.4 DISCOURSES OF RISK

A theme that has maintained a constant presence in the preceding pages is that of risk. Risk discourse permeates individualised notions of health and is a key element in the production and critique of responses to the epidemic[23]. It is also a dominant theme within current sociological theory and in Chapter Two there was a brief reference to figures such as Beck and Douglas who have been central to the growth of risk as a topic within sociology and anthropology in recent years. In this section I will consider the development of risk as an area of theoretical enquiry and its role in the construction and criticism of individualised responsibility for health in recent decades, before discussing the way it has impacted on experiences of and responses to the HIV/AIDS epidemic.

The word 'risk' was used in the *Exerpta Medica* database 5,500 times in 1980 and 15,000 times in 1993 (Carter 1995: 137). It is a concept that has recently pervaded expert terminology and has also firmly established itself as a popular concept. Douglas' work focuses on the important social role of risk in contemporary society. She characterises contemporary Western society as being less able to draw on traditional boundary markers (such as religion, moral codes and blood ties) and argues that their role is being taken on by the concept of risk (Douglas 1966; Douglas 1992). 'The neutral vocabulary of risk is all we have for making a bridge between the known facts of existence and the construction of a moral community' (Douglas 1992: 26). Her work emphasises the social necessity of the construction of risk: it is a means through which we are able to navigate myriad options and images in a society that is no longer so highly organised by the institutions of the past such as church and family.

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[23] For our purposes, it would impractical to talk about HIV transmission without reference to the 'objective' categories of high/low risk behaviours. Scientists have agreed upon a distinct set of behaviours leading to higher or lower potentialities of contracting the virus. 'Risky behaviour' is defined as that which leads to the exchange of blood and semen with a partner who is HIV positive, such as sharing intravenous needles, or having penetrative sex without using a condom. Pregnant women who are HIV positive can transmit the virus to their children through birth and/or breastfeeding, yet this effect can be mediated through medical treatment and modified birthing and feeding procedures. Yet, there is a need to recognise the paradox created by criticising notions of risk as social constructions while simultaneously employing these notions as part of the discussion about HIV and prevention.

The question of whether risk is an objective thing or a socially constructed entity is common with theorists of risk discourse and Beck (1992) in particular seems to fluctuate between the two positions. As with Douglas, Beck argues that risk is a central guiding principle of late capitalism. However, Beck is also guilty of reifying risk. For example, when discussing risk in relation to social class, Beck argues that those in most pressing need are least likely to acknowledge the 'real' risks that have the greatest potential to bring destruction: 'The tangibility of need suppresses the *perception* of risks, but only the perception, not their reality or their effects; risks denied grow especially quickly and well' (Beck 1992: 45).

It is certainly true that risk is often understood as an 'objective' concept in everyday life, used to navigate our lives by calculating acceptable levels of risk and minimising unacceptable ones. This practice is central to insurance, for example. Whether or not risk is 'actually' real is a matter for social ontology and will not be answered in this thesis. However, what is important for this thesis is the implication that if risk is *objective* it is also *valueless*. Risk is not a uniform category of abstraction, but a meaningful concept employed in a variety of different social settings. Risk is valued or censured depending upon these social meanings and on existing social norms. For example, the risk associated with speculating on the financial markets is generally more highly regarded than gambling on horse racing. Risk is therefore not a neutral category and the approaches that emphasise the objectivity of risk merely serve to eliminate the visibility of alternative interpretations (Gabe 1995: 5; Licence and Stark 2000) [24].

One of the key elements of risk theory is that the individual is able to appraise him or herself of their risks and act within this knowledge. In Beck's formulation, this individual is the *reflexive global citizen*. The reflexive global citizen is a pro-active social actor who makes choices based on a range of expert opinion. Beck regards increased individualisation as the key to the citizen's ability to be reflexive; thus we make choices based upon what is best for our own personal circumstances (Beck 1992: 153).

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[24] For example, some may be drawn toward taking risk (see footnote 32).

Giddens' work in this area also takes up this idea of what he calls *reflexive modernity* as a means of describing modern responses to risk and change through the individual's capacity to self-direct (Giddens 1994). In her comparison of these two theorists' work, Lupton concludes that Giddens is much more aware of the subjective perception of increased risk which is heightened by modernising processes than Beck, who sometimes makes the case that increased risk is a factual reality (Lupton 1999b: 81). However, more important than their differing attachments to reification, I would argue that it is their popularisation of reflexivity and requisite individualisation that requires problematisation. As was also the case with promoters of HBM, we find here that these theorists have neglected to pay sufficient attention to the power relationships, desires and concerns that impact upon individuals in complex social settings. Their work has had a significant impact on the pursuit of risk studies at academic and policy levels and yet it repeats many of the same assumptions that have been criticised for decades in sociological analyses of health.

The idea of risk has played a significant role in the formation of a response to HIV/AIDS, particularly the impact of creating 'risk-groups' in the first decade of the epidemic and it is worth questioning to what degree were those relegated to risk-groups able to generate and enact a reflexivity that might have made it possible for them to evade risk. When viral transmission of HIV was discovered in the mid-eighties, America led the way with its 'risk-elimination' approach (Maguire 1998). In relation to sex, this included discussion of abstinence, monogamy and non-penetrative sex with condom use as a last resort. In terms of illicit use of needles, it meant stopping heroin addiction. While behaviour change was dramatic in the urban spheres of a few urban areas such as New York and San Francisco (Catania *et al.* 1991), it took much longer for such change to take hold in other geographical locations. The approach has generally been dependent upon the notion of 'risk groups'. That is, prescribed behaviour changes were directed at those whom health promoters and epidemiologists had determined were most likely to be affected by the virus. It was believed that if members of risk groups stopped what they were doing, then the progress of the epidemic would stop too.

Those approaches seeking to 'eliminate' risk have been the most likely to employ the notion of risk groups in their epistemology. In the UK context for example, this has

usually meant gay men, haemophiliacs, African migrants and injecting drug users, as they appeared to be the demographic groups where the virus was concentrated. Individuals in these categories were simply assumed to be at higher risk, rather than taking the more complex approach that membership of specific groups cannot be assumed to be constitutive of specific behaviours. Some commentators such as (Brandt 1988; Crawford 1994; Glick Shiller 1994; and Watney 1994) have argued that official organisations' extensive dissemination of the idea of the 'risk group' exacerbated social polarisation.

> This tendency to distance the "general population" from "risk groups" has acted at cross-purposes to public health goals, facilitating public definitions of the HIV epidemic as a problem which concerns others, not oneself and one's own "group". (Glick Shiller, Crystal and Lewellen 1994: 1344)[25]

Rather than strengthening a 'reflexive citizen' identity among those whose behaviour meant that they were at highest risk of acquiring HIV, the creation of risk groups solidified moral power and lessened reflexivity among those who were furthest from the epidemic. 'The loss of health or simply the characterisation of a person as "high risk" entails a setting apart. Thus, the claim of health is simultaneously a declaration of identity: "I am responsible and rational"' (Crawford 1994). Crawford also makes the somewhat Foucaldian observation that categorisation of individuals said to be 'at-risk' leads to a public assumption that submitting to surveillance is the responsible choice: 'The "at-risk" self is vulnerable; and responsibility is currently said to consist of a willingness to monitor, confront and do something about that vulnerability' (1994: 1357). Frankenberg writes about the way in which considerations of the individual become lost by the practice of risk-grouping which was the hallmark of AIDS epidemiology and health promotion (Frankenberg 1994). While arguing that it is always easier for researchers to understand a group than it is to understand an individual (because non-cohesive data can be discarded from group study), he feels that health promotion which targets groups that are assumed to behave as a homogenous unit will always be doomed to failure. This failure results from the improbability that an individual will identify him- or herself within the language of

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[25] While it is evident that some prevention literature has emphasised risk groups, the broad range of AIDS literature released in the UK has been quite diverse, with the result of mixed messages and confusion on the part of the reader. Early UK prevention literature and campaigns by the HEA and the British Medical Association (BMA) would alternate between discussions of the whole nation at risk, and messages about specific risk groups. See Chapter Five for examples.

'risk-groups' and the additional problem that the individual cannot witness direct results from a personal change in behaviour[26].

Grouping people according to external variables rather than conducting a more complex analysis of what behaviours led to HIV transmission contributed heavily to the stigmatisation that characterised the epidemic from its earliest stages. Instead of allowing for the creation of a motivated response and change in behaviour by those most vulnerable, this process drove many people further underground, and has been a barrier to the transmission and reception of even the most basic messages about HIV prevention. In addition, it was an approach that enabled official responses to avoid discussion of broader structural determinants of vulnerability to infection.

The concept of risk is one of great importance to a sociological understanding of HIV/AIDS and responsibility. It is hardly surprising, given increasing individualism throughout society, that risk discourse has increased throughout the 1980s and 1990s. The version of risk theory popularised by Beck and Giddens is an individualised theory which updates the rational choice models outlined in the *responsibility as freedom* position. It makes the assumption that all actors have power to effectuate action (thus Giddens' assertion that even the man with a gun to his head has a choice in his course of action) and does not pay sufficient regard to structural constraints upon action. These constraints are hidden by the seeming neutrality of risk discourse. Risk is approached as an objective fact but this does not reflect varying social judgements placed on different types of risk that perpetuate stigma and divide society into the responsible and the irresponsible. Risk is a site of power and, as with individualistic approaches discussed earlier, it contains a moral imperative toward 'responsible' behaviour.

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[26] In contrast to *risk elimination* approaches, *harm reduction* encourages people to consider their own situation and external influences that may affect their behaviour. Campaigns designed under this model describe several possible courses of action that could be taken depending on the intersection of many factors in personal situations. The approach encourages people to consider how they can best make decisions that take their personal and social realities into consideration. This model has formed the basis of programmes that encourage IDUs to exchange their used needles for clean ones through publicly funded schemes. Rather than regarding quitting injection as the only means of avoiding HIV infection, such programmes recognise that there are other alternatives. This approach has been linked to a significant reduction in the rate of HIV amongst British IDUs (Stimson 1996).

3.5 THE TREATMENT OF RESPONSIBILITY IN HIV/AIDS LITERATURE

There have been a variety of ways in which HIV/AIDS literature has conceptualised responsibility. A predominant mode of apprehending responsibility in relation to the epidemic has been through the use of a behaviourist public health focus on the actions of the individual, as already discussed above in relation to the Health Belief Model. This approach targets the ways in which individuals can be encouraged to adopt responsible behaviours that will reduce their risk of infection. This has resulted in responses from academics, researchers and activists who argue that overemphasis of the behaviourist harm-elimination and reduction approaches enhanced the invisibility of larger socio-structural issues and interdependence. From some of these criticisms of the HBM, new models of responsibility began to emerge that extended beyond individual behaviour, individual pain and individual subjectification. These new ideas, which I shall outline in the last section, reflect the idea of an intersubjective responsibility that I outlined in the previous chapter. They involve discussions about collective liability for the epidemic and include an awareness of the political dimensions that have enabled the epidemic to spread, as well as those that have enabled successful prevention.

The individualised behaviourist model of responsibility relating to HIV/AIDS finds its most natural home among leading scientists and doctors involved in the epidemic. Anthony Fauci[27] has been at the heart of the American scientific response since the early eighties, often acting as media spokesperson on the topic. The behaviourist attitude towards prevention is clearly stated in an article discussing the future of the AIDS epidemic: 'HIV infection in adults is entirely preventable by behaviour modification' (Fauci 1999: 1048). Unsurprisingly, the majority of prevention measures he suggests are those revolving around changes in the lifestyle of the individual. In direct contrast to those who have argued that there can never be any one 'Magic Bullet' cure for sexually transmitted infections (Brandt 1987), Fauci also says: 'The solution to the HIV pandemic is the development and availability of a safe and effective vaccine against the infection' (1999: 1049). Fauci's comments are representative of the rational scientific approach that centres upon individual

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[27] Director of AIDS research at the National Institutes for Allergies and Infectious Diseases

behavioural change until the times comes that scientific research brings the ultimate triumph in the form of a vaccine.

Leading communitarian, Amitai Etzioni has also offered his own view on the behavioural causes of the epidemic:

> The only way to battle the AIDS epidemic in Africa effectively is for African men to change their behavior. If they stop frequenting prostitutes, abstain from intercourse when they are young, and remain monogamous once they have girlfriends or wives, the rate of HIV transmission will drop fast... Anybody who does not focus on fostering behavioral change and who invests all hope in drugs or vaccines should consider himself an accomplice to the AIDS epidemic. (Etzioni 2000)[28]

Etzioni makes it clear that he regards individual sexual irresponsibility as the primary (and apparently only) force that drives the epidemic. He goes further and implicates those seeking medical rather than social solutions as irresponsible. However, it is not only within some wings of the scientific, political, and academic establishment that the onus of responsibility has been placed upon the individual through simplistic calls for sexual behaviour change. Some vocal members of America's gay community have been the loudest proponents of this approach. For example, while ACT UP founder Larry Kramer has relentlessly lobbied for governments and research bodies to be held accountable for their inactivity, his most contentious efforts have included his continual cajoling of America's gay population to change their ways for their own self protection[29]. Although his motivation was firmly rooted in a belief that this was the only way to prevent the impending holocaust for gay men, he has been accused of being a collaborator with the moral majority because of his anti-promiscuous stance on gay sex (Kramer 1990). While ACT UP drew public attention towards the need to make institutions accountable for their part in the

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[28] These comments sparked off several heated responses on the email forum organised to coincide with the 2000 International AIDS Conference (called Break the Silence), highlighting Professors Etzioni's mistaken opposition between prevention and treatment, as well as his apparent ignorance of structural factors such as poverty, stigma and marginalisation which have formed the base of the epidemic's growth in Africa. Dr. Subiri from Kenya said: 'Of course, professor, the only thing I can tell you for now is that as long as people like you continue peddling their half-baked ideologies to an audience that has never been given a chance to defend itself, or explain itself out, then humanity is doomed' (Subiri 2001).

[29] ACT UP (The AIDS Coalition to Unleash Power) has had a powerful impact on the way in which health activism is now conceived. After his retreat from what he viewed as the failures of vision within the Gay Men's Health Crisis in New York, Kramer formed ACT UP to demand the release of experimental HIV drug treatments through direct and often highly creative demonstrations that created a good deal of media interest (Brown 1997; Epstein 1996; and Kramer 1990). ACT UP takes the

ongoing epidemic, Kramer simultaneously demanded that each gay man should also take personal responsibility for its course.

> I am sick of guys who moan that to give up careless sex until this blows over is worse than death. How can they value life so little and cocks and asses so much? Come with me guys, while I visit a few of our friends in Intensive Care at NYU. Notice the looks in their eyes, guys. They'd give up sex forever if you could promise them life. (Kramer 1995: 46)

Kramer has not been alone in his anger about way in which what he would characterise as debased urban gay sexuality has fuelled the epidemic. While being aware that his thoughts would be described as 'puritanical' and divisive, Andrew Sullivan who is also gay and HIV positive writes:

> Unlike the Spanish flu or the Black Death, it [AIDS] was not entirely random because it was spread by sex, and sex has rarely been understood to be as neutral an activity as shaking hands or breathing the air. Nor, of course, should it. The meeting of two human beings in a sexual encounter can never be a neutral or casual phenomenon. It has meaning, and danger, and promise. It betokens a particular form of responsibility, as well as liberation. And when it also involves the risk of death, that responsibility – and that meaning – is even more profound. (Sullivan 1998: 39)

Without differentiating between acts of sex that carry a risk of HIV transmission and those that do not, Sullivan agrees with what he identifies as the widespread view that the sexual is immanently moral. Therefore, sex should never be casual, as he feels that it involves a deeply responsible engagement between individuals.

To take one further example of a voice calling for individual change, Almond argues that the responsibility to protect others outweighs the argument that individuals have a 'right to ignorance' about their HIV status (Almond 1996: 10). In relation to the onus on the individual to take special precautions in relation to safer sex, she says: 'Where a person is prepared to take such a responsible attitude, the intervention of the state would be redundant' (Almond 1996: 10). Therefore, rather than taking a structural view of the role of the state and other institutions in the creation of conditions that perpetuate the epidemic, hers is a position that sees only the actions of the individual as having any relevance. The state is regarded as a necessary

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position that delays imposed by governments and pharmaceutical companies have been responsible for millions of deaths from HIV/AIDS.

buffer, one that will govern and discipline those who have not learned how to behave 'responsibly'.

In reaction to such perspectives, there has been a significant critical body of work that problematises the easy solutions and simplistic imagery characterising the behaviourist position. While Susan Sontag did not directly address responsibility in *AIDS and its Metaphors* (1988), those who pursue notions of responsibility within the epidemic have drawn many ideas from her work[30]. In it she outlines the ways in which AIDS is presented using metaphors of war, enemy, pariah status, foreignness, sexual disease, punishment and morality. Although she has been justifiably criticised for a lack of political perspective and rigorous methodology (Brandt 1988a), Sontag's work did serve the purpose of initiating further investigations of AIDS imagery and representation, and their relationship to responsibility[31]. For example, Wilson-Ross (1988) describes the harmful effect that newspaper constructions of 'otherness' have on the progression of the virus:

> By referring in print to AIDS as a 'gay disease' or a 'gay plague', those in the straight community are encouraged to think of AIDS as something happening beyond their borders, outside the 'general population' - as something happening to people for whom they have no human responsibility. The metaphor of otherness provides comfort to those who use it because it implies that they will be spared harm and responsibility. (Wilson-Ross 1988: 46)

Analysis of media coverage of AIDS has been undertaken across a range of developed, English-speaking countries, and the findings are similar to those reported above by Wilson-Ross[32]. With particular focus on the impact of press reporting in the earlier years of the epidemic, repeated analyses have demonstrated that divisions between 'innocent' and 'guilty' victims of the epidemic became firmly implanted images in public understandings of AIDS. Isolation of responsibility in this way has become a pervasive feature of AIDS reporting.

> AIDS is still almost entirely a disease passed on by poofters and junkies. Only their promiscuity and stupidity has spread it like wildfire. (*Daily Star*, 18 December 1990)

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[30] For examples see (Davies *et al.* 1993; Griffin 2000; Watney 1987; Weeks 1995; Wilson-Ross 1988).

[31] Also, see Triechler, 1987 and Gilman, 1987 whose works have also been of great significance in this area.

[32] For examples see: (Colby 1991; Triechler 1987; Watney 1989; Miller *et al.* 1998; deJongh 1986; Gwyn 1999; Kinsella 1989; Kitzinger 1998; Hallett 1997; Lupton, 1999c; and Wellings, 1988).

The primary concern expressed by those who have conducted such press analyses is that those who work to prevent transmission of HIV are faced with the challenge of having to conduct their efforts within a social context which contains contradictory values and highly stigmatised attitudes in relation to AIDS.

As already discussed, there has been a similar critical reaction in the analysis of HIV prevention efforts that place their focus on the responsibility of the individual to change HIV-related risk behaviours[33]. This body of work explores the flawed nature of the divisive discourse emergent within AIDS prevention as one that invariably positions responsibility for transmission with the infected individual. It is argued that such approaches eliminate a vision of prevention incorporating structural and broader social components, and as a result, create further social divisions between those who engage in high-risk behaviours and those who do not. Ultimately, this problematic focus on the individual can 'lend itself to frustrated health promoters and the temptation to blame victims who refuse to choose the "right" lifestyles' (Frankenberg 1994: 1334)[34].

In the late 1990s, it became evident that much of this criticism had begun to have some measure of impact on health promotion approaches to HIV/AIDS and sexual health. One example from the UK is that the Family Planning Association (FPA) has begun to demonstrate an approach to sexual health that situates the individual within a broader framework of power and inequality. This is indicative of a perspective that takes on board the problems brought about by what we may cautiously call 'social exclusion'.

> Sexual behaviour needs to be seen as the manifestation of individual
> choice in interaction with a range of economic, social and cultural
> pressures, which bear down upon and influence human behaviour, and
> indeed health and disease. Previous sexual health strategies have failed
> to locate private behaviour within this social and economic context, have
> failed indeed to accept that the personal is indeed political and that this is
> particularly applicable to the whole area of human sexuality. (Duggan
> and Weyman 1999: 7)

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[33] See: (Davies 1993; Keogh 2001; Keogh *et al.* 1998; Brown 2000; Bajos 1997; Lollis *et al.* 1997; Wolitski 1997; Crawford 1994; Aggleton 1999; Paicheler 1999; Kinsman 1996; Scott 1995; and McGrath 1990).

[34] This sense of outrage on the part of health promoters has also been raised by J.L. Russel at the *Roles and Responsibilities in HIV Prevention Expert Seminar*, October 29, 1998.

This change in tactic away from an exclusive focus on individual responsibility for practices that may lead to HIV transmission has come about following much academic, activist and personal resistance to earlier approaches. However it is still not representative of all approaches to HIV prevention where strong elements of the individual responsibility paradigm remain within the sector, as will be shown in later chapters.

At an expert seminar on HIV and responsibility held in 1998, participants indicated how the imperative for individual responsibility and those who react against it has led to division within communities affected by AIDS[35]. One participant spoke of the anger expressed by many positive gay men who felt that the onus for prevention had been passed to them as though it were a 'hot potato'. He felt that without honest exploration of some of the less comfortable issues, like the thrill of illicit or spontaneous sex – that many gay men would feel that health promotion was simply a means community behaviour policing (Russel 1998) [36]. He also felt that the rhetoric of individual responsibility was contributing to a growing division within the gay community between men of positive and negative status[37]. In addition to the burdens of being a responsible gay man, it is further argued that gay men who are HIV positive and those on combination therapy are expected to meet an even higher degree of responsibility in their sexual encounters and their adherence to treatment in order to avoid the development of drug-resistant viral strains (Flowers 2001).

From the critique of HIV health promotion presented throughout this chapter, we have seen the emergence of a perspective that regards the heavily targeted promotion of this particularly responsible lifestyle as a powerful mechanism of governance

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[35] *Roles and Responsibilities in HIV Prevention Expert Seminar*, organised by Terrence Higgins Trust London, October 29, 1998.

[36] Also see Wells, 2000 as well as Rofes, 2002, and his work on transgressive desires and the impulse to engage in high-risk behaviours precisely because they are disallowed.

[37] This feeling of internal division was expressed in an entirely different sense by a participant speaking about African issues at the same conference (Byaruhanga 1998). She spoke of the cultural difficulties with past HIV prevention strategies in the UK, alongside a growing sense of anger that some African women are directing toward men for their responsibility in bringing HIV to Black immigrant communities in Britain. From her perspective, it was only through this type of shaming that men of African descent might be prompted to change their behaviours. Thus within the same gathering, cultural and community experience demonstrated vastly differing attitudes to the notion of responsibility and HIV transmission.

reflecting the *responsibility as control* perspective outlined in Chapter Two. Such criticisms have been directed toward health promotion materials and policies produced by the state and also by some AIDS service organisations. They are accused of attempting to co-opt gay men into a moral universe which defines and polices 'acceptable' sexual behaviours (Epstein 1996; Keogh 2001; Kinsman 1996).

Kinsman (1996) regards the notion of 'empowerment' as an insidious signifier of the *responsibilising* approach. According to him, empowerment once entailed a critique of professional power which led to the development of techniques allowing those who were previously subjectified to participate in socially significant decision-making processes. However within the health promotion paradigm, he feels the idea has now been transformed into a mode of professional activity carried out among (individuals who would in turn become much more easy to manage from the point of view of social and medical agencies. In the context of people living with HIV, he says that statutory and voluntary organisations have been increasingly mandated to:

> 'empower' PWAs [people with AIDS] in responsibilizing self-management – to communicate to them the skills and languages of self-management and regulation. This can be seen in a growing number of self-help workshops and counselling sessions, and in the production of manuals on proper diet, treatment and care. This is not only the transfer and communication of practical information and advice, but also a transfer of responsibility to individuals. (Kinsman 1996: 399)

This is reminiscent of Pollack's statement that: 'In the policy field a... development .is taking place, away from coercion and social control and in favour of information and education policies with the aim of empowering people and reinforcing individual responsibility' (Pollack, Paicheler and Pierret 1992: 56). Kinsman also makes the point that for those who have fewer resources and are not able to participate in these responsibilising practices as well as others, that more repressive measures such as public health interventions and criminal law can be applied if they do not 'do' it right (Kinsman 1996: 400).

Keogh voices his wariness of the trend in HIV prevention that has moved away from the blatantly prescriptive behavioural messages of the 1980s, and toward a more subtle, yet strongly normative approach to target audiences of gay men.

> It involves providing gay men with a range of imperatives with which to regulate their own conduct. This process also involves a greater

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concentration on the production of knowledge and narratives about how to be a healthy gay man. That is, we see an increase in representations of normative behaviours and the production of images and narratives for gay men about how to conduct their lives generally. One no longer demonstrates one's 'gay healthiness' by doing something (wearing a condom), but by being something (temperate, transparent, considerate, assertive, clever, etc.)...This might be defined as promoting gay citizenship. (Keogh 2001: 14-15)

He goes on to identify the take-up of these norms in his qualitative analysis of interviews with gay men who talk about management of their health as an individual endeavour contained within the broader projects of personal responsibility, control and self-determination (Keogh 2001). It is argued that by packaging HIV health promotion for gay men within the trappings of a 'responsible' lifestyle, the model of individualised responsibility becomes even more entrenched than it did through the promotion of 'responsible' behaviours. These sentiments which reflect the *responsibility as control* argument will recur throughout the next three chapters.

Despite criticisms that conceptualise the community empowerment model as a means of increasing individual governance, there are also strong arguments contending that it is the work of Community Based Organisations (CBOs) that has revolutionised the response to HIV. This latter position highlights the impact that AIDS organising has had on a range of other issues relating to health, poverty, stigma and globalisation (Altman 1994; Altman 2001a). It is clear that CBOs have the potential to become subsumed by mainstream political agenda due to funding obligations, and it is also clear that they have co-opted roles created by governmental abdication of responsibility for treatment, care and prevention of HIV/AIDS (Altman 1994; Brown 1997; Epstein 1996). However, neither of these concerns are considered by such advocates to be valid reasons for the abdication of the community response model[38]. They argue instead that CBOs have been the central reason why individuals have not been left entirely alone in the face of the epidemic, and indeed have provided an important impetus to the critical perspective that has characterised the AIDS

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[38] Brown's research into AIDS service organisations in Vancouver demonstrates that such organisations have the capacity to gain significant governmental funding to provide interventions and services that the government itself chooses not to participate in directly because of potentially negative political outcomes. Seen this way, the community response has the capacity to enable the government to meet its own responsibilities by circuitous means. Whether or not this is a politically laudable role from the point of view of those trying to effect social change is another matter, however.

movement. The founder of Body Positive, a treatment information group for HIV positive people, frames this as a unifying imperative that constructs knowledge as group protection (cited in Epstein 1996: 126). Responsibility taken from this point of view regards the community as a resource that enables its members to uncover a range of knowledge about the epidemic from a host of unorthodox sources (Achmat 2001b). In addition to the construction of this ever-divergent and exhaustive knowledge-base, community-based responses have also produced a critique of structural factors such as poverty and stigma associated with the epidemic.

> AIDS interrogates existing regimes of gender, of sexuality, of health, and becomes political at the interface between those aspects of life traditionally conceived as private and public...Those people who established the early AIDS organisations set out only to respond to immediate needs, for care, support, information, and education. They have helped establish a movement that in many diverse forms, an on all continents, is helping revolutionize key aspects of everyday life. (Altman 1994: 167)

We will see the emergence of such themes in various places throughout the thesis, such as the examples of shared and communal responsibility in health promotion literature in Chapter Five, and most prominently in the discussions of activism, pragmatism and responsibility in Chapters Eight and Nine. While this thesis does not have the capacity to provide a complete analysis of the historical development and role of community responses to AIDS as social movements, this is not intended to diminish the importance of such movements in the active creation of responses that involves social and communal responsibility.

3.6 INTERSUBJECTIVE RESPONSIBILITY: ENCOURAGING OFFICIAL BODIES TO RECOGNISE THEIR ROLES

Much of the growth of community action in relation to AIDS has been because of a perceived abdication of responsibility by large institutions such as governments and multi-national corporations. Government policy-making surrounding HIV/AIDS (when it happens) has been seen as an attempt to: 'redistribute responsibilities from the realm of government to that of the individual, from the national to the local, from the public to the private sphere' (Scott and Freeman 1995: 159). As well as adopting their own forms of community responsibility, hosts of CBOs have pressured these institutions to accept their responsibility regarding prevention, treatment and care.

These latter forms of responsibility have been the basis for the most public displays of contestation from the earliest years of the epidemic up until the present day[39].

It is just this devolution of national-level responsibilities that has motivated activist groups and those most affected by the epidemic to mobilise and raise awareness about specific aspects of governmental responsibility. Considerable debate continues to take place about the most appropriate means for governments to act in accordance with their responsibilities regarding HIV/AIDS. For example, the American policy response has been criticised because of the disproportionate attention given over to issues surrounding widespread mandatory screening of groups such as immigrants, pregnant women, international travellers and prisoners – while the public health impact of such programmes have been shown to be negligible (Osborn 1989; Stoltz, Shap and Jurgens 1998).

One of the most significant aspects of debate on the current AIDS agenda is whether or not governments should be responsible for the provision of affordable and effective treatments. This was an issue initially brought to prominence by South Africa's Treatment Action Campaign (TAC), who sought to force their government to meet such alleged responsibilities under the strength of constitutional and international law. The TAC chairperson speaks of 'the failure of our government and state officials to act with courage, humility and urgency' in the face of some of the highest infection rates in the world (Achmat 2001b: 5). South African intellectual Dr. Mamphela Rampele has described the official government response in that country as 'irresponsibility that borders on criminality' (cited in Cameron 2000)[40]. As federal treatment funding begins to ebb away in the United States, similar right-to-treatment activism may emerge in that country (Russell 2002). Definitions of governmental-level responsibility continue to fluctuate based on changing factors including economics, political will and pressure from community

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[39] Writers such as Shilts, 1987 and Brown, 1997 cover demands for governmental responsibility in the North American context; while those such as Heywood, 1998 and Achmat of the Treatment Action Campaign have successfully challenged the South African government over its attempts to avoid provision of treatments for those infected.
[40] While the South African government was defeated through a series of court battles with TAC and members of its own health service, countries like Brazil and India decided of their own volition that it was in their citizens' best interest to produce generic versions of the necessary drugs and provide them for free (Bunting 2001; Elliott 2001).

and activist groups on the one hand and multinational corporations on the other.

The power exercised by multinational pharmaceutical agencies is now increasingly being understood as a key factor in the determination of how a country defines and shapes its responsibilities. The corporations have the power to protect pricing structures and have also fought to protect the patents of their products so that they can maintain complete control over the market[41]. Governments have had to make budgetary decisions around these constraints, especially since 1993 when intellectual property laws were tied in with wider trade agreements, and therefore with the possibility of wider trade sanctions. As a result, it has been argued that these companies also have an institutional humanitarian responsibility to provide treatment that countries and individuals can afford which supersedes the requirements of fiduciary responsibility to shareholders (Berwick 2002: 216).

The debate about the role of corporations and governments in the provision of affordable and effective anti-retroviral (ARV)[42] treatments has become one of the catalysts for a relatively recent discourse from within the AIDS community that has begun to develop a form of intersubjective responsibility. *One of the most influential* figures in the early development of this discourse was Jonathan Mann, former director of the organisation that was to become UNAIDS, and Professor of Health and Human Rights at Harvard School of Public Health. He continually reiterated the need for international bodies and national representatives to recognise their responsibility to protect the human rights of those most affected by the virus as this was a crucial component of successful prevention (Mann *et al.* 1996; Mann 1996a; see also Kirby 1994) and he argued that discrimination and stigma against gay men, injecting drug users, those living in poverty and women contributed to the high levels of infections among these groups. It was largely because of Mann's advocacy for this approach that the United Nations established a set of international guidelines on HIV/AIDS and human rights (United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS 1998). These guidelines are

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[41] Brazil and India are not signatories to the international agreements that protect such patents. However the thrust of the argument in South Africa has been that there are provisions in the agreements that will allow for the generic manufacture of life saving medications if the state in question declares a national emergency.

now used as the international standard for governmental responsibilities as they relate to the epidemic and have been recently augmented by the development of an International Declaration of Commitment on HIV/AIDS (United Nations 2001) and a report on 'Macroeconomics and Health' which makes forceful economic arguments for the necessity of access to essential health services for those in low and middle-income countries (Sachs 2001). Despite the numerous and justified criticisms that such international documents are vague and impossible to enforce, their symbolic importance in the establishment of a baseline of responsibility at the global level should not be diminished. It is conceivable that 'soft laws' and reports such as these function to legitimise and support humanitarian issues that otherwise would gain little attention on the official international political agenda (Mameli 2000).

The director of UNAIDS has repeatedly expressed his desire for a response to HIV/AIDS that reaches beyond the production of official documentation with a vision of what he calls *collective responsibility*.

> This is the path where we finally match the scale of the epidemic with the scale of our response. Where the fight against AIDS is truly embraced in every field of social action – by politicians, in the churches, mosques and temples, by unions and the women's movement, by business alongside government. This is the path where we abandon the fruitless debate between prevention versus care – and do as the best local responses to the epidemic have always done – realise that our common humanity demands both. (Piot 2001)

Piot's approach to responsibility in the face of HIV/AIDS is one that collapses the differences between individual and institution. He regards all levels of social *being* as necessarily being involved if the progress of the epidemic is to be slowed. Piot is not alone in his sentiments. Within a similar rhetoric of community level responsibility, as well as his critique of his government's abdication of its responsibility, TAC chairperson, Zachie Achmat collapses boundaries in a similar fashion to Piot. He advocates the need for individual activists to become educated in ethics, law, medicine and history while at the same time pressuring their government and the pharmaceutical companies to meet their responsibilities for the health of their people. He expresses concern about his own complicity in the continuing epidemic

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[42] When initially released in 1996, the first three drugs were commonly referred to as Highly Active Anti-Retroviral Therapy (HAART) but in the years since then this moniker has been changed to ARV.

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because of his 'civility' while conducting this debate and argues that those who do nothing in the 'battle to stop a holocaust against the poor' have 'blood on their hands' (Achmat 2001b: 5).

Edwin Cameron is a South African High Court Judge who expresses a similar approach to responsibility. He expresses outrage against the inactivity of governments and corporations and holds their combined inactivity responsible for the growth of the epidemic. Yet, as an HIV positive, affluent South African, he also problematises his own collusion in the maintenance of the status quo, because he pays for his treatment while living in a country where the majority of infected people cannot[43]. He argues that ignorance and naivety are no longer acceptable means of hiding from this reality because:

> The world has become a single sphere, in which communication, finance, trade and travel occur within a single entity. How we live our lives affects how others live theirs. We cannot wall off the plight of those whose lives are proximate to our own (Cameron 2000).

In her own addition to this perspective, Dr. Helene Gayle of the Bill and Melinda Gates Foundation draws from the insight offered by Thucydides who said that justice will have arrived when those who are not injured are just as indignant as those who are.

> It is up to all of us to develop a level of indignation that actively reflects our understanding of our common humanity and what is at stake for all of us. When will we all become as indignant to this injustice as the millions of people living with HIV and who face the ever-present risk of contracting HIV in the next several years? (Gayle 2002)

Piot, Cameron, Achmat and Gayle use words such as 'we' and 'our' in order to express the immediacy and intimacy of the intersubjective responsibility that they envisage. They use this language in order to demonstrate that discussions about AIDS, risk, treatment, research and prevention are no longer issues that can reasonably be understood to be issues outside of private concern and control. They are a matter of public action but, significantly, this action is not taken by governments and corporations out of their own volition, but rather has to be coaxed through community and private response. The collusion spoken of by Cameron and

Achmat lays the foundation for understanding one's own complicity for the epidemic and thus opening up a new type of responsible action. I shall return to this important point in the final two chapters.

Understandings of responsibility within discourses on AIDS and HIV are, of course, multi-faceted, contested and non-linear. However, out of this discourse there are certainly approaches to HIV that complement the paradigmatic positions outlined in the previous chapter. Much of the *responsibility as freedom* approach manifests itself within notions of individual responsibility that are features of wider discourses of health. This has resulted in a negative response to HIV/AIDS policy from those most affected by the epidemic, either by abdication of an imposed individual responsibility:

> I feel that if they are going to shag like that (without a condom) they can't be bothered, so why should I? – 29 year old HIV positive gay male (cited by Billington 1998)

Or by seeking to rest all of the blame with governments for their mishandling of the epidemic and their culpability in passing responsibility over to individuals:

> AIDS having... been caused to seed and sprout ...was allowed to grow and fester and increase a millionfold by the inaction of our government. (Kramer 1995: 275)

The most common response to such frustrations has been to brand all forms of responsibility as a means of control, which in turn should be resisted. Such vacillations within such a limited debate lead us nowhere: individual behaviour does not change without social change so far the primary path of resistance has only provided limited social change. However, out of these protests and community activism have emerged a new discourse of responsibility, one which emphasises an *intersubjective responsibility* shared between us all:

> AIDS is our problem. The ultimate challenge of AIDS is whether humans have the capacity to embrace the full implications of this simple realisation. (Singer 1994: 1324)

In the following chapters I will outline these changing notions of responsibility within HIV/AIDS discourse. Beginning with an analysis of three substantive arenas

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[43] The significance of Cameron's speech delivered at the International AIDS Conference in Durban

of AIDS policy (prevention literature, testing policy and criminal law), I will illustrate how the dichotomy of *responsibility as freedom* and *responsibility as control* have predominated over responses to the epidemic until the point where it was acknowledged to have become a global crisis. Following this, I will discuss the 2000 AIDS conference in Durban as a turning point where the new understanding of responsibility emerged on the world stage.

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will be discussed at greater length in Chapter Eight.

CHAPTER FOUR: METHODOLOGY

4.0 INTRODUCTION

The research process has taken me far from my original proposal, which began with the notion that the HIV/AIDS epidemic resulted from denial of responsibility at institutional levels. My initial intention was to compare these supposed evasions of accountability with similar explanations for the genocide carried out against Jews, homosexuals and the Romany in Nazi Germany, most apparent in the notion promulgated at subsequent trials which held that the accused were just 'following orders' (Arendt 1964). My initial literature search for this project took me in two directions. The first of these was an immersion in the body of work that focused on the holocaust; interrogating its causes, implications and the steps that had been taken toward some degree of resolution enacted through the development and prosecution of crimes against humanity. Some of this literature proved useful for the thesis in the end, though not in ways that I would have initially expected. The second body of literature that I researched in some depth was the philosophical approach to responsibility as evidenced by figures such as Kant, MacIntyre, Feinburg, as well as theorists such as Rose, Levinas and Bauman who focus primarily on understandings of responsibility in light of the events of the holocaust.

However, two events led me to question my original intentions. The first of these occurred after being immersed in philosophical approaches to responsibility for some time. I began to recognise that continuation in this direction would only lead me toward a project which would involve defining the essence of responsibility. What I did not want to do was to produce a universal moral framework by which I would then judge the outcome of the HIV/AIDS epidemic. The second event occurred at my first year review when a member of the panel asked if I wasn't seeking to find a singular source of blame upon which I could rest the entire AIDS catastrophe. Upon reflection, I came to see this criticism was justified, and it reinforced my concerns about normative moral frameworks from my reading. Releasing myself from this pursuit would mean that I could instead follow up on my new interest in the uses and different understandings of responsibility, as I began to recognise that it was these various models of responsibility that had significantly impacted upon responses to AIDS.

As I began to reflexively analyse my own assumptions about the functions of responsibility, I realised that my own personal experiences with HIV had influenced my thinking about the topic. The weakness of my assumptions became clear as I began to research the literature on health prevention. My original argument was to be that government inaction consisted of inadequate provision of HIV prevention information to individuals. However, as I investigated the sociological literature on the construction of health promotion (Bunton and Burrows 1995; Burrows, Nettleton and Bunton 1995; Crawford 1977; Etgeton 2000; Nettleton and Bunton 1995; Rhodes 1997), I became aware that my concerns about the lack of state-provided HIV health promotion contained problematic assumptions about individuals and their health behaviours. Therefore, in my original desire to locate responsibility for the epidemic with inadequate government provision of information, I found that I would simply be compounding the idea of responsibility by assuming what it meant to *be* responsible. Instead, I found myself to be much more interested in the way that responsibility is constructed through these processes.

It was with these realisations that I re-organised the direction of my research. I decided that I would look at the ways that *representations of responsibility* have influenced different responses to HIV/AIDS across a range of fields. There had been a considerable amount of research into the way that the news media in the United States and Britain had portrayed those who had contracted AIDS as being at fault[1]. Following further research, I also found work that was critical of the highly individualised focus of HIV prevention and education that characterises government responses to the epidemic. This body of literature utilises the approaches of the broader critique of health promotion mentioned above.

Much of the existing work in this corpus is theoretical, built around a small number of anecdotal examples. Rather than developing a further addition to this sizeable theoretical body of work, I was interested in producing a thesis that would use more abstract ideas of responsibility and apply them directly and in some detail to practical examples of responses to HIV/AIDS. Therefore I needed to choose a handful of areas that would serve as case studies which would help to illuminate the theoretical approaches to responsibility

that I was beginning to draw out. My first choice was to analyse health promotion literature created by different organisations. This would provide me with a fairly straight-forward means of sample collection, and it would be possible to pinpoint textual and graphic components of the materials that made direct and indirect inferences to responsibility. Other analyses had been conducted on these types of materials (Jewitt 1997; Keogh 2001; Wellings and Field 1996), but I had not found any work which made extensive comparisons across different organisations, or had looked exclusively at their constructions of responsibility.

The second case study on HIV testing practice and policy emerged partly through casual conversations with other graduate students who expressed an interest in my topic, and also through personal experience. As others spoke to me about HIV, it emerged that the cultural approach toward HIV testing in the UK was substantially different than what I had previously experienced in Canada. As I heard stories from people who said that they would never want to have an HIV test, as the act of testing itself would prevent them from buying property or having insurance in the future, I began to reflect upon my own assumptions about testing being 'a responsible thing to do'. When I asked my own GP for a test, her response was that I should not discuss the issue with her because of her inability to ensure future confidentiality (see footnote 15 in Chapter Six). This experience sparked off my investigation into HIV testing policy more broadly, and I soon came to learn that testing and the way that it is popularly represented is deeply implicated in the processes which construct notions of responsibility regarding HIV.

The third case study emerged as I sought an alternative field of analysis that was slightly more removed from traditional health topics. I wanted to investigate an area of response to the epidemic that would extend my developing argument about the individualisation of responsibility, and also demonstrate that this process is not one that only takes place within the field of health and medicine. At the time, the United Kingdom government was considering whether or not it should change an element of its criminal law in order to include the offence of knowing HIV transmission. This was an issue that was receiving a fair amount of attention among HIV policy lobbyists, and upon further research I found that several other countries were facing similar questions within their legislative

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[1] Examples of such work include: Watney 1989; Colby and Cook 1991; Brown, Chapman and Lupton

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frameworks. Pursuit of this topic would allow me to test my hypothesis in a different context from health policy.

These three case studies did seem to point in the same direction: that responsibility in relation to HIV/AIDS was heavily presented as the concern of the individual. My research had also highlighted the problems of such individualisation. However, up to this point work I had completed had not taken me too far beyond my original position: it was clear that placing the blame for the epidemic at the feet of individuals was wrong, but the predominant alternative to this in the critical literature seemed to leave little choice but to blame institutions instead. My experiences at the 13th International AIDS Conference in Durban provided me with a way of moving beyond this position in order to offer an alternative understanding of responsibility. This conceptualisation seemed to me to be increasingly evident in global responses to the AIDS epidemic, as demonstrated at Durban, but was not dominant in the theoretical literature on responsibility. I did however, manage to find some work by a range of different theorists across a range of disciplines that proved useful for the development of the final component of my own theoretical framework. Informal discussions with delegates at Durban combined with reports and media coverage of the event showed me that others shared the view that a new approach to the epidemic was emerging. As I related these impressions to the alternative theoretical areas that I had been investigating, I was able to elaborate a new intersubjective model of responsibility.

Each of the three case studies mentioned above presented me with different methodological issues to resolve. I will now deal with each of those substantive chapters in turn.

4.1 HEALTH PROMOTION LITERATURE

The analysis provided in Chapter Five is based on a sample of approximately 200 leaflets, brochures, postcards, posters and newspaper advertisements produced up until 1999 reflecting the range of HIV/AIDS prevention publications which people may have encountered in everyday situations in England (particularly in the Greater London area). The sample was confined to materials created by organisations operating within the

1996; Gwyn 1999; Kitzinger 1998; Sontag 1988; Watney 1987; Shilts 1987; Wellings 1988.

geographical area of London in an attempt to limit the number of variables that might hamper analysis London was chosen as the geographical centre for this data collection for a number of reasons, the most important being its high concentration of HIV related organisations, producing a broad selection of HIV prevention materials. This would allow for a sample with robust range, while at the same time being a manageable sample size for a thesis chapter. The limitation of this sample, however, is that it does not allow for comparisons with other national or international approaches, which might have demonstrated more diverse approaches to responsibility than my findings have. Having said that, the concentration of samples from a manageable number of organisations allowed for an analysis which could track the changes in approach from campaign to campaign, attesting to the reflexivity they contain as well as the demonstration that responsibility continues to be a contested issue in health promotion. In Figure 2, section 5.0 I present a chart tracking the years in which the sampled materials were produced. While most of the materials in the sample were published in the 1990s, this is somewhat predictable, because the most recent pieces of promotion are those most likely to be stored in great number and made easily accessible by each organisation. In addition, organisations such as NAZ Foundation and Rubberstuffers were only founded in the 1990s. With this in mind, there are a considerable number of materials in the sample that come from the 1980s that have been carefully archived by the THT, and also by the Sexual Health Programme, a part of the Health Promotion Sciences unit at the London School of Hygiene and Tropical Medicine.

The organisations selected are outlined in Figure 1, section 5.0, and include those with national scope and others that target more specific communities within London. It was not possible to conduct a survey of materials produced by all London-based organisations, so those selected were the ones from which I was able to gather more than twenty different items of printed health promotion[2]. While their materials can be said to be indicative of the English response to AIDS, the sample cannot be said to be exhaustive or evenly representative. It was possible to obtain numerous items produced by the Terrence Higgins Trust and the Health Education Authority in the 1980s and the 1990s so their

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[2] While it may be possible to make the case that the organisations with a more voluminous output of materials may have more of an 'establishment' or hegemonic perspective due to either funding obligations or other influence from dominant views, the materials of GMFA and Rubberstuffers demonstrate that organisations of their size and scope have the capacity to reflect broadly divergent views on responsibility when contrasted with the rest of the sample.

materials from each decade were analysed separately in order to balance out the greater numbers of items in each of these sub-samples.

With one exception, materials were gathered directly from the organisations who had produced them. Individual mass media co-ordinators at GMFA, Rubberstuffers, Terrence Higgins Trust and NAZ allowed me to come to their offices and take away original materials from their warehoused stores. GMFA and THT also allowed me to photocopy archived materials. When it came to collecting the HEA sample, I found it slightly more difficult to gain direct contact with an individual who could tell me if such an archive of HIV prevention materials existed. Instead, I found I had already unwittingly begun my own collection of their materials (with publication dates as far back as 1995) from those made publicly available in doctor's surgeries and accident and emergency waiting areas. Additional HEA produced-items were given to me by a Warwick colleague who had built up a substantial collection of HIV related information and health promotion for teaching purposes since the late 1980s. And finally, as a result of reading *Promoting Safer Sex* (1997) by Field, Wellings and McVey, I was aware that the Sexual Health Programme at the London School of Hygiene and Tropical Medicine housed a significant archive of HEA materials spanning across the 1980s and 1990s. The librarian at that unit gave me access to the collection, and again I was allowed to photocopy the materials.

As the sample consisted of leaflets, posters and stickers, I was aware that the print materials in my sample were created for consumption by individual readers. I was interested in going beyond prior investigations which made much of the fact that individuals were being targeted with education on behavioural change, in order to look into how the materials went about promoting particular representations of responsibility. Therefore, despite the intention that the medium was to be consumed by individual readers (be they GU clinic clients, sauna-goers or magazine readers) this did not mean that the producers were obliged to develop messages that incorporated individual responsibility. What interested me was evidence of this type of decision-making inscribed within the materials themselves, and to what varying extents different accounts of responsibility were conveyed through this same type of media.

As I began to catalogue the items in the sample (something which my visit to the LSHTM demonstrated as a clear advantage in terms of clarity and organisation) – it became clear

that different types of responsibility were being advocated in various ways. For example, some text listed behaviours that individuals should change, while others examined the ways in which the context of a relationship might influence decision-making. In terms of imagery, some pictures showed an isolated individual, looking to the camera and presumably listening to the advice being given in the printed text. Others showed groups of friends, sexual partner dyads, or cartoon drawings of a 'germ' or 'bug' meant to represent HIV itself. By looking closely at these different representations across the sample, it was possible to see how text and graphic representations combined to elicit three different types of responsibility. I called these thematic groupings *individual*, *shared*, and *organisational* responsibility.

In order to quantify the amount of materials promoting these three different types (the results of this are presented in Figure 3, section 5.1) – each printed item was recorded and coded, noting both the textual and graphic components of the message. The number of times that the imagery and/or text of each individual poster and leaflet made reference to a) organisations, b) community and partnership or c) the individual reader, was recorded in a Microsoft Access database in the sample. This allowed me to determine the extent to which an individual item directed its message to each of these three areas of responsibility. When this process was complete, I then quantified the proportion of each organisation's sampled literature that fell within each of the three typologies of responsibility. Some materials were coded for more than one of these typologies, and that is reflected in Figure 3, Section 5.1. However, it was more common to find that an individual item focussed on one type of message. Therefore, it was likely to find an item that was either about the responsibility that an individual has to change his behaviour, *or* about the ways in which governmental organisations owed a duty of care to protect people at risk from the virus. The one example of where this demarcation between the typologies of responsibility within the sample became slightly more blurred was in those items which discussed the individual's responsibility to protect himself as well as others. In light of these issues, the analysis was able to demonstrate that different types of responsibility are conveyed within this sample of health promotion literature, while also affirming the notion that responsibility is a key concept within these materials.

4.2 HIV TESTING

In order to help me establish some starting point for this case study, I decided to interview a small number of key informants with relevant clinical backgrounds. First I interviewed the head doctor of busy general practice surgery based at a university campus in the Midlands. I wanted to find out more about the ways that general practitioners were expected to handle patient requests for HIV tests, whether they had any guidelines on the issue from their professional bodies, and also what his own opinions were on these types of issues[3]. As a result of that interview I was able to become acquainted with British Medical Association and Association of British Insurer's Guidelines on HIV testing. I also arranged a group interview with three Sexual Health Advisors at the GUM clinic at Coventry and Warwickshire Hospital. By the time of that interview, I was already acquainted with a range guidance on HIV testing and related insurance and confidentiality issues from professional bodies. However, I was also interested in exploring what I had found to be a cultural assumption that issues of sexual health were best dealt with by sexual health specialists in GUM settings. This had been an issue that lay below the surface of so much literature on sexual health, and had also emerged through my personal experience and interview with GPs. It was also a perspective that was somewhat new to me, as past experiences and discussions in Canada did not belie a similar view. My interview with the three advisors helped me to learn a great deal about the position of GUM clinics within the overall system of health care, as well as their ongoing and historical changes. It was an important and helpful experience, which allowed me to better understand the role of the clinical settings which play such a large part in the HIV testing experience in the UK.

Many of the statistical and empirical resources used in Chapter Six were collected from the 12th and 13th International AIDS Conferences held in Geneva in 1998 and Durban in 2000 respectively. Also, the UK's Public Health Laboratory Service released statistics on anti-body testing behaviours, providing a large amount of useful data on this topic (PHLS AIDS and STD Centre 1998). As a result of an informal conversation with the person in charge of HIV health promotion for a Central London NHS Trust at the 1998 Geneva Conference, I later interviewed him upon our return to the UK. He gave me further insight into the important role of GUM clinical settings for urban gay men. He also

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[3] Interviews with all key informants were audio-recorded and later transcribed.

supplied me with materials produced by his NHS Trust that encouraged long term gay partners to test for HIV within negotiated safety arrangements. In turn, further research materials were collected with the use of database searches, newspaper clippings collected by the Terrence Higgins Trust in London, and access to a personal collection of articles on HIV and insurance issues provided by a colleague lecturing in law at Birkbeck College who had particular interest in the topic. The Association of British Insurers also provided assistance with a request for policy information. In addition to a number of formative discussions about HIV testing with other participants at the Geneva conference, I also found that a book arising from the European Commission Project 'AIDS: Ethics, Justice and European Policy' (Bennett and Erin 1999) played an important role in shaping my own ideas on the topic.

4.3 CRIMINAL LAW AND HIV TRANSMISSION

As I mentioned above, the consideration of changes in the UK criminal law relating to knowing HIV transmission that was happening during my period of study was what first drew my attention to this issue for inclusion in my analysis. I was introduced to a · Warwick colleague lecturing in law who had been researching and teaching about the human rights implications of HIV related law in Europe. After a long discussion with him on the implications of responsibility that are encoded across different legal contexts, I decided it would be best to gather materials about HIV within a broad range of legal topics in order to contrast their divergent representations of responsibility. For example, there was the issue of national immigration laws in various countries that allow for mandatory HIV testing and refusal of entry for specific groups; there was the inclusion of HIV/AIDS status in anti-discriminatory human rights laws; and there were the international intellectual property laws and agreements that were hampering access to affordable HIV treatments. I soon came to agree with Wilson's conclusion that use of the term 'AIDS law' was a fiction (Wilson 1994), as there were so many variants of law that related to the disease across a vast range of jurisdictions. In order to make sense of that legal terrain, I developed the organisational chart shown in Figure 4 below. It allowed me to conceptualise the different varieties of law relating to HIV/AIDS, while also addressing their different functions and targets.

↓ INDIVIDUALISED JUSTICE ↓   ↓ COLLECTIVISED JUSTICE ↓

Collective   (*State*)

OBJECTIVE ENFORCEMENT	Criminal Law	Regulatory Law
→	*Inclusion of HIV+ status in specific diseases transmission statutes, crimes of rape, assault, and prostitution *Criminal prosecution of those in positions of responsibility (i.e. health ministers, blood bank directors) who should have done more to prevent HIV	*Public heath (local, national and international) powers including restrictions and detention for non-compliant persons *Prison service guidelines *Blood service standards *Public laws regarding funding for HIV/AIDS prevention and general health spending priorities and statistical collection of information *Trade agreements regarding treatments (TRIPs)

→

	Individual	*Collective (Public)*
SUBJECTIVE ENFORCEMENT →	Civil Law	Human Rights Law
	*Use of tort law in order to gain financial compensation for being infected by another individual *Deterrent factor is seen to protect the uninfected from the already infected *Success often lies in cases where the individual brings a blood bank or medical organisation to court	*Human rights mechanisms – access to public services, counselling, treatment, housing, employment *Freedom from discrimination

I devised the four-part chart in order to allow me to align the different types of law that I was encountering with different means of enforcement and prosecution[4]. In turn, I reflected on the different ways that these issues reflected specific notions of responsibility. Before long, I realised that in order to pursue this complex comparison of all laws pertaining to AIDS, I would require direct legal training, and much more than a single thesis in which to complete it. As a result, I decided to return to criminalisation of transmission. This was the area of law that had first interested me because of its focusing of responsibility upon the HIV positive individual, therefore it would also be consistent with the theme which had already emerged in the first two case studies.

Not only would this be one of the more manageable areas in terms of the complexity of content, but it would also allow for a degree of international comparison. I began with a series of literature searches on WestlawUK, a legal database that allows for topic searches through academic commentary, case law, and case summaries of UK as well as international proceedings. There are several organisations (Canadian HIV/AIDS Legal Network and the HIV/AIDS Lawyers' Collective in India) which regularly report on ongoing criminal cases relating to HIV around the world. I used their updates and reports to help me locate relevant current cases that may not have come up through use of the legal database searches that I was simultaneously conducting. I also found that my subscription to several web-based newsgroups organised around general HIV/AIDS, as well as those pertaining more specifically to HIV and the law, meant that I was aware of practically all criminal cases relating to HIV that had captured mainstream and HIV press interest in Western developed countries such as the US, Canada, Australia, Denmark and the UK, as well as other sporadic reports from places such as Nigeria, Uganda and South Africa[5]. Important court proceedings occurring in Canada and Scotland and the redrafting of relevant legislation in England during the time of my research generated a great deal of academic literature and media interest in the criminalisation of HIV transmission from which my work has also benefited. It is unclear how far the other areas of law shown in Figure 4 may support or disprove my arguments, however I think it is certainly the case

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[4] The use of such axes was inspired by a similar diagram used to analyse the various roles of health promotion (Beattie, 1991 reproduced in Daykin and Naidoo, 1995). It has been adapted to suit this discussion of law in relation to HIV/AIDS, and retains some of the basic structure as set out by Beattie.

[5] One newsgroup was dedicated entirely to legal issues (hiv-law-digest@Web-Depot.com), while others offered reviews of HIV related headlines and news briefs from around the world (news@tac.org.za; and prevention-news-admin@cdcpin.org).

that many elements of public health law, for example, are premised on the individualised models of health promotion, as discussed in Chapter Three. These are questions that will have to be left for future research.

4.4 INTERNATIONAL AIDS CONFERENCES

In order to explain the significance of the international AIDS conferences within the context of this thesis, it is best to begin at the point where I started on this line of enquiry – with my participation at the Durban conference. While in Durban, I began to recognise the significance of the event, and shared in informal discussions with other delegates about their impressions of what was happening around them, and how they felt that the issues being discussed could be interpreted in relation to responsibility. We were taking part in an event that had generated a great deal of advance media interest, and as the five days unfolded in Durban, it felt as though we were partaking in a historically important moment. It is necessary to give some background information in order to explain why this singular conference had taken on such momentous symbolism.

4.4.1 Background

The initial reason for press interest in the political issues leading up to the conference sprang from the South African president's highly publicised doubts that HIV caused AIDS (Boseley 2000a; Editor 2000; Salopek 2000). Through the 1990s, then President Mandela had focussed his efforts on building democracy and providing basic housing and running water in post-apartheid rural homelands and urban townships. With hindsight, it now also appears that during that time undetected HIV transmission was increasing dramatically within the impoverished Black South African townships and rural homelands[6].

When Thabo Mbeki succeeded Mandela as President in 1999, he sought alternatives to the dominant scientific lines of inquiry on AIDS. He publicly questioned the toxic effects of AZT (the cheapest and most readily available HIV treatment) and has not allowed that drug or the later anti-retroviral therapies to be available in public clinics – even when offered cheaply or freely by the producers (Achmat 2001a; Lustig 2000;

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[6] This is illustrated by research which shows that rates of infection among women tested at ante-natal clinics in South Africa in 1990 were less than 1%, while this figure rose to 24.5% by 2000 (UNAIDS 2001).

McGreal 2001b; Mirken 2001a; Sidley 2001b)[7]. Faced with further decision-making over whether or not to pursue the complex issue of securing access to combination therapy, Mbeki said he first wanted to be sure that HIV was actually the cause of AIDS, and that drug toxicity would not induce further illness. Mbeki claimed that he wanted to hear from all sides of the debate before using government funds to provide AIDS treatment or carry out research (James 2000a; Lustig 2000; Pappas 2000; Salopek 2000). As a result, he made the heavily criticised decision to call together a panel of scientists to discuss the relationship between HIV and AIDS, as well as treatment options. The panel included infamous AIDS dissenters Peter Duesberg and David Rasnick[8].

Leading up to the conference, the email forum that had been set up by conference organisers was filled with debate about whether Mbeki's position justified a boycott of the event. This was a forum which would allow participants from different areas of expertise to exchange ideas and to arrange smaller meetings while in Durban. It was also a means of publicising protest events that would accompany the conference – particularly the Treatment Action Campaign rally and march which is discussed in detail in Chapter Eight. Thus even before it had officially started the Durban Conference was being promoted as a highly symbolic event that had the potential to bring the world's attention to critical issues affecting HIV/AIDS.

Having sensed that Durban was going to be a significant event, mainstream press reporters published 'preparatory' articles in the months leading up to the conference. They covered the devastation of AIDS in Africa and the impact that overpriced treatment and government inaction had on the situation[9]. It appeared that all the world's media arrived at Durban in unprecedented numbers, waiting for events to unfold. This meant that the 2000 conference probably received more intense media coverage than all the prior International AIDS Conferences combined (Altman 2001b).

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[7] There have been a significant series of court victories against the South African government on the issue of treatment access which will be discussed at length in the concluding chapter.
[8] The term 'AIDS dissenter' is used to describe someone who challenges the scientific basis for the established understanding that HIV infection causes AIDS. See Epstein, 1996, for a detailed review of Duesberg's role in scientific debates around AIDS.

Thus delegates and media representatives attending the conference were not surprised that drug access was on the agenda when they arrived in Durban (Barr 2000). In the months and weeks leading up to the event, it had become clear that this issue would share the political stage with the debate that Mbeki had re-ignited over the cause of AIDS. To some critics, the two issues were related. If Mbeki could cast doubt on the 'HIV paradigm', then his government could justify their decision to not provide treatment (Pappas, 2000; Marais 2000; McGreal 2001a). The Treatment Action Campaign in South Africa had been building its strength and international recognition in the lead-up to the conference. They were also preparing for a series of legal battles, arguing that the human rights of people with HIV/AIDS were being suppressed by the government's unwillingness to find a means of access to treatment (Treatment Action Campaign 2001).

Another contributory factor to events at Durban was the impending twentieth anniversary of the first notification at America's Centres for Disease Control that a mysterious illness was beginning to affect gay men. At the conference in 2000, many presenters referred to the lack of headway that had been made over the past twenty years, as well as the expansion of the disease well beyond an initial small cohort of American gay men. The twenty-year anniversary of AIDS symbolises a long relationship with an epidemic that shows no sign of abating. In the context of Durban, recognition of the events of the past twenty years brought about reflection on how things may have gone differently if there had been a more organised early response. Thinking back to concepts discussed in Chapter Two, Rose (1996) would have characterised this as a time of mourning, and as a result, there was a strong feeling at Durban that it was time to confront the mistakes of the past and respond differently (Piot 2000).

4.4.2 Collecting Data

As an observer, I had written research notes during and between conference sessions at both Geneva in 1998 and Durban in 2000. Those field notes attested to the elation and

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[9] For examples see: Garrett's series of eighteen Newsday articles in June and July 2000; Schoofs' Pulitzer Prize-winning series of eight Village Voice articles published in late 1999; D. Brown 2000; McGrory 2000; and O'Kane 2000).

exhaustion that accompanies such events, yet I knew that on their own they would not provide enough material to give shape to an entire chapter. I would need more than just the individual snapshots that these notes provided to write a chapter that would prove to be the foundation of my theoretical developments.

Other contacts who had not participated at Durban later commented on the overwhelming media coverage of that event, so I decided to investigate what the papers had reported. Using the archive functions of the webpages for the Guardian, New York Times, Toronto Star, Times (London), and USA Today newspapers I searched for all references to the Durban conference between 1-31 July 2000. As reported in Chapter Eight (footnote 25), this sample of articles demonstrated that human interest and stories about the humanitarian disaster caused by the epidemic and lack of affordable treatments in Southern Africa dominated the media coverage of the conference. This prompted me to check back to the coverage of the Geneva conference two years prior in the same newspapers. I found that not only were there far fewer reports on the Geneva conference, but that the majority of those that did exist reported on the scientific outcomes and announcements, rather than the political and social issues that dominated the press coverage of Durban. This confirmed my own experiences as a participant at these two conferences, and motivated me to examine this shift in more detail.

With regard to health promotion, testing policy and criminal law relating to HIV/AIDS, my greatest challenge was the management of vast numbers of articles and reference notes. However, once I decided that the exploration of AIDS conference history with a focus on Durban would be a key feature of my thesis, I had not anticipated that it would be so difficult to uncover detailed comment or critique through traditional means. Database searches and requests to colleagues in the field for relevant references left me with a handful of post-conference commentaries from 'industry' journals such as *Science*, and the *Journal of the American Medical Association*[10].

With renewed focus following on from the newspaper searches, I began to search out broader commentaries on the international conferences that were contained within larger

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[10] The exception to this was a response sent by Bruce Mirken to a request for help I had made on the Break the Silence (Durban conference) newsgroup. He sent me several articles he had written about

works on HIV/AIDS (Altman 1994; Berridge 1996; Patton 1986) as well key speeches (Mann 1996b). Examination of the collected conference abstracts at Sigma Research also allowed me to explore the organisational changes that had taken place over the years. I conducted email correspondence with a co-chair of the Durban conference as well as a representative from the South African Treatment Action Campaign in order to clarify several questions which arose as a result of my experiences in Durban. I also conducted two semi-structured interviews with key informants who had been involved in the organisation of national, regional and international AIDS conferences over a number of years. I interviewed Peter Davies in London, and Dennis Altman separately by telephone from Melbourne, Australia. These interviews allowed me to collect impressions of the international conferences, their changing nature, and pertinent organisational issues – as well as to close some of the gaps that the diverse method of data collection had left open. Some of the most extensive information collected about the Durban conference held in 2000 and the United Nations Special Session held the following year came from the Break the Silence email newsgroup: break-the-silence@hdnet.org/archives (located at: http://www.hdnet.org) that was organised in order to allow broader conference participation beyond those who were physically able to attend the event[11].

4.4.3 Reflexivity

During the course of writing the portions of the chapter about Durban, it became clear to me that the *act of participation* which had initiated so many questions about the role of international conferences and they types of responsibility that they reflect, had actually become a key aspect of the final product. Reading through the drafts of that chapter, I found myself reliving fragments of experience at both the Durban and Geneva conferences. I had come away from the Geneva conference in 1998 (the first I had ever attended) confused by the combination of academic stimulation, emotional acts of remembrance, and political and corporate posturing. I found myself wondering how I and my research fit into this monolithic event, and why all of the excitement and expense generated around the conferences seemed to produce such intangible results. My later experiences at Durban provided me with a complete contrast to Geneva, as they allowed

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AIDS conferences over the years that had been published in California-based magazines and the HIV positive press.

[11] Although it has not been reported upon so widely in this thesis, information on the conference held at Barcelona in 2002 was discussed on a similar newsgroup, archived at: http://archives.hst.org.za/intaids/

me to recognise the ways in which collectivity and intersubjectivity *itself* could be expressed as a form of responsibility transcending the more rigid understandings of responsibility that revolve only around the role of the individual. Therefore it was through the composition of this chapter in particular that I was also able to complete the organising principles of my overall theoretical exploration relating to responsibility more broadly.

Durban is located in the South African province of KwaZulu Natal, a province with the highest rates of AIDS infection in the country, with some townships having estimated rates of 70%[12]. It was not possible to be a delegate at the Durban conference without this figure regularly floating to the forefront of my consciousness. Embedded in every interaction with the socially marginalised in post-apartheid South Africa – black or coloured waiters, market vendors, post office workers, security guards, clerks, bus drivers and conference volunteers - was the reality of the statistics. One in four South African citizens are infected. The experience of living for a week within Durban meant that many Western delegates were personally confronted with the epidemic's human toll in the developing world. Up until that point the vast majority of delegates would have read figures or listened to colleagues from exotic-sounding places in the sanguine atmosphere of a European or North American conference centre. That experience would never arouse a sense of responsibility the way that being in KwaZulu Natal could. And it worked. Local tours of townships, AIDS clinics and male migrant miners' hostels guided by members of those communities were easily organised for conference attendees[13]. In these types of encounters, as well as in the city centre, it was impossible to ignore the strong connections between HIV/AIDS, social exclusion, and human rights to health, housing, food, security and education.

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[12] Free copies of the *Daily News*, a South African broadsheet, were distributed for free to all conference delegates. Significant coverage of the conference and associated cultural events appeared in the paper, as well as several full page adverts sponsored by the KwaZulu Natal Provincial Administration. In direct defiance of their national leadership, the province detailed estimated HIV/AIDS statistics in the region as well as the annual funding for prevention efforts (see in particular, *Daily News*, July 14, 2000).
[13] On one such trip to an AIDS clinic the homes of its clients, I witnessed an eminent AIDS doctor from San Francisco being asked by an HIV positive woman if he thought there would soon be a cure. She showed him a small bag of medicine that she had bought from a local healer and asked if he

It was because Durban had been purposefully chosen as a site for the conference, and because I lived in Durban for a week while attending that conference that latter portions of Chapter Eight probably read quite differently than the preceding case studies. This was the one area of research where I had gathered data as a participant; and it was while I was a participant that I came to realise exactly how my experiences related to the theoretical development of my thesis. Therefore, I have not hesitated to include a degree of personal perspective within the body of the chapter, because I think that to falsely assert an academic distance from these events would sacrifice a great deal of the energy which was an authentic aspect of the Durban conference in particular. As a result of this stylistic decision, Chapter Eight includes my own narrative voice more heavily than other segments of the thesis. While I am aware of the dangers of personal bias, particularly when writing as a participant observer – I also feel that the theoretical outcomes of the entire work have been significantly affected by allowing myself the space to explore my own experiences of the Durban conference within the context of responsibility. In addition, the use of a broad 'field strategy' (Silverman 1985: 105) including document and newspaper analysis as well as interviews and correspondence with key informants rounds out this investigation of international conferences to provide a robust and unique insight into the ways that the institutionalised and the ad hoc elements of the conferences both produce and reflect various notions of responsibility.

4.5 A NOTE ON INTERNATIONAL COMPARABILITY

In my original research proposal, I had intended to focus my thesis on the HIV/AIDS epidemic in the UK, as this was where I was conducting my research, and the collection of data from one country would help to simplify the analysis. However, as I explored the English language literature within my case study areas, I found that a large quantity of the criticism on topics such as HIV health promotion and criminal law also emanated from places such as America and Australia, which had strong academic and activist histories in these fields. While some of my samples would be collected from available UK materials (such as the sample of printed material used in Chapter Five), it was clear that it would be pointless to try to restrict my field of vision to only one country. This became more apparent as I began investigating the criminal law, as it would be necessary to contrast

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thought it would work. He assured her that it was good for her but would not be a cure. When I asked him later what was in the bag, he simply said: 'a clove of garlic' (Field notes 2000, Book 4: 16).

different national responses to the issue in order to gain any sort of insight into the various approaches to responsibility that they might reveal.

It was clear that there were some differences among the various countries that emerged at this point of the research. For example, Germany and Sweden implemented swift and pragmatic national responses to the epidemic in the 1980s, while America still struggles with the frank discussion of sexuality in the public sphere; and Canadians and Australians are generally much more likely to have had an HIV test than Britons. However, despite these surface differences, they are also all very similar countries. They are wealthy, capitalist nations with varying degrees of welfarism, and they have strong health infrastructures. In most of these countries the epidemic's initial pattern of spread was also similar, starting mainly among gay men and injecting drug users and later proliferating among other marginalised groups. These similarities supported my decision to allow for some degree of international input.

Therefore, in 1997, I would not have imagined that a significant portion of my thesis would turn toward a discussion of the impact of HIV/AIDS in sub-Saharan Africa and across the low-income countries of the world. Of course I was aware that it was causing devastating loss in those contexts, but at the time that was an issue that I regarded as quite separate from discussions of AIDS closer to home. However, in the course of my research on this area, these types of divisions both within the AIDS world and beyond it would largely be proven as illusory. The conference at Durban and the discourses about intersubjectivity that it brought onto the global stage would forever end those types of distinctions. Therefore my thesis attests to the dissolution of that type of research that may have once regarded the epidemic in one area of the world as distinct from another. The perpetuation of individualised models of responsibility and the attending spread of HIV/AIDS among those most marginalised in all societies are global phenomena, they take place across all national settings. As long as individualised notions of responsibility continue to dominate local implementation of HIV prevention and awareness, the structural and globalised aspects of power relations that fuel the epidemic will not be apparent. The point made in Chapter Nine is that as efforts to stabilise a Global Fund for HIV, Tuberculosis and Malaria and efforts to make effective treatment available to all gain more prominence in the international media, the individualised ideas that have characterised approaches to HIV for two decades are beginning to show signs of

weakening. Taking its place is a movement toward an intersubjective understanding of responsibility across a range of places, and among different peoples and organisational levels.

CHAPTER FIVE: MESSAGES OF RESPONSIBILITY IN HIV/AIDS HEALTH PROMOTION MATERIALS IN ENGLAND

5.0 INTRODUCTION

The intent of this chapter is to explore the ways in which messages of responsibility in HIV prevention materials impact upon cultural perceptions of the epidemic and those it affects. The core of this discussion is an exploration of messages of responsibility contained in printed material produced by five British organisations concerned with HIV prevention (see Figure 1). The analysis below uses HIV health promotion materials to demonstrate the ways in which efforts to engender personal responsibility in relation to 'risk behaviour'.

As was mentioned in the previous chapter, HIV prevention literature has been an area of considerable criticism from AIDS activists and academics. Consistent with the position that views all notions of individual responsibility as inherently controlling, critics have chastised HIV promotion material for emphasising the responsibility of the individual in a way that furthers self-surveillance and social division. For example, Lupton (1995b), Brown (2000) and Kinsman (1996) discuss HIV health promotion within the context of surveillance projects in late modernity. The authors implicate health promotion organisers as complicit conspirators in political distinctions between 'clean' and 'unclean' bodies; 'normal' and 'abnormal' behaviours[1]. Brandt warns about the negative impact of AIDS prevention that simplifies transmission of the virus into a matter of personal choice which he summarises in the following way:

> If one 'merely' avoids the risk behaviours associated with transmission of the virus - unprotected sexual intercourse and sharing needles for intravenous drug use - one can avoid AIDS. Therefore, infection is a clear - and usually terminal - marker of individual risk taking, of engaging in behaviours typically held to be deviant or criminal. According to this view, those who are infected are responsible for their plight. AIDS is caused by a moral failure of the individual. (Brandt 1997)

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[1] Other writers support this view, such as Denise Gastaldo who argues that health behaviour guidelines disempower the individual. While knowledge can be the foundation for power, what she calls 'traditional health education' results in self-surveillance for the purposes of the state. 'No educational process can only liberate because at the same time it disciplines bodies' (Gastaldo 1997: 130).

Applications of the Health Belief Model to HIV/AIDS (typified by advocacy of abstinence, 100% condom use, and use of new injecting equipment every time) neglect the interplay of power, trust, desire and addiction within sexual acts and drug injection that are not amenable to 'rationally' calculated action. In his critique of the prevalence of the HBM in HIV prevention, Pollack (1992) argues that it is a model that has little relevance to what is already understood about the spread of the epidemic in relation to specific social interactions. He points to research regarding the disparity between knowledge of infection and actual use of condoms as proof of this inadequacy. Knowing about the role of the condom or the clean needle in preventing HIV cannot automatically be assumed to lead to behaviour that reflects this knowledge. There are many factors that make human beings more than just rationally calculated actors and this is what such uniform applications of the HBM and other individualised health promotion models fail to take into account. Research undertaken with HIV health promotion professionals in the UK demonstrates that such human factors are often neglected within the materials that are targeted at gay men.

> ...the 'ideal subject' of health promotion (the sexually healthy gay adult) is one who has the capacity to determine his own destiny through the control of his environment and the making of rational personally beneficial choices. Conversely, signs of sexual ill-health are behaviours which are irrational, personally damaging or uncontrolled. (Keogh 2001:11)

In this chapter, I use the sampled materials to demonstrate that the bulk of HIV health promotion has been constructed around the model of individual responsibility that is most clearly reflected within the Health Belief Model. There will also be a discussion of those materials which contextualise HIV/AIDS socially and politically, but these form a much smaller proportion of the sample. Rather than conceiving of all health promotion as necessarily placing an inordinate amount of responsibility on the individual, this discussion will allow us to see that a possible range of alternatives. Indeed, some materials that I have collected include reference to organisational, governmental and social issues that contribute to the continuing spread of HIV, while simultaneously referring to individual responsibilities for change. Many offer a direct challenge to conservative attitudes toward sexuality and drug use, particularly those prevailing at the start of the epidemic and this reflects the

degree to which both HIV affected communities and governmental health departments have had an input into this material.

Thus we can understand the production of HIV prevention materials as a part of a dynamic process of social change which includes both tendencies toward the individuation of responsibility and toward the critique of this individuation (Miller *et al.* 1998). Several of the organisations selected for this study have recognised the potential for their materials to create further stigmatisation and, in a spirit of self-reflection have introduced new ways of communicating messages of responsibility. Some have created materials specifically designed to challenge existing approaches to AIDS and sexuality as a means of confronting complacency. At the same time, a large number of materials drawn from the organisations studied continue to (demonstrate a reliance on simplistic understandings of individual responsibility for behavioural change[2].

Therefore I would like to emphasise from the outset that most organisations do not have a singular approach to their presentation of responsibility and some demonstrate internal contradictions (Field, Wellings and McVey 1997; Miller *et al.* 1998). Research conducted by the Glasgow Media Group in *The Circuit of Mass Communication* (Miller *et al.* 1998), exposes complex relationships between personal beliefs, politics and public health that intertwine at each stage of the decision making process during the design of new HIV/AIDS public health campaigns. Messages of responsibility can change between campaigns and reflect changes in the perception of wider prevention needs of those who design them.

The method of analysis was grounded in an exploration of the thematic content of the text and imagery used in each item in the sample. As discussed in Chapter Four, thematic uses of the concept of responsibility emerged, and were used in the classification of each piece in the sample. While there is not a large analytic and comparative body of work on health promotion literature, Jewitt's (1997) work on images of male sexuality in sexual health print materials provided some helpful

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[2] These have particular affinity with the Health Belief Model (see Rosenstock 1974; Pollack 1992; Bloor 1995; Illingworth 1991; Lollis et.al. 1997 and the discussion in sections 3.2 and 3.3 of the preceding chapter).

guidance. That work refers explicitly to the methods developed by Kress and Leeuwen (1996) for the analysis of visual imagery. For another critical analysis of health promotion literature produced in the UK see Keogh (2001).

Figure 1: List of Organisations

Gay Men Fighting AIDS (GMFA)	Their publications and resources for gay men are actively distributed by volunteers in London (particularly in popular cruising parks). The materials are often sexually graphic and always challenge the reader to actively assess his own behaviour for acceptable levels of risk as well as his own political complacency.
Health Education Authority (HEA)	This official public health arm of the Department of Health has been involved in the production of HIV prevention materials for the general population and targeted groups since 1986. This organisation was reformulated from the dissolved Health Education Council in April 1987, and was again reorganised as the Health Development Agency in 2000.
NAZ Project London (NAZ)	NAZ began by producing HIV prevention materials exclusively for Asians in a wide variety of languages. More recently they have also begun to serve Latino, Eastern European and Muslim communities using religious and culturally sensitive approaches.
Rubberstuffers	Rubberstuffers distributed their print materials and condoms in gay venues, saunas and events around London. As a result of streamlining of AIDS Service Organisations (ASOs) and a change in contracting for condom distribution from the Department of Health, they closed in March 2000.
Terrence Higgins Trust (THT)	THT began in the early 1980s as an advocacy group for gay men concerned about the emerging epidemic. Since then it has grown into a wide ranging service provider and policy advocate for all those affected by HIV/AIDS with offices throughout England and Wales. It is now the largest AIDS Service Organisation in Europe. THT is a key partner in the CHAPS partnership which jointly produces some of the materials contained in this sample.

Specific details on the selection of the organisations used for this sample and the methods of analysis have already been given in Chapter Four. Figure 1 above is a list of five organisations used for this study and gives a brief overview of each in order to provide a context for the work that follows.

Figure 2 groups the materials in the sample over time in order to provide a chronological context to the analysis. This demonstrates that the sample has a strong bias toward materials produced in the 1990s, yet there are substantial numbers of those published by THT and the HEA in the 1980s.

Figure 2: Volume of sampled materials by date of publication
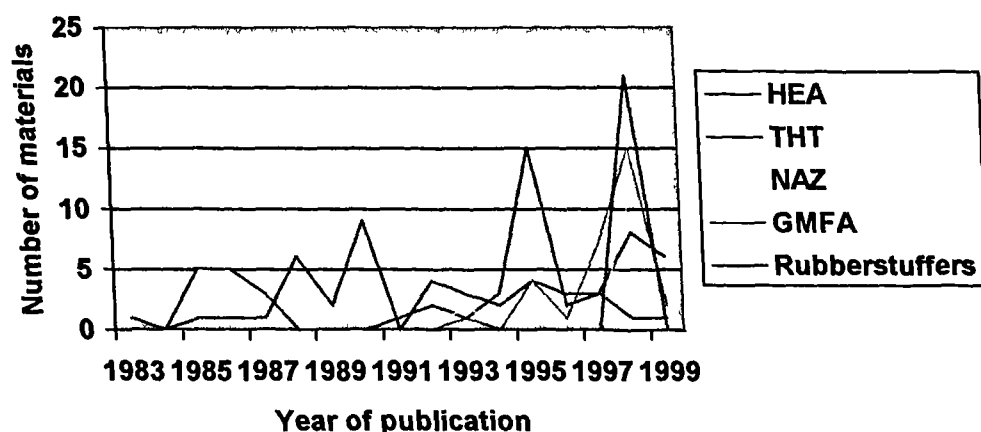
5.1 ANALYSIS

This section provides a summary of the qualitative analysis conducted on the HIV health promotion materials in the sample. As discussed in Chapter Four, it became apparent at the early stages of analysis that there were three broad categories of responsibility denoted across the materials: *individual*, *shared* and *organisational*. *Individual responsibility* is that which promotes care of the self as the domain of the individual reader. Following on from the problematisation of individualised responsibility in Chapters Two through the development of the *responsibility as freedom* and *responsibility as control* dichotomy, and Chapter Three with its analysis of the role of the individual in health promotion theory, the current chapter will provide a critical analysis of individual responsibility as represented in the sample. Somewhat differently, *shared responsibility* refers to those materials which appeal to the reader's consideration of loved ones, and their duty to hold attitudes and behave

in ways which protect others in the community[3]. However, this is still constructed as a responsibility that is entirely within the domain of the individual, and therefore will also meet with similar critical reflection. *Organisational responsibility* within the context of this sample makes reference to the role of organisations, the state and other institutional bodies and their place in HIV prevention. While this type of responsibility is not reflected in a great proportion of the sample, it offers us a divergent perspective from the shared and individual responsibility which are strongly characteristic of mainstream health promotion paradigms. Those materials that represent *organisational responsibility* are those that form the closest approximation to the model of *intersubjective responsibility* as developed in Chapter Two. This group of materials gains the furthest distance from the assumption that responsibility is solely the domain of the individual. Before discussing each of these types of responsibility and their examples in turn, Figure 3 below provides a breakdown of the proportion of the materials from each organisation that fall under the headings of individual, shared and organisational responsibility[4].

Figure 3: Percentage of materials representing different types of responsibility

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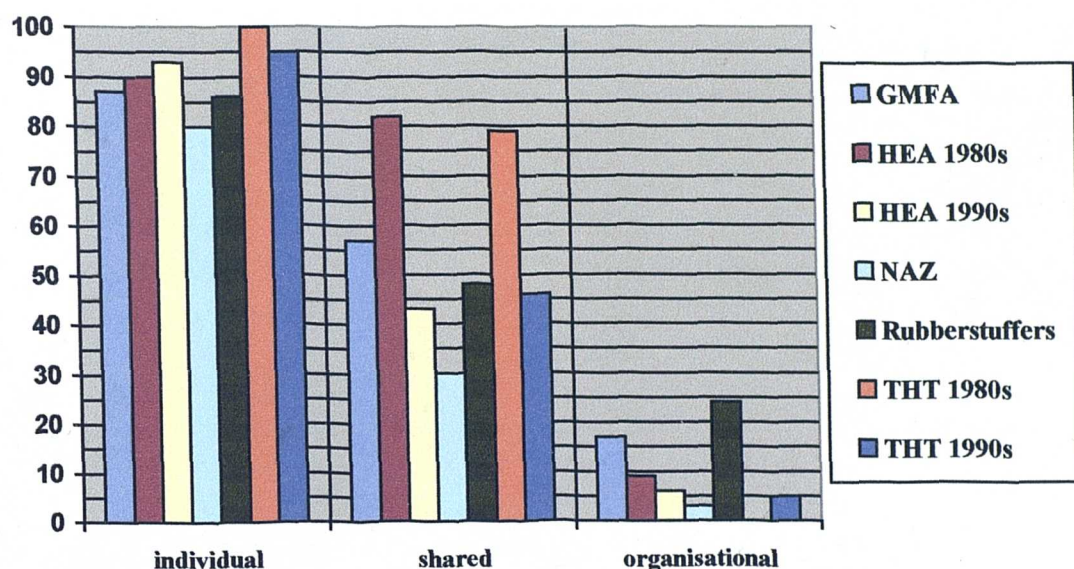
[3] We might conceive of this second type of responsibility as being supported by those 'traditional' social bonds of partnership, sociality and local community that were also referred to briefly in Chapter Two.

[4] Every item in the sample was included in at least one of the categories, and in cases where more than one category was applicable to a single item, it was recorded in two or three categories simultaneously.

5.1.1 Individual responsibility

The collated results of individual analyses on each item in the sample revealed that the primary focus of responsibility in the materials rested with the individual. Between 80% and 100% of materials from all organisations conveyed a message of individual responsibility. This provides immediate confirmation that the individualised basis of health promotion discussed in Chapter Three holds true for this sample of HIV/AIDS prevention materials.

The two organisations with the highest percentages of such materials are the HEA and the THT. Notably, both have the widest target populations as well as the longest history of production (they are the only two organisations in the sample that were publishing HIV/AIDS materials in the early and mid-1980s). We shall see however, that they each had very different ways of presenting individual responsibility in the earliest days of the epidemic.

The most characteristic examples of the first HEA materials promoted the national urgency of the problem and the individual's role in the solution. The title of the first national leaflet shown in Image 1 (page 107) conveyed that knowing about AIDS was everyone's concern and was the key to HIV prevention. The introduction said: 'You can find out what is known about AIDS by reading this booklet. The more you know and understand, the more you can do to reduce your risk of ever getting AIDS and help control the spread of AIDS in this country' [5]. Berridge (1996) says that this national call-to-arms approach was dropped in ensuing campaigns when it became apparent that a widespread AIDS epidemic among heterosexuals would not materialise.

This shift is evident when we contrast the initial example with the 'AIDS and YOU' pamphlet shown in Image 2 (page 107). Just comparing the covers, the focus quite clearly changes from 'everybody' to 'you'. In addition, 'AIDS and YOU' was the first of many HEA materials to have a crowd scene on the cover. Crowd images in

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[5] The campaign slogan: 'Don't aid AIDS' appears at the bottom of the pamphlet, making the inference that those who don't know about AIDS are assisting its spread.
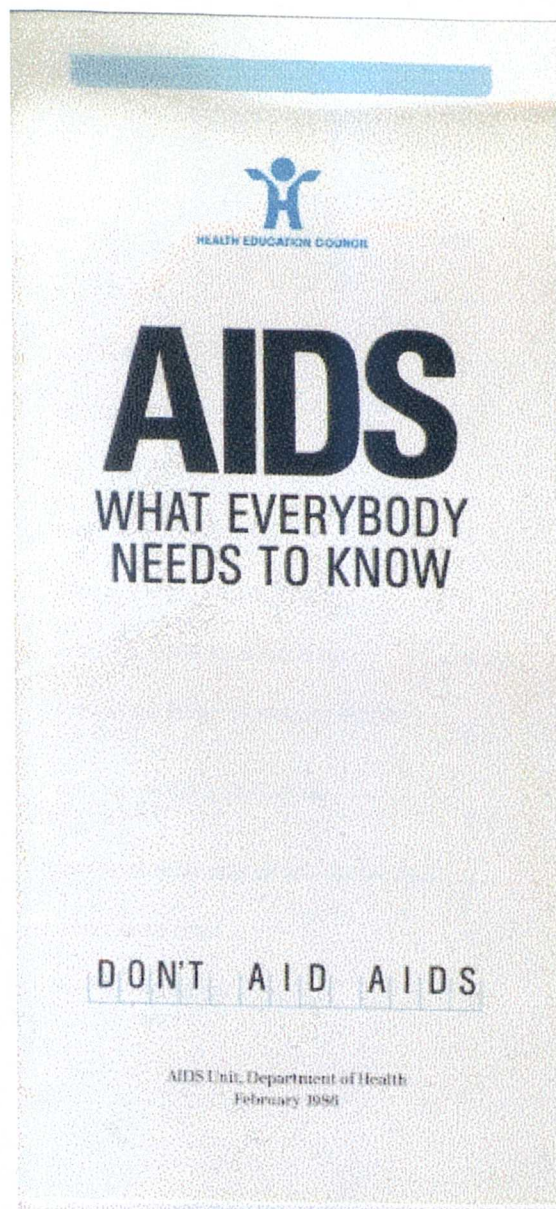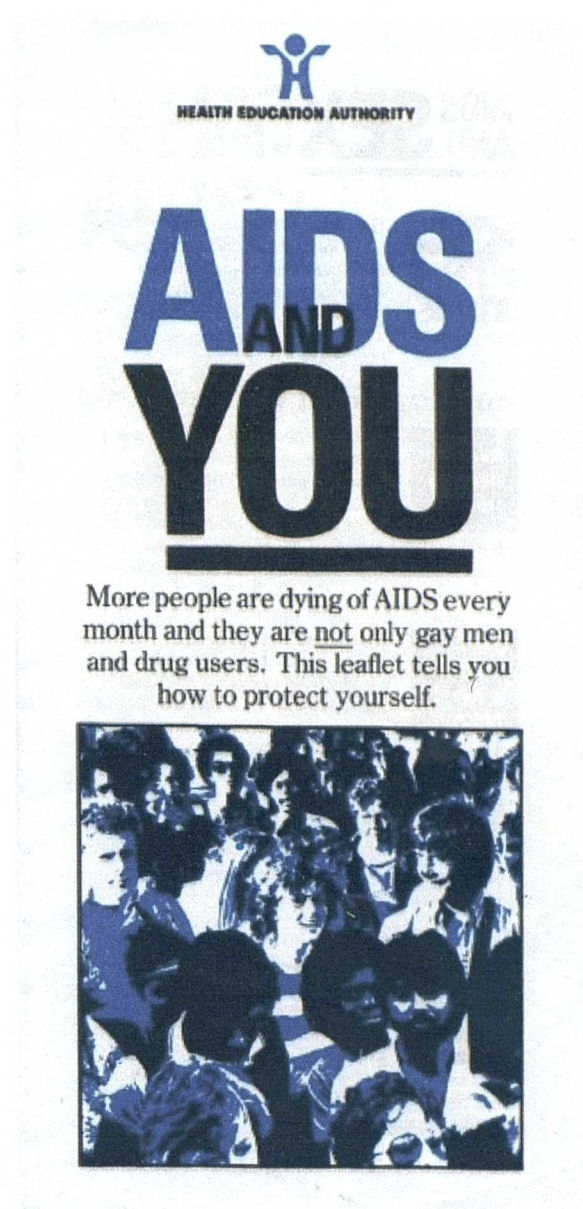
Image 1

Image 2

AIDS materials signify the 'general population' that is, the 'community of normal individuals' which excludes gay men and IV drug users (Kitzinger 1998). This leads to the readers' implicit moral division between 'them' and 'us' as highlighted earlier in Brandt's work. The text inside the pamphlet was still quite similar to the earlier example, with even more stress on the individual's accountability for general social well being: 'to stop AIDS spreading here everyone must take care'.

Such materials provide contrast to early THT publications. In Image 3 (page 109) we see an early THT piece directed at gay men which combines factual advice on behaviour change and risk while using cartoons of men with sex toys alongside familiar language for the readers[6]. Many items created by the Trust in those years were frankly worded. There appears to have been a deliberate emphasis on the use of familiar language so that gay men would easily understand the specific behaviours that required change and those that did not without feeling alienated by the use of clinical language to describe specific sexual acts.

Accompanying this frankness, however, there was also often a severe tone, matching the perceived urgency of the crisis. The cover of a 1986 THT brochure directed at gay men included stern directives relating to care for the self and for others, such as: 'DO NOT donate blood or semen; DO NOT carry an organ donor card' (these did not appear on the pamphlet for the wider public released simultaneously). Inside the same pamphlet were some strongly worded statements directed at men who had already tested positive: 'You must accept though that you are very likely to be infectious to others if you have "unsafe" sex with them. This means that they could eventually die because of it. Be responsible'. While this type of bold statement can be found throughout THT materials from this era, nothing comparable is found in their sampled materials from the 1990s [7]. Through various combinations of encouraging behaviour change as well as providing information using explicitly directive language, we see that the early HEA and THT materials were highly focused on individual responsibility. However, the context of such responsibility

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[6] Its language and imagery was considered highly immoral by a host of social critics at the time which points to a significant burden of responsibility taken on by the Trust for printing and distributing such controversial material.

[7] Interestingly, we will see that while the Trust moved away from this sort of moral tone, other AIDS organisations targeted at gay men (such as GMFA) took up this approach and maintain it currently.

Image 3

varied slightly between them. In the nation-wide HEA materials, the individual is constructed as the responsible citizen taking care of the self in order to protect the country. In the THT materials for gay men, the individual was to take responsibility for himself in order to protect his own health, that of the gay community and to prevent HIV from spreading to the heterosexual world through blood and tissue donation. Thus we can already see that messages of individual responsibility direct their impact in a range of social contexts, depending on how the organisation characterises their target reader.

This characterisation of the reader is also apparent in the excerpt from the NAZ booklet represented in Image 4 (page 111). The image of the Asian finger-wagging doctor who appeared on every page would have had a significant impact upon the way in which the 'expert' information about HIV transmission was received. In this example, the reader in the Asian target audience is constructed as someone who would respond best to an authority figure.

This focus on the importance of scientific facts was strong among many sampled materials from the 1980s. Factual awareness about the virus and its effects as well as routes of transmission continue to make up a large part of prevention materials aimed at those who may be learning about AIDS in detail for the first time.

The 1990s HEA examples collated in Images 5a-5d (pages 112-113) were intended for wide 'waiting room' audiences and were typical of the informative style that one would come to expect in a clinical setting. The crowd image was recurrent on many of the covers, again something which could lead to the promotion of a 'them' and 'us' mentality. However, in direct contrast to the communal mentality of the earlier materials, where AIDS was about everyone, here the dominant textual message was about the need for specific individuals to identify their risk behaviours and protect themselves[8]. The information and facts inside the pamphlets were intended to help the reader learn how to protect him or herself. They gave directions on proper condom use and issued strong directives on needle sharing. In materials from all of

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[8] Under the heading 'How to protect yourself' in one of these pamphlets, the answer given is: 'try to have safer sex'. Another says: 'Whether you have the test or not – remember, choose safer sex...don't share injecting drug equipment'.
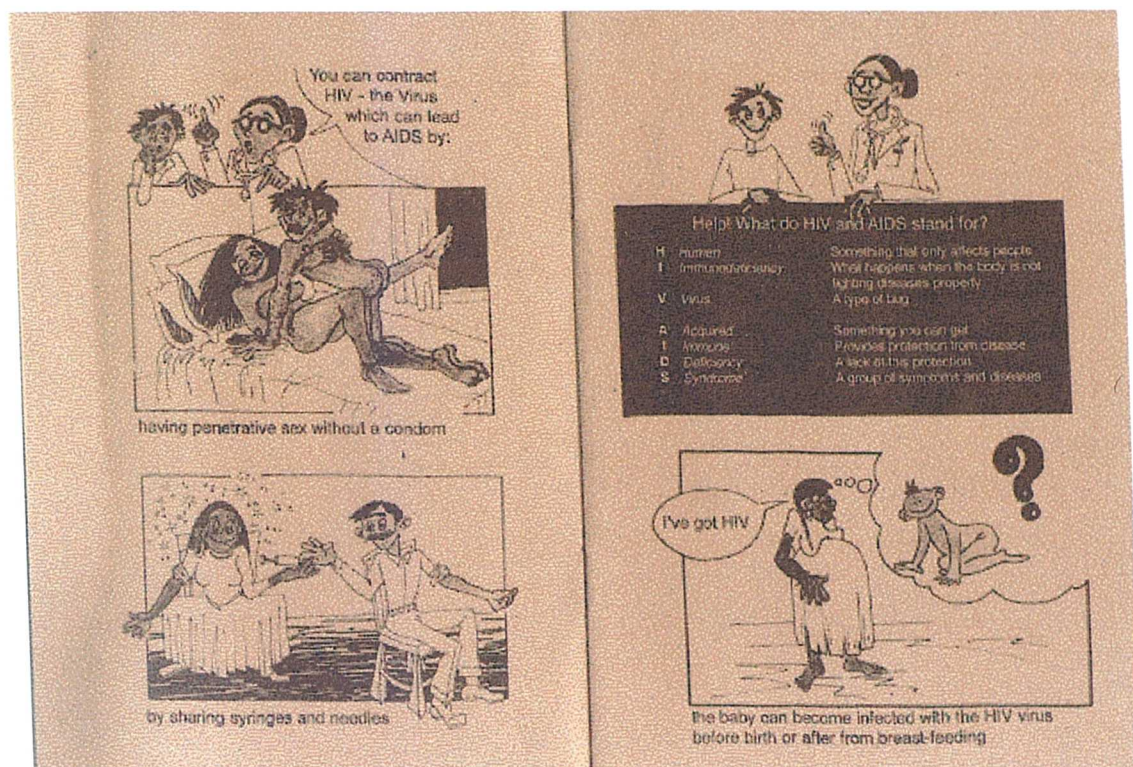
Image 4
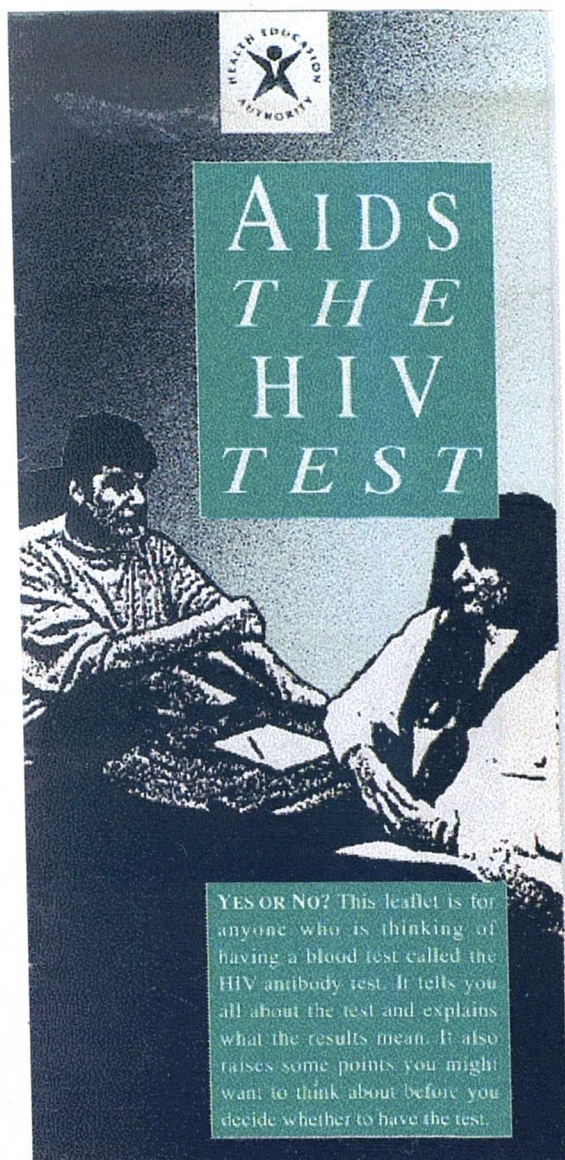
Image 5a
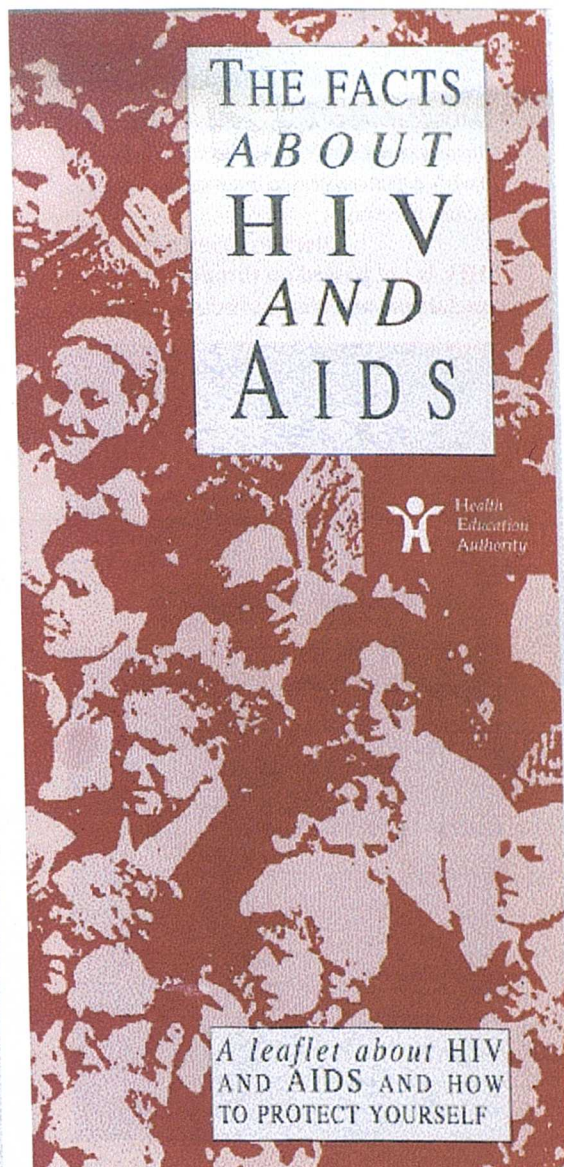
Image 5b
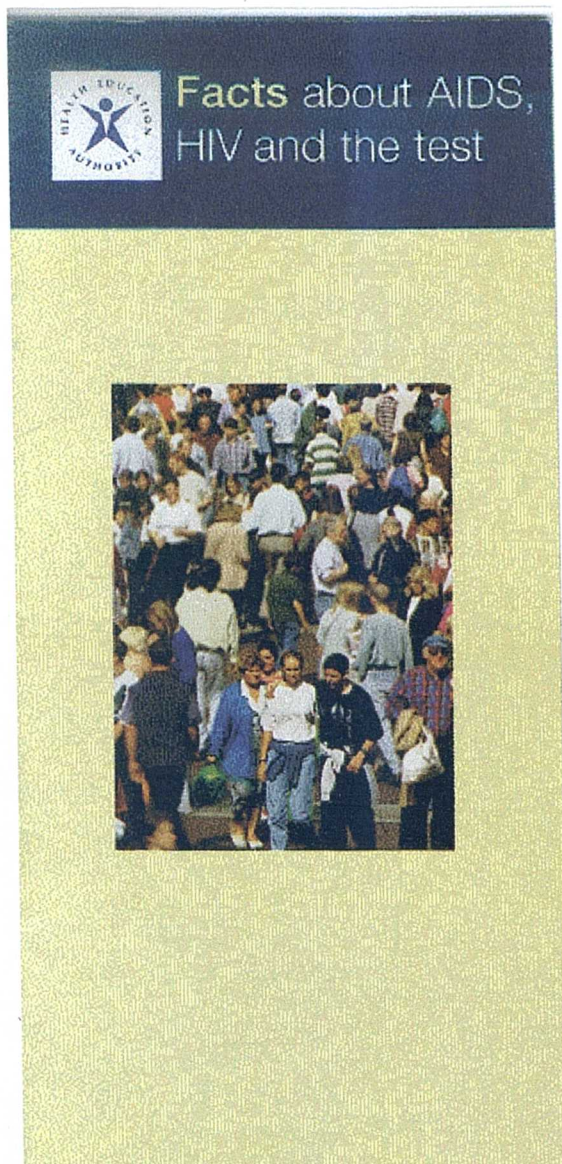
Image 5c
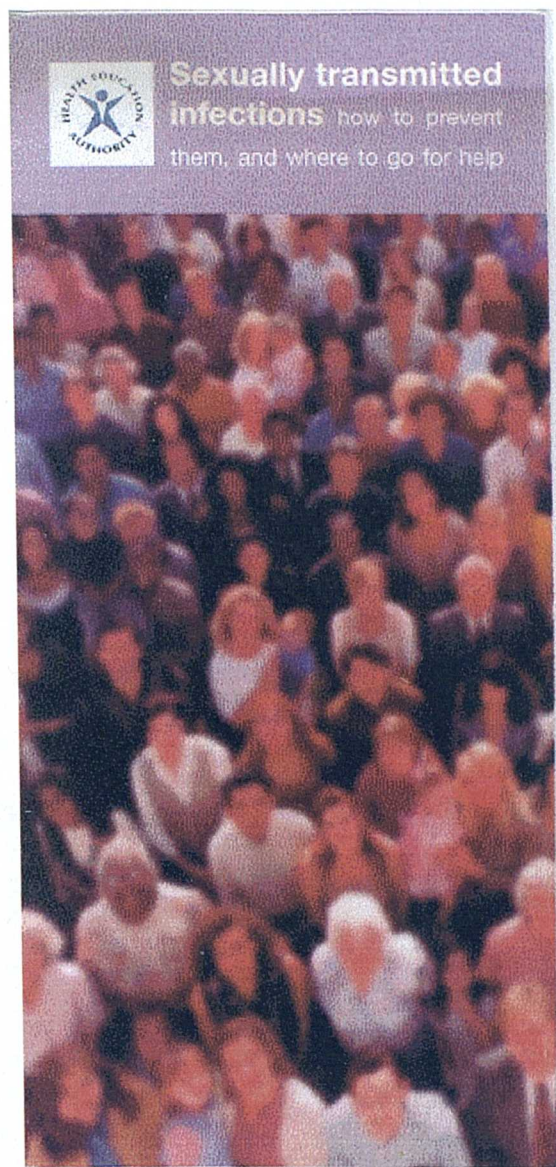
Image 5d

the sampled organisations, messages of behaviour change and factual awareness are almost always coupled with a firm focus on individual responsibility.

In contrast to these rather clinical and often directive materials, those campaigns targeting a specifically gay and bisexual male audience began to soften their approach in the 1990s and encourage individual responsibility through the portrayal of sexual scenarios and through asking the reader to consider his recent sexual experiences. This enabled the materials to remind gay men of the AIDS prevention message while avoiding repetition of extensive facts about HIV transmission. Image 6 (page 115) produced by the HEA presents text and imagery conveying an understanding of gay culture in its friendly attempt to encourage non-penetrative gay sex. The caption reads: 'He's into safer sex, so why not give him a hand?'.

Thus, by the 1990s, many materials aimed at gay men had replaced the stern directives from the 1980s with a more supportive tone. The THT released a series of comic strip style scenarios called Tales of Gay Sex. They dealt directly with the problems of assuming your partner's HIV status and offered safer sex as the alternative, teaching gay men about how to negotiate safer sex by offering the skills and phrases they would need. The narration section on the back did not give facts about transmission or list safer sex options. Rather, the purpose of this series was to get beyond 'arming oneself with knowledge' as we saw in the 1980s and toward the actual negotiation phrases for safer sex as a means of supporting behavioural change[9].

Another important change among some prevention materials of the 1990s was the move toward harm reduction. While still centring around a notion of individual responsibility, this was an approach which encouraged the reader to consider their own position and choices in relation to risk rather than instructing them how to act. Harm reduction approaches laid out the options and possible outcomes for the readers and then left the decision-making up to them.

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[9] The analysis revealed that all of the sampled (late 1990s) items from Gay Men Fighting AIDS (GMFA) encourage behaviour change, while simultaneously showing the lowest rate of factual awareness change. We can interpret this as confirmation of the current trend toward materials for gay men which reinforce behaviour change rather than repeat the factual components of HIV transmission.

114
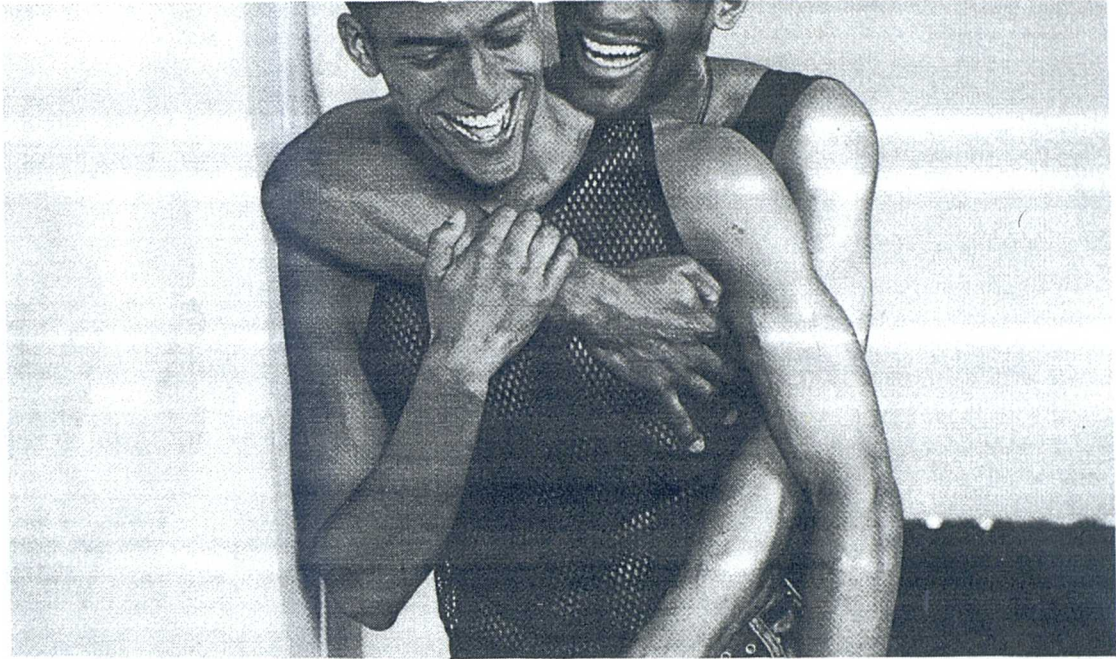
HE'S INTO SAFER SEX, SO WHY NOT GIVE HIM A HAND?

Image 6

An example of this subtle yet powerful shift is contained in a heterosexually focused booklet produced in the later 1990s by the HEA (Image 7, page 117). The cover image showed a heterosexual couple placed in focus amongst a blurry crowd. This imagery suggested that they were more than just part of a crowd, requiring individualised attention. Without changing much of the actual content of the text from earlier samples, the booklet was re-formatted in a question and answer style. This positioned the reader as questioner rather than simply the passive recipient of facts and lists of risky activities. Additionally, it suggested HIV testing as a harm reduction strategy to protect both self and partner from the possibility of infection.

This provides evidence of a much more complex message about responsibility than the early days of 'Always have safer sex'. It recognised that people needed more than one option in their sexual choices and that condom use was not the only way to demonstrate responsibility for the self or for others. It took the individual into consideration in the context of their relationship with a primary sexual partner, as well as allowing room for the possibility that there may be others. This same strategy would also become a strong theme in the later work of the THT and many other organisations.

The Hard Times workbook (Image 8, page 118) produced by GMFA carries individual harm reduction philosophy to a further level. After starting with a list of minimum standard guidelines for safer sex, the majority of the book is a reflective journal/workbook for men to record their thoughts, feelings, and behaviours based on situational and emotional issues (ideally with the assistance of a skilled helper). The reader becomes the author of his own prevention booklet. This approach clearly places responsibility for change with the individual. However, that change is situated in a social context where the individual is asked to reflect on and balance his need for sexual health with his need for sexual and personal fulfilment.

These types of socially located messages are indicative of an awareness that individually targeted responsibility excluding extraneous factors in the life of the reader would not be effective. Rather than falling directly under Crawford's strong criticism of victim-blaming health promotion, the newer harm reduction approaches make an effort to steer away from exclusive focus on the vulnerable individual.

116
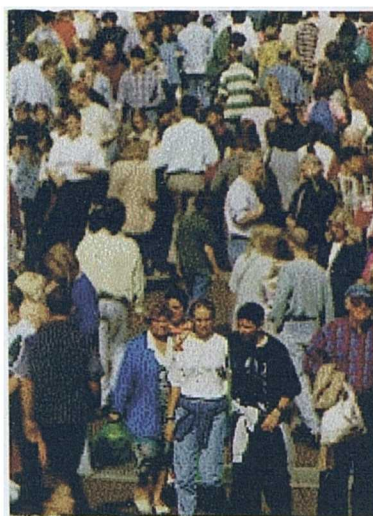
Image 7

ok now try this

Before you go any further, look back at the page 7.
Be clear to yourself about what is safe enough for you and
how you plan to stay safe and keep your partners safe.

Think about the last time you had sex that wasn't as
safe as you would want. Write down the real story
and list the real reasons as honestly as you can.

DAY AND TIME OF DAY:

WHERE WERE YOU?
DID YOU GO ALONE OR WITH FRIENDS?

Image 8

They aim to help readers situate their decisions in a broader context, taking issues such as power, stigma and desire into account. However, I think it is still important to be aware that harm-reduction approaches demonstrate what is essentially a more elaborate implementation of the individualised basis of health promotion. That is, information is offered to individuals (albeit more appropriate information), and the expected outcome is that the individual reader will make a 'healthy' decision.

Lastly in this section on individual responsibility in the sampled prevention literature, we turn to the materials which focus on attitude, thus encouraging the reader to reconsider stereotypes or traditional ways of thinking that prevent openness and equality. Each of the organisations in the study produced materials challenging readers to question their assumptions about who is affected by HIV and AIDS. Somewhat different approaches are found in materials produced by the two gay organisations GMFA and Rubberstuffers. These can employ strong messages about the need for individual gay men to improve their self-perception as a necessary precursor to self-care and individual responsibility.

The Rubberstuffers postcard in Image 9 (page 120) was designed for those leaving gay spas or baths. It displayed the vulnerable image on the front while asking the reader some searching questions on the reverse side: 'Did you have the sex you wanted? Did you cheat on your boyfriend? Did you have safer sex or unsafe sex? How are you feeling now?' The language situated the reader in his real context, discussing sex using his own terminology while being supportive of his emotional state. It encouraged him to sort out these issues before entering into potentially unwanted sexual patterns once again. This approach is comparable to the self-affirming text we see in the postcard produced by GMFA in Image 10 (page 120). Like Rubberstuffers, GMFA emphasises the role of self-esteem and responsibility to the gay community in its HIV prevention materials, yet it is unique in this sample in that some of its messages stand as a challenge to the reader, rather than a support. One card says: 'the next time you're about to put yourself at risk from HIV, remember that you are worth much more than that fuck - however good. Dump the baggage of homophobia'. The narrative voice of such literature recognises the struggle which gay men face within the context of daily social rejection. However,

Image 9

Image 10

the answer to such pressures as recommended by both GMFA and Rubberstuffers (in different ways) is to personally decide how to rise above this, which returns us again to individual responsibility. Such materials also present a challenge to this research in that they place simultaneous emphasis on individual responsibility as well as the need for change within the broader social context of their gay male audience.

Changing attitudes toward respect for self also appears as an approach for female audiences who are perhaps learning how to assert their own needs for the first time. A NAZ booklet entitled 'What every woman should know' stated: 'We believe there is no shame about wanting to preserve and maintain our sexual health. We can only achieve this by being open and taking responsibility for our bodies.' In this case women are urged to consider themselves first in an attempt to alter cultural values that emphasise their primary responsibility to other family members through traditional gender roles. While bringing wider social issues into focus, we must also be very aware that this text stresses the role of the individual, without necessarily taking into account the cultural and sometimes material pressures which can make these types of changes very challenging.

5.1.2 Shared responsibility

The analysis revealed a lower proportion of materials in the sample expressing shared responsibility as compared to individual responsibility. While approximately 80% of HEA and THT materials sampled from the 1980s contained messages of shared responsibility, in the 1990s percentages in this category dropped to less than 50% for most organisations. As already noted with individual responsibility, there are also distinct differences in the tenor of messages about shared responsibility depending on whether or not the materials are directed at specifically gay communities. Some of the examples discussed below will highlight this distinction. The text on the Rubberstuffers postcard shown in Image 11 (page 122) stressed the responsibility owed to loved ones while the image was clearly about honour and respectability (as well as incorporating the eroticism of men in uniform). The text says: 'Aren't there better ways to show your feelings than putting each other at risk of HIV and worrying each time you make love? Staying healthy and being there for each other proves so much more. Relationships take love and courage'. Rather than

Image 11

portraying safer sex as a consideration for one's self, this campaign emphasised the impact of HIV within the context of a loving partnership. As already seen with other materials directed at gay men, the factual details of the safer sex message are often left to one side in order to emphasise issues of shared responsibility and attitude.

Yet in contrast to this approach, a campaign from THT (1999) asks the reader how much they would tell others on a first date. The end-line states: 'Whatever your own views, remember it isn't a duty to tell, it's not a right to be told' [10]. The campaign openly lifts the responsibility for disclosure from the shoulders of the positive person, acknowledging that privacy is still a right for those living with HIV. Here the implication is that communication and behavioural choices are shared between sexual partners rather than falling solely to the person who is HIV positive. While all of the organisations represented here would also support the right to privacy, this campaign in particular raises many of the questions which lie at the heart of this thesis, and certainly demonstrates the broad differences between representations of responsibility toward others.

In each of the two examples compared above, there is a sense of background knowledge about HIV that exists among gay men prior to any sexual encounter. The issue at hand is how to deal with the matter of belonging to a community so heavily impacted by the disease, no matter how safely one attempts to make one's own behaviours. In the end, these messages both imply that responsibility is (or should be) shared equally by all members of the gay community in order for its own continued survival and protection.

While we have examples of shared responsibility messages occurring in materials directed at other audiences, the impact seems to be far less personal. Instead we find more broadly optimistic portrayals of how 'the good society' should react to the epidemic. Returning once again to the early work of the HEA, we find materials that sounded a clarion call for national action against AIDS. The 'AIDS Charter' published by the HEA in national newspapers in 1988 is one such example: 'unless

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[10] Chapter Six discusses the criminalisation of HIV transmission in a range of countries. The Terrence Higgins Trust has formally challenged the development of such policy in Britain.

we act now many thousands more people will become infected, and lives that could have been saved will be lost'. It discussed the need for compassion and inclusion in a society that recognises 'AIDS as everyone's problem'. This conveys a strong sense of shared response, making the connection between the actions and values of the individual and the safety of the nation. It is a particularly interesting sample of an attitude changing, shared responsibility approach that was subsequently abandoned.

An early mandate for the THT was to de-stigmatise the image of people living with HIV/AIDS to the 'outside' world. Image 12 (page 125) contains a page from a 1985 THT booklet designed to educate those concerned about AIDS in the workplace [11]. The text said: 'So now you've learned the less than terrible truth about AIDS. Don't let your fears about AIDS imprison you or cause you to become strangers to your co-workers.' This took account of people's fears about HIV positive co-workers and taught them about the development of a rational and responsible attitude toward others.

More recent examples of the shared responsibility approach include those directed at ethnic and cultural groups. Combined with text about global HIV statistics, or simple directives like 'love safely', the pictures seen in Image 13 (page 126) on the front of NAZ's information materials implore the individual to be aware of the impact of AIDS on distinct cultural communities. There is an implied sense in these examples of the need to develop an attitude of shared responsibility for preventing the further spread of HIV within the Asian community.

A THT booklet aimed at African women considering childbearing is shown in Image 14 (page 127). The introduction stated that if a pregnant woman 'knows she is positive, she can take steps to reduce the risk of passing the virus to another person, including her baby' and informs the reader that 'you want to plan for a healthy baby'. The overall tone is one of support and concern, but the primary concern is that the mother does not infect the baby. While other THT brochures for women deal with protecting the self, this booklet shows how the issue of pregnancy can bring

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[11] Such images contrast greatly with those which the THT was concurrently using in their materials for gay men and this division continues today within most organisations serving a range of audiences (materials for gay men tend to be erotic, while those for heterosexuals are often de-sexualised).

PERSONAL CONTACT

Bear hugs may be a threat from grizzlies, but NOT from a friend or co-worker who has AIDS. The AIDS virus is not carried on clothing or in the air, so a pat on the back does not make you an endangered species. You can safely shake hands with someone who has AIDS *without* rubber gloves. People who give an occasional hug or touch (especially family members) are NOT at risk for coming down with AIDS. And in fact, it helps everyone concerned to maintain the same everyday relationships and behaviors they have always had. That way no one will feel badly about ignoring or deserting a friend, and that friend with AIDS won't feel like an outcast.

Image 12

125
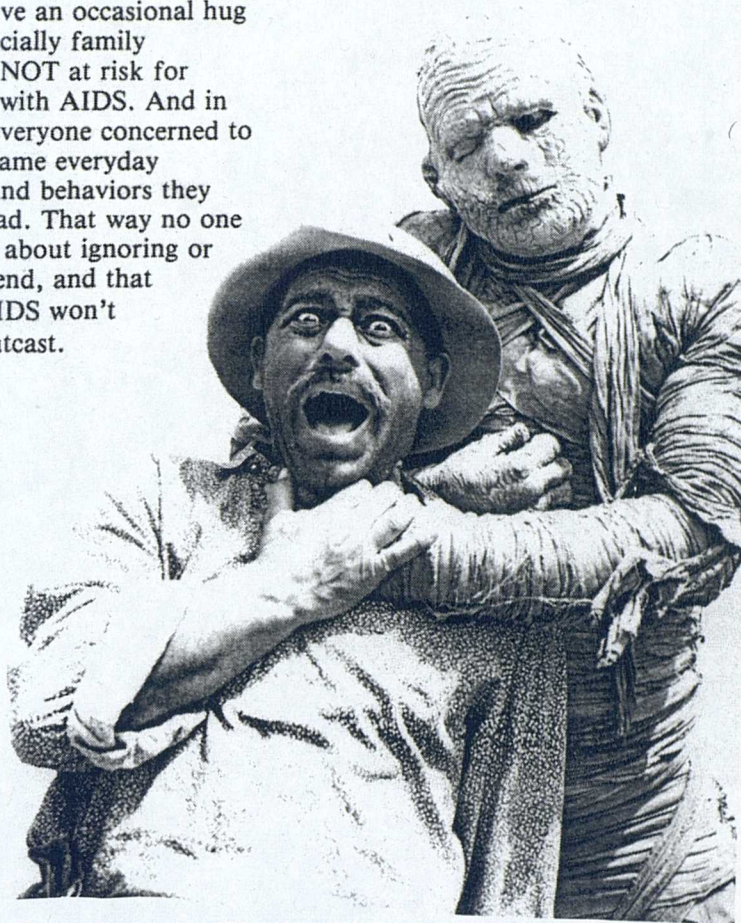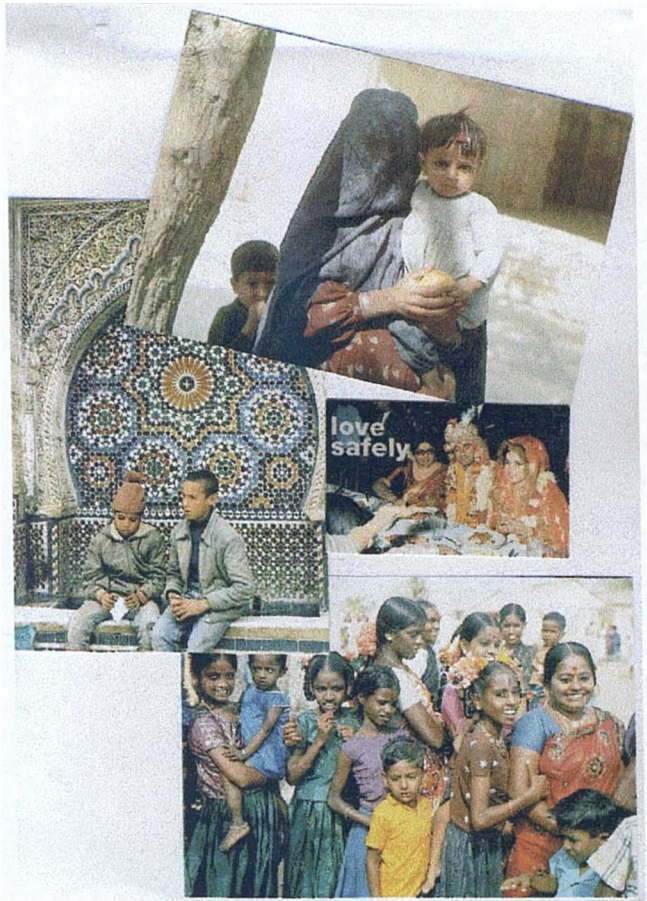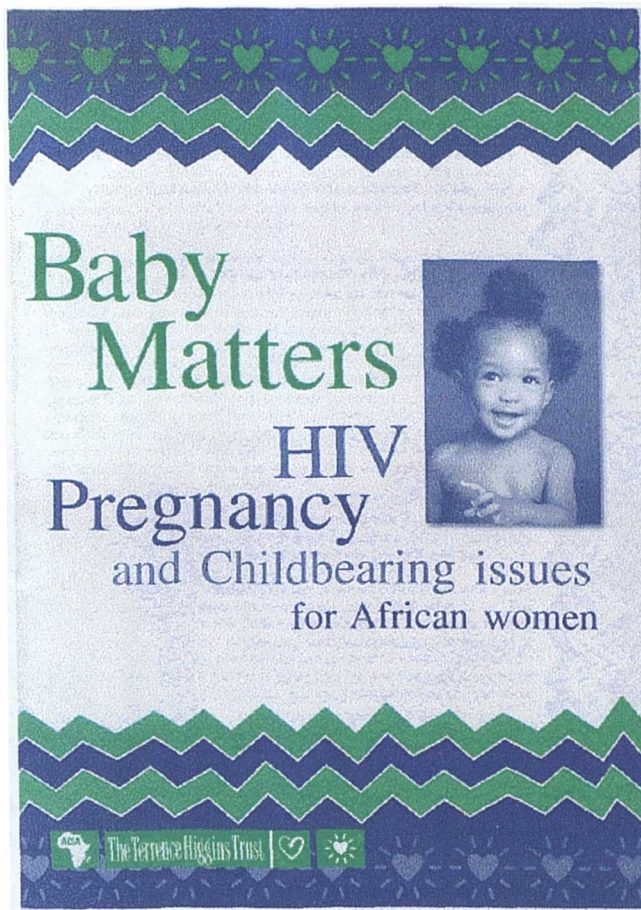
Image 13

Image 14

responsibility for others to the fore in a very direct manner. In the case of a potentially HIV positive pregnant woman, such materials can be interpreted to be encouraging her to place her responsibility to her child's well-being ahead of all other considerations.

5.1.3 Organisational responsibility

This final category for consideration represents by far the smallest number of materials in the sample. Less than 10% of all sampled materials for organisations apart from Rubberstuffers and GMFA include representations of organisational responsibility. In this context, it is noticeable that one quarter of Rubberstuffers' selected materials convey such messages, which is the highest proportion in the overall sample. The sticker shown in Image 15 (page 129) was placed inside every locker at sex-on-premises saunas. The simple message: 'We care....do you?' referred to individual as well as organisational responsibility.

Rubberstuffers presented itself very clearly as an organisation that took responsibility for the community it served. Materials from other organisations often describe their activities, but not always in a tone which claims organisational responsibility as directly as in this example.

In Image 16 (page 129), GMFA makes it clear that the state should be taking more responsibility in its approach to AIDS spending and prevention work. In part, this engages with a debate springing from the work of ACT UP founder Larry Kramer who wondered why community groups were taking up the slack in AIDS prevention and care when this should be the responsibility of the state (Kramer 1990). Once again, this demonstrates that models of responsibility continue to be strongly contested among those working in the AIDS field. At the organisational level, some would argue that it is more responsible to lobby government to carry out its duty in relation to HIV/AIDS, while others feel that direct support, care and education carried out by the community is the best means of demonstrating responsibility.

Image 15

Image 16

5.2 SUMMARY

This analysis has revealed marked differences in the proportion of materials expressing individual, shared and organisational responsibility. We would expect that the print medium and its modes of distribution are aimed at the readers as individuals, but this does not automatically mandate the disproportionate representation of individual responsibility as we have seen here. There are other messages about responsibility that can be conveyed through HIV/AIDS health promotion literature, such as those shown above that discuss the social and organisational responses that are necessary in order to address the epidemic successfully. I would argue that the overwhelming use of the individual responsibility approach is a reflection of those trends toward individualism and health discussed in earlier chapters. In particular, HIV/AIDS has become a potent signifier of this way of thinking in the English context.

The evolution of the harm reduction model of individual responsibility has moved prevention efforts slightly further away from the isolation of the individual toward an approach that includes social context in the message. It resonates with the calls from Jonathan Mann and UNAIDS for equality and positive self-identity in order for HIV prevention efforts to succeed, because it is cautious not to stigmatise or isolate 'unacceptable' behaviours. Yet however contextual the harm reduction model becomes, there is no escaping the fact that it is a means of encouraging behaviour change among individuals and that the concomitant of this is that if the individual does not change his behaviour once the facts have been given, then the consequences are his responsibility. While this approach should be one component of successful HIV prevention, a persistent and unrelenting focus on the individual will not stop the epidemic, no matter how contextualised the individually directed message.

It is interesting to note the organisations producing high percentages of materials with messages of shared and organisational responsibility. The originally high number of messages of shared responsibility declined after the 1980s within both the HEA and THT as a reaction to changing perceptions of target audiences, national urgency and, arguably, a consolidation of individualised health approaches in the 1990s. Yet this still leaves us with questions to ask about the approaches to responsibility on all levels expressed by GMFA and Rubberstuffers. Indeed, it

would be interesting to see future research that studied the relationship between their fairly moral messages about responsibility to self, partner and society, and the radical nature of these two groups. The strong communal bond conveyed by such organisations involves an inherently moral responsibility for others within that community. It has been widely agreed that the reason for the overwhelming behavioural change that took place in gay communities in North America and Europe in the late 1980s early 1990s is down to this shared sense of ownership of the issue (Denning, A.K. and Wortley 2000; Mays 2000; Ortega and Ko Tval 2000).

5.3 DISCUSSION

The three typologies of responsibility that have emerged from this analysis of HIV prevention materials are not the same as the three theoretical models of responsibility that were developed in Chapter Two. However, that does not mean that they are not interrelated. In the final section of this chapter, I will explore the ways in which *individual, shared* and *organisational* responsibility can be interrogated with the broader understandings of responsibility as *freedom, control,* and *intersubjectivity.*

When we consider the arguments expounded by the *responsibility as freedom* model, we see them directly reflected in the health promotion materials that encourage the individual to change risk behaviour for the good of his own health. Although I have presented evidence of a broad range of messages that focus on individual responsibility, their similarity lies in the assumption that an individual's highest priority should be health-seeking behaviour, both for the self and also for others. As a result, we can see this imperative across what appear to be vastly different approaches: directives to always use condoms; having an HIV test together with a partner; learning the skills and language that will enable an individual to negotiate condom use with a partner. All of these are different means of achieving the same goal. I have presented a range of examples in both sections 5.1.1 and 5.1.2 that demonstrate the ways in which individual and shared responsibility in HIV prevention materials reiterate the *responsibility as freedom* approach. That is, they focus on the duties held by individuals to practice responsibility in exchange for the rights enjoyed by participants in what is represented as an orderly society. There is no point at which the images or text in these types of materials question this key assumption. Instead, the elimination or even the reduction of risk is presented as a

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self-evident necessity, with little regard for other factors that might influence the proliferation of HIV at a local or population-wide level.

Application of the *responsibility as control* position would in turn require us to question the utility of an approach to health which isolates and potentially alienates its target audience. According to this approach, individualised messages will allow some readers to dismiss AIDS rather than incorporate it into their personal reality. Members of already excluded groups will react against the authoritarian stance taken by health promotion, while those who are less vulnerable will have an opportunity to gain even more distance from the epidemic. This type of result is contradictory to the aims of public health prevention. Partly because of their institutional context, the organisations under consideration here demonstrate an awareness of the thin line between personal responsibility and victim blaming and some examples of their work demonstrate the development of approaches that do not employ morality at the expense of the vulnerable. However, this does not change the fact that underlying the vast majority of this sample is an obligation for the individual to follow the advice given and to change sexual behaviour in order to avoid contracting HIV or transmitting it to others

Yet to fully implement the *responsibility as control* position, it would be necessary to take a further step and advocate the abolition of HIV/AIDS prevention and education. The rationale for such a drastic measure would be based in the argument that all attempts to communicate responsibility are simple attempts made by the powerful to control dangerous populations. However, I would strongly argue that to abandon all work towards the dissemination of clear information about HIV prevention would also be counter-productive. Awareness is an essential feature of prevention and also a necessary component in the development *of intersubjective responsibility*. In order to allow for balance, it will be necessary for effective printed materials to decrease the focus on the individual, and include expressions of responsibility that allow the reader to see that individual behaviour change is one component of a much broader web of social changes that will be necessary in order to prevent HIV. Some may say that this is too much to expect from simple posters and leaflets, yet there is little evidence that the current individualised approach that is so common in this medium is meeting with much success (Keogh 2001).

Several of these organisations within the sample campaign in their community to combat social exclusion, influence governmental policy and to make inroads into the wider social issues which contribute to the existence of AIDS. They have crossed over the old boundaries that would have only defined them as producers of HIV prevention information and are now also part of a political and social lobby force. This force is encouraging England's Labour government to consider the ways in which Section 28 and other forms of social exclusion experienced by those most vulnerable to HIV prevent the success awareness and education efforts [12]. The reasons for policy advocacy became clear to those working at the organisational level when they recognised the severe limitations to HIV/AIDS prevention programmes taking place in a wider social milieu that takes little account of the inequalities suffered by the disenfranchised. Therefore carefully crafted HIV prevention materials must be incorporated alongside effective public health strategies which are in turn integrated with broader policy and legislative change in areas such as housing, education and criminal law. Prevention materials will need to include promotion of the reasons and necessity for such social changes. Readers need to understand the wider relationship between equality and health in addition to understanding their own roles in prevention. What is required is government-led policy which eliminates current exclusionary outcomes in areas such as sex work, poverty, race, homosexuality and drug use which serve as important barriers to the reduction of HIV transmission. Only in this way will the wider public, as well as members of the groups most affected by AIDS, be able to transform the misinformed notion that HIV infection is simply the result of individual behaviour choices. As Mann argued: 'To address the vulnerability of such individuals and communities to HIV/AIDS, it is particularly essential that the response be expanded beyond risk-reduction strategies' (UNAIDS 1998a: 6). Promoting the view that HIV transmission is only the responsibility of the individual leads to the commonly held perception that the individual who contracted the disease must have behaved irresponsibly. It simultaneously allows the unaffected to maintain a moral high ground and it is this

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[12] Section 28 of England's Local Government Act disallows the promotion of homosexuality as a 'pretended family relationship'- in turn leading to great fears about addressing the issues of homosexuality in schools at all. While there has been much talk about the need to repeal this amendment by politicians, such change has been repeatedly blocked and delayed.

type of divisiveness that negates any achievements made through HIV prevention efforts.

CHAPTER SIX: HIV/AIDS TESTING POLICY AND ITS IMPLICATIONS FOR NOTIONS OF RESPONSIBILITY

6.0 INTRODUCTION

The previous chapter reviewed the high proportion of HIV/AIDS prevention materials that promoted a notion of individual responsibility for the self. The analysis was conducted on printed words and images as they are presented to individual readers. However, health promotion exists beyond these limits and it is important to move beyond the analysis of visual and printed media in order to pursue a more far-reaching exploration of how responsibility is infused within approaches to the epidemic enacted in civil society. This chapter engages with policy-making that relates to the voluntary HIV-antibody test. Making the decision to have an HIV test is in many cases a profoundly individualised experience, as the person involved weighs up the benefits of knowing their HIV status against concerns that testing positive may damage their physical, social and psychological well-being. Responsibility and the way it is presented to the individual both before, during and after this decision-making process can have an important impact upon the way that one relates to the test itself and HIV more generally.

Global HIV prevention efforts uniformly advocate free access to HIV testing as an important means of slowing the epidemic. This is generally an uncontested position, and it is not being brought into question by the work presented in this chapter. What I would like to investigate here are the more subtle implications that different approaches to testing can potentially have on individuals' perceptions regarding responsibility. Therefore this chapter will explore the ways in which voluntary testing and counselling have been infused with notions of individual responsibility through discussion of several features of testing policy and practice. These will include: the assumption that behaviour change will result from being tested; the proliferation of HIV testing amongst those at lowest risk; and the ways in which insurance policy has raised concern about confidentiality of HIV test results.

While these features related to HIV testing may appear to be unconnected, the analysis of documentary and primary research conducted for this chapter reveals that they are very closely related. Both quantitative (European Centre for the

Epidemiological Monitoring of AIDS 2001, 2002; Holtzman *et al.* 1998; PHLS AIDS and STD Centre 1998) and qualitative (Lupton 1995a, 1995b; Henderson *et al.* 2001; Bennett and Erin 1999) research carried out in developed countries demonstrates that those who are the lowest risk of HIV transmission can be highly likely to test, and in the UK they comprise the vast majority of testers. This is because the test carries a different meaning and weight for those who regard themselves as either more or less at risk. A subsequent analysis of sampled health promotion documentation conducted in light of this information demonstrates that there has been little interaction between the theoretical drive behind HIV testing, and an examination of the outcomes, as health promoters continued to make the assumption that having an HIV test would significantly reduce individual risk behaviour. Yet about half of reviewed studies have demonstrated that there is no relationship between testing and a reduction in such behaviours (Wolitski *et al.* 1997). In addition, when we consider the case of the UK, the majority of testers are already *not* at risk of transmission. These realities raise serious questions about the feasibility of promoting HIV testing in the UK as a means of imposing individual responsibility on those most likely to be diagnosed positive. Firstly, the target audience is probably being missed, and secondly, there is evidence to demonstrate that an individualised focus on behaviour change is often ineffective within this setting.

Examples and research used in this chapter come from a range of international sources. However, much of the discussion surrounding specific policy and its implications will emanate from the British experience. Not only is this because of the availability of materials, but also because the UK demonstrates patterns in its rates of VCT that are significantly lower than most other developed countries which raises specific questions about what has led to limited uptake of the test in this country, and what factors are implicated in the meaning of the test among those who consider taking it.

Upon further examination of HIV testing in the UK, the issues of future insurance applications and confidentiality of medical records have imposed a further complication on the relationship between individual responsibility and the test. A small number of interviews with key informants, and a review of gay press clippings

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and academic commentary on this issue reveals the confusion that the British insurance industry has imposed on the already complex decision to test [1]. The implications of this will be explored toward the end of the chapter. Before reviewing all of this information in light of different models of responsibility, I will begin with a brief overview of the history and implementation of HIV testing more generally.

6.1 ESTABLISHMENT AND PROMOTION OF THE HIV ANTIBODY TEST IN DEVELOPED COUNTRIES

HIV-antibody testing first became available in 1985 and it was immediately put to use screening donated blood and blood products. Despite this prioritised function of implementing HIV testing, it was also made available in many developed countries to individuals who wanted to know their HIV status for either personal or clinical reasons (Department of Health and Human Services 1998; Valdiserri 1997). While we now take for granted the preventive role of the test in relation to the screening of donated blood there continues to be a lot of discussion centring on the individual who comes forward to test as the focus of behavioural HIV prevention (Valdiserri 1997; Willis 1992).

Since testing was introduced, it was understood that information gathered from testers would offer a great deal of epidemiological information that in turn would inform broader prevention efforts. However, there was more weight placed behind the notion that voluntary testing would lend itself to the dissemination of information about protected sexual and injecting practices: those seeking a test would not only find out their status in such interactions, they would also be in an environment to learn how to prevent transmission in future. The notion that a testing session would relate directly to individual behaviour change involves the same logic outlined in Chapter Three in relation to individualised health promotion such as the HBM. This view of testing relies on the notion that if a person were to find out she was HIV negative, she would ensure that her future behaviour would protect her from the virus; if she were positive, she would do everything possible to prevent transmission of the virus to others. Later sections of this chapter will problematise these assumptions.

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[1] See section 4.2 in Chapter Four for more details.

The subject matter of this chapter relates exclusively to voluntary testing, often referred to with the acronym VCT (voluntary counselling and testing). In most countries, it is now agreed that this type of individualised HIV testing should be voluntary and accompanied by fully informed consent and counselling both before the test and after results have been received (UNAIDS 1997). VCT focuses on the person who submits to a blood or saliva test in order to determine the presence or absence of HIV antibodies (finding them indicates that the person is HIV positive) and is then informed of the result of that test[2]. Advocacy of testing for those who may be at risk of infection has become a core practice within HIV health promotion in addition to the provision of information and advice on the reduction of risk behaviours (BMA Foundation for AIDS 1998; Curless 1996; DeCock and Johnson 1998). Yet approaches that regard individual VCT as a primary means of behavioural prevention have not been without their critics. Questions have been raised by those working directly with people at high risk of HIV exposure about the negative social, economic and psychological impact of discovering one's positive status (Canty 1995; Henderson *et al.* 2001; Sherr 1999). There have also been concerns that VCT occurs with less than optimal pre- and post-test counselling, meaning that such individuals being tested may not be able to give fully informed consent to the procedure (McCann and Wadsworth 1991; Sherr 1999)[3].

The HIV test was initially regarded as distinct from other types of medical screening. This 'exceptional' status was ascribed to the test because of the intense social and moral repercussions associated with being diagnosed HIV positive (even associated with the concern that one may be HIV positive). Therefore, in order to meet the

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[2] This process should be differentiated from practices such as anonymous unlinked screening of nationally collected blood samples in order to determine estimates of HIV prevalence throughout the population. This latter practice is for the purposes of epidemiology only, as the blood samples are never given markers that can identify the individuals from which they came. As those providing such blood samples (sometimes taken from leftovers in routine blood screening at hospitals, doctors' surgeries or antenatal clinics) will never be told via this process if they are HIV anti-body positive or negative, and as laboratory and medical staff cannot identify the source of any of the samples, there is not necessarily a requirement for consent to be given for this type of testing. HIV testing for the purposes of employment, immigration, insurance or in some cases, in order to be a licensed sex worker cannot be considered VCT and will not be dealt with here. Nor will there be an opportunity to have an extensive discussion about the impact of HIV screening imperatives in ante-natal clinical settings.

[3] In the UK, guidelines for HIV pre-test discussions stipulate that any health care worker with appropriate knowledge and skill is able to conduct such counselling and gain informed consent (Department of Health 1996). However this does not provide any assurance as to the quality of information or time spent with each client.

demands of appropriate informed consent, policies surrounding the implementation of VCT included the need for cautious explanations to ensure that the potential tester was absolutely sure that she was ready for the outcome of the HIV test. Discussions about whether or not the HIV test is still an 'exceptional' process because of the stigma surrounding AIDS - or whether it should now be 'normalised' and mixed in with a range of other screening tests - have dominated the AIDS field for years (Bayer 1991; DeCock and Johnson 1998; Stoltz and Shap 1999). However, this debate ignores queries about how the test operates as a means of social governance (Willis 1992). Such criticism includes investigation of the assumptions made in relation to individual responsibility within the testing paradigm; for example, whether the test result is positive or negative, there is a presumption that in future the individual will actively avoid transmission of the virus. The implied expectation is that this consideration will come before all others (i.e. privacy; fear of physical reprisal; withdrawal of economic and emotional support) (Manuel 1999). Thus it is possible to regard the voluntary HIV test as the ultimate means of individualised responsibility in relation to the epidemic. Once more, this is an obvious concomitant of the Health Belief Model (Rosenstock 1974): individuals should be tested if they feel they have been exposed to HIV. Within this logic, the person should want to know their status so that they adapt their own future practices with full consideration of this knowledge. As discussed below, this model is not able to comprehend that, even if the individual feels that they may have been exposed to HIV, they may not follow through with the test.

In order to contextualise the amount of VCT that occurs in various developed countries it is useful to provide a statistical snapshot. Because of the different methods of collection and the differing time periods being taken into account (i.e. lifetime tests versus number of tests taken over the course of a given year) in the various national statistics on the topic, what follows gives us the ability to gain some understanding of how much testing takes place, but not to make direct comparisons between countries. In 1996 (the most recent data available), 225 000 people in the UK had a voluntary HIV test – amounting to approximately 3.9 per thousand of the population (European Centre for the Epidemiological Monitoring of AIDS 2001:

$39)^4$. When considering numbers of those who have had at least one test in their lifetime, researchers in the United States report that between 40% and 44% of adults have had a least one HIV test (Anderson, Carey and Taveras 2000; Rotheram-Borus *et al.* 2001). In comparison, 33% of adults in Switzerland (Zwahlen *et al.* 2000) and 17% of adults in Canada (Houston *et al.* 1998) have tested voluntarily at least once. Despite these differences in testing rates, we find that the promotion of testing as a key means of HIV prevention is similar across most developed countries.

6.2 PROFESSIONAL ASSUMPTIONS THAT THE HIV TEST WILL RESULT IN BEHAVIOUR CHANGE

> Knowledge of infection status by individuals at risk could help them to take action to prevent becoming infected or from transmitting HIV infection to others. (Holtzman *et al.* 1998)

> People who know that they are infected have the opportunity to adopt behaviours that minimise the risks of transmitting the virus to others (Department of Health 1992)

The first of these quotes comes from a *Centres for Disease Control* (government-based) researcher in America who investigated national VCT increases in the 1990s. The second is from a *Department of Health* guidance for England and Wales, discussing among other things, the reasons for making additional VCT sites available. The perspectives reflected in these passages are representative of the health promotion position on HIV testing. They are also remarkably similar, denoting little variation over time and place in official positions on the role of VCT in individual behaviour change relating to HIV/AIDS transmission risk. The latter example provides a clear indication of the burden of responsibility on the HIV-positive individual to change risk behaviour.

Despite ambivalence and concern expressed by medical and AIDS organisations in relation to the negative outcomes of testing and problems with informed consent, official policy in most developed countries has been to encourage more people to take the test (Altman 1994; Berridge 1996; Macdowall and Wellings 1997). Often

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[4] The same document reports an average of 32.18 tests per thousand population in other Western European countries in 2000 (European Centre for the Epidemiological Monitoring of AIDS 2001: 39). While this average is not for 1996 (as is the most recent available date from the UK) it is still evident that rates of testing in the UK are significantly lower than they are elsewhere in Europe.

this policy has been directed towards efforts to remove barriers to VCT such as concerns about confidentiality of results, stigmatisation, or difficulties discussing HIV with GPs (BMA Foundation for AIDS 1998; Department of Health 2001). The efforts prior to 1996 revolved around convincing those at high risk of infection that it was worthwhile to know their status, despite the fact that the medical resources to prevent morbidity and mortality at that time were very limited.

After 1996, VCT was promoted even more vigorously once it became clear that early intervention with protease-inhibitors was meeting with widespread success (BMA Foundation for AIDS 1998; DeCock and Johnson 1998)[5]. This provided a reason for having a test that did not exist previously, and suddenly there appeared to be a benefit that could outweigh the negative outcomes. Research conducted in the mid-1990s demonstrated increases in voluntary testing in developed countries among some parts of the population (Holtzman *et al.* 1998; Lupton, Mccarthy and Chapman 1995a; PHLS AIDS and STD Centre 1998). However, evidence of a link between increased testing and awareness of recent treatment success is not proven. For example, in the UK, numbers of gay men going for their first HIV test did not change in the four years following the introduction of anti-retroviral treatments (Henderson *et al.* 2001). This indicates that the success of therapies introduced in 1996 and subsequent campaigns in the UK to encourage gay men to test in order to gain early access to treatment have not had an impact among this key target group (Dodds *et al.* 2000; Henderson *et al.* 2001; Hickson, Hartley and Weatherburn 2001; Hickson *et al.* 1998). British gay men who believed themselves to be at risk of transmission were not queuing up at test sites because they could suddenly begin to see the benefit of early intervention with protease-inhibitors. It was a simple demonstration that the Health Belief Model and other similar theoretical health promotion models were not good predictors of human behaviour.

Even with evidence that availability of treatment had not significantly influenced testing rates, there was still a persistent and influential component of health promotion that held to the initial argument that HIV testing would lead to a decline in

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[5] In addition, AIDS organisations that had previously expressed ambivalence about testing were now suggesting that access to treatment could be a significant benefit to knowing one's status (i.e. see Terrence Higgins Trust's 1999 leaflet called *Testing Issues*).

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risk behaviour. Even UNAIDS policy promotes testing and counselling as a means of providing 'motivation to initiate or maintain safer sexual and drug-related behaviours' (UNAIDS 1997). There is, however, very little evidence to support such a rationale. From reading official policy or guidance documents alone, one would not recognise that international independent research has failed to establish a clear link between VCT and a reduction in HIV risk behaviours. The concluding sentence of one research paper states: 'Overall, these results, then, can help target strategies toward increasing the numbers of individuals who know their sero-status, an important step in the behaviour modification process' (Mack and Holtzman 2000), despite the fact that there was no evidence presented in the paper itself that could substantiate this link between knowledge of HIV status and behaviour change.

UK research as early as 1989 demonstrated that early assumptions about the relation between testing and behaviour change had not come to fruition (Miller and Pinching 1989). More recent literature reviews have raised a number of questions about the assumed link between testing and risk behaviour. In a review of thirty-five studies conducted between 1990 and 1997, Wolitski et al (1997) found that only about half demonstrated some relationship between VCT and the adoption of risk-reducing practices. There was some indication that such change was most evident among those who tested HIV positive and, in particular, those who were heterosexual and had an HIV negative partner (Wolitski et al. 1997). From this review, the authors conclude that while VCT demonstrates that it can motivate behaviour change in some individuals in some cases, it does not do so consistently, nor across a range of settings or populations. For example, some research demonstrates that gay men with more partners are more likely to test repeatedly (Elford et al. 2001; Leaity et al. 2000).

In her review of the issue, Beardsell (1994) questions whether it is possible to establish a clear and causative link between VCT and subsequent behaviour. She raises the question about other factors that may influence people (HIV positive people in particular) to employ risk-reducing strategies, such as media pressure or increased psychological isolation after diagnosis (Beardsell 1994). She also questions whether behaviour change is sustained over the long term, as many studies on this issue only follow up respondents for a short time after testing.

It is also important to consider how the available data may be skewed through an element of self-selection bias among those who choose to test. Some of those who make the active choice to determine their HIV status may already have undergone an internal process of decision-making including a shift toward a healthier lifestyle that includes risk reduction (Wolitski *et al.* 1997). In such instances, subsequent behaviour would not be so much a direct consequence of the test as a marker of altered decision-making that included the choice to test in the first place. Having said this, we should not assume that this is the case for all testers, as Henderson *et al.* (2001) reveal that gay men with high risk behaviour who test repeatedly are unlikely to demonstrate any change in their sexual practices. Similarly, a study conducted amongst over 6 300 current and former intravenous drug users in England and Wales could find no substantial difference in recent risk behaviour between those who had a prior HIV test and those who did not (Hope *et al.* 1998).

Despite research demonstrating the weakness of HIV testing as a tool of behavioural change[6], there continues to be a steady flow of policy documentation and academic work that promotes the importance of the test on precisely these grounds. This is clear evidence of the strength of the paradigm of individual responsibility surrounding HIV/AIDS. It appears that those in the business of health promotion strongly resist the notion that taking a test *may not* be part of an overall risk-reduction strategy and *may not* induce a desire to change one's ways in order to prevent future transmission. Thus alongside the imperative to test there continues to exist an equally strong imperative to regulate individual behaviour.

> [I]f we are attempting to modify the dissemination of the disease – which is still the final aim of the community – the process of making the individual in question responsible must begin as soon as he [sic] suspects that he [sic] may have taken risks and continue until a rational prevention is attained. The resort to testing should then be a logical part of this procedure; it should intervene on a voluntary, well-thought-out basis, with full knowledge of the facts, and should be followed by sensible changes in behaviours deemed dangerous. (Manuel 1999: 70)

Although there are not many instances where the rational thought process ascribed to behavioural change is spelled out in the way that Manuel has here, it is precisely this

chain of thinking that underlies the majority of official approaches to testing. However it is the folly of the academic or the official who believes that her own thinking is synonymous with those who consider taking an HIV test. In order to find out why individuals test it is necessary to look to qualitative research that has asked the individuals in question.

6.3 MEANINGS OF THE TEST FOR THOSE AT BOTH HIGH AND LOW RISK

In order to explore the implications of some assumptions about the test, this section will provide a comparison between understandings expressed by those testers who are at higher risk of infection and those who are at lower risk[7]. A study conducted by the Centres for Disease Control (CDC) in the United States revealed that of those who voluntarily tested, the majority considered themselves to be at high or medium risk of HIV transmission. However, there was also a marked increase in testing among those stating they were at low or no risk, from 11% of the testing population in 1993 to 18% in 1996. Testing rates among those at higher levels of risk did not demonstrate a similar rate of increase during this time (Holtzman et al. 1998).

In contrast to the US experience, the Public Health Laboratory Service in the UK reports that those with 'no reported risk' comprise the vast majority of voluntary HIV testers (PHLS AIDS and STD Centre 1998). This group of testers is three to four times larger than homosexuals or heterosexuals reporting high-risk behaviours in pre-test counselling[8]. Testing rates among the 'no reported risk' group also tend to peak when media attention turned to HIV/AIDS because of famous deaths or soap story lines, whereas the testing rates among those at greater risk have stayed quite stable over the years (Henderson et al. 2001; PHLS AIDS and STD Centre 1998; GUM Advisors 1998: 9).

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[6] As well as those mentioned here, see also (Hickson et al. 2001; Higgins et al. 1991; Landis, Earp and Koch 1992).

[7] Although it would be preferable to be able to review a broad range of qualitative studies investigating this issue, there have only been a limited number of such projects conducted and published in developed, English language settings. Those that are available are discussed here.

[8] It is worth noting here the action of risk-grouping that was mentioned in Chapter 3. The majority of epidemiological surveillance breaks down the heterosexual population into smaller groups depending upon risk behaviours, yet homosexual men form a category of their own, regardless of reported behaviour.

Research conducted in Australia attempted to uncover the reasons for testing patterns among those at lower risk of HIV transmission and to find means of communication which may help those at higher and lower risk make better informed decisions about whether or not they should test (Lupton, Mccarthy and Chapman 1995a; Lupton, Mccarthy and Chapman 1995b; Lupton and Tulloch 1996)[9]. This study revealed that heterosexual women with low risk behaviours would initiate testing when embarking upon a new relationship and, in some cases, would insist on using condoms with a new partner until he had a negative HIV result. Some respondents also said that they tested at the end of a relationship as an emotional cleansing ritual within the grieving process. Lupton and her colleagues discuss the possibility that the focus on women in AIDS discourse as a source of infection and as the guardians of safer sex has meant that some women use their known HIV negative status as a symbol of power within the sexual relationship[10]. Some of those interviewed revealed a sense of moral righteousness in relation to HIV testing. Described as 'an act of affection and commitment to a relationship' and 'a responsible thing to do', many female respondents reported feeling that HIV testing is a sign of a serious, long-term bond (Lupton, Mccarthy and Chapman 1995a: 176). From this the writers extrapolated the unexplored notion of HIV negative status as sexual currency, meaning that a person who is responsible enough to have themselves tested can be seen as more sexually desirable[11]. The writers summarise such trends as a part of a 'new sexual etiquette', wherein partners have a right to know each other's status. A Swiss study of heterosexuals requesting HIV tests appears to confirm this, as 48% of respondents sought the test because they had a new partner (Gebhardt and Paget 1998). However, one must not jump to conclusions, as it may only be the case that such individuals see themselves as more desirable or committed because of testing. It is also not clear from the small amount of qualitative research conducted among those at lower risk of transmission how potential partners might regard those who test, or

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[9] The study cites 1993 statistics stating that 13.7% of HIV/AIDS cases in Australia are transmitted heterosexually (Lupton, Mccarthy and Chapman 1995a).

[10] On the other hand, it is important to account for the scores of women who do not consider testing in this way, who may have difficulty negotiating condom use, or may not even be aware of sexual health implications. Lupton's study only focuses on people whose concerns about sexual health have translated into action, and it does not explore the reasons why others do not think or behave similarly.

[11] This can be directly contrasted with the claim that among some groups of gay men, unprotected anal intercourse among sero-discordant couples is sexually arousing precisely because of the risk involved (Rofes 2002; Russel 1998; Wells 2000).

how other factors such as gender, class and ethnicity might play a role in understandings of the test.

Alternatively, some of those interviewed by Lupton in this research outlined how the HIV test merely forms one part of what they regard as a responsible health routine. For this group, an HIV test is added to a list of other tests that may be sought annually during what they view as a 'routine' check-up. They view it 'like a Pap smear in that sense, we'll do it because it's easy, you can get access to it and it's better to have it than not' (Lupton, Mccarthy and Chapman 1995a: 177). One co-author of the CDC study which noted the rise in HIV testing among those who see themselves at low risk agreed that it was fair to surmise that these trends were a result of a spreading sense of preventive health in America (Holtzman 1998). A major component of this approach to health includes annual check-ups and a host of screening processes, including potentially an HIV antibody test. This model of individual preventive screening is relatively new in the UK. Given the ongoing economic strain within the National Health Service and the corresponding rationing of health care, there does not exist a widespread impetus toward the annual check-up model outside of the private system[12].

While considering the reasons why so much of the testing population across a range of developed countries is comprised of those who report low levels of risk behaviour, we also need to take into account the reasons why those at higher risk may choose not to test. Stated simply, if there is a strong possibility that one may be positive, concerns about the negative impact of that diagnosis may very well outweigh any perceived benefits of having that knowledge. Whereas in the Lupton study above, using the test as assurance of negative status is interpreted as a beneficial form of power among those at lower risk, this is precisely because such testers do not have to seriously contemplate the possibility of a positive result. This is not the pre-test context for those who have strong reason to believe that they will test positive.

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[12] However there have been campaigns encouraging gay men in the UK to have a sexual health check every six months- or 'MOT' – which is exclusively reliant on this model of individual preventive health. Again, despite such campaigns, there has been little change in testing rates among this population over the past several years (Henderson *et al.* 2001).

> As long as I am healthy, I just don't want to know [my HIV status] because of the negative psychological and emotional effect it would have upon me...the cost of that knowledge is too high.

> I'd probably lose me [sic] job. I'd certainly lose friends at work. I'd have to be segregated I suppose. I feel like I'd just have to disappear somewhere. I can't imagine what it would be like. I think if I was positive I actually wouldn't want to know. I'd almost prefer not to know. (two respondents cited in (Henderson *et al.* 2001: 31,15))

Thus we cannot make the assumption that a recognition of one's own vulnerability to HIV will necessarily translate that into a desire to test. There are many other social factors that will impinge upon the individual that may prevent them from following the 'responsible' course of action.

In addition, when such people do make the choice to test, it may not be associated with the types of reasoning that would be most expected by health promoters. For example, in a qualitative study with thirty-four gay men in England who did not know their HIV status, Henderson *et al.* (2001) found that testing was not related to changes in risk behaviour. The authors challenged prior quantitative research that suggested that gay men who test repeatedly had developed a sense of invincibility which resulted in them having unprotected anal intercourse (UAI) with partners of unknown status. Through their work Henderson and her colleagues found that repeat testers continued to engage in high-risk behaviours because for them *the test had nothing to do with their future contemplation of risk*. These men reported that they wanted to test for their own peace of mind because they had engaged in UAI in the past.

> Those men who have engaged in significant HIV risk and have tested, have done so in order to re-establish their negativity as a priority. They were in a state of transition. However, this was not in order for them to make more informed decisions about their HIV risk, but rather to put their minds at ease about their health and personal future. In short, it is clear that testing is almost universally related to personal well-being rather than future HIV risk. (Henderson *et al.* 2001: 33)

This study concludes that instead of trying to promote HIV testing as the final goal of an HIV prevention strategy, health promoters should begin to question their own assumptions concerning outcomes from testing. The authors suggest that instead of providing the individual with a sense of certainty upon which they can make future

decisions about risk, that the meaning of a test result can quickly become contingent on a host of sexual, emotional, social and psychological factors. Rather than providing a fixed knowledge, a negative test result will fade in significance once risk behaviour begins again. The way that people engage in risk reduction can have a lot more to do with the contingencies upon which they judge their own status and a host of other competing needs rather than simply the fleeting provision of certainty given by an HIV test (Henderson *et al.* 2001: 36).

Through their actions, such individuals demonstrate that they do not align their HIV risk-taking behaviour in ways that health promoters might describe as 'responsible' (according to the criteria set out in the extended quote by Manuel above). They do not necessarily take on the messages of self-constraint and control that have become a routine part of the VCT process. Thus we can begin to see that some people who may be at the highest risk of HIV transmission have their own meanings and uses in association with the HIV test which do not correlate with official understandings. While some may regard having a test as providing them with peace of mind and are then willing to take on the responsibilities of protecting others if they turn out to be HIV positive, this is certainly not the case for all. 'Considerations of quality of life (am I infected? will I get ill?) inform men's testing practice far more than intentions to use a test result to reduce risk' (Henderson *et al.* 2001: 27). Those who avoid testing precisely because they judge themselves to have engaged in high-risk behaviours often conflate having the test with being diagnosed positive. Thus, to their minds, it is a healthier option to not know their (presumed positive) status until it is absolutely necessary, because knowing now would be accompanied by too much trauma (Henderson *et al.* 2001: 12). It is also worth highlighting that this presumed positive status does not automatically result in a withdrawal from high- risk activities. These people are making reasonable choices and seeking responsible approaches to their own health but these are not aligned with the rationality reflected in the Health Belief Model that is so frequently relied upon within traditional health promotion (Davies *et al.* 1993).

Many people who engage in HIV testing do so precisely because they have concerns about the possibility of viral transmission during high risk behaviours. However, the overview of these two contrasting and emblematic pieces of research helps us to

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understand why it is much more straightforward and unproblematic for those at lower levels of risk to be tested. For this latter group, meanings associated with test-taking range from self-care via regular screenings to emotional and physical cleansing between relationships. However, for those who strongly suspect they could be positive, the meanings associated with testing are loaded with the complexities of the serious and unwelcome changes that they see following on from a positive diagnosis. Viewed from this perspective, we can begin to understand why having a test may not always be an attractive option for those at higher risk.

This also allows us to reflect on the different uses of the notion of responsibility that are dependant upon the self-determination of risk within the individual. For those who see themselves being at low risk of infection, it is usually easy to regard taking the test as 'doing the right thing'. It is right and responsible for such people to test, because they presume that by doing so they will be able to maintain and extend whatever equilibrium they currently enjoy. For them, the test can be seen as a rite of passage, taking them into a new relationship, or into a time of replenishment after the close of an old relationship. For others, the test carries meanings associated with a health ritual that includes a range of screenings of which HIV is just one. In all of these constructions, an HIV test is unproblematically associated with a 'responsible' and self-regulating outlook – toward both the inner and the physical self. It is no coincidence that those who are categorised as being at lowest risk (i.e. those who are not socially marginalised, who are heterosexual, who are middle class) are involved in self-governing processes such as HIV screening. The models of individual responsibility reflected through the narratives of preventive health provide a construction of self that sits ideally with their own.

However, for the individual who has strong reason to believe that he/she will test positive, undergoing an HIV test can carry very different meanings. Those who test under these conditions may be checking on their status with a view to access effective early treatment; or to assess their personal well being. But for a significant proportion of those at high risk of infection, the right course of action may include

the decision *not* to test[13]. In order to maintain equilibrium in emotional, familial and financial spheres, the individual may feel that it is best not to know their status. For them, *knowledge* would mean *disruption* of equilibrium. For people in such circumstances, demonstrating responsibility for themselves and those closest to them involves doing their best to maintain a steady course in life – despite the contingent existence that may result from not having a confirmation of perceived HIV status (Henderson *et al.* 2001).

6.4 INSURANCE COMPANIES, THE HIV TEST, AND CONFIDENTIALITY IN THE UK

A significant contribution to this notion of not testing in order to maintain equilibrium involves the belief that having an HIV test will hamper one's ability to obtain life insurance (often an important aspect of property ownership). Patients and GPs in the UK have felt restricted in their ability to discuss HIV and the antibody test in a primary care setting because of concerns over confidentiality and insurance companies' access to GP records. Those who test with their GPs will then have contents of their discussion and test results contained within their personal medical records. In contrast, HIV tests at GUM clinics in the UK are conducted confidentially, therefore the client does not have to give their full name. This means that there is no record of HIV counselling or test results that can be traced back to specific individuals who have tested in this manner. Those who test at GUM clinics are then able to make a choice about whether or not to inform their insurer or mortgage provider about their action. Many of those who test at GUM clinics do so in order to keep HIV test discussions and results confidential and, while not all of them do so in direct relation to matters regarding insurance, it remains a significant issue for a good proportion (Madge *et al.* 1998). As a result of this situation, there is a need to address how stigmatisation may dissuade potential testers because of concerns about the insurance implications of having an HIV test (Kingman 1993). Although there have been changes brought about within insurance policy regarding the types of questions that can be asked about HIV testing history (discussed in full below), the key issue to be covered in this section is the current confusion that has

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[13] In the UK, around 41% of gay men have *never* had an HIV test (Hickson *et al.* 2001), while in the USA this figure stands at about 11% (Hecht *et al.* 1998); and in Australia it is 22% (Van de Ven et.al. 2000: 13).

been brought about by earlier stances taken by insurance companies. As a result, many potential testers, as well as their GPs, have been wary of declared changes within the industry (that is, where they are aware of such changes), thus maintaining the position that it is safest for HIV test requests, discussions and results not to be recorded in the patient's named medical records (Madge *et al.* 1998; Mihill 1991; Roth 1995).

> The conflict arises because GPs primarily have a duty of care to the patient. To do what is best for the patient. But also, legal requirements, some of which are to do with protection of yourself, the GP, like you're meant to keep notes and record what's happened. So in theory, if someone comes and discusses HIV testing with you, you should make a record of that in their medical records, even if you are referring them to the GU clinic or sending them somewhere else. But I think very often people don't. They regard it just as a general inquiry, rather than a specific complaint. (General Practitioner 1998: 1)

Written advice given to potential testers makes reference to the fact that insurance companies pay GPs to complete forms regarding each applicant's medical history. 'If you are tested through your GP the result goes on your medical records. It might therefore form part of any medical report your GP later writes about you' (Terrence Higgins Trust 1998). A requirement of any application for life insurance in the UK is that the applicant is required to give permission for the insurance company to question his/her doctor. Many GP questionnaires have historically included questions about whether or not the proposer sought testing or counselling in connection with HIV, and if they have lifestyles that could lead to high risk for infection (General Practitioner from Ramsgate 1989; General Practitioner 1998; GUM Health Advisors 1998; Samuel 1989; Slade 1998).

Research conducted in London revealed that 85% of those being tested at a GUM clinic did not intend to discuss the test with their GP (Madge *et al.* 1998)[14]. The researchers drew attention to insurance issues as a major barrier to testing. A situation of extreme confusion and weakened trust exists where clients and GPs are unsure if notes should be taken regarding such conversations which may later be uncovered by insurance companies (Sorell and Draper 1999). As a result, it is not unusual for people who would like to discuss the test with their GP to find

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[14] This is supported by further research which found that less that one third of gay men had discussed HIV risk with their GP (Elford *et al.* 2000).

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themselves directed toward an anonymous clinic instead so that future financial decisions will not be affected[15]. 'I think on a practical level, most...a lot of GPs do send their patients to GUM clinics, and do not record anything in their notes' (General Practitioner 1998: 3).

Within some segments of the population this situation is not highly problematic, as it is likely that many gay men and sex workers engaging in high-risk behaviour might feel that their sexual health needs are better met through the GUM clinic[16]. However, this situation sometimes raises difficulties for those who do not fall into or identify with such groups. In these cases, where risk may be high – for example, among heterosexual male African migrants who engage in unprotected sex with more than one partner – attendance at a GUM clinic is not likely either because such individuals are not aware that such services exist (McMunn et al. 1998), or they regard them as highly stigmatising (African HIV Steering Group 1999; Elam et al. 1997). In such cases, the doctor's referral to the GUM clinic is unlikely to be followed up. Following through with the example, it is now the case that most HIV positive Africans in this country are diagnosed so late in their disease progression that the impact of anti-retroviral treatment is severely limited (BMA Foundation for AIDS 1998; Revill 2000).

Apart from this broad-based concern about stigma, many of the reasons for concern about even discussing HIV in a clinical setting stemmed from questions that appeared on insurance applications in the late 1980s and early 1990s. The first Association of British Insurers' (ABI) guidelines on this topic recommended that insurers ask: 'Have you ever been personally counselled or medically advised in connection with AIDS or any sexually transmitted disease?' and 'Have you ever had an HIV/AIDS test? If so, please give details, dates and results' (Papworth 1991:14). ABI Guidelines released in 1994 encouraged this practice be changed to only include a question about whether or not the applicant had tested positive for HIV antibodies

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[15] I experienced this first hand, when in early 1998 I told my GP that I would like to be tested for HIV. She explained that she would not conduct the test because of her concerns about the confidentiality of those results in terms of her patients' financial futures. She advised me to attend the GUM clinic at the local hospital if I wanted to be tested, and the consultation was brought to a close.
[16] Factors contributing to this increased sense of comfort among these groups may include: perceptions that the GUM setting is less judgmental; staff are better trained and are sometimes members

(Association of British Insurers 1994). However, many years on, there is still a lot of confusion about the extent to which insurers are following these guidelines and what other means of information-gathering are being employed.

> I do remember something coming through a few years ago, where they seemed to give the impression that they had changed things, but on reading it, it seemed that things were pretty much the same. (GUM Advisors 1998: 6)

Another example which signifies that insurance companies have not substantially changed their approach is the fact that single men applying for life insurance or a mortgage are likely to be sent supplementary questionnaires about their 'lifestyle' (Sorell and Draper 1999: 219; GUM Advisors 1998: 5). I have included a sample of such a questionnaire on page 154. Returning again to a personal anecdote, this questionnaire was sent to my partner when he purchased a property on his own and applied for life insurance as a single male. Subsequently, when we purchased a different property jointly, we made a new life insurance to the same company (only eighteen months later), and no such supplementary questionnaires were sent to either one of us.

If on such questionnaires, applicants reply that they are homosexual, bisexual, or IV drug users, premium payments can be increased by an average of 250 percent (Slade 1998: 7). Doctors have been advised to refuse to answer questions on insurance medical reports regarding prior HIV negative tests and their patients' sexuality (BMA Foundation for AIDS 1998) but the extent to which GPs are aware of and follow this advice is unknown. Just as significantly, it is also not known what is the likelihood that potential testers are aware of this approach, which means their decisions will be made in the belief that insurers do have access to this information. In light of this confusion and the ongoing practice of sending out supplementary questions to single male applicants, the most confidential option for HIV testing is still the GUM clinic, although many people equally are unsure about the degree of confidentiality that can be offered to them by GUM services, or the outcome of having a confidential test and then lying about it on an insurance declaration. As a result, many decide that it is in their best interests not to test (Kingman 1993). One gay man who has never tested, states:

dditional Information Form

Full Name

In order to assist us in assessing your recent Life Assurance/Sickness Assurance application. we require the additional information requested below. Would you kindly answer each of the questions fully and to the best of your knowledge. If the answer to any of the questions is "Yes" please give full details disclosing all material facts as they can influence the assessment and acceptance of your application. A "Yes" answer will not automatically mean that cover will be refused. Your answers will be treated confidentially.

We would ask you to read carefully the declaration at the end of this form. If you are in any doubt as to whether any fact is material you should disclose it. Failure to do so may invalidate any future claim.

1. In which of the following sexual groups would you place yourself?

    * Heterosexual / Homosexual / Bisexual

2. Have you ever belonged to either of the other groups indicated in Question 1?

    * Yes / No   If "Yes" please state which.

.. Are you now or have you ever been an intravenous (I.V.) drug user, or taken drugs other than for medical purposes?

    * Yes / No   If "Yes" please state which and provide full details including type of drug and dates of use.

4. Do you, or have you ever, suffered from a blood clotting disorder, (eg. Haemophilia)?

    * Yes / No   If "Yes" please give full details.

5. Have you ever undergone any surgical procedure outside the U.K. or been a recipient of blood or blood products outside the U.K.?

    * Yes / No   If "Yes" please give full details including dates, countries and circumstances.

6. Are you now, or have you ever been, a sexual partner of anyone in the following categories:

    Homosexual   * Yes / No

    Bisexual   * Yes / No

    Intravenous (I.V.) Drug User   * Yes / No

    Haemophiliac   * Yes / No

    Anyone whose normal Residence is or was outside the U.K.   * Yes / No   If "Yes" please give the country of residence and date(s).

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* Please circle whichever answer applies.

...the consequences of an HIV test can sometimes be difficult in terms of insurance, in terms of mortgages. Having gone through house purchasing a couple of times in the last few years I've been aware of insurance based mortgage products requiring statements about not only HIV status but also having HIV tests (cited in Henderson 2001: 14).

Insurance companies rely on risk assessment for actuarial calculations by imposing their own conceptions of risk on applicants. Many health professionals, and AIDS organisations have fought to make it clear to underwriters that it is behaviour among men who have sex with men which establishes HIV risk rather than a simple classification as a gay male.

'Many of those classified as high risk may have modified their lifestyles to such an extent that they pose a lower risk than an individual who ostensibly poses no risk at all' (Scott 1994:16). Actuarial assessment based only on the theory that gay men are a 'risk group' ignore those who are in monogamous relationships, those who practice non-penetrative sex or use condoms, those who are not sexually active, and those who test in order to ensure that they and their partner are HIV negative. As discussed in Chapter Three, defining risk groups assumes that members behave as a homogenous unit in a way that is untenable. The ramifications of this type of classification in this circumstance can actively dissuade categorised individuals from taking an HIV test.

The continuation of this targeting of gay men by insurance companies also fails to take into consideration the fact that new infections diagnosed in the UK among heterosexuals have surpassed those occurring among gay men for the past two years (PHLS AIDS Centre 2000; Revill 2000). In addition to this, it is estimated that approximately 50% of heterosexuals living with HIV in the UK do not know that they are infected (Revill 2000)[17]. Being a sexually active heterosexual in the UK does not carry with it the statistical likelihood of infection to nearly the same extent as if one is a gay man, but risk of HIV transmission among some heterosexual sub-

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of the community; and that anonymity is preserved and sense of difference lessened in a setting which is better designed for their use.

[17] This compares with recent estimates that 19% of HIV positive gay men in the UK do not know their status (PHLS 2002 personal correspondence).

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groups is a significant element of the epidemic that has been virtually ignored by the actuaries who focus exclusively on homosexuality and drug taking as risk factors for acquiring HIV/AIDS.

The ongoing confusion among clients and doctors with regard to HIV counselling and testing, and its impact upon access to insurance and property ownership attests to a contradiction in attitudes toward responsibility in relation to the test (General Practitioner 1998: 10). The BMA asserts: 'We are worried that if at any time you have had an HIV test because you think you have indulged in risky behaviour in the past - quite a responsible course of action - the life insurers still make an issue of it' (Cole 1991: 22). Health promoters advocate testing as a responsible behaviour among those who think that they may have been at risk of transmission. This position has been problematised in the previous sections, yet is made even more difficult by the position of insurance companies which initially made it clear that HIV testing, or even discussion of whether to have a test, was seen as an indication of living a high risk lifestyle and was thus a marker of irresponsibility. Such a conception not only has real material consequences, such as increased premiums or denial of coverage, but also acts a deterrent to those who may want to test. Thus the insurance companies' view of individual responsibility appears to be completely at odd with health promoters' view. This clash of approaches which see testing as both responsible and irresponsible behaviour has doubtless resulted in an ongoing sense of confusion among potential testers and health professionals. If someone approaches a GP with a desire to have the HIV test, it is likely that the practitioner will refer the individual on to a GUM clinic in an effort to obviate the need to put any notes in the patient's records (BMA Foundation for AIDS 1998). This degree of curtailment could well have a negative impact upon the individual's sense of 'doing the right thing'. While some will comfortably attend the GUM clinic with the idea that it is best to be a part of a specialist service, other GP attendees will be left in bewilderment at being directed to a place that they associate with great shame and embarrassment. In these instances, what begins as a pursuit of what health promoters classify as a *responsible* action becomes transformed into stigma – a mark irresponsibility. This confusion, and the conflict it entails, are a perfect representation of the difficulty that individuals in the UK face when trying to sort out what it means to make a *responsible* choice in the face of HIV risk. It points to the

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inherent weaknesses of models of responsibility that rely only upon the individual, and perfectly encapsulates the struggle between understandings of responsibility as *freedom* and as *control*.

6.5 DISCUSSION

Notions of responsibility are an implicit part of the voluntary HIV testing process. Many of the issues raised here are of particular relevance to UK policy but the themes resonate with experience of a range of comparable countries (Canadian HIV/AIDS Legal Network 2000; Danziger 1998; Stoltz and Shap 1999). This chapter has raised questions about the efficacy of the notion of individualised responsibility that is implicit within policies advocating VCT. Firstly, no matter how much effort is given over to promotion of the test as a means of achieving HIV prevention, the results are negligible. Those who are at highest risk of acquiring the virus maintain steady rates of testing – and there appears little that anyone can do to stimulate more testing among these high priority target groups, in spite of the advent of effective treatments. Instead, we find that testing occurs at a high (and in the UK and US among others, the highest) rate among those who report very little to no risk activity whatsoever and, if any increase is evident, it is among those who practice low risk behaviours. Thus promotion of the HIV test as a means of preventing transmission has met with limited success. There is also little evidence that participation in an HIV test leads to behavioural change. Approaches which isolate the test as a key means of individual health promotion are therefore seriously flawed.

The persistence of individualised models of health promotion in the HIV field attests to the continued dominance of a theoretical position which regards *responsibility as freedom*. This is a perspective which understands responsible action as being exclusively in the domain of the individual; a part of the social contract through which the individual has a duty to govern and monitor his or her own behaviours in accordance with what is best for the well-being of self and others. Thus the HIV antibody test is symbolically presented as the best thing to do for someone who feels there is a possibility that transmission has occurred. Within the purview of the *responsibility as freedom* model, knowing one's own status will be the best for all, because it is assumed that socially beneficial modifications in risk behaviour will follow as a result of this knowledge.

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However, the evidence about the ways in which people actually regard and use the test raises questions about the selected application of this model. It also allows us to consider the other dominant theoretical model: *responsibility as control*. There are many reasons for people who are most vulnerable to HIV transmission to demonstrate ambivalence or hostility to VCT, precisely because they are aware of the impediments that can result from submitting to surveillance. These might include: domestic disruption; psychological trauma; and loss of personal subjectivity. If indeed they do decide to test, they very well may *not* be doing so in order to determine how they can best protect themselves and others from transmission in the future. They may have many more immediate and personal reasons for testing or for not testing at a specific time, which may never occur to approaches within health promotion which draw its main influences from notions of rational action, risk and individualised responsibility. Therefore when we examine the ways that the test is actually used by those who are most likely to be diagnosed positive, we can see the ways in which the *responsibility as control* position opens up a whole host of other considerations that incorporate power, social status and inequality. These are considerations have rarely been taken into account by mainstream health promotion approaches, largely because they have been so overwhelmingly infused with an understanding that *responsibility* leads to *freedom*.

Those who are most likely to mould themselves to the expectations of individualised responsibility via health promotion are testers who report low HIV transmission risk as they will also be less likely to be confronted with the possibility that their life will be irreversibly changed as a result of the test. It is very likely that low risk testers expect that their negative result will move their life forward in some way and the test is regarded as a means of clearing out unfinished business or an assurance of good health. It is among this group rather than the high-risk testers, that I would argue the test can be seen as a means of assuring oneself that it is correct to continue on with past practice. As a result, it is among these low-risk individuals that the rational thought-processes governed by the Health Belief Model sustains its relevance, and for whom the *responsibility as freedom* model is applicable. With this in mind, the example of HIV testing demonstrates how 'responsible' practices can thus be understood as *freedom* or as *control*, depending on the standpoint of the individual in

question; rather than something that can be assigned by the hegemonic imperatives of health promotion[18].

The historical relationship between HIV testing and problems with acquiring insurance in the UK complicates the situation for those who have tried to advocate testing as a responsible action. This is because the insurance industry chose early on to take HIV testing as a signifier of irresponsibility, thus contributing to the development of a social environment that is hostile towards those who test. According to the rationale of the insurer, those who have not tested must not have any need to test and thus pose a lower actuarial risk than those who have tested. From what we have learned above, this is distinctly not the case. Framed from this perspective, the insurance companies can be seen to have 'prejudice[d] the position of people who had made a socially responsible decision to take a test, against those who might be equally at risk but had decided not to confront the issue' (Scott 1994:16). It is a position that has led many who have contemplated testing to decide that the negative outcomes of *control* outweigh the arguments for *freedom* made by health promoters. Yet efforts continue to work towards the increased normalisation and uptake of testing with the assumption that responsibility is best demonstrated in this way by those who are most likely to contract HIV. Past experience demonstrates that such efforts will probably have little overall impact on testing patterns in the UK - with the notable exception the many more pregnant women will 'agree' to VCT in accordance with government targets[19]. Understandings of responsibility which dwell on individual actions continue to dominate policy implementation, while the lives and social environments of those most at risk of HIV transmission remain relatively unchanged by all of the health promotion and health policies centring around VCT that take place in their name.

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[18] As has already been elaborated, Crawford 1977, and Brandt 1987, 1988 and 1997, argue that these imperatives are formulated on the basis of 'middle class' moral norms regarding independence and individual responsibility.

[19] In the case of ante-natal clinical screening, the UK government determined that too many HIV positive children were being born annually to women who were not aware of their own HIV status. As a result, recent policy has been implemented which aims for 90% uptake of HIV testing in ante-natal facilities nation-wide by December 2002 (Nicoll 1999). There have been strong critiques of the means through which this policy has been implemented, raising concerns about whether or not such pregnant women will receive adequate pre-and post- test counselling and will be able to give informed consent to the procedure, and whether they will feel pressured into testing at a time when they may not be prepared for the results (Davies and Moran 2000; Sherr, Bergenstrom and Hudson 2000). It is

Thus far, Chapters Five and Six have presented practical examples of the way that models of individualised responsibility dominate public health responses to HIV with regard to promotion and anti-body testing. In the next chapter, I move away from the health field in order to analyse the way in which these same models are used to substantiate the use of criminal law in relation to HIV transmission.

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a highly problematic issue in terms of the abrogation of pregnant women's rights to make responsible choices for themselves by the state, but one that is not covered by this thesis.

CHAPTER SEVEN: CRIMINAL LAW, HIV/AIDS AND INDIVIDUALISED RESPONSIBILITY

7.0 INTRODUCTION

Societies establish legal codes and structures in order to support the notion of accountability for actions. This means that law is an important formal expression of the ways in which a given society apportions responsibilities among its members and its institutions. Even when looking at a topic as specific as HIV, this codification covers vast areas, ranging from laws that determine government responsibilities for standards of public health; to strict definitions of the circumstances under which an HIV positive individual is obliged to inform others of his/her status.

This chapter reviews one specific application of 'AIDS law'[1]: the use of criminal law in relation to viral transmission. I begin with an overview of the practical barriers and inefficiencies inherent in the introduction and application of such laws that have been highlighted by experts in the field. Following on from this I present my analysis of the ways that societies have employed criminal law in relation to the epidemic, as illustrated by a range of examples that have gained attention in the popular press. This series of stories that have individually gained sensationalised press coverage was specifically chosen for two reasons. Firstly, there were far too many cases and jurisdictions covered in the literature review to sensibly find any means of presenting them all in a brief chapter section, therefore the cases discussed below should be regarded as representative snapshots of different uses of the criminal law as it relates to HIV transmission. Secondly, the fact that these cases gained media attention makes them significant. These are the means through which public audiences have come to apprehend HIV transmission as an event for which an individual can be held individually criminally liable. For this reason, an understanding of these particular cases allows us to consider the ways in which members of the public are given messages about the relationship between HIV and responsibility, and how this relates to the broader notions of responsibility raised within the context of this thesis. Later sections of the chapter will examine who is protected by such laws, concluding with a reflection upon the implications this has

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[1] See the discussion in Chapter Four for an explanation of this term and the problems it poses.

for the concept of responsibility. Criminal law has been selected because it has as its focus the role of the individual in the spread of the epidemic. There are, of course, other areas of law that are applicable to HIV, such as human rights law, and public health regulations and such laws may contain differing notions of responsibility than those within criminal law. However, as explained in Chapter Four, there is not space in this thesis to fully discuss all aspects of AIDS law.

The previous two chapters outlined the ways in which health promotion operates to present an understanding of health that concentrates on the activities of the rational individual which in turn results in an overriding focus on individual responsibility. The legal issues discussed in this chapter function in similar ways and this chapter highlights the critiques of the criminalisation debate, allowing us to see how issues such as criminal prosecution, self-protection, public health concerns and media attention operate intersubjectively to contravene the overall aim of preventing HIV transmission. In relation to the previous two chapters, such an approach can result in the situation whereby HIV risk reduction strategies which aim to change individual behaviour are undermined. This subversion occurs because press attention to the use of the criminal law in cases of HIV transmission may encourage those who engage in high risk behaviours to decide that knowing their HIV status may cause more personal harm than not knowing it; and also because those who perceive themselves not to be at risk are encouraged to assume that they are protected by a legal system that incarcerates those who present a 'threat' of infection. In this latter understanding, if the law is seen to be serving as a means of protection, some will see little need in changing their own behaviour as a further protective measure – a typical example of the way in which responsibility attributed to *others* can mistakenly be regarded as *freedom* for the self.

> Criminalisation generally, and an HIV-specific offence in particular, sends the misleading message that the law will protect against the risk of infection. This would undermine HIV/AIDS education campaigns that stress that it is the responsibility of everyone - people who are HIV-negative as well as people who are HIV-positive - to take precautions, and that try to ensure that all people have the information and support they need to discharge this responsibility. (Canadian HIV/AIDS Legal Network 1999: 6)

Through the creation of a legal 'safety net', individuals come to believe that only guilty 'others' are capable of becoming involved in transmission of HIV. Rather

than sustaining prevention and anti-stigmatisation messages, such uses of the law contradict them.

7.1 HIV/AIDS AND CRIMINALISATION: THE ISSUES

In most cases of HIV transmission world-wide, the person who HIV positive does not know their HIV status (UNAIDS 2000: 78). Even if one has been diagnosed, there are a host of reasons why transmission may still occur rather than as a wilful act of malice: that person may have no means of negotiating safer sex or drug injecting, or may not be in a safe position to reveal their HIV status; the condom may break; they may believe that drug therapy makes them less infectious; or sometimes sexual desire and addiction can each lead us all to do things which we otherwise wouldn't 'in the cold light of day'[2]. We can summarise this by saying that most transmissions continue to happen because of ignorance, accident, passion or power. Despite this, calls for criminalisation of knowing transmission[3] of HIV have arisen in large part due to the perceived threat posed by those who know their HIV positive status and continue to expose people to risk of transmission through their behaviour. This position has been aided by sensationalist journalism conjuring up images of bad 'HIV carriers' threatening 'innocent victims' which is not representative of the vast majority of cases of viral transmission (Colby and Cook 1991; Gwyn 1999; Sontag 1988; Watney 1989).

The pressure toward criminalisation of knowing HIV transmission has proved too strong to resist in a number of countries and regional jurisdictions. Prosecution of HIV positive individuals who have exposed others to the virus has been pursued either through the use of existing statutes or the codification of new HIV specific laws (Canadian HIV/AIDS Legal Network 1999; Elliott 2002a; Policek and Doupe 2000; Whitehorn 2000)[4]. The rationale demonstrated by these efforts is exemplified in the quote below:

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[2] From a Gay Men Fighting AIDS (UK) campaign.

[3] This general term is used to signify the various criminal laws codified differently in various jurisdictions which make it illegal for a person to have been diagnosed HIV positive and engage in acts that could lead to exposing another person to the virus (as will be discussed below, risk of exposure has been interpreted very broadly by some courts).

[4] It is also important to bear in mind that in some countries the relevant legal powers reside at the state or provincial level, resulting in a situation such as that in the United States, Germany and Australia where some states and provinces have specific HIV transmission laws in their criminal code, and others do not.

> Criminalization may force people to think twice before acting, and to be more responsible in their decision making. This will be beneficial both for the individuals involved and society at large. Ideally, criminalization would lead to a reduction in both the intentional and the unintentional transmission of a disease which, despite being present for almost two decades, fills most people with dread and is still not completely understood (Ruby 1999: 335)

Aside from the more substantive criticisms of such an approach, which are outlined below, there is a major practical legal issue that makes the criminalisation of intentional HIV transmission problematic: it has proven to be extremely difficult to prove intent relating to HIV transmission (Elliott 2002b; Kromm 1999). When weighing up the risks of disclosure versus the risks of transmission, how does the prosecution prove that such an individual is *intending* to infect a partner (Elliott 2002b)? Evidence collection in some cases can also be very difficult, as after the fact it may be impossible to prove if the defendant did reveal his/her status in advance; or to prove who was the first to be infected and to rule out all other possible sources of infection (Elliott 2002b; Kelly 1995; Kromm 1999).

Opponents of blanket criminalisation of HIV transmission agree that some form of law should be applied for those rare cases where an individual demonstrates clear intent to cause public harm through exposure to the virus (Terrence Higgins Trust 1998). Yet at the same time, they do not feel that an HIV specific criminal law would do anything to reduce HIV transmission on a population-wide scale. Instead there is a concern that such laws can increase the risk of transmission by increasing stigma and driving those who suspect they may be infected underground (Earle 1998; Elliott 2000; Leonard 2000; Weait 1998).

This response highlights the more serious issues concerning the criminalisation of HIV transmission. Firstly, the idea of criminalisation relies on the role of law as a deterrent by forcing individuals to think twice about their actions. However, as outlined at the beginning of this section, there are a variety of reasons why individuals engage in high-risk activity even if they are aware that they are HIV positive. Secondly, criminalisation takes no account of the ways in which stigma and blame interact to exacerbate the spread of the virus. Chapters Two and Three established the way in which notions of individual responsibility contribute to the

stigma that accompanies AIDS. It is the stigma surrounding the disease that most often disables people who are HIV positive from taking action to prevent it from spreading to others. Disclosure of positive status carries the risk of eliciting a range of negative social reactions and, as a result, insisting on condom use or clean injecting equipment carries implied untrustworthiness and can often damage an existing bond between two people (Holland *et al.* 1990; Rhodes and Quirk 1998). Thus in social contexts where such meanings have not been radically challenged there continues to be a multitude of social reasons why HIV transmission persists. Thirdly, as with the example of life insurance in the previous chapter, criminalisation of HIV transmission creates an incentive for the individual not to get tested because knowledge of one's status could lead to legal culpability (Bird and Brown 2001; Elliott 2000). All of these are issues that arise in the discussions below regarding the ways that various jurisdictions have decided to approach HIV transmission.

7.2 CRIMINALISATION OF HIV TRANSMISSION: CASE STUDIES

In this section we will compare specific cases that received media attention across a range of developed countries. This review allows for a better understanding of the ways in which specific uses of criminal law contribute to a social environment where it is considered necessary to prosecute and imprison individual who have potentially exposed others to the virus. Consideration of such cases and their circumstances provides an opportunity to reflect upon the individualised focus of responsibility in the criminal context, and upon how the proliferation of media reports on such cases might impact on public views of responsibility as it relates to HIV/AIDS. As discussed in Chapter Four, the selection of these cases followed from detailed review of case law through the use of a legal database, and with ongoing input on current cases from a range of sources. What follows is not intended to be an exhaustive explication of that review. Instead, I present a series of typical enforcements and exemplar cases that demonstrate the ways that specific legislation is applied in specific legal jurisdictions and what type of implication this has on understandings of the responsibility of the individuals involved. These cases are also important because of the media coverage that each has received within their various jurisdictions. There are aspects of each story that have made them media worthy: including the characteristics of the individuals involved; the nature of their relationships; and the circumstances surrounding the alleged exposures. Therefore

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consideration of these cases also invites us to reflect upon the reasons why they might be of interest for media consumption. What views of responsibility are they feeding or reinforcing? More detailed analysis demonstrated that these cases shared key sub-themes. The first was a commonality between the types of individuals who were typically prosecuted, and the second was the development of a tension within the legal terrain between intentional versus reckless behaviour as a means of successful prosecution.

Recent criminal cases relating to HIV transmission have been widely reported throughout the United States. Each state has different ways of approaching HIV using the criminal law and more than thirty have HIV specific laws regarding intentional or knowing transmission (Janega 2002a; Lambda Legal Defence and Education Fund 2001; Whitehorn 2000). A contributing factor to the development of the criminal law in this area in the United Sates is the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 which directs the centralised distribution of AIDS care and research funding to each of the states. This law contains a clause which denies the release of any federal funding to a state until it has encoded criminal laws in relation to HIV transmission[5]. Therefore active prosecutions are symbols to central government that the state has enacted the necessary laws and is prepared to enforce them.

Criminal cases of HIV transmission seem to affect certain segments of the population more frequently than others (Elliott 2002b). In the US, criminalisation of HIV exposure appears to have been most readily enforced among sex workers. For example, Californian prostitutes who are arrested are tested for HIV, and if they test positive and are caught a second time for prostitution, the charge is converted to felony prostitution – which can carry a nine-year sentence (Associated Press 2002c)[6]. There appears to be no distinction made in the 1988 law regarding whether or not

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[5] The act states that in order for a state to receive federal money, the state must show that 'the criminal laws of the state are adequate to prosecute any HIV-infected individual' who 'knows that he or she is infected with HIV and intends...to expose another to HIV' by means of donating blood, semen, or breast milk; through sexual activity; or through sharing a hypodermic needle. (Pub.L. [USA] No.101-381, § 2647, 104 Stat. 576, 603 (1990))

[6] California Penal Code § 12022.85 (Added by Stats.1988, c. 1597, § 4, operative Jan. 1, 1989. Amended by Stats.1998, c. 55 (S.B.351), § 3, eff. June 5, 1998, operative July 1, 1998.)

such sex workers are having unprotected intercourse; their HIV status alone is the salient issue. Since this law was enacted, 217 convictions have been secured (Associated Press 2002c).

Some might regard it as surprising that very few criminal cases regarding HIV transmission have involved homosexual men. Some reasons for this will be discussed below. Instead, the other main group prosecuted in such cases in the US are heterosexual men accused of exposing their female sexual partners[7]. American media attention recently turned to Nikkos Briteramos, an eighteen year old in South Dakota who was sentenced to fifteen years and a fine of $15,000 for five counts of intentionally exposing his girlfriend to HIV (Kafka 2002). Briteramos found out that he was HIV positive and began an unprotected sexual relationship with this girlfriend the following month without telling her his status. Some have reacted to the successful conviction of this case and the accompanying publicity by pointing to the harmful impact it will have on HIV prevention:

> Now consider the lessons that Nikko's experience may teach us about
> HIV testing. Nikko learned his status, co-operated with public health
> officials and honestly named his sexual partners. He was immediately
> arrested, imprisoned and branded a murderer on national television.
> Surely many other young people at risk for HIV saw what happened to
> Nikko. Will they rush to get tested, because they understand that they are
> at risk? Or will they decide that the burdens of knowing their HIV status
> are so great and the risks of public vilification so high that only a fool
> would want to know his status?...If you have HIV, how can you now feel
> safe identifying your partners or discussing your sexual or drug habits
> with a public health worker? (Hilton-Fisher 2002)

Another of these sensationalised cases was that of Nushawn Williams in 1997 which began when his image, headed with 'Health Alert', was posted around Chautauqua County, NY. He had been linked to 13 young women who were HIV positive. Nushawn (a teenager himself) had unprotected sex with at least 28 women in the area, many after the date when he was informed that he was HIV positive. His

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[7] Men convicted in the past year include: Morris Lindenbaum from Long Island who plead guilty to reckless endangerment after infecting his wife and was sentenced to five years probation (Smith 2002); Ronald DeWayne Dillard of Michigan was convicted of assault with intent to commit sexual contact and AIDS-attempted sexual penetration with an uniformed partner and will serve up to 60 months in prison (Associated Press 2002d); and an Ohio police officer convicted of twelve counts of spreading contagion for having unprotected sex with his partner twelve times for which he could serve three years in prison (Columbus Dispatch 2002). Roughly one hundred such charges have been successfully prosecuted in the United States (Janega 2002b; Whitehorn 2000).

behaviour was characterised as 'basic attempted murder' by a Queen's Assemblywoman who pushed for specific laws against HIV transmission (Kennedy 2000). Williams' case was ultimately plea bargained to four to 12 years for statutory rape (some of his partners were underage) and reckless endangerment (in direct relation to the transmission of HIV) (Kennedy 2000; Kromm 1999).

While his own defence changed several times, an ex-girlfriend said Williams was convinced that the HIV positive diagnosis was simply a ruse by clinic advisors to get him to stop dating white women, thus he did not believe that he was actually infected (Kennedy 2000). This assessment coincides closely with the observation that criminal prosecutions are predominantly taking place in heterosexual cases of(transmission where women are constructed as the innocent 'victims' of non-conformist, often black 'aggressors' (Weait 1998). Williams was a young, sexually active black man and petty criminal who mainly had sex with white girls. His construction as a pariah was something about which he expressed an acute consciousness, to the extent that it may have cause him to doubt his own diagnosis.

The Williams case in New York has parallels with that of Steve Thomas, another black man prosecuted for attempted manslaughter in relation to his role in HIV transmission, this time in Finland. Thomas is an HIV positive black man from Brooklyn who lived in Finland since 1991, and it was alleged that he had unprotected sex with over 100 women (Panos 1997). His picture was on the front page of national Finnish papers when the story broke and Thomas' lawyer argued that had his client been a white American or Finn, his privacy would have been protected and that the sensationalism in this case was largely due to the defendant's race (Henley 1997)[8].

The first similar prosecution in the UK occurred under Scottish law in February 2001. Stephen Kelly, an ex-prisoner was convicted of culpable and recklessness conduct and sentenced to five years in jail for infecting his long term girlfriend, Ann Craig with the virus (Scott 2001). Kelly testified that he had told his partner of his

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[8] This type of scapegoating may have also been a factor in the conviction of Fawzi Ali Batum in Sweden in February 2002. Batum was a Somali refugee sentenced to 5 years in prison plus financial

past heroin use and that he was HIV positive, while she maintained that he had not shared this information when they first began having sex. In order to establish that Craig was indeed infected by Kelly, a sample of her virus was compared to a sample that Kelly had given as a part of a confidential study in which he had participated while in prison (Bird and Brown 2001)[9].

Criminal law, where it has been applied to men involved in the sexual transmission of HIV, has been predominantly targeted at heterosexual men who match particular stereotypes (i.e. Black, drug using, and/or criminal), rather than at gay men. However, the specific ways that such prosecutions have proceeded has varied across jurisdictions. In particular, there is disagreement over the role of 'intent' in HIV transmission cases. Those statutes that focus on the individual's 'intention', or 'deliberate action' require evidence that the defendant not only knew his HIV positive status but also had intent to cause harm to another through transmission[10]. In contrast, there are cases where a notion of 'recklessness' is employed to accuse individuals who 'should know better' than to behave in the way that puts others at risk of transmission. While specific intentionality is not required in such instances, the defendant is situated within a rational framework where concern for the other is expected to supersede all others. While these two approaches share a moral imperative to do no harm, the notion of recklessness relies upon a much broader understanding of the realm of responsibility and makes it much easier to prosecute.

This contrast between intentionality and recklessness can be illustrated through case law and legal debate over the criminalisation of HIV transmission in the UK following the Jeanette Pink case. Pink was an English citizen whose Cypriot lover had not informed her that he was HIV positive when they began their relationship nor at any time when they lived together. When she found out her own positive status, and that he had known his all along, he was successfully convicted by a

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damages for aggravated assault because he knowingly infected two women with HIV (Associated Press 2002a).

[9] The collection of evidence in this manner has raised concerns about the protection of confidentiality, potentially dissuading future participants from taking part in valuable research if they cannot be assured that their samples will not be used against them in future criminal proceedings (Bird and Brown 2001; Dyer 2001; The Independent 2001).

[10] I use the pronoun 'his' in this instance in order to emphasise the fact that in the majority of such cases the defendant is male.

Cypriot court with negligently committing an act which carried the risk of transmitting a life-threatening disease (Power 1997). Upon completion of that case, the British Home Secretary commented that there should be a law in the UK similar to the Cypriot one that convicted Pink's ex-partner (Earle 1998).

The British government invited comments on the Green Paper *Reforming the Offences Against the Person Act 1861* in an effort to determine if the act should be amended to include those who *deliberately* transmit the virus or if a separate law should be created to criminalise those who *knowingly* transmit HIV (Earle 1998; Terrence Higgins Trust 1998; Weait 1998). AIDS service organisations responded with arguments against a specific law for HIV transmission, arguing that existing laws were sufficient to deal with those rare cases where individuals purposely caused a threat to public health (Terrence Higgins Trust 1998). However, the drafted revision of the Act included acts of intentional HIV transmission. Intention is defined as purposefully causing a result, as well as knowing 'that it would occur in the ordinary course of events if he [defendant] were to succeed in his purpose of causing some other result' (Dine and Watt 1998: 3).

Therefore, British law on this issue was codified around the fact that the infected individual must intend to infect the other person. However, the first case brought in Britain – the Stephen Kelly case – convicted Kelly on grounds of recklessness rather than intent. Although this case was brought under separate Scottish law, it now stands as UK precedent that cases of reckless transmission can be convicted (Scott 2001). Given what was stated earlier – that it is far easier to prosecute for recklessness than for deliberate intent – and there is now a precedent-setting case, there is concern about further prosecutions of reckless transmission of HIV in the UK.

However, the debate over whether the criminalisation of HIV transmission should depend upon intent or merely reckless behaviour is important, it is also something of a red herring. In both of these instances, the onus is upon the infected individual to act responsibly rather than conceiving of responsibility as something which may be shared between partners (Weait 1998). This places the entire burden of responsible action upon the infected party and relieves the plaintiff of any share in that burden.

This directly contradicts much prevention work such as the THT poster, discussed in Chapter Five, which pointed out that 'it's not a right to be told'. The different understandings of the law and health promotion in this instance could be explained by the fact that the law is seen to be protecting the general (heterosexual) population whereas the prevention material used in this example is geared towards gay men. This raises a question about the contradictions in messages of responsibility which on the one hand encourage all gay men to treat every sexual encounter as risky; while on the other hand lulls heterosexuals into the mindset that because their sexual partners are required by law to inform them of their HIV status that this operates as a protection from risk.

In instances where criminalisation has been established, once an individual is aware that they are HIV positive, then the imperative of responsible action is placed upon them, with punitive penalties if they do not adhere. Along with knowledge of status comes a duty to disclose and the fact of actual transmission or not becomes negligible. For example, in one of the few cases brought to involve gay men, two men in South Dakota were charged with having sex with men while being aware of their positive status. Thirty-one people who had sex with the two accused were tested for HIV, and none were positive. However, the state attorney said that 'the letter of the law... states that it isn't pertinent whether their victims are infected' (Associated Press 2002b). In some cases an HIV positive individual who engages in behaviour which could - or which s/he *believes* could - potentially transmit the virus is enough for prosecution. This has led to the situation where an HIV positive prisoner in Texas who spit at and intended to infect a guard was found guilty of attempted murder despite establishment that this is a route of infection is outside the reasonable realms of possibility (Belbot and delCarmen 1991). Greg Smith, another prisoner in New Jersey was convicted of attempted murder, terroristic threats and aggravated assault and sentenced to twenty five years in prison because he allegedly spit at and bit prison guards during a medical visit. In a recent development, a fellow prisoner has accused Smith of spitting at him, leading prosecutors to lay new attempted murder charges (Davids and Russell 2002).

In jurisdictions that have not enacted specific anti-HIV transmission laws, the implementation of existing laws on this issue has had the same outcome on the

burden of responsibility (Leonard 2000). In one example that prompted significant reactions among those considering the issue of HIV and criminalisation (Canadian HIV/AIDS Legal Network 1999; Yamada 1999), the Canadian Supreme Court convicted Cuerrier on two counts of aggravated sexual assault[11]. Cuerrier had exposed two women to HIV within the context of separate heterosexual relationships. The Supreme Court decided that because the defendant knew his HIV status, did not disclose it to his sexual partners, and proceeded to have unprotected sexual intercourse with them, then his partners' consent to sex was, in fact, vitiated because they were not aware of his HIV positive status. This case hinged not on the harm Cuerrier may have caused by exposing his partners to HIV (at the time of trial, neither woman had tested positive) but that the act of sex was not consensual because the defendant had not informed them that he had been diagnosed positive (Canadian HIV/AIDS Legal Network 1999)[12].

These cases clearly isolate responsibility for transmission with the accused HIV positive individual. This is the case whether or not such individuals actively lied to their partners about their status or if they withheld such information. In some cases there is also no distinction made about whether there was any likelihood that exposure may occur, such as those involving the use of condoms during sex, or those convicted on charges of spitting.

Most AIDS organisations are against the criminalisation of HIV transmission in cases involving consensual activity, or those where the potential for viral transmission is virtually non-existent. Following the Kelly verdict in Scotland, a THT representative stated that 'It is really going to help restigmatise HIV in a way that is hugely unhelpful. We have been working towards a situation where people with HIV are able to talk about their status and don't feel afraid or feel they need to

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[11] *R* v *Cuerrier*, [1998] 2 SCR 371. When considering this case, it is necessary to know that there is no legally defined crime of 'rape' in Canada, it is covered under assault legislation; this is a situation which has generated its own separate controversy. 'Aggravated' crimes carry a stronger sentence, and here refers to the women's' exposure to HIV.

[12] There were two other cases reported in Canada in the past year. Edgard Monge from Kitchener Ontario was sentenced to ten years in prison for having unprotected sex with four women (resulting in the infection of two women and a baby) while knowing that he was HIV positive (Guelph Mercury 2002). In addition, Paul Charbonneau was sentenced to just under four years in prison for having sex with a woman while knowing he was HIV positive – she has not yet tested positive (Ottawa Citizen

conceal it' (Scott 2001). However, it would appear that the high degree of state commitment involved in these criminal prosecutions demonstrates where these governments are prepared to focus their resources in relation to HIV. This is because criminalisation is founded on the model of individual responsibility which enables them to overlook the structural contributions to the continued transmission of HIV/AIDS. As Rhetta Moran states, attempts to bring HIV transmission within the realm of criminal law:

> abstracts the act of transmission from its essentially social nature and its social context. At the same time it diminishes the significance of the fact that the legal system is part and parcel of the society that has produced the emotive and fear-laden discourse that is HIV's socially contested construction. (Moran 2000)

7.3 SELECTIVE PROTECTION UNDER THE LAW

It is difficult to discuss the impact of criminal law relating to HIV because it does not impact upon all individuals and social groups equally, nor is it viewed in the same way by such groups and individuals. One of the first things to discuss in relation to this topic, therefore, is how these variations in law persist. As discussed in Chapter Two, the state in liberal democratic societies is seen as the guarantor of certain rights for all members of society equally. One such right is to protect the individual against harm, either from others or from oneself, and therefore laws such as assault or libel exist to protect the individual from a variety of 'harms'. However, as well as securing rights for individuals, the state also has a duty to look after the interests of the population as a whole and, as Foucault points out, the law operates through the state's ability to identify and make distinct specific behaviours and groups from what is defined as 'acceptable' (Foucault 1967). Such laws are socially defined and reflect social prejudice (Becker 1973).

This is particularly pertinent regarding HIV, as the 'general population' is often understood to mean the 'uninfected population'. This means that the rights of the uninfected majority are understood to require protections in order to maintain their uninfected status, even if this means suppression of freedom for those who are

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2002). There have been approximately six men convicted of similar crimes in Canada (Ottawa Citizen 2002)

infected[13]. Historically this type of reasoning has been used to support quarantine and mandatory vaccination in order to reduce epidemics (Harrington 1999) and, concerning the current epidemic, it has been argued that the population has been divided into two types: those who have HIV and those who do not[14]. This segmentation means that the law does not protect all individuals from harm equally.

> From the perspective of the so-called 'general public', the law has been very protective, protecting the majority of the (supposedly) uninfected from the minority of the known infected population. But from the perspective of the HIV-positive person, those same laws seem to be far from protective. (Wilson 1994: 315)

This means that the law is not treating all social groups equally, breaking one of its own fundamental principles. Furthermore, this type of separation enhanced by the law heightens vulnerability for already weakened and stigmatised groups, who are considered to be engaged in 'high risk' activity, such as drug taking and sex work. These individuals have already been socially defined as a member of a deviant group (see for example Becker 1973 and Young 1973 on the deviancy of drug use), and the level of protection given by law is therefore dubious. Indeed, many members of such groups feel specifically targeted by a body of laws that does little to protect them (Musheno 1995). Musheno found that various groups in the US heavily affected by AIDS perceived law differently depending upon their identification as gay men, heroin addicts or sex workers. While gay men who were diagnosed HIV positive understood themselves as rights-bearers who ensured that the state was providing them with adequate financial and legal protections after losing their jobs, diagnosed HIV positive female injecting drug users [IDUs] and sex workers did their best to avoid interaction with the state. 'Rather than embracing the view that law serves both to bring order to society and transform it, many of them [IDUs] see law as a stark, negative force to be avoided if at all possible' (Musheno 1995:109). As an example, Musheno discusses an IDU who would like to enrol in an abuse treatment programme. However, for this to happen it is likely that she would have to surrender her children (often permanently) to state care. As a result, he reports that many women in this situation have sheltered their children away from the gaze of the state,

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[13] For a critique of this perspective in relation to HIV, and the notion of legal proportionality upon which it relies, see (Harrington 2000).

[14] It is important to recognise that some who assume they are negative may already be infected without realising or acknowledging their status.

taking low paying, informal or illegal means of income in order to steer clear of social workers and bureaucrats who represent a threat rather than a support to their family's future. This type of decision making, and its repercussions, is similar to the priority related risk-assessment made in relation to HIV testing by those who may be at higher risk of transmission, as discussed through the work of Henderson *et al* (2001) in the previous chapter.

The cases above illustrate that punitive criminal law is constructed in ways that exclude social deviants from its realm of protection. For example, as long as prisons refuse to allow prisoners access to condoms and sterile injecting equipment, they will be consensually and non-consensually exposed to extremely high degrees of (transmission risk (Strang *et al.* 1998). The act of incarceration is presented as a measure to protect those outside the gates, however, prison regulations often place those inside at an insurmountable degree of risk which is out of their control. This would make it appear the prevention needs of those who are not incarcerated are given more priority than the needs of the prisoners, despite the fact that in terms of potential exposure, the opposite should be true (Canadian HIV/AIDS Legal Network 1999).

Such an argument can also be used to explain the lack of criminal cases involving gay men. If we trade 'prisoners' for 'homosexuals', a similar logic applies – while the state claims to implement this criminal law because it is concerned with protecting the majority of the heterosexual (innocent) population, the lack of prosecution among gay men seems to demonstrate that the state cares little for their protection. Already constructed as deviants, these individuals are expected to know better than engage in risky behaviour – the burden of responsibility is shared between parties – in contradiction to heterosexual cases where the woman is constructed as a victim of assault inflicted by a predatory aggressor. Such policies reflect wider social stereotypes and leaves the gay community to be responsible for its own behaviour whereas the state takes on responsibility for less stigmatised dominant social groups (Kramer 1995).

Similarly, the continued criminalisation of sex workers in most jurisdictions places them outside the protection of the state and makes many cautious of using 'public'

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sexual health clinics for fear of further surveillance (Alexander 2001). Once again, the aims of public health are subverted by criminalisation and a direct example of this can be taken from cases in England where possession of condoms has been used as proof of prostitution. In such instances, condoms are used by the state as a marker of illegal rather than responsible behaviour, thereby dissuading sex workers from their use (Moran 2000). The problems of such a policy can be contrasted with the success of Thailand in granting official recognition to sex workers. This has allowed them to unionise, dramatically reducing transmission rates among sex workers. Rather than being excluded from state protection, these women became an integral part of the open nation-wide response to AIDS (Janyam 1998; UNAIDS 1998b).

The argument outlined here is that the law is exacerbating the vulnerability to economic and social inequality that contributes to the spread of HIV. The use of criminal law to isolate those who are regarded as deviant has the further potential to demonise all those who are diagnosed HIV positive without regard to their adoption of safer behaviours. Critics are concerned about the way in which such laws will dissuade concerned individuals from having an HIV antibody test, as a key element of prosecution rests on the fact that the accused knew their status[15] (Bird and Brown 2001; Elliott 2000; Elliott 2002b). The Kelly case in Scotland also demonstrates cause for concern regarding the dissolution of confidentiality, as one's own research participation as well as records kept in counselling and medical contexts could be summoned for the purposes of evidence collection. Measures such as these will convince some people that testing will not be a protective option as it will increase the amount of surveillance into their lives with the possible outcome that they could be incarcerated. These are not the types of conditions that are favourable for the protection of public health. Just as we saw in Chapter Six, where insurance policy had the potential to dissuade testing, we find the same potential here with criminalisation. And, while that chapter raised questions about the assumptions surrounding testing and the means through which it can impose a highly individualised responsibility, this does not mean that I support any measures that actively dissuade people from seeking the test.

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[15] Even this may not serve as protection, as some US courts have found that an individual who had participated in high risk activities in the past should have had knowledge of his/her potential risk to others (Canadian HIV/AIDS Legal Network 1999).

7.4 IMPLICATIONS OF CRIMINALISATION FOR 'RESPONSIBLE' ACTION

Elliott asserts that the primary principle of any criminal law relating to HIV transmission should be preventive and that any legal measures which sacrifice HIV prevention to other traditional legal goals are ill-advised (Elliott 2000: 3)[16]. In the context of legal scholarship, prison sentences can be understood to serve the goals of incapacitation, retribution and deterrence. However, as I have acknowledged above, those prison settings where inmates have no access to condoms or clean needles mean that transmission rates in prisons are accelerated. Thus the incarceration of more HIV positive people means that their ability to transmit the virus is not incapacitated, it is simply transferred to the incarcerated population instead. When considering the retributive function of the law, we should consider that the line between the morally reprehensible intention to infect, and those who cannot bring themselves to admit their status to partners is often difficult to draw when using the blunt instrument of the law.

The most frequent argument used in support of criminalisation has involved the notion that it will act as a deterrent to knowing transmission. Yet, as Elliott argues, a singular and external threat can have very little impact on the personal and complex lives of those who are infected. Desire, fear and addiction are much more powerful and immediate concerns than the invisible arm of the law. One commentator states: 'adding further reflective considerations such as laws or moral maxims is singularly unsuccessful. The fact that reason has already failed suggests that further reason will not fare any better' (Gillett, 1987: 107 cited in Elliott, 2000:6). As discussed elsewhere, perhaps instead of viewing HIV transmission as a result of failed reason, we should also consider the range of other factors that weigh on decision-making – particularly those involving stigma and inequality.

There is also the possibility that criminalisation will encourage a false sense of security among those who believe that HIV transmission is a culpable offence, and that the law will therefore protect them from becoming infected. Press coverage of

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[16] These goals are taken to be: incapacitation, rehabilitation, retribution and deterrence.

these criminal cases has undoubtedly led to the notion that 'others' who spread disease are 'criminals' allows those who make such distinctions to disassociate themselves from engagement with HIV prevention. Stigmatisation will result from this notion that only 'certain' types of undesirable individuals transmit the virus. These are outcomes that directly contradict the imperatives of prevention that have already been covered at length in this thesis. Therefore while criminalisation of transmission is portrayed as a means of protecting the public health, it essentially works against this very goal.

Criminal law frames HIV as a virus for which one individual can be exclusively responsible for its transmission to another. Those who bring such cases forward to the criminal courts may be seeking to relieve themselves of the stigma associated with their infection by transferring responsibility onto the one who infected them[17]. This strengthens the construction of the innocent victim /guilty carrier image discussed in Chapter Three by directing the blame away from the 'victim'.

While concern about HIV transmission is not a high priority for the vast majority of heterosexuals in affluent countries, a new conceptualisation of shared responsibility for protection has evolved in those communities heavily affected by the disease. Beginning with gay men, and now established among injecting drug users, sex worker collectives and heavily affected heterosexual communities, the normalisation of condom use and clean injecting equipment has transformed communication and trust within interactions by establishing that protected behaviours are responsible behaviours for all parties. This diminishes the need to seek out criminal law as a means of apportioning responsibility[18]. It was this common as well as personal interest that has, for example, shaped the reaction to AIDS across gay communities in different countries. This in turn was responsible for not only dramatic changes in sexual behaviour leading to radically lowered rates of transmission at certain points

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[17] Rhetta Moran 1997, developed the notion of the Personal Responsibility Paradigm, in her description of HIV infected victims of rape who struggle to dissociate themselves from blame. This idea contributes to the notion being developed here about how infected people in general may try to pass responsibility for infection away from themselves and onto others.

[18] For example, there was a different feature in the self-protective nature of 'safer sex' in San Francisco's gay community in the late 1980s that was based on the concern that an entire community was at risk of infection, not simply a random combination of individuals. In addition, the crisis was understood to be compounded by the fact that wider society would have little concern for an epidemic among gay men, so it was up to the gay community to protect itself (Shilts 1987).

in the epidemic, but also indicates a reason why gay men have not brought their grievances about the fact of transmission to the courts en masse. Generally speaking, retribution and attribution of responsibility at the individual level have not formed a large part of gay communities' response to AIDS. Instead, many effective gay responses have focussed on the responsibilities of governments and pharmaceutical companies in relation to the epidemic. AIDS service organisations (many with historical roots in gay communities and others based in ethnic and drug using populations) have responded almost unanimously against the criminalisation of HIV transmission. This is because of their community based perspective, rather than the 'individual v rest-of-society' view undertaken in criminal conceptualisations of the law. As I explained in Chapter Two, such an approach will not always prove (successful. It is, however, likely to be more effective than the heightening of individual responsibility through the criminal courts.

This chapter has demonstrated that the governance strategies embodied in the application of criminal laws relating to HIV transmission contribute to the problematic individualisation of responsibility that has also been explored in detail in the preceding chapters. More specifically, the detailed debates taking place over the ways and means through which these criminal laws should be implemented allow us to once again witness the ways in which the false dualism between *responsibility as freedom* and *responsibility as control* operates to focus exclusive attention on the individual. Those who come from the position supporting *responsibility as freedom* argue for criminalisation in order to apportion responsibility for the individual act of transmission. The assumption is that if responsibility can be controlled and contained in this manner, then the continued freedom of the broader society is ensured. The arguments raised in this chapter provide a serious challenge to this perspective. Indeed, it is possible that the supposed 'freedoms' of all social members will be even more curtailed as a result of such legislation. Those who come from a *responsibility as control* position rightly counter the pro-criminalisation perspective by arguing that specific stigmatised groups are disproportionately targeted by the application of such laws. They also raise the important point that those who are concerned about their HIV status may be dissuaded from testing because of their concerns about later being held culpable for transmission.

These concerns about control and governance are valid in their own right, however they only can be converted into a strong and unified challenge to criminalisation once they have been contextualised within an argument backed by the perspective that regards *responsibility as intersubjective*. As discussed above, the harmful effects of criminalisation can only be understood once we understand how the many issues contributing to HIV transmission operate intersubjectively. Therefore, we need to consider the way that the social stigma which drives the epidemic is increased by measures which aim to target those who are most vulnerable to infection, thus contributing to a vicious cycle of increasing transmission. All of these practical issues are overlaid with the broader problem that use of the criminal law in relation to HIV transmission contributes to a general sense that the virus exists within 'guilty' pockets of the population; and is subsequently something that will be dealt with by police. It is precisely this type of construction of HIV that operates to camouflage the *intersubjective* elements of social existence that could be mobilised to reduce its spread. It has been made clear from experience that it is only when connections are made between socio-political environments the persistence of poverty, inequality and insecurity that it has been possible to address continuing transmission of HIV/AIDS. As long as attempts are made to focus attention upon the persecution of people involved in transmission at the individual level, recognition of these much larger factors is occluded. Over a decade ago, Australian Appeal Court President Justice Kirby said: 'Laws and public policies on HIV/AIDS will have only a minor part to play in the reduction of the spread of the virus. Do not put too much faith in coercive laws as a means of stopping the spread' (Kirby 1991: 30). His warning can be understood to highlight the weaknesses of a legislative approach that overshadows the development of *intersubjective* notions of responsibility.

CHAPTER EIGHT: INTERNATIONAL AIDS CONFERENCES AND THE EMERGENCE OF INTERSUBJECTIVE RESPONSIBILITY

8.0 INTRODUCTION

Since 1985 there have been fourteen international AIDS conferences. They began as a means for the medical community to pool resources and experience in response to a new epidemic that was killing thousands of people, not only in America but also in a cluster of developing countries in Africa and the Caribbean. Since that time, the conferences have developed a role extending far beyond that of a traditional scientific meeting. These biennial conferences now attract over fifteen thousand delegates who attend wide ranging sessions on clinical virology and prevention, human rights, impact of media coverage, gender inequality, the role of grassroots activism and community based care. Their scope has come to represent the positive potential for integrated approaches in public health:

> The world's capacity to respond with solidarity to HIV/AIDS has been symbolized by these conferences, which determine, more than any other single event, the critical sense of where we are and where we are going in research, prevention, and care. (Mann 1993: 1378)

Attendees include sales representatives from multinational drug firms, NGOs and aid agencies as well as government policy advisors, social workers, people living with HIV/AIDS, academics, unionised sex workers and medical researchers. The evolution of the conferences and their composition have demonstrated a growing recognition of the complex medical, political and social challenges presented by the epidemic.

However, a key function of the international AIDS conferences remains unrecognised: at a symbolic level, they have made a significant contribution to the shaping of responsibility in relation to HIV/AIDS. Through the development of increasingly diverse participation and wide-ranging discussions, the struggle over 'responsible' reaction to the epidemic lies at the core of these conferences. Questions about individual behaviour, government budgets, and pharmaceutical self-interest make up the content of the conferences – and they each reveal a distinct understanding of responsibility. The conferences have become the site where those in the field and those affected by the epidemic have confronted each others' various

models of responsibility. Thus, in addition to the 'basic science' elements of these events, the other key component to these events is the increasingly important question, 'Who should be doing what?'. Answers are plentiful and diverse, and they each reflect particular understandings of responsibility.

The international conferences are important events for those working within the HIV/AIDS field in a broad range of capacities, and their participation in and response to the conferences contribute significantly to the various forms of responsibility that these events project. However, the conferences do not only impact on researchers, policy-makers and community leaders. The conferences are widely publicised events. Findings, protests and debates that surface at these (meetings are disseminated by the world media, and have had significant impact on the ways in which HIV treatment, prevention and care are provided in all regions. Therefore, to consider the way that the conferences produce and reflect changing understandings of responsibility in relation to the epidemic is to consider the potential that AIDS conferences have to influence public and civil society responses to the disease. It is for this reason that a chapter on the conferences makes a significant contribution to this thesis. This chapter aims to frame a sociological analysis of the ways in which understandings of responsibility are operationalised within the setting of the international AIDS conference and how this has impacted on broader responses to the epidemic.

The chapter begins with an introduction to the history and structure of the international AIDS conferences as a means to begin analysis of the ways that they have shaped responsibility in relation to the epidemic. Subsequently, I will draw specific attention to the 13th conference held in Durban, South Africa. This meeting, perhaps the most dramatic of all the AIDS conferences, relates directly to the work of this thesis, as it became the site where *intersubjective responsibility* and its role in addressing HIV/AIDS was brought to the forefront of the international stage. Not only did many of the features of this emergent ethic of *intersubjectivity* gain cross-sector backing in Durban, but it also represented a symbolic shift in the way that responsibility for HIV/AIDS was conceptualised up until that point. Individualised conceptions of responsibility as typified by official responses dominating past conferences that had been largely dependant upon the *responsibility as freedom* and

responsibility as control perspectives, looked set to be displaced. Therefore, this chapter has two key elements. Firstly, I present contextual information that allows us to explore the role of the conferences, and the different ways that they have expressed responsibility in a public forum over the years. Secondly, I report on the details of the Durban conference and the way in which it continued many important symbolic functions of the international AIDS conference, yet at the same time represented a moment of significant change to the way in which responsibility relating to HIV/AIDS would be apprehended in the future. This shift held significant implications for conference participants, powerful international bodies, and for millions who were watching the events unfold in the daily press.

8.1 THE GROWTH AND CHANGING ROLE OF INTERNATIONAL AIDS CONFERENCES

Despite the public and expert attention given to international AIDS conferences, there is little literature on their sociological significance[1]. The handful of writers who do address the topic comment on the various ways in which the structures of international AIDS conferences have adapted to meet the demands of treatment and community activists (Altman 1994; Berridge 1996; Patton 1986). Yet there is no unified body of work that analyses ways in which these meetings have symbolic outcomes or cumulative effects on understandings of HIV/AIDS.

However, it is possible to find attentive comment on the conferences from both inside and outside the 'AIDS world'. Academic comments on AIDS conferences can be found scattered among expert reports submitted to scientific journals and AIDS expert communications such as newsletters, web-sites and newsgroups. Such reports usually focus on the most recent conference and its scientific or political outcomes, and in some cases may be compared with the preceding international conference (examples include: Ezzell, 1989; Concar, 1990; Campbell and Rader 1991; LeBourdais 1996; Mane *et al.* 1996; Mann 1993; Stephenson 2000). In addition, it is possible to find insightful reflections on AIDS conferences in the mainstream and alternative press – often by those assigned to the areas of science and medicine. In some instances such staff writers have attended more international AIDS conferences

than many of those presenting research[2]. However we must also be aware that AIDS conference coverage varies in tone and purpose depending upon its target audience[3].

An important source of information on the first AIDS conference and the early years of the epidemic, is Randy Shilts' *And the Band Played On* (1987). Despite some controversial aspects, it continues to be referenced by researchers because of its sheer compilation of early data, and tracing of the earliest expert networks[4]. To a lesser extent, Cindy Patton's *Sex and Germs: the politics of AIDS* (1986) plays a similar role. Both works give detailed accounts of the first international conference which are infused with simplified characterisations of the attendees. On the one hand were those doctors, scientists, volunteers and activists who were trying to get on with saving lives. On the other were the government representatives and civil servants who held more concern about public image and spending than the welfare of those who were already socially marginalised[5].

This mixed participation at the conferences resulted in direct and indirect struggles over who was to take responsibility for various aspects of the epidemic, and in what manner. These include issues such as: state responsibility for HIV prevention and research; treatment costs; the ethics of human vaccine trials; honest reporting on treatment failure and toxicity; how to deal with dissenting opinions on HIV and its origins; and the place of community involvement in all aspects of response. Such issues have not only been raised in the context of the conferences, they have

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[1] Altman, 1994, comments that there is virtually no literature on the increasingly central role of conferences in the realms of science or academia, let alone on specific AIDS conferences.

[2] The most renowned Western reporters have all worked for American papers. These include: Laurie Garrett (*Newsday*), Mark Schoofs (*The Village Voice*), Larry Altman (*New York Times*) and Randy Shilts (*San Francisco Chronicle*). Schoofs and Garrett were also took part in various presentation panels at the Durban conference, significantly crossing the boundary between reporter and active participant.

[3] See Chapter Four for a discussion on the limitations of materials gathered on international AIDS conferences. As a result of the limited range of academic sources, there is a strong reliance within this chapter on the views of Dennis Altman, because he is one of the few academics in the field who has a small selection of writings on the impact and outcomes of the international AIDS conferences. While I agree with many of his observations (but not all of them) I am also aware of the lack of contrasting academic viewpoints.

[4] While some of Shilts' theories have come under fire from critics such as Crimp 1988, the work of other researchers such as Larry Kramer 1995, Steven Epstein 1996, Simon Watney 1989 and 1994, and Cindy Patton 1986, backs up his account of the clash between scientific and activist responses.

[5] At the same time, the lines of division are not always so simple. See Epstein 1996 for an excellent account of the blurring of the lines between activist, scientist and civil servant in the sphere of American HIV/AIDS politics.

continually been at the heart of ongoing debates in all regions. The international conferences become sites where regional and national debates regarding responsibility are magnified, because it is possible to find allies which intensify the struggle in the conference environment, and because the media has increasingly focussed on the social and political issues being discussed.

The role of the media has become more central since reporters have begun to look beyond scientific press releases and a few of the more imaginative protests. As a result, the international conference provides a global platform for disparate elements of the AIDS activist and research worlds. Therefore, media coverage has played an important role in broadening the debate beyond conventional notions that place HIV exclusively in the realm of individual responsibility. When we consider how public perceptions of the epidemic – including understandings of responsibility – are influenced by the coverage given to the international conferences, it is possible to understand how this influence expands to the level of government and corporate policy-making. It is for these reasons that the symbolic function of the conferences in relation to responsibility is an important issue for investigation within this thesis.

Expansion and diversification of the conferences has happened to such a degree that many have begun to question their usefulness. As Altman argues, 'To promote a global response to AIDS requires the sort of networking and international mobilisation which large conferences promise but rarely achieve' (Altman 1994: 134). Year upon year the international conferences grew so much that by 1992, organisations were finding it difficult to cover all aspects of the conference even if they sent ten participants (Berridge 1996: 162). Some organisations have stopped sending participants or have drastically reduced their numbers because they cannot be sure of the immediate relevance of mass meetings to their own aims and objectives[6]. At the same time, organisations which intend to maintain high levels of professional status in the HIV/AIDS field face pressure to attend the international conferences, in large part to see and be seen. According to Altman, the driving force

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[6] For example, in recent years leading UK AIDS organisations such as Sigma Research and Terrence Higgins Trust have cut back on the numbers of people they send out to international conferences. Instead they focus more of their research resources on dissemination at local and national levels which have more relevance to the immediate populations they serve (Field notes 2001, Book 5: 15).

behind the international conferences is that 'the AIDS industry, both the commercial and the non-commercial, need them to get together' (Altman 2001b).

Debates about the expense and purpose of such meetings led to the decision to hold them biennially rather than annually (Mann 1993), although questions of practicality still remain[7]. Perhaps one of the strongest reasons why the conferences have maintained their high status is that they serve as public markers (for those outside the 'AIDS world') in the progress of both medical and social sciences' response to the epidemic, as well as often being sites of political and social change. This will become more apparent as we review the historical progression of the conferences themselves.

8.1.1 The First Conference: narrow parameters of responsibility

The first International AIDS Conference, held in Atlanta, Georgia in 1985 was an important occasion for activists and researchers who had yearned for appropriate attention to be paid to the new epidemic. The Atlanta conference was attended by just over 2,000 participants, with 392 presentations divided between topics such as epidemiology, social aspects and medicine (Altman 1994; Patton 1986; Shilts 1987). It was the first time that the international medical establishment was seen to be mobilising a co-ordinated response to an epidemic that was most prevalent among gay men, Haitians, Africans and injecting drug users and that had been identified four years earlier. By January 1985, the number of cases of AIDS in America surpassed 8,000 (Shilts 1987: 525). At the end of 1984, Western Europe reported just under 800 cases, while thousands of AIDS related illnesses and deaths were suspected in Africa in the absence of formal reporting[8] (Shilts 1987: 500). This initial mobilisation acquired the symbolic expectation that finally those in power would finally begin to address the epidemic. Thus, from the very first meeting, responsibility was at issue. The symbolic role of that first international conference is

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[7] It has been recently put forward that regional AIDS conferences (for Africa, Asia-Pacific, Europe, etc.) can defray travelling costs and allow participants to discuss more immediately relevant issues (Altman 2001b; Davies 2001).

[8] Shilts attributes the difficulty of obtaining accurate estimates about African cases of AIDS to a combination of local lack of information, a weak medical infrastructure and reporting system, and reluctance on the part of some governments to admit that the epidemic was spreading within their borders (1987: 500).

probably the reason why several historical and sociological accounts of HIV/AIDS have documented as many known details as possible about the event.

What these accounts reveal is the extent to which assumptions about responsibility, risk and individual 'deviant' behaviour were deeply infused into conference proceedings right from the start. Another problematic, and perhaps with hindsight the most dramatic oversight documented by these texts was the almost exclusive American focus of the Atlanta conference at the expense of a recognition that HIV/AIDS was also spreading in the rest of the world.

What participants did learn for the first time at that conference, was how long HIV positive individuals could be infected while having no symptoms of illness (Patton 1986).

> Pencils dropped and jaws gaped throughout the auditorium as [US
> Centres for Disease Control researcher] Dale Lawrence calmly laid out
> his projection that the mean incubation period for the AIDS virus was 5.5
> years. Some people, he added, would not get AIDS until 14 years after
> their infection (Shilts 1987: 552).

This announcement helped researchers realise that the disease would have already spread far beyond that group of patients who were currently showing symptoms. In turn, this meant that successful prevention and care would be an immense task, as a significant amount of undetected HIV transmission was already taking place. Epidemiological mathematical modelling provided evidence of the new public health emergency but it was going to be difficult to translate these types of abstract future projections into public health measures that would have an impact on the behaviours that transmitted the virus. The first challenge would be how to convince politicians to back such initiatives under these circumstances. The next would be how to convince average people of the urgency of behaviour change in the absence of a visible mass epidemic.

Thus, one of the biggest issues that participants at the Atlanta conference (and subsequent participants throughout the 1980s) would have to grapple with was how to generate a political and shared sense of responsibility for stopping an intangible epidemic that the public imagined to be very distant from their own concerns. In 1985 most American or European citizens first hearing of HIV/AIDS could not imagine that they would ever know someone who was affected by the virus. The

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limited media coverage of the disease up until that point had strongly characterised it as an illness affecting hyper-promiscuous gay men in New York and San Francisco or destitute junkies (Colby and Cook 1991; Kinsella 1989). This made it a challenge for scientists to convince politicians that immediate and expensive measures were required in order to curtail the spread of the disease[9]. Additionally, there was little political will to put tax money toward the prevention of a virus that most people strictly associated with gay men[10]. Not only did it appear to the public that the numbers affected would be negligible, but the atmosphere of neo-Conservatism at that time propped up the notion that promiscuous gay men with AIDS simply had what was coming to them. Some understood it as a disease that was clearing away a dispensable and unwanted segment of the population (Berridge 1996; Kramer 1995; Shilts 1987). As I reviewed in Chapter Three, this type of thinking concluded that society should not have to foot the bill for the outcomes of 'irresponsible' individual choice.

In the mid-1980s popular attitudes to HIV/AIDS were largely shaped by various schools of neo-conservative opinion that ranged from unconcern to outright hostility towards those affected by the disease. Alternatives to this were apparent in the earliest responses by gay men in America, and the Atlanta conference provides us with early examples of the overt struggles over how best to demonstrate responsibility for dealing with AIDS. In one address, the director of San Francisco Hospital's AIDS Clinic challenged other cities to 'take AIDS half as seriously as San Francisco has' (Shilts 1987)[11]. This speaker expressed pride in a local response to AIDS that worked in partnership with gay community leaders, and demonstrated municipal responsibility for prevention, treatment and research. In direct contrast to this approach was the presentation made by the US Secretary of Health and Human Services who stated that the government intended to 'stop the spread of AIDS before

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[9] See Shilts, 1987 and Berridge, 1996 for comprehensive coverage of this struggle in the US and the UK respectively.

[10] At this early stage, few people in the West had any idea about the HIV/AIDS epidemic that was simultaneously affecting African countries.

[11] Shilts outlines the early differences in local reactions to the epidemic – particularly San Francisco and New York. For years San Francisco's municipal government collaborated with and was fully integrated into that city's strong gay community. As a result, community involvement and quick response from the city's public health structures meant that San Francisco could easily demonstrate the positive outcomes of their existing collaborative structures. See Bayer, 1991 for more on the

it hits the heterosexual community' (Patton 1986: 38). Secretary Heckler's statement appeared to indicate that the US government only took responsibility for the health of heterosexual citizens. Key accounts of the Atlanta conference dedicate significant passages to the implications of this one speech, emphasising that it enraged scientists and activists alike (Patton 1986: 38; Shilts 1987: 554). The Secretary's sentiments proved to become emblematic of the initial political response to HIV/AIDS: that official bodies were only responsible to prevent the spread of the epidemic when it was no longer confined to marginalised 'risk groups' [12].

Accounts of the Atlanta conference mention epidemiological input from countries such as Haiti, Zaire, Rwanda, Canada and Australia, but any mainstream retrospective references to political responsibility for AIDS only discuss the role of Americans in this debate (Patton 1986)[13]. Perhaps this is because a conference on American soil would draw more involvement from American activists – resulting in debates about local and national efforts (Mirken 2001b). The imbalances of input between Western and non-Western regions will be an issue discussed at greater length later in this chapter. However at this point it is worth noting that many of the earliest conferences took place in the United States and were dominated by American concerns[14].

The first AIDS conference in Atlanta thus symbolised an organised opportunity to share and implement effective action to prevent the spread of the epidemic, but many delegates would have left with mixed emotions as to the messages they had received. Of particular salience was the clear signal from the American government that they were most concerned about the American heterosexual population which would leave many activist groups with a confirmed belief that effective preventative action

collaborative approach in San Francisco, through a contrast of the early policies to close bathhouses in both San Francisco and New York.

[12] As discussed in Chapter Three, the early categorisation of 'high risk groups' allowed for the symbolic characterisation of guilty carriers and innocent victims (Frankenberg 1994; Crawford 1994; Brandt 1997). Thus what appeared to be objective epidemiological practice contributed to the notion that some people infected with the HIV virus were to be held personally responsible for their status, while those who were deemed innocent were worthy of government protection and even a degree of government responsibility. This type of differentiation was confirmed by civil and criminal legal protection in the event of transmission; and through compensation for infected haemophiliacs (Driscoll 1989; Kinsman 1996; Steffen 1999; Veitch 1987; Wilkie 1996).

[13] This is probably also a feature that the vast majority of available literature on that period of the epidemic is written by Americans.

would become their own responsibility by default. This political (and as a result, scientific) abandonment of HIV meant that for many years, addressing the epidemic was left to the organised and largely voluntary elements of those groups most affected by it. The lack of governmental response in most countries contributed to the general belief that HIV was not a responsibility that was to be shared within civil society at large – and this first conference provided significant support to this perspective.

8.1.2 After Atlanta: establishing responsibility on the agenda

The conferences following after Atlanta did develop a tradition of political resonance, although this has not been a uni-linear development. Some have become sites of intense activist protest over issues such as government inaction; inattention to the developing world; treatments and drug trials; and the question about whether HIV causes AIDS. Altman (1994) comments that with the gradual growth of the conferences came increases in participation from community activists to the extent that dramatic outbursts and protests became an expected part of the proceedings (see also Barinaga 1990; Concar 1990; Ezzell 1989)[15].

Activist groups such as ACT UP and South Africa's Treatment Action Campaign have repeatedly used the international conferences to raise awareness of their understandings of responsibility. In the context of the conferences, they have made public charges against those who they feel should be responsible for dealing with particular aspects of research and prevention while also demanding that such measures are carried out in accordance with that responsibility. Through the use of rallies, marches, vandalism and take-over of pharmaceutical marketing booths, the conferences give activist groups (most notably, ACT UP) the opportunity to publicise issues of responsibility to HIV/AIDS experts, government representatives and the global media.

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[14] See the list of conference years and locations in the Appendix.

[15] Berridge, 1996: 162, confirms the trend, but she comments that even from the time of the first conference, UK civil servants were amazed to see 'men in black leather writhing on the floor'. She goes on to assert that activism was not a new feature of medical conferences, citing similar events from international conferences on alcohol in the early 1900s.

The growth of the conferences, both in numbers of participants as well as public stature, has been complicated by the increasing struggle between the sharing of scientific research - which is understood by some as the original purpose of the conferences - and the development of the conference as a platform for activists to voice alternative perspectives on political and shared responsibility. The San Francisco conference in 1990 illuminated this divide. The conference was at the centre of protest and calls for boycott because the United States' immigration policy made it impossible for foreign delegates to openly declare their HIV positive status and still gain entry at the American border (Altman 1994; Berridge 1996; Concar 1990)[16]. A full page *Science* article before that meeting was headed, 'AIDS conference: science or circus?' and warned that 'the meeting is going to be á zoo' (Barinaga 1990). Concern about the increasingly politicised nature of the conferences was expressed again during the opening address of the 1991 conference at Florence which was entitled 'Science, not a political jamboree' (Altman 1994 132). There was a growing gulf between the vision that the scientific world had for these meetings and their chaotic reality, and at one point serious consideration was given to making a concrete division between science and politics (Barinaga 1990; Davies 2001; Ezzell 1989). This proposal involved splitting the conference into two, dividing clinical and lab science from social science and public policy in order to avoid the potential of 'people throwing bricks at cell biologists' (Barinaga 1990: 1181).

This internal struggle indicates the degree to which different understandings of responsibility was effectively a core issue around which the conferences had evolved. Organisers ignored this reality at their peril, and now the conference was in danger of splitting apart. The very suggestion from scientists that the realms of politics and social activism should be separated from their own concerns indicated a belief that 'responsible' scientific practice could be objective and insulated from external concerns. On the other hand, those involved with social and political

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[16] No further international AIDS conferences have been held in America for this reason. In 1993, the Organizational Committee (OC) of the UN Administrative Committee on Coordination (ACC) endorsed a policy of non-sponsorship of international conferences and meetings on AIDS in countries with HIV/AIDS-specific short term travel restrictions, as set out in document ACC/1993/OC/II/CRP.6 (Burzynski 2001). Despite this policy, the UN special session on HIV/AIDS was held in New York in June 2001. This lead to an international boycott and denunciation of the session.

aspects of the epidemic would demand that 'responsible' scientific practice could only be carried out with full awareness of the socio-political context of the epidemic as well as the impact of research decisions. Ultimately this meant giving communities most affected by HIV/AIDS a share in the decision-making that would impact upon their own futures most directly. As long as science tried to absent itself from the realms of political struggle then activists and community members continued to demonstrate that this was an ineffective model to implement against the epidemic.

The emergence of these ideas from within the struggles over the role of the conference meant that the notions of *intersubjective responsibility* that had for so long been the mainstay of community-based activities – had spilled out onto the international stage. Even a small degree of acceptance from scientists that they were not removed from political and social debates was a significant climb-down. This would lead to a seismic shift in future understandings of the HIV clinician's role, and would also prove to be the initial foothold for dramatic changes in widespread understandings of responsibility as it related to the epidemic.

This ideological conflict about the nature of 'responsible science' became a continuous undercurrent of the international conferences. In their decision to keep the conference as one unified event, organisers were subsequently faced with the task of finding ways to provide for the scientific and the political motivations of the delegates. As outlined below, one means of managing the tensions was to attempt to structure the conference into a small number of discrete 'tracks', keeping the two factions both physically and ideologically separate. The outcome of this organisation has been that some of the conferences have appeared more heavily weighted on the side of science, while others are remembered for their political salience. For example, a measured, scientific tone dominated proceedings at Stockholm (1988), Florence (1991), Berlin (1993) and Vancouver (1996)[17]. Yet these provoked even stronger reactions from social commentators who felt that the reason for holding AIDS conferences was being buried below high level corporate networking. One

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[17] Vancouver was the conference where the positive outcomes of new anti-retroviral treatments were made public. For this reason I say that science predominated, but at the same time there was also a large presence of political and social activism at that event (Davies 2001; Mirken 1996)

commentator raged against events such as a gala 'wine-swigging' opening attended by thousands of doctors, lab researchers and drug company representatives, 'while scattered around the hall hung occasional panels from the AIDS quilt, apparently to remind us all why we were there' (Mirken 1993).

While the Berlin conference in 1993 was an ordered, scientific affair, it appeared that most of the news from the researchers was not promising. Many hopeful avenues for treatment and vaccination had been exhausted (Mann 1993; Mirken 1993). The failure of large-scale treatment experiments led to a widespread sense of deflation both during and after the gathering at Berlin. Jonathan Mann issued a bitter scolding in his report on Berlin.

> In place of dialogue about critical, larger problems, there was an intense focus on what could be measured, regardless of real importance...
> ...There was also a return to the past – a repetition of the now familiar calls for the right things to be done...Why these 'right things' – widespread sex education, universal availability of condoms, development of a vaginal microbicide, availability of needle exchanges, tolerance for homosexuals – have not advanced very much was not considered. (Mann 1993: 1379)

Mann argued that the surface features of the epidemic (on display at Berlin) were not nearly of as much importance as rooting out social discrimination which constrains the individual's capacity to respond to HIV risks (Mann 1993). He underlined his belief that science cannot and should not be divorced from social context. Within that belief was the position that powerful social institutions needed become aware of their role in continued transmission, as well as their responsibility to change social, political and economic relations to a point where spread of the disease could be controlled.

Referring to their 'responsibility' to make a useful impact on the epidemic, Mann said a 'heavy mantle of history' weighed on attendees (Mann 1993: 1379). He insisted that there were already more than enough pressures working against AIDS researchers and people affected by the disease and neither scientists or community members were going to get anywhere if their internal struggles distracted them from answering what he called the 'critical, larger problems'. Mann's work would always be filled with his own sense that the fight against HIV/AIDS would only be

successful within a global framework modelled on *intersubjective responsibility* that included the combined commitment of individuals, organisations and states[18].

The picture thus far has demonstrated the gulf that existed between those pressuring for political and social change on the one hand and scientists and policy makers who distanced themselves from such concerns on the other. However this ideological division was dwarfed by the problem of Western dominance in all aspects of the conference (Altman 1994; Altman 2001b). For example, American activists and scientists formed such a numerous and powerful presence at the conferences that discussions and disagreements about drug trials, basic research and political issues were often only addressed within an American context (Altman 1998). Participants from developing countries would find it difficult to be heard, regardless of whether the topic at hand was cell biology or grassroots organising (Altman 2001b). From the perspective of non-Western delegates, the issue of exclusion was of far more concern than the rather bourgeois ideological conflict between the medics and the protesters (Mirken 1996). From this perspective it was perceived that Americans were arguing about the minutiae of highly evolved treatment and prevention in their own country while unheard representatives from other regions were struggling with the basics of generating AIDS awareness in nations with little health care, education or economic opportunity.

Although the scale of HIV/AIDS had become most pronounced in developing countries by the mid-1990s, the vast majority of presenters and delegates at the 1996 Vancouver conference were from North America and Europe (Teixeira *et al.* 1998). Thus the regions with the greatest need for researchers experienced the lowest levels of research production and dissemination at the international level. Without enough funding even to send delegates to the conferences, these areas did not benefit from the process of researchers sharing information and approaches with others from both inside and outside their own region (Sitthi-amorn and Somrongthong 2000).

This issue was brought out into the open at the Vancouver Conference, which was entitled 'One World, One Hope'. Despite the limited attendance from diverse

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[18] See Mann 1990, 1996a and 1996b for more examples of his approach.

regions, its explicit aim had been to express the global need for progress against HIV/AIDS, (Vancouver International Conference Secretariat 1996). But instead of equal participation from developed as well as developing countries, the conference was overtaken by the euphoric unveiling of the early successes of Highly Active Anti-retroviral Therapy (HAART) which was accompanied by a great deal of optimism from Western activists (Altman 1998).

Yet in his speech at that same conference, Jonathan Mann's warnings of the continuation of inequality broke the optimistic mood that had been fostered both by the conference theme and the announcements about HAART. He claimed that the early years of solidarity had been overtaken by complacency and distancing between various factions such as rich and poor; infected and uninfected; men and women; experts and non-experts. 'For the past five years we have experienced enormous fragmentation, isolation and splitting within the AIDS world' (Mann 1996b). Given the growing gap in research and treatment funding between wealthy and developing nations, Mann was able to foresee the outcome of the promising drug treatments that were being celebrated at Vancouver. He knew this news would be meaningless to those living with HIV/AIDS in the developing world unless something significant was done to address the costs of treatment provision (Mann 1996b). Again, Mann reminded participants of the importance of addressing HIV/AIDS from a position rooted in *intersubjective responsibility*. He refused to take part in the treatment euphoria that was going on around him, because he knew that inequity, stigma and corporate pressures laid on by pharmaceutical industry were not going to eliminate the epidemic, but just drive it into new territories. Continued divisiveness among those working in the field would obscure these issues.

Seemingly in response to Mann's widely publicised concerns about shared responsibilities within the AIDS field itself, the theme for the 1998 conference at Geneva was 'Bridging the Gap' – referring to the need to bring together the more developed and less developed countries in the fight against the epidemic. Plenary speakers at Geneva used their platforms as a means of expounding about the need to keep the developed world up to pace with all scientific advancements. Yet participants commented that the cultural gap seemed most pronounced at the very conference which had been intended to address the issue. On more than one

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occasion, Western delegates at Geneva left the auditorium once the stage was taken by someone intending to present research from a developing region (Horton 1998). The organisers of the Durban conference in 2000 made great efforts to prevent this from happening again (Coovadia 2001).

The history of international AIDS conferences is more complex than can be relayed briefly here. This section has merely given some background to the development of a biennial event that does not suit straightforward description as a scientific gathering nor a political event. The international AIDS conferences have become events which focus around a particular public health crisis, including not only clinicians and policy experts but also participants from affected groups, NGOs, and activist organisations. This diverse participation has required changes in the way that delegates approach the conference and the way the gathering is organised. In this way, the conferences have quietly come to represent the challenges and strains presented by *intersubjective responsibility*. The claims for attention demanded by these very different groups of conference participants have increasingly demonstrated that HIV can not be expected to disappear just with the dissemination of condoms and 'safer sex' information. Such expectation arose from a model of prevention and essentially a model of responsibility that does not apply to the real-world interaction of power, desire, poverty, inequality and an incapacity to deal openly with sexuality.

While ongoing research continued to advance the argument for a changed paradigm to effectively address HIV/AIDS, it was the international conference where this message had the opportunity to be disseminated to those outside of the field. With the ever increasing global media attention that accompanied the growing symbolic importance of the conference, came an opportunity to appeal directly for a broad change in the way that people perceived responsibility as it related to the epidemic. The conferences have come to represent the cultural and disciplinary diversity of the response to AIDS, even when such elements are at odds with each other. A great deal of their symbolism emerges from their role as places that offer the opportunity for community members and affected groups to confront and question those who have the most political, intellectual and financial control over how the epidemic is addressed. These opportunities for direct confrontation of conflicting views have made a significant contribution to the changing perceptions of responsibility

accompanying the epidemic. Although the debate continues as to whether or not there is much practical relevance in conference participation at the individual and organisational level, I maintain that the conferences operate as important markers in the public signification of responsibility in relation to the epidemic.

8.2 CONFERENCE STRUCTURE: IDEOLOGY AND RESPONSIBILITY

The organisational structure of the international AIDS conference offers concrete evidence of the split between science and politics contained within. Although they have undergone significant change since 1985, Altman (1994, 1998) argues that the conferences reinforce a rigid 'scientific' approach because the discussions at many conferences are 'squeezed' into four pre-determined 'tracks': A – Basic Science; B – Clinical Care and Science; C – Epidemiology; and D – Social Impact and Response. While all of the conferences have conformed to a segregated track structure (where basic and clinical sciences symbolically occupy the first several spaces) their scope has been a dynamic site of contestation.

The 1988 conference at Stockholm had nine tracks including several with a social focus and at Montreal the following year there were eight tracks[19]. The four-track system mentioned above appears to have been implemented for the first time in 1990 at San Francisco, the event where science made an obvious attempt to re-establish itself at the helm of the international conference. This structure remained the same throughout the 1990s. The Durban 2000 conference saw an addition of a fifth track E: Rights, Politics, Commitment and Action[20]. The organisers of the Barcelona conference in 2002 again introduced significant structural changes creating a total of seven tracks. The final three were entitled: Social Science; Interventions, Program Implementation; and Advocacy and Policy. There was also a structure in place for 'directed bridging sessions' at Barcelona which were intended to enhance dialogue

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[19] The Stockholm track titles were: Virology, Pathogenesis and Immunology, Anti-viral Therapy; Epidemiology, Developing World, Prevention, Clinical Management, Psycho-social Aspects, Health Care and Society (Stockholm International Fairs 1988). The Montreal track titles were: Epidemiology and Public Health; Clinical Aspects; Basic Research; AIDS and the Individual; AIDS, Society and Behaviour; Ethics and Law; International Issues; and The Economic Impact of AIDS (Montreal International AIDS Conference Secretariat 1989).

[20] Although Altman has argued that the organisation of this track was led by medical scientists who were unfamiliar with key debates and figures in the field (Altman 2001b).

between the scientific and action-oriented components of the conference (Casabona and Gatell 2000).

While the use of an abstract-driven track system and its primary placement of basic science have remained consistent over the course of the international AIDS conferences, the fact that neither the quantity nor content of tracks has remained constant demonstrates a degree of discord. The addition and removal of tracks such as 'Ethics and Law' or 'Rights Politics Commitment and Action' are indicators of a fluid exchange of opinions among organisers on the place of socio-political issues in the conference framework. Track changes over the years are concrete demonstrations of the ideological struggles between science and politics that have already been elaborated. While it may now be impossible to conceive of an international AIDS conference that does not create a significant place for social and political concerns, the track structure that predominated throughout the 1990s demonstrates that this was not always the case. This point alone demonstrates the shift in the most recent conferences toward some recognition of the important role played by socio-political actors such as activists, members of civil society, and people living with HIV/AIDS.

These changes have impacted upon the way that the conferences are perceived, and by extension, on the evolving conceptions of responsibility surrounding the epidemic. However, such musings must also be tempered with recognition of two important realities: a) science remains unmoved at the top of the track hierarchy; and b) the entrenchment of an abstract-driven track system demonstrates the rational, scientific presumptions of the entire AIDS conference structure[21]. The result is a meeting where there is a continuing attempt to separate science from discussions of

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[21] In his recounting of the selection process for the 1996 Vancouver conference, a co-chair of one track described how non-existent this veneer of scientific rationality can be (interview with the author, 2001). While teams of reviewers had narrowed the field of submissions to a pile of abstracts worthy of presentation in the previous months, he and fellow track organisers found the quality of work in this pile was lacking. As a result, over the course of a few days, the small group of track organisers undertook a review all of the submissions again, returning to abstracts that had first been given flat rejection. Some of those were selected for primary slots in the proceedings. Not only does this reinforce questions about the existence of scientific objectivity – but it also calls into question the appropriateness of this model of organisation for the AIDS conferences.

social, economic, political and cultural complexities of the epidemic (Altman 1998)[22].

Altman's wide ranging critique of the track structure of the international conferences stems from the concern that clinical scientists, social scientists, contact workers and activists will only concentrate on their own track and never interact constructively. This is a valid concern which is further confirmed by the rare moments during International AIDS Conferences when traditional boundaries between tracks begin to blur. Indeed, many self-taught treatment activists attend Track A sessions and question the presenters at a remarkable level about treatment regimens, drug toxicity and resistance (Field notes 1998, Book 2: 3). However this does not escape the ⟨ problem that Western Track A participants would rarely find themselves, for example, at a session on a Brazilian intervention led by organised sex-workers (Davies 2001).

Efforts have been made to encourage 'track mixing', and appear to be meeting with increasing success. Keeping in line with broader experiences of the conference setting, perhaps the most interesting discussions at AIDS conferences happen in those contexts that are less structured[23]. For example, community leaders have found themselves chatting to lab researchers on the transport route between the conference centre and the downtown hotel district. Meanwhile, both hotel and hostel breakfast areas are sites for interaction between people who intend to see vastly different presentations in the upcoming day (Field notes 1998, Book 2: 1; 2000, Book 4: 4). Having said this, an 'accommodation apartheid' is evident at these gatherings, with large Western corporate groups and policy advisors dominating the luxury hotels; and delegates from regions with limited funding, smaller NGO representatives, students and activists staying at hostels (Field notes 1998, Book 2: 3; 2000, Book 4:

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[22] The Sixth International Conference on AIDS in Asia and the Pacific (ICAAP) demonstrated a radical alternative to the track system, ultimately abandoning these separations. It was organised around four cross-disciplinary themes. One example was 'Treatment and Care', which enabled a plenary session including an expert on International Vaccine Development alongside an HIV positive woman from the Philippines who discussed the impact of limited treatment access on her life (Altman, interview 2001: 9).
[23] One contributor to the Break the Silence email forum noted: 'Creating an 'enabling environment' starts with ourselves. Frequent reference has been made to the 'open faces', the sharing, interactive and receptive attitudes evident at the XIII International Conference in Durban - in cafeterias, corridors

6). Yet as a further means of encouraging mixing, conference organisers have consciously added to the programme and arranged presentation space in ways that have encouraged intermingling of different track participants over the past four to five conferences. Such innovations have included NGO display areas, space for cultural events, internal newspapers reporting on the significant presentations and events of each day, and displays of the memorial quilt and HIV/AIDS art. At the Geneva conference it was necessary to pass through the NGO display area in order to get to the larger presentation halls and to the pharmaceutical company displays. This meant that representatives from pharmaceutical companies and laboratory scientists would be physically confronted with the noisy and colourful atmosphere surrounding the community group displays (Field notes 1998, Book 2: 1). It would seem that recognition of the divisiveness at conferences in the early nineties (as highlighted by Mann) has led to this increasing effort to create interdisciplinary and cultural space that will encourage conference participants to mix among tracks.

Electronic innovations have also opened up the potential for interaction between different tracks, as well as extending the contents of the conference to non-participants. Increasingly complex conference websites with areas for post-presentation reporting and comment have led on to the development of newsgroups and email networks for people both inside and outside the conference. Plenary presentations and key papers are captured for broadcast on the internet (although this kind of access also perpetuates some social divisions, as the majority of the world's population do not have access to the internet). The use of technology in this way allows for all sorts of people to involve themselves in a broad range of conference activities, with fewer obstacles such as time, professional status or geographical location getting in the way. The Break the Silence (BTS) email forum established before the Durban conference was predominantly filled with discussion about issues such as political responsibility, conference access and human rights barriers to HIV/AIDS prevention. Researchers and commentators from around the world took part in the discussions. The BTS forum has been revived for two occasions since Durban (to be discussed below) and continued participation and debate in such fora allows for further contestation of responsibility as it relates to HIV/AIDS.

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and in conference halls. This attitude hopefully sets the tone for our future working relationships, for

We see within the ongoing development of the conference structure the continued struggle by some organising bodies and participants to keep science at the structural and ideological centre of the epidemic. Yet visions of medical science abstracted from social, economic and political concerns have been heavily contested by various members of civil society – most notably those directly affected by HIV/AIDS. What has emerged from this conflict is still unclear. In organisational terms, we witness the ongoing evolution of track names – yet the track system itself has not yet been undermined, nor the hierarchy of tracks. On the other hand, the meaningful inclusion of skill-building sessions for those living with HIV/AIDS and broad debates including experts from diverse areas have demonstrated changing attitudes in contrast to the earlier arrangements. While the structures continue to evolve there is a clear indication that they reflect evolution in understandings of responsibility in relation to AIDS.

In Chapter Two, I outlined a model of *intersubjective responsibility* that has emerged from recognition of the need to move beyond traditional notions of responsibility which have a severely limited capacity to successfully address the HIV/AIDS epidemic. With regard to specific awareness in the AIDS world, I think that two key features of such responsibility (though not the only features) are, firstly, an awareness that medical science is not neutral but is part of a wider network of social relations; and secondly, a willingness to treat the epidemic in the developed and the developing world not as separate issues but as part of the same process. Through this analysis of the history of AIDS conferences and their changing organisational structure, I believe that we can see these two aspects beginning to emerge[24]. However, it was at the 2000 conference at Durban that such issues were brought forcefully onto the international stage, not only within the conference itself, but through the intensive media coverage that accompanied it. This conference carried with it a new approach to responsibility. The Durban conference became the public

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how we deal collectively with HIV/AIDS.' (Mason 2000)

[24] My position here should not be understood to mean that it is only the conferences that have contributed to the development of the intersubjective responsibility perspective. However, I do argue that the conferences have facilitated and contributed to the significant broadening of the audience for this message, as well as having had a degree of impact on policy change.

arena where individualised models of responsibility were convincingly deposed, and the *intersubjective* approach stood in the foreground.

8.3 DURBAN AS A MODEL FOR CHANGE

> This is not an academic conference, this is a gathering of human beings concerned about turning around one of the greatest threats faced by the human race. (Mandela N. 2000)

The Durban conference has been broadly recognised for two key achievements. It brought unprecedented attention to the impact of the epidemic in Southern Africa; and it resulted in an environment where scientific, humanitarian and political concerns appeared to have united. These achievements can be credited in some part to the conference being held in a developing country for the first time, and also to political factors that coincided with the conference. As a result it gained more global media attention than any other previous AIDS conference (Altman 2001b). This section will look at the political, physical and organisational elements that contributed to the unique environment which emerged at Durban, and how the conference became a symbol of a changed perspective on responsibility relating to the epidemic.

As discussed above, the role of the media has always been an important aspect of AIDS conferences. As sites of ideological conflict, and the place where scientific breakthroughs are often announced, the conferences have historically gained significant global media coverage. In turn, recognition of this global attention ensures that they continue to be well attended and that participants compete for the limelight through press briefings, activist demonstrations and through question periods after formal presentations. As pointed out by the International AIDS Society that sponsors the conferences, the intense media coverage has far reaching implications.

> This media barrage probably does more to influence policy and to promote HIV awareness, education, and prevention around the globe than the scientists, who present the papers that are reported on by the press, could ever accomplish on their own. (Wainberg and Kallings 1999)

Indeed some feel that the political implication of attention from the media is the core reason for continuing with an international conference format – despite complaints

that it is difficult to make a direct correlation between cost and effectiveness (Altman 2001b).

However, media attention at the Durban conference stood out within this context, for two key reasons. Firstly, the amount of coverage seemed much higher than at previous conferences. Secondly, a brief survey of stories from the immense newspaper coverage of the event demonstrated that the political and social aspects of that conference demanded more attention than science (Boseley 2000b; Dynes 2000; Editor 2000; Lustig 2000; McGrory 2000; O'Kane 2000; Schoofs 2000)[25]. Reporters focussed less on the medical debates and advances, and more on items concerning political and social barriers to prevention and treatment. This shift in media angle on the conference was indicative of an important change in perspective. The focus of this new brand of news story was the way in which powerful interrelationships at governmental and multi-national corporate levels provided environments where HIV flourished and useful treatments and technologies were unavailable. It signified a tremendous change in acceptable ways of representing responsibility as it relates to the epidemic – and this in itself contributed to an atmosphere where it began to look possible to tackle these complex issues.

Mbeki's questioning of the causative relationship between HIV and AIDS and his consultation with 'outlaw' scientists provoked outrage from AIDS researchers and activists around the world. Rumours began to circulate about boycotting the impending conference as a form of protest. However, in an editorial of the journal *AIDS*, the present and former directors of the International AIDS Society (lead sponsor of International AIDS Conferences) laid out the reasons why a boycott would be ineffective (Wainberg and Kallings 1999). They emphasised the way in which a stimulating conference at Durban would highlight the South African government's inaction as well as instituting change on a much broader scale:

> Attending the Durban conference gives scientists the opportunity to
> demonstrate that they identify with the global aspects of the HIV problem
> and, at the same time, participate in an event that will hopefully become a

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[25] This may be a result of the fact that since 1996 there has not been a lot of positive progress on clinical fronts, apart from successes in reducing parent to child transmission. In a review of newspaper coverage of the Durban conference, the numbers of stories focussing on political, social and human interest aspects of the Conference outnumbered those which centred on scientific or clinical issues (see Chapter Four for further details).

powerful instrument for social and political change. (Wainberg and
Kallings 1999)

All of a sudden, scientists were thrust into the heart of a political AIDS debate. In an
echo of the San Francisco conference boycott about American entry restrictions for
people with HIV a decade earlier, attendance at the Durban conference would itself
be a political statement.

As an overt political action, over 5,000 AIDS scientists from all regions signed their
names to the Durban Declaration – a statement reasserting the scientific majority
view that HIV causes AIDS (Sidley 2000). This was a direct response to Mbeki's
evidence-gathering on HIV and causality. This public demonstration of scientific
solidarity was meant to counter what was popularly regarded as Mbeki's hesitation to
acknowledge the AIDS epidemic. There was widespread concern that his
questioning of HIV as a causal factor in AIDS would cause South Africans to doubt
the connection as well, meaning that all efforts in reducing levels of viral
transmission (such as condom campaigns) would be rendered useless (Salopek
2000). Thus, scientists were thrust into the position of battling against government
inactivity, stigma and the effects of limited access to treatment. Before the
conference even began, it was clear that it would be impossible to keep science
abstracted from politics at Durban. The simple act of attendance raised the issue of
responsibility.

Thus the event at Durban that had been entitled 'Break the Silence' carried the
burden of high expectations regarding its potential for symbolic impact. In an
interview before the conference, UNAIDS director, Peter Piot explained that the
conference theme referred to:

> [the] need to break the silence around the world's responsibility. It will be
> one of the great moral tests of our time, how the richer countries are
> finally going to take responsibility and assist the poor nations in
> containing the AIDS epidemic -- not only to do good, but also in the
> interest of the whole world. (quoted in James 2000b]

The world's leading expert was speaking within a framework that fits precisely with
what I have called *intersubjective responsibility*. Thus in the weeks leading up to the
event, there could be little doubt that this conference would become the rallying
point for those who had struggled to push forward this agenda for so long. Using

South Africa as a model where so many things had gone wrong, an important goal of the conference was to bring attention to the problematic issues shared by many countries in the developing world:

> These include complacency, ignorance and denial which are still common in many countries, inequities in access to care, tardiness in the development of HIV vaccines and vaginal microbicides, lack of commitment in providing resources for research, education and public health interventions. (Durban Secretariat 2000)

This list of barriers to prevention had come a long way from the assertion that a focus on individual behaviour change was the most important means of stopping the epidemic. However, instead of abandoning responsibility, the organisers of this conference were intent to change the way it was understood. To them, responsibility for addressing HIV/AIDS should be shared by all social participants – with a special onus on powerful decision-makers to create environments were prevention is possible.

The structural planning of the Durban conference included innovations which meant that the meeting's scope went far beyond the traditional scientific track structure. Although the abstract driven track A-E sessions still maintained a central role in the event, community programmes such as the *Indaba* (forum), *Mamelang* (symposia), *Vukani!* (debates), *Ahang-Fundani* (skill building workshops) and *Amasiko* (cultural events) were given an important place in the overall presentation of the conference (Durban Secretariat 2000:2). As a result, the levels of local community involvement and cultural programming at Durban were unprecedented. Some formal conference sessions were two-way video-linked to a community centre in the city centre so local individuals could listen to presentations as well as question the researchers (Field notes 2000, Book 4: 8).

Meanwhile, quite a few Track A and B (i.e. 'science') sessions were placed outside of the core conference site, meaning that participants had to walk through the city-centre to attend. Key organisers have said that there was not a deliberate plan to move specific tracks outside of the conference centre (Coovadia 2001); however there was symbolic significance attached to this decision by delegates from tracks D and E. For several years, the growth of the conference often meant that additional

sites had to be used, and often the social science sessions were the ones to be displaced. I heard many passing comments at Durban about how wonderful it was to see the clinicians forced to leave the protective confines of the conference centre and experience Durban's city centre with its mix of people from all socio-economic backgrounds, while at the same time allowing tracks D and E to share some of the spotlight on the main stages of the conference (Field notes 2000, Book 4: 9).

One of the catalysts for interaction between conference delegates and the local community was the massive demonstration march organised by the Treatment Action Campaign (TAC) which immediately preceded the opening of the conference. They called for the march in order to demand that their government support the people's right to affordable AIDS treatment drugs from the major pharmaceutical companies (Treatment Action Campaign 2001). Amid the boycott discussions in the months leading up to the conference, TAC invited Western delegates to participate in their march as a means of demonstrating to Mbeki urgent need for access to HIV treatment in his country (Mandela W. 2000). In the end, the expected number of delegates did attend the conference and many thousands also participated in the TAC rally and march.

The protesters marched from city hall (festooned with mammoth red ribbons and banners) through the downtown financial district of the city and into Kingsmead stadium while media helicopters flew above and local residents waved from open windows and doors. The march comprised a mixture of South African activists and foreign conference attendees (Fieldnotes 2000, Book 4: 2). Within the crowd many participants wore t-shirts which declared in bold block letters that the wearer was 'HIV POSITIVE' (see Image 17 on the following page). These simple shirts carried potent symbolism[26]. Looks of recognition flicked between their wearers – both black South Africans from the local townships and gay white conference delegates. The political statement made by wearing such t-shirts in that setting was unmistakable:

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[26] The HIV Positive t-shirts emerged soon after TAC's formation in December 1998. In a protest march on parliament two months later, participants wore shirts with the picture of activist Gugu Dlamini who had been murdered after declaring that she was HIV positive at a public World AIDS Day ceremony on December 1, 1998. She was beaten in her home by members of the local community on December 12 and died the following day. (Barr 2000; Cameron 2000; UNAIDS 1999). The words 'HIV positive' were boldly printed on the shirts for that protest and many others in order to demonstrate collective solidarity among those with the disease (Sharone 2002).

those who were positive should not be silenced by stigma any longer. 'The image of AIDS in Africa is usually one of powerless people, emaciated and dying. What the march showed is that there are many of us who are healthy and fighting to stay healthy' (Achmat quoted in Denes 2001). In addition to these community-level messages about stigma and acceptance were formal addresses by well-known religious and cultural figures. They spoke of the responsibility held by people in developed nations to stand in solidarity with those who have no treatment and whose governments have not adequately responded to the epidemic (Mandela W. 2000). The marchers themselves became the physical embodiment of all of these messages. The March for access to AIDS treatment drugs that preceded the opening ceremony became the event that set the tone for the ensuing week. While there have always been outbursts of activism at other international conferences, the march at Durban had been the first ever to bring together thousands of delegates and locally affected people. From that march onward, treatment access was a central issue in addressing AIDS - it was no longer going to be relegated to the periphery.

However, the euphoria that had been sparked off by the rally and march to the stadium was soon dampened. The TAC march led to the stadium where expectant members of the crowd sat through the opening ceremonies that night waiting to hear from the man at the centre of the controversy, Thabo Mbeki. This would be his opportunity to signal a great move forward against HIV in his country by admitting that the government had a responsibility to confront the epidemic. Instead his speech reaffirmed his belief that the deaths among South Africans were being caused by a general weakening of the immune system due to poverty. He said:

> It seemed to me that we could not blame every thing on a single virus. It seemed to me also that every living African, whether in good or ill health, is prey to many enemies of health that would interact one upon the other in many ways within one human body. (Mbeki cited in Boseley 2000b)

The South African marchers, still wearing their HIV-Positive shirts, roared their protest back at their leader and, as a block, left the stadium.

Image 17

© Gideon Mendel. Gideon Mendel, 2001, <u>A Broken Landscape</u>,

Network Photographers/ ActionAid, London.

This image first appeared in *The Guardian Weekend*

Edition 27 October 2001, p.49.

8.4 TURNING POINT: EDWIN CAMERON'S SPEECH

On the following morning, conference delegates at Durban were able to witness what is considered to be a pivotal moment in the response to HIV/AIDS (Schoofs 2000). *Science* writer Jon Cohen remarked that Justice Edwin Cameron's opening plenary speech in honour of the late Jonathan Mann was 'one of the most remarkable acts of activism I've seen in 12 years of covering AIDS' (Mirken 2001a). As this was the first ever Jonathan Mann Memorial Lecture, the audience expected to hear homage paid to Mann's legacy of a 'human rights approach' to the epidemic[27]. Cameron did indeed remind his audience of Mann's influential speech at the Vancouver 1996 Conference when he said that of all the walls dividing people in the AIDS epidemic, 'the gap between the rich and the poor is most pervasive and pernicious' (Mann 1996b). None of that rhetoric was new to the thousands of conference delegates sitting in the vast hall at Durban. But what made the White South African judge's speech so memorable was its jarring honesty.

> ...I have been privileged to lead a vigorous, healthy, and productive life. I am able to do so because, twice a day, I take two tablets – one containing a combination of AZT (Zidovudine) and 3TC, and the other Nevirapine (Viramune). I can take these tablets because,.on the salary of a judge, I am able to afford their cost... In this I exist as a living embodiment of the inequity of drug availability and access in Africa... My presence here embodies the injustices of AIDS in Africa because, on a continent in which 290 million Africans survive on less than one US dollar a day, I can afford monthly medication costs of about US $400 per month. Amidst the poverty of Africa, I stand before you because I am able to purchase health and vigour. I am here because I can afford to pay for life itself. (Cameron 2000)

The facts of Cameron's story are not all that remarkable. His progression into full-blown AIDS and its reversal after treatment can be compared to thousands of similar cases throughout the developed world. But what makes Cameron's own situation incredible, even to himself, is that he lives in context where very few in his country can afford to pay the treatment costs and the government has not granted a licence for the treatments. However, despite his affluence, he is not afforded the comfortable distance from untreated people living with HIV/AIDS that is possible in Western Europe or North America. In South Africa the cheapest available triple-

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[27] Mann died in a Swissair plane crash shortly after the 1998 Geneva conference. His wife and many other AIDS researchers were also among the passengers who died in the crash which was returning from a smaller AIDS conference in New York (Schoofs 1998).

therapy drug costs R2000 per month. In a country where most employed people earn less than R1500 each month, and unemployment rates are higher than 20%, treatment pricing makes access impossible for most individuals (Achmat 2001a). It also makes it prohibitive for the state to provide; anti-retroviral therapy at current costs would amount to ten times the current total health budget of South Africa (TVE 2001)[28]. In order to rectify the inequities of the situation, Cameron's speech pointed to several solutions: a radical turnaround in the South African government's own approach to AIDS; the international vaccine initiative; and most centrally, affordable access to AIDS treatments through inexpensive generic production[29].

Cameron called for the audience to 'make the future different'. Thousands of people listening to him had participated in the rally and march for equitable drug access the previous day and his speech directed listeners to his own embodiment of those issues. Many Black South Africans who crowded toward the front of the massive hall during Cameron's speech were still wearing their HIV POSITIVE t-shirts from previous day's march. He was clearly touched by their heartfelt and warm outbursts of support as he spoke (Barr 2000); (Field notes 2000, Book 4: 3). His affluence was buying him time which was inaccessible to most of the people in front of him and it was his public expression of the distress and horror he feels as a result of this situation that made his speech evoke such a response. Fellow South Africans did not blame him for buying treatment; instead his speech strongly reinforced calls for action against governments and drug companies whose power over the potential outcomes of the epidemic made them immensely responsible for its effects, regardless of whether they chose to recognise that responsibility.

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[28] Schoofs, 2000, has written about the few African AIDS activists who have gained access to recycled drugs channelled through American charity programmes. He reports that the fact that they can survive while others die has often led to the issue of drugs inequality being one that brings about high levels of internalised guilt. Some treatments have been subsequently offered to South Africa at cost by their producers, yet the state would still not be able to afford them even if it agreed to licensing (Kraft 2002).

[29] Generic production of drugs refers to the manufacture, sale and distribution of pharmaceuticals by a non-patent holding company. If generics are disallowed by international law such as the World Trade Organisation's Treaty on Trade Related Aspects of Intellectual Property (TRIPs), the patent-holder can sustain a virtual monopoly over the product and can charge a price that they may argue will allow them to regain some of the capital that went into researching and developing the drug in the first place (Duckett 1999). As will be discussed in the subsequent chapter, however, TRIPs makes the provision that the rules which disallow the trade of generics are over-ridden in cases of national emergency.

The impact of Cameron's speech, the TAC march and the atmosphere they created at the Durban conference reached well beyond South African participants. 'Big time AIDS researchers [were] getting passionate and fired up and talking like an activist. You could see the fire in their eyes' (Barr 2000). This atmosphere had the effect of turning guilt into anger. Cameron's openness about his place in the unequal structure of drug access allowed the issue to then be turned back upon governments and drug companies. He was demanding that they rectify the situation which meant that he was allowed to live more healthily simply because he was a White, affluent South African. He was calling for direct action at all levels against the structures that allowed for a world where treatment was only available to the rich and a handful of lucky charity recipients.

Cameron attacked the ways in which corporations and governments had contributed to the vast spread of HIV/AIDS, but he did not think that these powerful organisations were wholly responsible. He made a very direct point about the ways in which 'we' (meaning all of humanity, including HIV/AIDS experts) have played a complicit role in supporting those institutional powers through our inaction. In the late 1980s when ACT UP founder Larry Kramer equated AIDS to the Holocaust (Kramer 1990) he was branded an alarmist. Yet by 2000, with the accumulation of 52 million cases of HIV/AIDS since the start of the pandemic (UNAIDS 2000), Cameron's comparison between the lack of serious action to stop AIDS and both Nazism and apartheid did not seem so outrageous (Cameron 2000).

Cameron's speech demarcated the moment in AIDS history when a notion of *intersubjective responsibility* that recognised the inequalities brought about by global capitalism became the key strategy in the fight against the epidemic. This new vision incorporated the responsibility of individuals benefiting from treatments in the developed world to point to global access needs, as well as the responsibility of the uninfected and those unaware of their status to ensure that the epidemic remains on the public agenda in all countries. It also addressed the responsibility of governments, multinational companies and international organisations to appropriately address the prevention, care and treatment needs of those most vulnerable to infection. It was a vision that accommodated no excuses for inaction at any of these levels because inaction had already lead to millions of deaths and

continues to grow exponentially. Cameron did not single-handedly design this position, but his speech can be seen as the moment when it was released most forcefully on a global audience.

In later reflections on the conference and his own role in it, Justice Cameron commented that the real success of the Durban conference was that it changed the direction of discourse about drug access (Mirken 2001a). He said that rhetoric had needed to shift before action could happen and he was happy to see direct action such as lowered drug prices and the international AIDS fund proposed by Kofi Annan beginning to happen. However, Cameron's speech and the conference as a whole went beyond just changing the rhetoric on affordable drug access. In order to shift this rhetoric, it was necessary to first make a change to traditional approaches to responsibility in relation to HIV/AIDS. While Cameron's speech was primarily about access to treatment for all, he also conveyed a much deeper message about the nature of responsibility – signalled through his allegorical references to Nazi Germany and apartheid in South Africa. There was a sense at Durban that the tame scientific agenda of the conference had been replaced by impassioned politics. Whatever the planned content of a presentation, the connections between human rights inequalities and vulnerability to HIV seemed to surface time and again. The overwhelming current of the conference became the notion that all individuals and institutions were intersubjectively responsible for actively ensuring that barriers to AIDS prevention, care and treatment would be removed. Cameron's speech and other events at Durban created an atmosphere charged with optimism about building the political will to change the course of the epidemic. Responsibility at all levels was on the public agenda.

8.5 THE 'DURBAN EFFECT'[30]

With reference to the local issues surrounding AIDS in South Africa, prominent speakers at Durban focussed on the responsibility of all participants to contribute to efforts to break through the silence and stigma that characterised the government's response (Karim 2000; Mandela N. 2000; Mandela W. 2000). However, the local situation actually served as a means to magnify the ongoing cause of transmission

globally. The challenge presented to participants was to find a way to articulate and activate the new model of responsibility that caused so much enthusiasm at Durban, in the practical activities in which we engage between conferences.

> By our mere presence here, we identify ourselves as the 11 000 best-resourced and most powerful people in the epidemic. By our action and resolutions and collective will, we can make the future different for many millions of people with AIDS and HIV for whom the present only offers illness and death. (Cameron 2000)

This call to arms, and the emotive response that met it, created an unprecedented conference atmosphere among diverse participants such as scientific delegates, governmental representatives, members of the press, and volunteers. Participation in the conference and its satellite events appeared to be a turning point for many ordinary South Africans who had never been involved in organised AIDS events at the international or even national level[31].

Volunteers had come from all over Africa to staff the event, as this was the only opportunity for many to have access to such an event. I witnessed and participated in involved discussions between volunteers and delegates on treatment, care and prevention issues. In some cases, these volunteers were local organisers and community AIDS educators who Africa to staff the event as stewards, as this was the only opportunity for many to have access to such an event. I witnessed and participated in involved discussions between volunteers and delegates on treatment, care and prevention issues. In some cases, these volunteers were local organisers and community AIDS educators who took full advantage of their access to international experts in order to both gain information as well as impart their own experience (Field notes 2000; Book 4: 10). The absorbed atmosphere of discussion between South African community members and international conference attendees was a

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[30] This phrase was coined in a BTS communication (May 21, 2001) by Lars Kallings, Secretary-General of the International AIDS Society, leading sponsor of the International AIDS conferences.
[31] In his report on the conference, Mark Schoofs of New York's *Village Voice* ends with the story of Sabina Khoza:

> Her son's infection meant she also had the virus, but 'I didn't tell anyone about the disease, not even my boyfriend,' she says. When she finally told her mother, word spread and her brothers kicked her out. 'They said I must take my clothes and go, because I might infect them,' she recalls. That was five years ago. Last week, Khoza was not only at the conference, she marched in the demonstration for drug access, wearing one of the T-shirts emblazoned with the block letters 'HIV-POSITIVE'. (Schoofs 2000)

sign that the social taboos concerning discussion about HIV in South Africa were beginning to weaken (Mirken 2001a).

There was a strong sense within the vast presentation halls, the tightly packed corridors and the community events of a 'collective effervescence' (Durkheim 1971). According to Durkheim, in this state a person feels transformed, and consequently begins to transform the surrounding environment (Durkheim 1971: 422). Collective effervescence is central to the effectiveness of any conference. It is commonly understood that the value of such events lies in the ability to meet with others and share ideas in a way that simply does not happen in the depersonalised realms of academic or scientific research, email communication or even local community organising. Conferences are largely about 'networking', and the International AIDS Conferences of the past all contained an aspect of 'collective effervescence' about them. But in the case of the Durban meeting, this intangible energy sparked off an unprecedented level of common feeling among participants.

Durban delegates witnessed and participated in the creation of a changed relationship to the AIDS epidemic, and a changed meaning of responsibility within that relationship. This change was ignited by events preceding the conference, and was fanned by the effects of the mass march at the opening; the disappointments of Mbeki's speech and by Cameron's speech the following day. Having Nelson Mandela round off the conference by giving the closing plenary consolidated the sense of historical significance that had developed throughout the week of the conference. Central to this significance was the way in which it released a vision of intersubjective responsibility into the public realm. It was a vision calling for provision of the conditions which would enable economic, social and political equality, which would then allow for equal access to HIV/AIDS prevention, care and treatment. It was a significant conference because it represented a serious and very public challenge to the dominant view that responsibility in relation to HIV was predominantly an individual concern.

As different events unfolded at the conference, it was increasingly evident that key players in the AIDS world were ready to make new commitments to the epidemic. For example, Boehringer Ingelheim International (BII), the makers of the anti-

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retroviral Nevirapene, came to the Durban conference prepared to announce that they were going to make their drug freely available to South Africa for the next five years. Even on its own, access to this drug is crucial in the developing world, because a single dose given to mother and child at the point of delivery demonstrated a substantial reduction in the chance that that child would become HIV positive (Guay et.al. 1999). This announcement had the effect of electrifying the conference delegates as well as the world beyond. This was the first indication that a drug company would weaken its stance on patent protection. The feeling was that the rest would have to follow. This sense of momentum was followed up by calls from the director of UNAIDS for annual international spending on HIV/AIDS in excess of $10 billion (Piot 2000).

These events described here, however, do not mark the solution to the AIDS epidemic, nor even of the triumph of *intersubjective responsibility* over traditional understandings. Developments that followed the conference, outlined in the next chapter, make that clear. It did, however, in my mind, and in the minds of many others touched by Durban, mark a dramatic blossoming of *intersubjective responsibility* whereas before the glimpses of it had been fragmented and half formed. The challenge for the delegates was to continue to spread the idea of *intersubjective responsibility*, to pressure those not yet convinced by such a notion, in order to continue the advances made at Durban.

CHAPTER NINE: CONCLUSION

9.0 INTRODUCTION

The 13th International AIDS conference at Durban developed a sense of *intersubjective responsibility* among those within the AIDS world and those outside of it to a degree that was unprecedented. In the immediate aftermath of the conference, the momentum it had created was carried along by three significant developments: court victories concerning treatment access; the announcement of a UN special session on HIV/AIDS; and the creation of a Global Health Fund that would treat AIDS as one of its primary concerns. Upon first glance, these events made it appear that the mobilisation catalysed at Durban might be sustainable. However, it would turn out to be unrealistic to expect that the conference would signal a complete and immediate change to the way that responsibility would be interpreted in relation to the epidemic. *Intersubjective responsibility* had emerged, but it had by no means been triumphant, as evidenced by the disappointments embedded in the events to follow. Such potential for setbacks, combined with the need for continued development of this ethic was recognised at the time by some of the participants at Durban. In her summation of the conference, a plenary speaker said:

> We must not bask too long in our sense of self-satisfaction and now our challenge is to take forward this renewed and enhanced sense of purpose, energy and meaningfulness we have felt over the last week and translate it into sustained action. Also amongst our challenges is to break the silence to which we fall prey between these international conferences. (Dhaliwal 2000)

A press report immediately following the conference also wondered if the events at Durban could be extended, or if it had all simply been a 'one-off':

> But who will remember Africa when the world meets again to discuss HIV/AIDS in 2002 in Barcelona, or in 2004 in Toronto?[1] (Horton 2000)

Such notes of caution were to prove prophetic during the months that were to follow the Durban conference, when the momentum that had been gained suffered a series of setbacks. Before discussing how these events impact upon a notion of *intersubjective responsibility*, I will offer a brief outline of them.

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[1] The International AIDS Society announced in July 2001 that it had changed the location of the 2004 conference from Toronto to Bangkok for precisely this reason (see http://www.ias.se).

9.1 INTERNATIONAL DEVELOPMENTS FOLLOWING DURBAN

The first of the three key events that took place involved significant changes to the legislative framework which governed the sale and production of affordable treatments. Secondly, in June 2001 the United Nations convened a Special Session of the General Assembly on HIV/AIDS (UNGASS) which was the first such special session to ever take place on a public health issue. Finally, in the build up to the June UNGASS session, UN Secretary General Kofi Annan announced that he had made HIV/AIDS his personal priority, launching the development of the Global Health Fund. Its aim was to collect $10 billion a year from governments, organisations and individuals to provide for prevention, treatment and infrastructure needs in order to combat HIV/AIDS and associated diseases such as tuberculosis and malaria (Curtis 2001) [2]. This section will review each of these developments in turn (although they overlap chronologically and substantively), although it will emphasise the events and outcomes at UNGASS because of the direct contrast they provide to the earlier conference at Durban.

The most symbolically significant and well-known legal cases regarding treatment access have occurred in South Africa, where the Treatment Action Campaign (TAC) won a succession of court battles which each take that country one step closer to the provision of affordable anti-retrovirals. In April 2001, TAC effectively 'won' its fight to permit the import of generic HIV anti-retroviral drugs when the largest pharmaceutical firms in the world withdrew from their legal claim against the South African government over legislation allowing the importation of generic treatment drugs (Sidley 2001a)[3]. Subsequently, on December 14, 2001 the Pretoria High Court ruled that the South African government's refusal to allow HIV positive pregnant women access to anti-retroviral treatments in order to prevent transmission to their children 'is an unjustifiable barrier to the progressive realisation of the right to health care'. The court found that the government had violated the sections of the South African Constitution guaranteeing access to health care services including the right to reproductive health care. The

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[2] This was precisely the type of scaled-up financial response that Peter Piot of UNAIDS and Jeffrey Sachs, WHO's top health economist, had called for at Durban.

[3] The government had been taken to court by the five leading pharmaceutical multinationals claiming that its pursuit of generic versions of a broad range of pharmaceuticals was illegal. Neither the government nor the companies could anticipate that TAC would seize the opportunity to demonstrate how vital generic access to HIV/AIDS anti-retrovirals would be for the country. TAC submitted its evidence on the issue as 'a friend of the court', resulting in the multinationals withdrawing the case. See http://www.tac.org.za.

government was ordered to have appropriate treatment distribution in place by March 2002 (Achmat 2001a). Citing concerns that the drugs' toxicity had still not been disproved, the government only licensed eighteen clinics to pilot administration. Then in a further court victory, hundreds of state-employed doctors and nurses together with TAC successfully challenged the government in the Constitutional Court and, as of July 2002, all hospitals have been ordered to supply the preventive treatment to any woman who wants it (Sidley 2002). All of these cases have amounted to an extraordinarily speedy erosion of the two key barriers that had prevented the majority of diagnosed HIV positive people in South Africa from accessing life-saving treatment; multinational patent protection and governmental ambivalence. TAC's strategic approach is based on their belief that once treatment is freely provided to pregnant South African women under the auspices of the law then it will be difficult to justify withholding it from the rest of the population in need. However, the legal victories have not resulted in governmental compliance with the judgements, and the TAC continually organises public demonstrations that aim to induce shame within a government that resists its own judicial orders.

From the point of view of other low-income countries facing similar HIV/AIDS crises, the events in South Africa have taken on critical importance. For example, there is little doubt that the first TAC High Court victory contributed to the declaration on affordable treatment access made in November 2001 at the World Trade Organisation meeting in Doha, Qatar. It stated that the Treaty on Trade Related Aspects of Intellectual Property (TRIPs): 'does not and should not prevent Members from taking measures to protect public health' thus affirming the 'right to protect public health and, in particular, to promote access to medicines for all' (World Trade Organisation 2001: 1).

Within the same time period, it was announced by UN General Secretary Kofi Annan that the United Nations General Assembly would hold a Special Session on HIV/AIDS in June 2001. There was a tremendous amount of expectation that UNGASS would help to carry forward the demands for treatment access and for unprecedented governmental commitment to slowing the epidemic that had characterised the Durban conference.

However, the results of the latter conference did not meet these expectations[4]. The key reason for the starkly different outcomes of these two conferences resided in the fact that UNGASS would be strictly mandated to follow the procedural and politically diplomatic structures which govern all events hosted by the United Nations. A key outcome of this highly formulaic procedure is the production of a single document positioning the international community's response to the issue at hand. Fomerand emphasises the central role of such documents in the fabric of the United Nations conference and the frustrations which inevitably result from this structure: 'the primacy of politics pervading UN conferences eventually leads to debates driven less by the need to make substantive progress than to reach agreements on ambiguous texts lending themselves to conflicting interpretations' (Fomerand 1996: 36). Thus the text of the document becomes the dominant focus of UN Special Sessions at the expense of other aims (Clark, Friedman and Hochstetler 1999). NGOs have become increasingly skilled at applying direct pressure to national delegates at UN conferences which has generally had a positive effect on the documents because NGOs are able to express grassroots opinion and have a wider understanding of the issue than government representatives. However, to prevent this unwelcome influence, at a number of UN conferences governments have only allowed NGOs access to several levels of preparatory discussions leading up to the conferences while at the final stage of preparatory meetings (when the text of the draft document is agreed), NGOs were excluded. This meant that governments themselves took control of the final wording of document texts[5] (Clark, Friedman and Hochstetler 1999).

It should therefore have come as no surprise when exactly the same thing happened at the UNGASS on HIV/AIDS in June 2001. Reports began to filter onto the BTS email network in early June that civil society and NGO participants could not gain access to the final preparatory meeting because of delays in the issuing of security passes and confusion about meeting times (Patterson 2001). During the conference itself, the United States

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[4] In addition to the substantive difficulties at UNGASS to be discussed below, the organisation of the conference was strongly condemned before it began. Because it was held in the United States, travel restrictions would make it difficult for people who were diagnosed with HIV to attend. It was the same issue that had arisen in preparation for the San Francisco AIDS conference, and which had the result that no future international AIDS conferences would be held in the U.S. Thus, holding this UNGASS in New York was highly controversial, and in the end, the American government instituted a special visa for HIV+ attendees to enter the country only for the purposes of the conference.
[5] This occurred during previous UN conferences including the Fourth World Conference on Women, 1995 in Beijing; the UN Conference on Environment and Development 1992, in Rio; and the United Nations World Conference on Human Rights 1993 in Vienna (Clark, Friedman and Hochstetler 1999).

insisted that all NGO and civil society members (even those with full accreditation) leave the proceedings when the draft document was being finalised (Global Treatment Access Campaign 2001). Non-governmental participants were outraged at this act of direct exclusion[6].

A handful of media reports on the disharmony at UNGASS began to make the reasons for such exclusions quite clear. The Vatican had joined conservative Muslim countries in successful efforts to block any explicit reference to 'men who have sex with men' or 'sex workers and their clients' (Bone 2001). The final text only made reference to 'those in vulnerable groups' – refusing to define who they may be (United Nations 2001)[7]. In addition, the Declaration did not take a clear position on global access to medicines, stating that 'there is a need to reduce the cost of these drugs and technologies in close collaboration with the private sector and pharmaceutical companies' (United Nations 2001: Section 24). It went on to say that 'the impact of international trade agreements on access to or local manufacturing of, essential drugs and on the development of new drugs needs to be further evaluated' (United Nations 2001: Section 26).

Neither of these statements on affordable treatment carried with them the full weight of demands being made by the NGOs. Their united public position since Durban had been to demand the implementation of clause 30 in the TRIPs international treaty that allowed patent rights to be overridden in cases where HIV/AIDS was creating a state of national emergency (Pappas 2000)[8]. The final draft of the Declaration led many civil society participants to feel that their contributions to the process had been useless[9]. On the BTS email forum, an HIV positive participant reflected: 'I would say that we got the privilege of using UN Facilities to talk to ourselves' (Vazques 2001)[10].

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[6] Yet following Clark's (1999) research it might have been possible to predict, as similar exclusions had taken place at most recent UN conferences.

[7] See (International Council of AIDS Service Organisations 2001) for a report on the harmful effects of such exclusion; as well as a call to all AIDS organisations to name these vulnerable groups as often as possible in all printed materials.

[8] UNGASS took place some months before the World Trade Organisation backed down on the issue of generic drug manufacturing for the sake of public health at Doha.

[9] The term 'civil society' was used by the UNGASS organisers to refer to participants (largely from NGOs and affected communities) who were not national representatives.

[10] Patterson (2001) explains that NGO representatives were transferred to the UNICEF Hall, which is across the road from the General Assembly. At this alternative and unexpected assembly, the NGOs drafted 'A Civil Society Perspective on the UNGASS Declaration of Commitment', including the naming of the most vulnerable groups who were simultaneously being taken out of the document across the road.

In direct contrast to the experience at Durban, most media coverage of UNGASS was confined to the opening day. The drama of Kofi Annan's sound-bite: 'The world has awoken to the scourge of AIDS' and the image of the United Nations building in New York lit up with a red ribbon made for positive news coverage (Boseley 2001). Yet as the week progressed, there were few significant articles on the conflict and controversy over the text of the declaration in the mainstream press[11]. One exception to this was a review of the conference in London's *The Times* that pointed to the challenge facing many countries to be open about topics such as sexuality, let alone the financial implications of properly funded prevention and treatment. 'The UN Special Session', it stated '...will go down in history as a symbol of the world's delay in facing up to the epidemic' (Bone 2001).

The contrasting outcomes of these two international AIDS conferences that took place within a year give us some cause for reflection. Durban seemed to turn everyone it touched into an advocate for immediate and multi-level change because of a recognition of profound intersubjectivity. For a time it even felt as though the rest of the world was not only interested in stories about HIV/AIDS but would be ready to take up a share of responsibility for prevention, treatment and care. Those in the field felt a surge of collective will to move beyond AIDS research and become the social actors who would alter the social and economic conditions of the epidemic's continued spread. This new sense of responsibility was shared among individuals, but it was also reflected in symbolic actions at the institutional level, such as the German manufacturer's offer of free Neviropene to pregnant women in South Africa. This had a profound effect on Durban participants and became the first meaningful sign that change was on the way in terms of how large institutions could demonstrate responsibility for changing the path of the epidemic. In addition to this, Brazil was hailed at the conference as a model country which had marshalled its resources to reverse a burgeoning national epidemic and provide cheap treatment for all people living with HIV/AIDS through its universal health system

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[11] Most of the real frustration of NGO participants leading up to and during the conference was vented within more specialist realms, such as the Break the Silence email forum originally set up before Durban, and resurrected in the build up to UNGASS. The BTS forum provided an invaluable reporting service and debating floor for those who were not in a position to attend in New York.

(UNAIDS 2000: 101) [12]. The announcement of free Neviropene for South Africa from the manufacturer and the provision of 'generics' funded by the government of Brazil demonstrated that there existed the potential for new forms of responsibility within the hierarchies of power. At Durban the connection had been made in people's minds that direct agitation and logical arguments about interdependence could bring about significant social change at the highest levels. It was this type of multi-layered responsibility – among individuals, organisations and within the international system - that Justice Cameron had addressed so strongly in his speech.

Yet the UN special session on HIV/AIDS provided a stark contrast to the optimism and energy of Durban. At this New York meeting, the burden of political and financial interests seemed to call a halt to the momentum sparked off a year earlier in South Africa. The political will and economic resources that appeared to be rallying in Durban were interrupted in New York because of haggling over language (direct references to homosexuality and sex work) that many in the AIDS world thought was no longer controversial. It was also clear that the United Nations was not going to be willing to confront the patent issue head-on, choosing instead to negotiate with pharmaceutical firms, thus ensuring the companies' continuing control.

In addition to the disappointment of UNGASS itself was the simultaneous realisation that the Global Health Fund was never going to attain its original financial target of $10 billion per year as originally proposed by Jeffrey Sachs of the Harvard AIDS Institute and reinforced by Peter Piot and Kofi Annan. Estimates made within that first year predicted that the fund *might* raise $1 billion a year instead, with the US initially pledging only $200 million and Britain offering $200 million over five years (Bone 2001) [13]. By the end of UNGASS – a few short months after the initiation of the fund – Annan said that the existence of the fund was more important than concerns over the precise levels of contribution (Bone 2001). Following his own tireless efforts to secure adequate funding, this resigned sentiment from the General Secretary signalled the restriction of a grand vision of global responsibility which had been building since Durban (Donnelly 2001;

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[12] As it is not a signatory to TRIPS, Brazil's national government took the opportunity to manufacture its own generic anti-retroviral medications. The free provision of treatment has played a key role in Brazil's successful turnaround in its epidemic.
[13] It was suggested that the US should pledge 25% of the total fund, reflecting the US share of global GDP. (Yale AIDS Network 2001).

Krikorian 2001). Following its first year of operation, the organisation has now distributed its first round of international funding, and the United States has promised $500 million over the next two years. In total, the pledges over the first three years of the fund only come to $2.1 billion, amounting to only 7% of what was calculated to be necessary for the reversal of the epidemic. According to Stephen Lewis, UN special envoy for HIV/AIDS in Africa: 'It's a shocking piece of international financial delinquency, and it's a shocking rejection of Africa. It's so deeply disappointing that words are hard to find' (Lewis 2002).

9.2 THE IMPACT OF THESE EVENTS FOR A THEORY OF INTERSUBJECTIVE RESPONSIBILITY

In spite of the successes in the effort to legislate for affordable treatments, the combined impact of the disappointing results of the UNGASS declaration and the inability of the Global Health Fund to meet even a fraction of its original targets have resulted in a sense that the feeling of progress following Durban had been illusory. Those following the events expressed concern that they were back at square one because the political and economic will that was necessary to effect the vision created at Durban had evaporated once the decisions were placed in the hands of the powerful.

> I don't know how to make sense of it. Is the behaviour of the western world just appalling insensitivity, is it unacknowledged racism, is it sheer unbridled indifference, is it the comfortable assumption of hopelessness in order to avoid contributing money?...I feel so angry and so impotent simultaneously. (Lewis 2002)

The events after Durban and feelings of disillusionment they have engendered could be used to cast doubt on the notion of *intersubjective responsibility* that I have outlined in this thesis. One might argue that it is a flawed model that contributes to the creation of utopian visions which fail to materialise in the face of counter-active economic and political pressures. Such criticisms would be wrong and be based on an understanding of *intersubjective responsibility* that is undifferentiated from communitarianism. Instead, it is important to acknowledge that change will not occur simply because it is 'the right thing to do' because conflicting interests must be taken into account. This highlights the importance of Weber's politically pragmatic framework as introduced in Chapter Two. As he outlined, successful political change unites passion and pragmatism in that it relies on the responsibility of those advocating change to recognise that they are operating in a social context in which a) not everyone is necessarily 'good' and b) people and

institutions have a variety of interests and expectations that may not coincide with the 'right thing to do'. Durban contributed to the development of the type of passion spoken about by Weber, but he made it very clear that an ethic premised solely on vision would not be able to make very much progress on its own. Change of the scope required by the vision developed at Durban does not simply happen, no matter how much we are touched by the lofty idea that 'our common humanity' demands it (Clinton, Pelosi and Frist 2002). A notion of common humanity does not provide the predominant force that drives the most powerful political and economic engines of the globalised world in the twenty-first century. With this in mind, I would like to take a moment to discuss how such engines contributed to the specific failings of the post-Durban momentum.

In terms of the Global Health Fund, its failure to generate more than $1 billion in its first year became clear very soon after its inception, as it was immediately apparent that the United States was not going to provide the example upon which the success of the fund had clearly relied. This is not because the United States could not afford its $2 billion dollar share; it clearly could, as the cost of the 'war on terror' has shown[14]. Rather, it is that under the leadership of George Bush, an extraordinary shift toward a focus on individual responsibility relating to HIV/AIDS took place almost as soon as he took office. This sea-change seriously impacted upon the tone of HIV prevention within America as federal funding for all sex education and AIDS service organisations was now attached with the proviso that 50% of the funds had to be directed toward the advocacy of sexual abstinence as the primary means of HIV prevention. The impact of this new Republican approach to HIV/AIDS did not stop with domestic policy, as it included the withdrawal of American funding from all international programmes that operated in family planning settings offering access to abortion services. The new political administration in America made it clear that it was not going to freely distribute any funds without also being able to exercise control over the sexual (im)morality that funded programmes promoted[15]. From the start it was acknowledged that America would be the most important contributor to the Global Health Fund, partly because it has the largest national GNP but also because it holds so much international symbolic and diplomatic

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[14] $1.5 billion alone was spent by the US in order to create a domestic stockpile drugs and vaccines in case of biological attack (Gilden 2001).
[15] The advocacy of sexual abstinence is the exemplar of the *responsibility as freedom* paradigm, in that it directs the burden of responsibility toward the individual while simultaneously diverting all attention away from structural factors.

influence. What is important for America becomes important for most of its friends. Thus, when the new administration made it clear that they were not persuaded of the need to commit a significant amount to fighting the epidemic, it was highly unlikely that the Global Health Fund would achieve its target.

The two biggest failings of the UNGASS declaration were its ambivalent position on pharmaceutical industry patenting and pricing policy, and the absence of direct language which identifies men who have sex with men and sex workers as being among the groups most heavily affected by the virus in various social contexts. Although there has been movement on the patent issue as signalled by the Doha declaration and the TAC court victories, we should recognise that provision of treatment on the ground remains a problematic issue not only for the pharmaceutical companies aiming to protect the profits gained from their ownership of patents, but also for the countries most affected by HIV. The provision of treatment would require a mammoth investment in healthcare systems that will be instantly required to cope with the diagnosis and treatment of thousands and millions of citizens. Many countries have desperately tried to downplay their HIV/AIDS epidemics because of their fears about both the political and economic repercussions of honest admission[16]. Not only do admissions about exponential rates of transmission cause political administrations concern about attendant health costs, they will also have concerns about declining foreign investment and trade when it becomes known that a significant proportion of the workforce is infected with HIV. These are not the economic and political conditions that enable honest and frank confrontation with the realities of the epidemic. The alternative option, taken by many religiously conservative countries for example, is to adopt a moral standpoint regarding sexuality and drug use. As long as they continue to project sex work, sex between men and drug injecting as immoral practices that are solely the abhorrent choice of the individual – a familiar application of the *responsibility as freedom* approach – there is no need for the more difficult project of developing a model of *intersubjective responsibility* which would aim to address the social relations that drive the epidemic. However, this thesis has demonstrated that this individualised approach toward HIV/AIDS does not only govern Catholic or Muslim societies, it is inscribed into the practices used in the health promotion materials, testing

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[16] To the dismay of international human rights groups, Wan Yanhai, a leading Chinese AIDS activist was detained and later charged with illegally leaking state secrets because of his attempts to bring international attention to the heavily underreported epidemic in China (Associated Press 2002).

policy and criminalisation of HIV transmission that take place in countries such as Britain, America, Canada and Australia. All of these practices continue in the absence of a strong model of *intersubjective responsibility*.

9.3 FREEDOM, CONTROL AND INTERSUBJECTIVITY: RESPONSIBILITY AT THE CENTRE OF THE EPIDEMIC

Through the analysis presented in this thesis, I have sought to explicate the means through which various approaches toward responsibility are reproduced within responses to the HIV/AIDS epidemic, and in turn how these approaches impact upon issues of prevention, treatment and care. Thus an initial aim of this work was to establish a theoretical framework that would allow for a distillation of key aspects of these different understandings of responsibility. In Chapter Two I presented a typology of responsibility made up of three contrasting approaches: *responsibility as freedom*, *responsibility as control* and *intersubjective responsibility*. The *responsibility as freedom* approach regards responsibility as an incorporation of public duties that the individual must necessarily carry out in exchange for an ordered and strengthened community. In return, the individual expects that community to provide the protection necessary for the flourishing of his own freedom. An alternative to this account is given by those who present responsibility as a means of *control*, claiming that responsibility can only be understood as a means through which the powerful assert behaviour regulation over the masses. They argue that social structures dictate responsibility as a means of defining boundaries between citizen and deviant. This process maintains social hierarchy by rendering liminal groups to the periphery. While all of these are valid and important critiques of the prior approach, I have argued that the resulting dichotomy disallows us from reflecting on the inherently relational aspects of a type of responsibility that can contribute to social cohesion and a more successful response to HIV/AIDS through political motivation.

The final account in this typology which incorporates the relational and political aspects of responsibility is what I have entitled *intersubjective responsibility*. Rather than getting caught in the over-simplified arguments between the effects of agency and structure over the individual, as the two earlier typologies do, this model focuses on the complex interrelationships between individuals, organisations and states. I have argued that the application of *intersubective responsibility* in responses to HIV/AIDS has meant that issues of power and equality are directly addressed rather than assumed to be either non-

existent (*responsibility as freedom*) or too overwhelming to allow for the possibility of change (*responsibility as control*). Incorporating a notion of *intersubjective responsibility* allows for meaningful reflections upon the ways in which people and structures function together in ways that balance and influence one another, and it is this approach which has been demonstrated to achieve success in addressing the HIV/AIDS epidemic (Piot 2000; Sachs 2001; UNAIDS 2002; United Nations 2001).

The case study chapters which make up the body of this thesis have illuminated the means through which responsibility has functioned within various responses to the epidemic. Rather than choosing a singular disciplinary focus, I presented the divergent themes of health promotion, testing policy, criminal law and the impact of the international AIDS conferences with particular reference to Durban, in order to examine the similarities and differences between understandings of responsibility in these varied arenas. Within the first three of these case studies, particular attention was drawn to the means through which individual (ir)responsibility has been constructed as the dominant focus of HIV prevention, policy and law.

Chapter Five examined the ways in which printed HIV prevention materials in England have continually reinforced the message that individual behaviour change is the singular means through which the epidemic can be addressed. Examples demonstrated the ever changing tenor and approach of HIV health promotion which in some instances has meant that it can be more inclusive and less directive. However, throughout the sample which spans two decades, it was also evident that the focus of responsibility in these materials was most often presented in terms of an individual's responsibility for the self and also for one's partner. Analysis of the sample revealed that the materials produced by the two largest organisations in both the 1980s and 1990s demonstrated an increase in the latter decade in messages of individual responsibility. The results of this quantitative analysis were presented alongside a range of representative examples which demonstrated the ways in which the vast majority of health promotion materials actively utilise the *responsibility as freedom* approach. Within this paradigm, individual behaviour change that reduces HIV transmission risk is presented as the primary social duty which will be rewarded not only with individual health but communal order, protection and flourishing. Structures which impact on the individual are largely disregarded in these representations, as is the stigmatised social context within which HIV continues to be transmitted. Yet to

attack all HIV-related health promotion from the *responsibility as control* position would be to argue that the individual has absolutely no part to play in transmission, and that all attempts to change behaviour should be disregarded because they reinforce boundary maintenance between empowered and disempowered social groups. This is not a position that I adopt in this thesis, because while I consider that the *responsibility as control* approach highlights important critiques on these issues, it disallows a conceptualisation of responsibility that has the capacity to extend beyond this debate. The challenge, therefore, is to address the individualised focus which pervades the culture of health promotion. As a first step in this process, it might be necessary to move the centre of health promoters' attention away from print and poster campaigns, and toward increased policy and social advocacy that aims to reduce barriers to preventive and health-seeking behaviours.

Chapters Three and Five outlined the way in which the *responsibility as freedom* perspective resides at the base of the majority of visible health promotion interventions. As a project, modern health promotion focuses in upon the requirement for individuals to recognise their health needs and to act on them, often with little regard for important contextual features which place that individual in a particular social, economic, and political environment. The follies of this perspective are evidenced through the outcome of HIV testing policy and response across a range of developed countries. In Chapter Six I reviewed the ways in which assumptions that accompany HIV testing policy and different responses to testing demonstrate contrasting understandings of responsibility. Those who are at highest risk of transmission are in many instances less likely to test – not always because they fail to recognise their own risk, but precisely because they have the most to lose from the very real possibility of a positive diagnosis. On the other hand, the group of people who are most likely to demonstrate an affinity with the *responsibility as freedom* perspective with its focus on liberal norm-adherence, are those who are least likely to have been with partners or to have engaged in behaviours that carry a high risk of HIV transmission. Yet it is this latter group who are increasingly likely to request an HIV test voluntarily. Thus the promotion of self-monitoring and regulation within the medical context proves itself to be most effective among those who are in the least amount of need. In this chapter I also questioned ongoing assumptions that knowing one's own HIV status (whether positive or negative) would be likely to have an influence on future risk behaviour when the majority of research on this issue has proven to be inconclusive.

Again, this demonstrates the forcefulness with which the *responsibility as freedom* approach is embedded in both popular and medicalised perceptions of HIV transmission, with little or no evidence of its efficacy. Toward the end of the chapter I raised the particular example of conflicting understandings of responsibility with consideration of the way in which HIV testing in the UK has been utilised by insurance companies as a marker of risk. In this instance, we find that engaging in HIV testing has been presented by health promotion policy as a social benefit, while at the same time it has been received by insurers as an indication that an individual has behaved irresponsibly. Research has demonstrated that potentially high-risk testers in the UK have avoided testing because of the negative social and emotional impact a positive result would engender. The continued situation has mythologised lack of patient confidentiality, despite changes in insurance policy – and in staying away from testing under these conditions, such individuals demonstrate a resistance to responsibility that presents itself to them as a means of *control*. Thus when we analyse the conflicting issues that are brought about by consideration of HIV testing, we are able to see the ways in which the two dominant approaches to responsibility are inscribed in HIV testing promotion, practice, and response.

The third case study, presented in Chapter Seven, explored a topic outside of the health field and shifted analytical focus onto the uses of the criminal law in relation to HIV transmission. Here again, there was clear evidence of the *responsibility as freedom* perspective taking dominance. Proponents of criminalisation have argued that such laws deters those who are HIV positive from engaging in risky behaviour, and that their implementation will contribute to the public health aims of reducing rates of transmission. In this way, the law is used to enforce the notion that the entire burden of responsibility for transmission transpires at the individual level, and if diagnosed positive individuals are not willing to comply, they will be punished for the good of the social order. Yet again this reasoning has been proven to have serious flaws because it fails to take into account responses that will regard such use of the law as an unwanted exertion of *social control*. Acting on this interpretation, many will avoid being tested so that they cannot be prosecuted on the grounds of acting inappropriately with a known HIV diagnosis. Contrary to the original justification for criminalisation, this situation will result in an increased public health problem, as greater numbers of people will have undiagnosed HIV infection amid a resurgence in stigma associated with HIV testing. Within this context,

those who are diagnosed positive will be less inclined to be open about their status, and the advances that had been gained toward meaningful social inclusion of HIV positive people will be lost. In short, the implementation of legislation that makes increased HIV stigma highly likely is directly contrary to globally established evidence about the most effective means to prevent HIV transmission. The attempt to control HIV with the criminal law in this way demonstrates a profound lack of understanding about the broader repercussions of the *responsibility as freedom* paradigm and the way that it isolates responsibility with the stigmatised individual, drives the epidemic further underground and exacerbates the already attendant problems of prevention. It is also one instance where application of the *responsibility as control* critique fits well with an intersubjective approach to demonstrate the weaknesses of the approach which regards *responsibility as freedom*.

The final case study, presented in Chapter Eight, was probably the most unusual in the thesis, as it turned to the role of the international AIDS conferences with a particular focus on the events at Durban in 2000. This review allowed for an analysis of the ways in which responsibility for HIV has been represented in the public sphere through the responses of civil society actors from states and multinational pharmaceutical companies to grass-roots activist groups who come together for a week every other year to thrash out their broadly divergent approaches to responsibility in the face of the ongoing epidemic. Although the conferences are most frequently discussed in relation to the role that they play in the dissemination of scientific results as they relate to treatment and prevention of HIV, I argued that their symbolic role in relation to responsibility is also of tremendous importance. Through a review of the debates and organisational changes that have taken place since the first conference was held in 1985, I demonstrated the ways in which a subtle and persistent transformation of these events has gradually meant that those engaged in the bureaucratic and scientific aspects of the field have been denied the option of immersion in the *responsibility as freedom* approach. Over the year, growing numbers of participants have been bombarded with the alternative view that HIV is a political, social and essentially an *intersubjective* global issue that is as much about the power of trans-national capital; forced migration and human rights as it is about the exchange of bodily fluids that happens when two people have sex without a condom; share needles in order to inject drugs; or when a mother gives birth and later breastfeeds her child. This transformation in the symbolic role of the international conferences was strikingly evident

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in the press coverage and the events at Durban in 2000. It was because of the coverage of that conference that the global press was deluged with articles about the social, political and economic reasons for the increasing spread of HIV, and the inaccessibility of treatment for 95% of those who are diagnosed positive. This represented a dramatic change in the way that the conferences were presented to the world, and the way that the responsibility as it related to the epidemic was examined. The Treatment Action Campaign's march for drugs access, the strong involvement by local South Africans heavily affected by HIV, and the reverberations of key speeches made by Thabo Mbeki, Edwin Cameron and Nelson Mandela combined to make the experience at the Durban conference a catalyst for broad exposure and development of new support for an *intersubjective* model of responsibility in response to the epidemic. However, as related in the opening sections of the current chapter, events after Durban have demonstrated that even with this surge toward an *intersubjective* stance that advancement is never guaranteed to be direct or immediate. Delay, retrenchment, reversal and diplomatic. struggles have characterised many aspects of international response since 2000, however, as argued above, these conflicts should not only be anticipated, but are an essential aspect of the diverse priorities and power struggles that ground *intersubjective responsibility* in a political landscape.

9.4 THE CURRENT STATE OF PLAY: HIV/AIDS AND INTERSUBJECTIVE RESPONSIBILITY ON THE GLOBAL STAGE

In this section I will focus on two interrelated aspects of the current conflicts that prevent significant advances in effective response to the epidemic, and both will be considered within the framework of *intersubjective responsibility*. The first of these is the fact that 'the right thing to do' often gets overtaken by other economic and political concerns. As discussed above (section 9.2), this is the case both with rich countries – where constituents demand funding for domestic issues rather than for an illness in another continent – and for poor ones – where admission of the scale of infection promotes fears of bankruptcy. Corporations, often with a legal requirement to act in the best interests of their shareholders, view this responsibility as more important than grand visions of saving humanity. In all these instances, claims for *intersubjective responsibility* are rejected in favour of 'economic reality'.

The second trend, fundamentally related to the first, is the emphasis upon individual responsibility as the key to preventing HIV/AIDS. Rather than viewing us all as jointly responsible for the epidemic, it is left to those with the disease to solve their problems while ensuring that they don't transmit it to others, and for those without the disease to make sure they do not catch it. Some such responses, such as the refusal to discuss homosexuality, or the Bush administration's moves to promote abstinence as a primary means of prevention, are simple products of normative morality. Others, such as the Chinese government's refusal to acknowledge the scale of the epidemic because of economic and political fears, are more functional, even if they are misguided. But both are examples of how governments refuse to admit their active role in the worsening of the epidemic and place the burden of responsibility at the feet of the individual. For these reasons, it would be unrealistic to expect an idea of *intersubjective responsibility* to overtake the world overnight. Indeed, without a radical reorganisation of the current global system of global capitalism, it is likely that *intersubjective responsibility* will never attain the hegemonic status currently maintained by notions of individual responsibility. Left with this situation, the tendencies toward individual responsibility in the fields of promotion, testing and criminalisation that I have outlined in this thesis will not only continue but will intensify.

Given this state of affairs, it may seem that the model of *intersubjective subjectivity* that I have outlined here – and that has begun to emerge in global AIDS activism – is a naïve model that expects things to happen because they are the right thing to do. Such a response would be endorsed by those from within the *responsibility as control* position. From this perspective, responsibility is an inherently limiting means of existence because it is solely a technique of individual surveillance that constrains individuals and maintains unequal power relations. From this perspective, any attempt to outline an *intersubjective* theory of responsibility will only meet with failure because all responsibility inevitably rebounds onto the individual. Such a position paralyses agency and disallows an understanding of responsibility as a shared and intersubjective feature of modern existence. This often results in responsibility being converted into blame, which serves to deflect responsibility away from the critic and is directed exclusively outward: normally toward governments and institutions. This type of blaming protects the critic from having to interrogate her own relationship to these interrelated systems of power and results in a situation of either name-calling or inaction. It is a position that regards all responsibility

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as a means of individual control and therefore it eliminates the possibility that it is possible to develop an understanding of responsibility that is beneficial to everyday people and systems that are low in the social hierarchy[17].

Such approaches have an air of piety about them[18]. Piety is located among those who refuse to engage in meaningful action because the scale of the project seems too great to comprehend. It is also a mark of those who refuse to untangle their own complicity in maintaining the social relations that foster the growth of the epidemic. The outcome of such piety is to shrink away from the task in hand, which is an unacceptable conclusion. The aim of those who are *intersubjectively responsible* is to bring others out of their piety, to make them mourn – realise their own role in the continuing crisis – which will then allow them to engage in *intersubjectively responsible* action too.

The criticisms of the model of *intersubjective responsibility* – that it cannot overcome economic and political barriers; that it will inevitably rebound upon the individual – do not take sufficient account of the progress that has been made since the Durban conference, nor offer adequate explanation for them. The events outlined above were achieved because of a model of *intersubjective responsibility* that has emphasised two things. The first of these is an awareness that we are all complicit in spread of AIDS. The epidemic is not the responsibility of individuals, nor of governments or corporations, it is a shared responsibility. What has mobilised meaningful change in efforts against HIV are those developments that work towards the model that regards responsibility for the epidemic as *intersubjectively* shared among and between individuals, communities, organisations and states. Past experience has clearly shown this to be the case. In countries such as Brazil and Uganda, unprecedented political commitment was given over to the transformation of treatment and prevention policy – AIDS has been embraced in those countries as a priority issue across all operational levels, the resources were raised to implement change, and the result has been that AIDS related deaths in Brazil have declined steeply, while the growth rate of new infections in Uganda has been significantly

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[17] A similar practical outcome emerges from those who argue that the sheer scale of the crisis leads to individuals and institutions feeling powerless in any attempt to influence its course (Geras 1998; Tester 1997). Tester argues that in such a situation, merely knowing about the situation can act as a substitute for doing anything about it (Tester 1997: 43). Such an approach could be used to explain the events following the Durban conference: the world had awoken to the scourge of AIDS, but that is all.
[18] See Chapter Two for a brief outline of Rose's notion of piety.

stemmed. The world's largest mining firm, Anglo American has announced that it will pay for HIV diagnosis and treatment for all its South African employees and has made initial advances toward the dismantling of working practices that separate workers from their families (Wall Street Journal 2002)[19]. Despite his own sharply declining health, Zachie Achmat – who is the HIV positive spokesperson for TAC – has maintained his public position that he will not take anti-retroviral medication until it is made freely available to all who need it in South Africa. His personal protest has drawn the attention of the international media to the embarrassment of his own government, and support from scores of other HIV positive South Africans through their attendance at TAC rallies and work toward the success of the legal efforts undertaken by TAC in their name. All of these are the actions of those who have undertaken the path demanded by *intersubjective responsibility*, not one of self-righteous blaming, but one of introspection, reflexivity and subsequent change. Peter Piot holds that it is this combined and over-arching approach to responsibility that holds opens the only door towards control over the epidemic:

> At the historic [UNGASS] on AIDS in June in New York I said that the world faced two paths. Two possible futures. One path: the current situation: an epidemic that we are fighting, but is gradually defeating us…but the other path is one of collective responsibility…freed from the shackles of shame and fear. This is the path where we finally match the scale of the epidemic with the scale of our response. Where the fight against AIDS is truly embraced in every field of social action – by politicians, in the churches, mosques and temples, by unions and the women's movement, by business alongside government (Piot 2001b).

Such an awareness of *intersubjective responsibility* does not just happen because it should. Individuals, communities and institutions need to become aware of their own role in the spread of the crisis for these types of responses to happen. This process is only the outcome of sustained effort and it is worth recalling the suggestion in Chapter Two that mourning may be important for this realisation.

Recognition that responsible behaviour is not an automatic consequence of a moral imperative is the second important part of *intersubjective responsibility* and relies on Weber's notion of proportionality. There are other priorities for people and institutions, other senses of duty, and economic and political structures that shape response to the calls for responsible action. Those activists who are overly idealistic, who claim that it is a

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[19] All-male mining hostels and the related use of sex workers in these environments have contributed significantly toward the transmission of HIV in South Africa.

humanitarian duty to give more to the global AIDS fund will meet with little success and much disillusionment. However, the intersubjectively responsible activist will chip away at the weakest points of the defence, will turn the apparent weakness of 'economic reality' into a strength. By exerting continuous pressure on points of weakness, while acknowledging alternative individual and institutional interests, the intersubjectively responsible can gradually increase their numbers.

Such an approach is being pursued, and is fundamental to the path envisaged by Piot. It is the kind of path that is slowly, and often grudgingly pursued as a result of the forms of activism and intellectual shifts that are committed to *intersubjective responsibility*. The demand that access to treatment is necessary in order to maintain global security and trade stability has been an important persuasive tool. The United Nations Security Council convened to discuss the impact of HIV/AIDS on global security in January 2000, an event which instantly converted the epidemic from an issue that was primarily regarded as an issue of public health into something of much broader international significance. Jeffrey Sachs' report for the World Health Organisation called *Macroeconomics and Health* demonstrates the necessity that HIV/AIDS must be curtailed in order to protect the stability of the global economy. Bill Clinton makes speech after speech where he underlines the connection between poverty, health and global instability:

> I don't think the United States fully appreciates yet how interdependent the world is. And how, if we want to live in a world that is globalised, and reap the economic benefits of it without becoming more exposed to its violence and danger as we were on September 11th then we have to keep working on these terrible problems. We have to keep resolving the paradoxes of a world in which infant mortality is down and life expectancy is up, but we think AIDS will grow from 40 million to 100 million people. We have to keep resolving the paradoxes of a world where education is a great benefit, but 130 million kids aren't in school – where the global economy has brought more prosperity than ever before, but half of the world's people live on $2 a day or less (Clinton 2002).

These types of argument aim to gain acceptance by appealing to the alternative interests of institutions and individuals. This pattern has existed throughout the past twenty years of responses to HIV/AIDS: the big victories often occur not because the powerful have been persuaded of the 'justness' of the cause, but because of a shift in the economic or political viability (and at times, necessity) of a given option. For example, government money began to flow for prevention activities in many national settings once it could be proven that they were more cost effective than treatment and care. Similarly,

pharmaceutical research began in earnest once there was enough of an infected constituency to make it a profitable venture. However, the hope of such activists is that, once some form of interest has been acknowledged, those involved may become more aware of their own complicity in the spread of the epidemic. Such an awareness will then hopefully lead to an understanding of *intersubjective responsibility*.

When conceptualised with this pragmatic idea of proportionality, we can see that the successes against the epidemic have occurred when those advocating change have taken advantage of potential weakness that becomes exposed in the power structure. Currently those areas of weakness that are increasingly exposed in the debate over AIDS include globalised trade and security. The use of this type of approach toward the development of *intersubjective responsibility* relating to HIV/AIDS has resulted in an unpredictable history of successes and retreats. As outlined above, progress toward adequate resourcing for successful treatment and prevention happens in jumps and starts depending upon changes in political, social and economic conditions. This movement has been sprinkled with isolated acts of altruism, yet without continuous pressure from activists, the gay community, academics and people affected by HIV/AIDS about the concrete ways in which the growth of the epidemic harms us all, very little of the progress that we have seen thus far would have happened in the way that it has.

In this thesis I have argued that social theories of responsibility have played a critical role in the outcomes of the HIV/AIDS epidemic thus far, and will continue to do so into the foreseeable future. The dominant model which I have labelled *responsibility as freedom*, and its critique, *responsibility as control* have been examined through a range of health promotion, policy and legal responses to the epidemic. However, these two models have serious shortcomings in their ability to apprehend the broad social, political, and economic contexts within which individual vulnerability to HIV risk continues to exist. The continued focus of these two approaches to responsibility result in ongoing debates about, on the one hand, the necessity of individual duty for the protection of the public good; and on the other hand the inability of an individual to overcome the social control imposed by such demands. The analyses presented in three different case study chapters elucidated the way in which these two approaches are continuously present the production of and responses

to HIV prevention materials, testing policy and criminalisation of HIV transmission. However, the final case allowed for the consideration of a different and potentially much more powerful means of apprehending responsibility as it relates to the epidemic. Upon examination of the international AIDS conferences, and the specific coverage and events at the Durban conference it was possible to demonstrate the dramatic emergence of *intersubjective responsibility* as a model which can guide responses to the epidemic is uniquely able to address the broader contextual factors that have been proven to be crucial to the ongoing transmission of HIV.

As sociologists we know that social practices rely on what are variously called world-views, particular moral stances, paradigms....theories. Therefore, not only is it possible to exercise theory in the context of an epidemic, it is unavoidable. Yet thus far, most examinations of the HIV/AIDS epidemic have neglected to explore the overarching social theories that connect a diverse range of responses. My aim here has been to demonstrate that this epidemic unfolded in the way that it did because of the dominance of a particular theoretical framework relating to specific understandings of responsibility. My exploration of the notion of *intersubjective responsibility* and its enactment in highly visible arenas in recent years demonstrates that there is an alternative way of understanding responsibility as it relates to HIV/AIDS, which can be far more successful in fighting the epidemic than most mainstream attempts to date. The path is there, and it is being advocated by those who are most highly placed to lead the international response. The question remains whether or not they will be able to successfully convince the rest of the world to follow.

APPENDIX: LIST OF INTERNATIONAL AIDS CONFERENCES – YEARS AND LOCATIONS

1985   Atlanta, United States

1986   Paris, France

1987   Washington, D.C, United States

1988   Stockholm, Sweden

1989   Montreal, Canada

1990   San Francisco, United States

1991   Florence, Italy

1992   Amsterdam, Holland

1993   Berlin, Germany

1994   Yokohama, Japan

1996   Vancouver, Canada

1998   Geneva, Switzerland

2000   Durban, South Africa

2002   Barcelona, Spain

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