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Abstract

Redefining Health in Development:

A Feminist Approach to HIV/AIDS as a Development Issue

This thesis presents the argument that inadequate definitions of development and health have limited our understanding of the Human Immunodeficiency Virus (HIV) and the Acquired Immune Deficiency Syndrome (AIDS). It is argued that broader, more holistic definitions of development and health will improve understanding of HIV and AIDS and thus planning and programming for the pandemic.

After appropriate definitions of development and health are established the extent to which they are applied in current HIV/AIDS development literature is discussed. Extensive quotations from an anthology that gathers the voices of women from various parts of the world who are HIV positive or who have AIDS support the central argument in regards to the need for broad definitions of development and health.

The thesis concludes by noting that while at the policy level there has been some acceptance of the need for broad definitions of development and health, there has been little practical work done using these definitions. Reasons for the limited application of broad definitions, such as reluctance to change power structures and increased complexity in programming are discussed and suggestions are made for the inclusion of broad definitions of development and health in policy, planning and the teaching of International Development Studies.

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Meredith Campbell

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Chapter One

Our current understanding of the Human Immunodeficiency Virus (HIV) and the Acquired Immune Deficiency Syndrome (AIDS) is limited in a number of ways. One of the primary reasons for this is how we define health. Our inadequate understanding of health limits how we understand and face the realities of HIV/AIDS. When an inadequate understanding of health is coupled with an inadequate understanding of development the challenges of HIV/AIDS are compounded. Thus it is the purpose of this thesis to demonstrate how our limited definitions of health and development affect our understanding of HIV and AIDS, and how better definitions can improve our understanding and better prepare us to face the challenges of HIV/AIDS.

The prevalence of HIV/AIDS globally, and the impact of HIV/AIDS on communities are the chief arguments for their inclusion in discussions of development and health. Awareness of the HIV/AIDS pandemic began in the early nineteen eighties, and since that time both awareness and infection have spread rapidly. In 1985 approximately 100,000 people globally were infected with HIV (Interagency Coalition on AIDS and Development 1994, Appendix i). In

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1995 an estimated 16 million adults and adolescents were HIV positive worldwide (UNDP 1995, 1). By the year 2000 between 26 million and 110 million cumulative HIV infections are expected (Interagency Coalition on AIDS and Development 1994, Appendix i).

The financial cost of caring for these individuals is staggering; medical AIDS care for adults (in constant 1990 dollars US) rose from 2.5 billion dollars in 1990 to 3.5 billion dollars in 1992 to a projected 4.8 billion in 1995 (Interagency Coalition on AIDS and Development 1994, Appendix i) By the year 2000 lost productivity and trade due to the epidemic may reach between 350 and 500 billion dollars (Interagency Coalition on AIDS and Development 1994, Appendix ii).

The emotional, cultural and spiritual costs of the pandemic are beyond estimate. Some indication of the impact on individuals infected by HIV/AIDS at the emotional and spiritual level is given in chapter four. At the community level this impact is even more difficult to evaluate as added to the emotional and spiritual impacts are potential losses to cultural advancement and additional responsibilities towards remaining family members.

In both financial and societal terms the most vulnerable members of communities are the most likely to be infected with HIV and to suffer the most harm when affected by HIV/AIDS. Approximately 85 per cent of cumulative HIV infections are in poorer countries, and in these countries only 7 per cent of global resources invested on HIV/AIDS are spent (Interagency Coalition on AIDS and

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Development 1994, Appendix iv). In richer countries 60 per cent of total global

HIV/AIDS expenditure is spent on care, while 33 per cent is spent on prevention;

the breakdown in poorer countries is 4 per cent for care and 3 per cent for

prevention (Interagency Coalition on AIDS and Development 1994, Appendix iv).

In communities there are many ways of being marginalized and

marginalization leads to greater vulnerability to AIDS. The various types of

vulnerability are demonstrated by the Interagency Coalition on AIDS and

Development;

> Vulnerability to HIV can be understood on several levels. For
> individuals, physical factors (presence of another sexually
> transmitted infection, relatively fragile genitalia in younger girls, lack
> of circumcision in men) interact with behaviour (sexual practice,
> condom use) and epidemiological context (HIV infection rates
> among actual or potential partners) to shape vulnerability to
> infection. These factors are themselves shaped by programmatic
> influences (such as access to condoms, STD control, and AIDS
> risk-reduction information and support), and social influences
> (including the role and status of women, the extent and degree of
> societal discrimination, literacy rates, and economic development
> patterns). Vulnerability to inadequate care once infected is most
> often determined at a household, community, or societal level
> (Interagency Coalition on AIDS and Development 1994, Appendix
> iii-iv).

For women vulnerability to HIV infection is even greater than for men for a

wide variety of reasons. In terms of sexual contact it is twice as likely for a

woman to contract HIV through a single exposure than a man (UNDP 1995, 1).

For women with genital lesions, inflammation or secretions the chance of

infection is even higher (UNDP 1995, 3). The likelihood of genital disorders is

increased by infection, infibulation or other types of genital mutilation, lack of

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access to information, diagnostic facilities or treatment for these conditions or sexually transmitted diseases (UNDP 1995, 3).

Young women in particular are at higher risk of infection with HIV. As mentioned above women are more likely to contract HIV (and other sexually transmitted diseases) from our male partners than they from us. This is due to the larger mucosal surface exposed in women during sexual intercourse and to the higher concentration of HIV in semen (as opposed to vaginal fluids) (UNDP 1995, 2). Young women tend to have sexual intercourse with older men who may have had more sexual partners and thus a greater potential for exposure to HIV (UNDP 1995, 2). Women in many developing countries frequently receive blood transfusions during pregnancy or childbirth or as treatment for anaemia, and so they face another possible means of transmission (UNDP 1995, 2).

Another important influence on vulnerability is what is generally termed economic development. As Dennis Altman writes,

> In many cases 'development' itself contributes to vulnerability to infection, as when economic changes force many out of rural life, pushing young men to leave their villages for the cities or minefields, and young women into urban factories or 'hospitality' work, disrupting families and increasing commercial sex (Altman 1995, 9).

Those who are marginalized are vulnerable, not only to potentially dangerous work, but also to impaired health.

The above description of the prevalence and impact of HIV/AIDS globally gives only the most basic idea of the complicated interrelationship of HIV/AIDS,

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health and development. This thesis will elaborate on the interrelationship and discuss what can be gained by taking a broad approach when defining development and health particularly when discussing HIV/AIDS.

This thesis draws on several bodies of knowledge in order to develop a theoretical approach. This approach will be expanded upon in the second chapter, but it is first and foremost a feminist one. I draw on several other theoretical approaches including alternative models of development and holistic understandings of health.

My theoretical approach is discussed in chapter two in which the first section is devoted to expanding on what is meant by development. In that section I will discuss the evolution of feminist development and what I mean by development. Many of us who enter the field of development spend a great deal of time considering exactly what is meant by development. Historically development has often been synonymous with economic growth. The term developing country is often used by those who wish to be polite, for what they really mean when they say "developing country" is poor country, unsophisticated country, or uneducated child-like country. The desire of those holding that view is that "those" countries, through economic growth, will modernise and become more like western countries.

Sanders (1985, 63) points out that all countries are unevenly developed

and asks why it is that underdevelopment is most severe in the Third World.[1] He

concludes that the problem is not excess population coupled with inadequate

food production in the underdeveloped world, as is often asserted, but rather that

the problem is inappropriate production and inequitable distribution (Sanders

1985, 71). Inequities between and within nations would be reduced if we

followed the path of real development, and thus health would be promoted.

The second section of chapter two will discuss the various meanings of

health and define what is meant by a holistic definition of health. It will be shown

that a restricted understanding of development prevents the full recognition of

human potential, and likewise, a restricted understanding of health prevents the

full achievement of health. When societies proceed with inadequate

understandings of development and health the possibilities for prevention and

education about disease become severely limited, this is particularly true for

HIV/AIDS.

Chapter three will present the current discussions of AIDS and

development. This review of literature will show how various authors approach

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[1] When the terms third world, North and South, developed and developing
countries are used I understand them to refer to those with power, and those
without. We have all searched for terms to refer to those with and those without,
but have seldom been happy with what we have found. North and South are
geographically inaccurate, not to mention misleading especially within countries
when the term "South" could be used to refer to the poor or women or any group
lacking the power of self determination. Developed implies completion or
success and few of us in "developed" nations consider this success. Therefore
when I use these phrases I understand them to refer to power relations between
and within nations and communities.

AIDS as a development issue and it will discuss the strengths and weaknesses of their approaches.

Chapter four will apply the theoretical framework presented in chapter two to the experiences of various individuals who are or were living with AIDS. In this way a clear understanding of why it is essential to understand development as more than economic growth and why health needs to be understood holistically will be reached.

A note on methodology is appropriate here. In order to demonstrate why holistic approaches are necessary when facing HIV/AIDS I cite the voices of women having HIV or AIDS in chapter four. There are several reasons for this. One is to let the lived experience of women having HIV/AIDS demonstrate that they experience HIV/AIDS in many ways that do not fit a biomedical model of HIV/AIDS. A second reason for using this collection is to prevent my biases from altering how the women explain their experiences.

All that was asked by the women who collected these voices is that women create something that reflects their experience of living with HIV or AIDS. This is not to imply that bias has been removed from this collection. The editors of the collection may have phrased their call for submissions in a way that encouraged submissions from women with particular views, their selection process may have done the same. Thus, the resulting anthology expresses how many different impacts there are on the experience of HIV/AIDS. The conclusions that can be drawn from this thesis will be presented in chapter five.

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The next chapter will discuss how we understand both development and health and will present a case for a broad-based understanding of both terms. In this manner the framework for subsequent analysis will be established.

Chapter Two

In examining the issue of HIV/AIDS and development it is necessary to be clear about the terminology that one is using. One of the first questions that must therefore be asked is what is meant by the term development. Once this is clear, the next question must be what is meant by health. Finally the interaction of development and health must be determined. After this is accomplished HIV and AIDS can be considered. The first section of this chapter will be devoted to exploring the term development and demonstrating how our understanding of development has changed over time. The second section of the chapter will focus on the meaning of health, and what is meant when one takes a holistic approach to health. The chapter will conclude with a brief note on the interaction between development and health.

I must begin this section by stating that my approach to development is feminist. I see little utility in any approach that is not feminist. Theory is used as a guide to our view of the world. We use this worldview to organize research, planning, and programming. If we want to do the most useful research and take the most useful action that we can, we need a realistic worldview. A worldview

which excludes women, diverse ethnic or racial groups, people who live in poverty and other marginalized groups is hardly realistic. Far too often development theory has been created by privileged men and has reflected their experience and has thus not been realistic.

To begin analysis of any question with the exclusion of women and diverse other groups is ludicrous. As Peggy Antrobus has written,

> Feminism offers the only politics which can transform our world into a more humane place and deal with global issues like equality, development, and peace, because it asks the right questions: about power, about the links between the personal and the political; and because it cuts through race and class. Feminism implies consciousness of all the sources of oppression: race, class, gender, homophobia, and it resists them all. Feminism is a call for action. (as cited in Bunch and Carrillo 1990, 73)

Ironically, it is to this very exclusion that many trace the first flaw in our understanding of development.

The most common understanding of development is development as economic growth. This understanding is particularly prevalent in the modernization school. As Hettne writes of the modernization school,

> Development was seen in an evolutionary perspective, and the state of underdevelopment defined in terms of observable economic, political, social and cultural differences between rich and poor nations. Development implied the bridging of these gaps by means of an imitative process, in which the less-developed countries gradually assumed the qualities of the industrialized nations (1990, 60).

For those who accept this view, economics, or industrialization (specifically the model of industrialization common in Europe) was of central importance in the

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process of development.

The dependency school is another approach to understanding development and it was formed by two main influences; neo-Marxism and the Economic Commission for Latin America (commonly known as CEPAL, the Spanish acronym). The concept of the centre-periphery model is of great importance in this school, particularly for those who agree with the CEPAL analysis. This model explains that "centre" nations benefit from trade while "peripheral" nations suffered (Hettne 1990, 86). Reasons for this imbalance ranged from disadvantages in the terms of trade, and various technological factors (Hettne 1990, 86). Neo-Marxists broadened this economic analysis to include the relations between local dominant classes and international dominant classes (Hettne 1990, 88). Again, it is clear that economic development is the main interest in the theoretical foundations of this school.

It is these understandings of development, with their emphasis on the economic, which have led to many of the failures of development. As Shiva (1988) points out,

> 'Development' was to have been a post-colonial project, a choice for accepting a model of progress in which the entire world remade itself on the model of the colonising modern west, without having to undergo the subjugation and exploitation that colonialism entailed. The assumption was that western style progress was possible for all. Development, as the improved well-being of all, was thus equated with the westernisation of economic categories - of needs, of productivity, of growth. Concepts and categories about economic development and natural resource utilization that had emerged in the specific context of industrialization and capitalist growth in a centre of colonial power, were raised to the level of

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universalist assumptions and applicability in the entirely different context of basic needs satisfaction for the people of newly independent Third World countries (p. 1).

This understanding of development as a western project, historically linked to the period of post-colonialism and the power relationships that existed at that period is the beginning of the explanation of the weakness of development defined without women.

Shiva (1988) terms this type of limited development maldevelopment[1] and links it with the concept of modernisation, modernisation which introduces "new forms of dominance" (p. 5). The new concepts of dominance and inequality replace previous ways of life which included separate but interdependent and complimentary roles for men and women (Shiva 1988, 5). Thus equality in diversity is replaced with new values, values in which western technological man is superior,

> Diversity, and unity and harmony in diversity, become
> epistemologically unattainable in the context of maldevelopment,
> which then becomes synonymous with women's underdevelopment
> (increasing sexist domination), and nature's depletion (deepening
> ecological crises) (Shiva 1988, 5).

It was in this atmosphere and out of this understanding of development that the

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[1] The definition provided by Shiva (1988) reads, "Maldevelopment is usually called 'economic growth', measured by the Gross National Product" (p. 6). She goes on to add that, "The problem with GNP is that it measures some costs as benefits (eg. pollution control) and fails to measure other costs completely. Among these hidden costs are the new burdens created by ecological devastation, costs that are invariably heavier for women, both in the North and South" (Shiva 1988, 7).

first feminist critiques of development arose.

It is important to note at this point that although the following discussion will describe three main stages in the feminist understanding of development they are not necessarily chronological. That is to say that while the "women in development" or WID stage will be described first it was not replaced by the second stage. Projects, policies and government planning continue to be designed with WID in mind. Within projects, concepts or practices from all stages can be used. Most frequently it is the language of the most recent stage (gender and development or GAD) that is used while the actual practice is quite different.

In fact, in recent years policies associated with neoliberal theories have become quite dominant. As such, liberal and neoliberal WID policy makers are determining much current-day policy. A prominent example of neoliberal theories are the Structural Adjustment Policies (SAPs), which determine government policy in much of the world today. Some even claim that SAPs have become development policy (Tadesse 1991, 45-46). What is clear is that SAPs have had a negative impact on women (Tadesse 1991, 55-59; Beneria 1995, 1842, 1844-45; Kanji, Kanji, and Manji 1991). The women in development or WID stage[2] is characterised by the desire to integrate women into development

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[2] These stages and acronyms are described by Rathgeber (1989). For the purpose of this paper I am adopting them and accepting that each acronym refers to a particular body of thought related to feminist development. But this is not necessarily the case. Authors and organizations may use the various

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and it is associated with liberal feminist theory. WID came into being after the publication in 1970 of Women's Role in Economic Development by Ester Boserup (Rathgeber 1989, 1). The importance of this work lay in the fact that Boserup "was the first to systematically use gender as an variable in her analysis" (Rathgeber 1989, 2). Boserup established the different impacts that development has on women and men. The liberal feminist approach gives prominence to legal and administrative change as a means of integrating women into development (Gallin and Ferguson 1993, 3). This approach is consistent with the modernization paradigm, wherein development proceeds in a linear manner from agrarian to modern industrial (Boserup 1990, 14). Development for liberals clearly related only to economic growth. The whole society would benefit from this growth eventually as benefits "trickled down".

For liberal feminists, like Boserup, women would achieve these benefits when it was recognised that through a variety of blockages women were not integrated into development. The removal of these blockages (lack of education, training etc.) would then allow for the integration of women. Then women too would experience the benefits of economic growth.

There are many difficulties with this analysis, but one of the most obvious is the assumption that women were not already a part of development. The

phrases women in development, women and development or gender and development without espousing any particular theoretical approach. This should be born in mind by the reader.

problem was not that we were not a part of development, the problem was how

development as economic growth treated women. As Antrobus understands it,

> women's contribution was central to 'development', the very base
> on which development was constructed, but in a way that was
> deeply exploitive of their time, labour, both paid (in the workplace)
> and unpaid (in the household), and their sexuality. This has been
> illuminated by the policies of structural adjustment (1991, 313).

Antrobus goes on to argue that with SAPs women are expected to take on the

increasing burden of cuts in social services by working even more in support of

their families. She also points to the role of women in reproduction of the labour

force as being central to the needs of SAPs (Antrobus 1991, 313).

A second major weakness of WID was its acceptance of existing social

structures. As Mbilinyi states in Rathgeber,

> This non-confrontational approach avoided questioning the sources
> and nature of women's subordination and oppression and focused
> instead on advocacy for more equal participation in education,
> employment and other spheres of society (1989, 5).

This lack of insight avoided as well issues of class, race, and sexuality that might

challenge the existing balance of power. Inequality between nations and

amongst women were also ignored. And, as development was defined as

economic growth the reproductive aspect of women's lives was ignored. In

summation it might be said that WID, "is based on the assumption that gender

relations will change of themselves as women become full economic partners in

development" (Rathgeber 1989, 7).

The second stage of feminist development or women and development

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(WAD) is quite strongly a Marxist feminist approach, and is also associated with dependency theory. WAD arose in response to the inadequacies of WID and to the bizarre assumption that women were not a part of development prior to WID intervention strategies. WAD attempted to answer the question, "Is it enough to integrate women into an unequal and unjust economic system?" (Mwau 1991, 285). The primary assumption of WAD, then, is that women have always been a part of development (Rathgeber 1989, 7).

The relationship between women and the development process is the focus of WAD; this and the ongoing economic activities of women inside and outside the household is the focus of analysis (Rathgeber 1989, 8). The assertion that women's work is vital to the maintenance of the societies in which we live is a primary contribution of WAD. The analysis of WAD has a strong class focus, and this is essential to our understanding of development from the WAD perspective.

Class analysis is a strength for WAD theory, but it also presents an area of weakness in WAD writings and practice. While WAD studies the relationships between classes little analysis is provided within classes. That is to say that women and men in the South are seen to be disempowered in relation to women and men in the North, but no attention is given to the social relations of gender within classes in the South (Rathgeber 1989, 8), or the North. This is also the case in the WAD treatment of women. Women are grouped together as a monolith and differences of class, race, ethnicity, and sexual orientation are not

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considered.

WAD also succumbs to the more general Marxist weakness of assuming

that when inequitable international structures change so too will the position of

women. But this is not the case.

> The oppression of women differs too from class and race because
> it has not come out of capitalism and imperialism. The sexual
> division of labour and the possession of women by men predates
> capitalism. Patriarchal authority is based on male control over the
> women's productive capacity, and over her person. This control
> existed before the development of capitalist commodity production
> (Rowbotham 1992, 96).

While feminist Marxist's might recognize this fact they make little effort to provide

suggestions for change. As a result the only solution offered by WAD is

intervention strategies similar to those suggested by WID (Rathgeber 1989, 9).

WAD too ignores the need for fundamental societal change.

The most recent stage of feminist development is known as Gender and

Development (GAD), and it offers an alternative to the intervention strategies of

the other two stages. While Rathgeber suggests that the dominant influence in

GAD comes from socialist feminists (1989, 10), I would argue that GAD is a

collection of feminisms. That is to say that many of the developments in feminist

thought since the 1980s have contributed to how GAD understands

development. These various feminisms include, in addition to socialist feminism,

lesbian feminism (or any feminism that provides a critique of heterosexism),

environmental or ecofeminism, postmodern feminism and the feminisms of the

South.

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Socialist feminism provides the link between production and reproduction

that was missing in previous analysis. As is stated in Rathgeber,

> Socialist feminists have identified the social construction of
> production and reproduction as the basis of women's oppression
> and have focussed attention on the social relations of gender,
> questioning the validity of roles which have been ascribed to both
> women and men in different societies (1989, 10).

With socialist feminism women are seen as actors in development, not

individuals requiring integration into the development process. Socialist feminist

development examines basic societal structures and seeks ways to change

power structures that give advantage to one group over another (Rathgeber

1989, 13). As Froines (1992, 125) summarizes,

> Recent socialist feminist analysis has tended to acknowledge
> social class difference primarily as one aspect of diversity, with an
> emphasis on understanding and appreciating class diversity, rather
> than analyzing the social and economic injustices of class
> difference. Yet what was distinctive about socialist feminist thought
> as it developed in the 1960s and 1970s was precisely the linking of
> social and economic class difference to a critique of capitalism as a
> whole, not as an abstraction, but as it exists today in the world.

The problem with socialist feminist development and with the other types

of feminism that will be mentioned here is that they express a commitment to

fundamental change not likely to be accepted by those in power globally. It is

the search for fundamental change that posses the greatest challenge to the

acceptance of GAD.

Lesbian feminism has made a major contribution to the GAD

understanding of development due to its examination of heterosexism.

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Heterosexism or what Adrienne Rich (1983) terms "compulsory heterosexuality" is the normalizing of heterosexual existence to the point that all other options (ie homosexual or Queer[3]) are abnormal.

This means that the western style nuclear family is assumed to be the norm. Lesbian feminism rejects the notion that the nuclear family is the basic unit of production and consumption in society (Bunch 1987, 161-167). In practical terms heterosexism has lead to concepts like the family wage which has meant that women received inadequate wages. In the South the most obvious impact of heterosexism has been the gender roles that those of the North have assigned to women of the South. The fact that liberal defined development did not see women involved in it is a case in point.

A lesbian feminist definition of development would therefore exclude not only the possibility of homophobia, but also the existence of heterosexism. This would mean that we would cease to make assumptions about gender roles, including the assumption that all people want or need heterosexual identities. This, of course, only applies to the development of theory. In other words, the framework applies to research or project planning; the theoretical end to homophobia and heterosexism does not mean they cease to exist in society. That will be a much longer process that will begin with the end to homophobia

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[3] The challenging acceptance of diversity present in Queer and recent lesbian feminist theory is of great utility to development theory. For further discussion of Queer theory see Duggan (1992) and for more recent changes in lesbian feminism see, Stein (1992).

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and heterosexism at the policy level.

Environmental or ecofeminism has made a significant contribution to GAD definitions of development. Blindness to the finite nature of the environment has been one of the greatest threats to which humanity has subjected the planet. Ecofeminists and others have brought this recognition to the fore and incorporate this understanding into development.

Ecofeminists like Shiva (1988) combine their belief in the spiritual connection between women and the environment with a critique of patriarchal society which accepts and promotes the primacy of industry over sustainability and men over women. Environmental feminists tend to base the connection between women and the environment in specific historical and economic circumstances. Both ecofeminists and environmental feminists demonstrate that the costs of environmental destruction are disproportionately borne by women, particularly women of the South (Thomas-Slayter and Rocheleau 1995, 87). Environmental feminists and ecofeminists would then stress the importance of considering the way that development interacts with the environment in their definition of development.

Another type of feminism that has contributed to GAD is postmodern feminism. While opinions on the utility of postmodern theory are many and varied it is my opinion that it has many valuable reminders to offer those of us

trying to define development.[4] First amongst these reminders is that there is no universal truth.

No one theory, no one way of being is applicable in every situation. To attempt to impose a theory or a truth on every situation will render the evaluation useless. The practice of essentializing that which is not universal is what postmodernism questions (Beneria 1995, 1842). Further, postmodernism has caused us to question those categories of analysis which were once wholeheartedly accepted; we now must ask ourselves, what is the best way to theorize and to do research (Beneria 1995, 1842)?

Perhaps the most significant feminist voices to be heard in GAD are the voices of women from the South. Not only do these women have their experiences as women to draw upon in understanding the problems of society, but they also have first hand experience of living with development that is inadequately conceived. As Kiswar and Vanita write,

> Today we no longer say, 'give us more jobs, more rights, consider
> us your "equals" or even allow us to compete with you better.' But
> rather: Let us not only re-define ourselves, our role, our image -
> but also the kind of society we want to live in (as cited in Bunch and
> Carrillo 1990, 72).

This then leads us to how GAD defines development. As has been seen GAD's understanding of development is one which calls for fundamental change. For this reason GAD defined development is more than a definition, it is a vision

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[4] For a wide ranging discussion of postmodernism and development theory see, Parpart (1993).

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of how the world should be if development were just.

The words of DAWN (Development Alternatives with Women for a New Era) provide perhaps the best articulation of this vision that I have seen. They state:

> We want a world where inequality based on class, gender, and race is absent from every country, and from the relationships among countries. We want a world where basic needs become basic rights and where poverty and all forms of violence are eliminated. Each person will have the opportunity to develop her or his full potential and creativity, and women's values of nurturance and solidarity will characterize human relationships. In such a world women's reproductive role will be redefined: child care will be shared by men, women and society as a whole. We want a world where the massive resources now used in the production of the means of destruction will be diverted to areas where they will help to relieve   pression both inside and outside the home. This technological revolution will eliminate disease and hunger, and give women means for the safe control of their fertility. We want a world where all institutions are open to participatory democratic processes, where women share in determining priorities and making decisions (Sen and Grown 1987, 80-81).

Clearly, in this vision discrimination of any kind would not be possible and we would have a chance, as a planet, at sustaining life and developing to our full potential.

More recently DAWN has refined its definition of development to include five principles for human development. These are:

i)   Human development means supporting the development of people's potential to lead creative, useful and fulfilling lives.

ii)   Human development for all is or should be the **primary and direct** goal of economic growth processes.

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iii)   Transforming gender relations is central to the human development of both women and men.

iv)   Class, caste, race and other social relations of power are embedded in inequalities between and within nations, and interwoven with gender relations so as to pose major barriers; their transformation is key to human development.

v)   Human development must be environmentally sound and ensure secure and adequate livelihoods for poor people, especially women (DAWN 1995, 22).

Development in this definition and directed by these principles is the recognition of our full potential as a global community. To achieve this potential we must, most would agree, be healthy. But what is meant by the term health? For many, especially those in the North (Kelly and Lewis 1987, 27-34), health means medicine and disease[5]. I would argue that there is much more to health than disease and its treatment, in fact I would argue for a far more holistic approach to the concept of health.

As we in the North have assumed that our view of development is, and ought to be, a universal one so too have we done with health. How we have come to understand health has been to divorce health from the whole person and to equate it with purely biological conditions. One is healthy if all the body's biological systems are functioning. One is unhealthy if the functioning of the biological systems is impaired. We have developed a complicated and highly

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[5] In this thesis I will use the term disease to refer to a biomedical condition. Illness will be used to refer to sickness that may or may not have a biomedically discernable cause.

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structured system to deal with the body and its functions, and we have exported

this system to the rest of the world. The most common definition of health in this

system is the absence of disease.

This type of health system, and this view of health is associated with the

biomedical point of view. Biomedicine has been defined as,

> relating to a body of medical knowledge based on scientific
> interpretations of illness. Biomedicine recognizes the existence of
> microbiological phenomena and explains illness symptoms in terms
> of ideas about germs and/or malfunctions in the patient's body. It
> is associated with sophisticated technology, a hierarchy of
> professionals and the curing and controlling of diseases. It is
> sometimes referred to as modern, scientific, conventional or
> cosmopolitan medicine. The term 'Western medicine' is also
> commonly used, but it is misleading for three reasons. First, there
> is a great deal of health care in Western countries which is not
> biomedical (psychoanalysis, acupuncture, homeopathy, faith
> healing, etc.). Second, biomedicine has historical origins in non-
> Western as well as Western countries (e.g. Arab countries). Third,
> biomedicine is established as the basis of formal health care
> services run under ministry of health auspices throughout the world
> (Allen 1992, 218).

Many individuals and organizations have become critical of this approach,

not only because it defines health as the absence of disease, but because it

separates biological and all other aspects of life. By ignoring the whole person

and community biomedicine ignores or prevents the attainment of real health.

As Dinyar Godrej (1995, 9) writes of biomedicine it,

> ...is a single closed system of rules, which pooh-poohs other
> discrete systems and claims to be the only acceptable, universal
> approach. It has narrowed our conceptions of health and disease
> to biology, separating the individual from the wider environment.

Separation from our environment will, as Godrej (1995, 9) sees it, lead to

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"healthism", or a system of health taboos which are designed to lead to longer life. Being linked to our environment is essential as it is from the environment that "most ill health directly or indirectly arrives" (Godrej 1995, 9).

In the last couple of decades more people have been questioning not only the separation from the environment inherent in the biomedical health care system, but also the separation of the individual from her or his community. The very idea of treating the health of the individual as somehow apart from the world in which the individual lives has been found to be ridiculous. For example if an individual is malnourished teaching her or him about the four food groups makes very little sense. It would be better to ask why is the individual malnourished? Does she live in poverty? Does he use his financial resources to pay off a debt? Is food even available? People do not exist in a place removed from our environment. Why we are ill is as important a question as what disease we have.

The World Health Organization (WHO), which is the United Nations agency responsible for health, began to search for an approach to health that would not only broaden its definition, but improve the approach to health maintenance. WHO's first step was to define health in its constitution as "the state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity" (as cited in Kelly and Lewis 1987, 13). The next step was to determine what approach to health care would best implement this definition. The approach selected by WHO is known as Primary Health Care

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(PHC) and it was developed at the 1978 Alm Ata conference.

The problem with PHC and with the WHO definition of health is that they are subject to a wide variety of interpretations. And, while I would not suggest that it is at all desirable to limit how the definitions are interpreted I would suggest that some interpretations are designed to benefit those in power and other interpretations are designed to benefit the disempowered many. As those with power can enforce their interpretations they have been dominant. For this reason many authors have rejected both the WHO definition of health and PHC.

Despite the fact that the WHO definition of health specifically rejects the definition of health as only the absence of disease, this definition has lingered and has lead to the concept of selective PHC. Selective PHC is what has become the most common means of PHC implementation. Selective PHC couples a medical definition of health with some medical means of disease prevention. In other words, curing disease is still the focus while interventions like immunization are encouraged as the means of disease prevention. This focus on selective PHC is one reason why many have been critical of the whole concept of PHC.

An example of selective PHC is provided by Walsh and Warren.[6] They feel that total primary health care for all would be the best solution to poor health, but in a period of diminishing resources selective primary health care is the next

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[6] See also Werner's more critical discussion of current examples of selective PHC (1995).

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best thing (Walsh and Warren 1980, 145). Walsh and Warren state that ill health

is "...a complex, many-faceted problem, an amalgam of many diseases with

multiple causes" (1980, 145). In order to implement selective PHC the authors

feel that those diseases causing the most death or disability with the least

expensive cure or prevention should be targeted (Walsh and Warren 1980, 146).

David Werner is one of the many who have been critical of selective

PHC's targeting of "high-risk groups" with "cost-effective interventions" (1995,

28). Werner suggests that this is a "politically sanitized version" of PHC (1995,

28). United Nation's agencies (ie. UNICEF) have been strong adherents of this

type of PHC, as selective PHC can improve selected health indicators, "...while

skirting in all but rhetoric the social and economic inequities underlying poor

health" (Werner 1995, 29). Werner sights recent increases in rates of

undernutrition and morbidity, as well as stagnation in child-mortality rates as

indications that selective PHC has failed (1995, 29).

One author who has not rejected PHC, but rather reinterpreted it is John

Macdonald who feels that a participatory model of health care, based on the

three pillars of PHC; participation, intersectoral collaboration and equity, would

redirect health services towards the needs of communities (1993, 14). This

model calls for a broader understanding of health, one that understands ill health

as having societal as well as medical causes. Macdonald encourages us to treat

the symptoms of inequity while looking for the means to tackle its causes, which

include the pattern of economic relationships between and within countries

(1993, 128).

In contrast to Macdonald's attempts to revitalize what he sees as the drifting off course of PHC, Vincente Navarro (1984) provides a much more basic critique. His criticisms of the Brandt Report and the Alma Ata declaration are based on his feeling that the two are written from the position of the dominant class(es). While he explains that this position makes sense for the class that holds it, it is inadequate in his opinion, especially as the diseases of he majority of the world's population can be traced to exploitve class relations and poverty (Navarro 1984, 164).

Navarro argues that it is not improved access to health services that is required by the majority of the world, but rather fundamental changes in social economic and political structures (1984, 169). In other words Navarro would not link his definition of health so closely with health services and the health care system.

What most critiques of PHC and of the medicalized definitions of health have in common is that they are critiques of the dominant definitions in society. Critics are saying that the way things are being done is inadequate and needs to be changed. And this means real change, not rhetoric as has often been the case.

Werner gives us one example of health rhetoric in the World Bank's 1993 World Development Report 'Investing in Health' (1995, 29). Werner claims that this report attempts to justify keeping people healthy as a means of promoting

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economic growth (1995, 29). What Werner finds particularly pernicious about the report is that it recognises "the economic roots of ill health", but goes on to make recommendations for improvement of this situation from "the same paradigm that has worsened poverty and health levels" (1995, 29). Werner, like Navarro (1984), is arguing for a real change in how we define and think about health, not a change on paper while practice remains consistent.

In other words we need an holistic definition of health that fits in with the type of development previously discussed. We need to change how we direct society and this will allow a real concept of health to be established. But where do we begin this new, holistic definition of health?

First, a new definition of health must not make the mistake of rejecting all that has gone before. This means that the knowledge of traditional healers should be given as much respect as the knowledge of biomedical practitioners. It also means that while the negative aspects of biomedicine will be rejected its positive aspects will be maintained.

As I am suggesting a holistic approach to health this means that all components of life will be considered. This means several things for the health of the individual, and for the communities in which we live. At the individual level physical health will be included on an equal basis with mental and spiritual health.

Mental health must include not only biomedically diagnosed disease, but all types of mental illness. Mental health must therefore include the sense that

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the individual can direct her or his own life. Wallerstein (1992) points out that

powerlessness or lack of control over individual destiny is a risk factor for

disease. She writes,

> a working hypothesis is that lack of control over destiny promotes a
> susceptibility to ill health for people who live in high demand or
> chronically marginalized situations and who lack adequate
> resources, supports, or abilities to exert control in their lives
> (Wallerstein 1992, 202).

When individuals are empowered and can make their own choices, real health

can be achieved.

This need for empowerment extends not only to individuals but also to

communities. If, as Godrej suggests, we stop thinking about medicine as pills

and start thinking about it as "basic rights for all, respect for the environment, an

end to conflict" (1995, 10), we will be well on the way to a better definition. This

definition will include not only an end to conflict within nations but between

nations. For how can we as a global community be healthy when we are all

dying due to war?

The spiritual components of health and health care are as important as

the physical or mental aspects. Spiritual health has different meanings for

different individuals and in different communities, but it is not limited to organized

religion, or how those religions perceive health. The spiritual component of the

individual can be understood as the total personality that links all aspects of the

person (Labum as cited in Stoter 1995, 3). All of an individual's life experiences,

background and beliefs influence her or his spirituality and worldview (Stoter

1995, 3). An individual's spirituality should be considered in any definition of health.

Various medical or health systems which are viewed with great scepticism by the biomedical establishment integrate spiritual and physical health. For example, acupuncture considers that disease is caused not only by external forces but also by disruptions in the life force (Brown 1994, 17). Other therapies which closely link emotional and spiritual life to health include: art therapy, Bach flower remedies, colour therapy, dance therapy, hydrotherapy, polarity therapy, radionics, Rolfing and shiatsu (Brown 1994, 119-126).

It is important to note that there are many medical systems other than the biomedical that provide ways of understanding and treating disease. Many of these systems approach health from a much more holistic perspective than is common with biomedical approaches. Some of these systems include:[7] acupuncture, aromatherapy, chiropractic, western herbalism, homoeopathy, naturopathy and osteopathy. Traditional medical systems also have long histories of successfully integrating all aspects of life in their definitions of health. Traditional medical systems include:[8] traditional Chinese medicine, Qigong, Ayurveda, Maharishi Ayurveda, Curanderismo, and various other global health traditions. Each of these traditions and systems has a unique approach to

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[7] For descriptions of the systems mentioned here see Brown, 1994 or Micozzi 1996.

[8] See Micozzi (1996) for descriptions of these medical systems.

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disease definition and treatment; definitions of health should take these understandings into account.

As mentioned above, health has many factors acting upon it. Ostergaard refers to theses many influences as "carriers of good or bad health" (1992, 111). Ostergaard writes of,

> health needs in terms of those human activities and social
> structures which are actually carriers of good or bad health.
> Economic, social and cultural conditions, lifestyle and life stress are
> the major determinants of health (1992, 111).

These carriers of health ought to be included in any definition of health.

One of the chief carriers of health is our community life, or how we live in our community. By this token, how individuals are perceived by the communities in which they live is quite significant. In other words any type of discrimination has an effect on health. The impact of discrimination can be as direct as being denied health care due to the colour of one's skin or as tenuous as the impact of daily discrimination on the immune system. Discrimination in its many forms mediates how we experience health.

A wealthy African woman living with HIV/AIDS will have a different experience of the syndrome than a poor African woman. Both of these women will have different experiences than an African man. A non-English speaking individual in an English speaking country will have a different experience than an English speaker seeking the same type of care.

Particularly significant types of discrimination are those of gender, race,

and class. An excellent example of this is provided by Navarro (1990). Navarro points out that in order to understand the mortality differentials between whites and blacks in the U.S. one needs to examine more than race; class differentials are equally important (1990, 1238). Navarro shows that for many illnesses class differentials are greater than race differentials (1990, 1238). Within income groups, race differentials are less pronounced than differentials between income groups (Navarro 1990, 1239). These income or class differentials have been increasing during the eighties (Navarro 1990, 1240). In conclusion Navarro indicates that in order to understand why the health of U.S. "minorities" is getting worse one must examine not only race but class. It is interesting to note that while Navarro mentions than many members of the working class are women he does not mention whether within classes mortality differentials are greater for men or women. In this case as in many others the failure to include a breakdown of data by gender may be hiding the real situation of women.

Patricia McFadden sums up a major problem not only in how we define health, but in how women's health is often defined; she writes,

> Conceptually and practically, the meaning of health for women differs from that of health for men and children, and in virtually all societies today, the definition of women's health is directly or indirectly related to their reproductive health status (1993/4, 59).

McFadden goes on to write,

> health as a total concept is rarely extended to women, nor do women themselves perceive it in this holistic sense. Yet, the majority of women on the African continent are the least healthy people in our communities (1993/4, 59).

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She feels that women should be understood not only as mothers, but as children, as teenagers, as students, as professionals, as older women, and in this way our total health needs will be the focus of definitions of health and of health policy (McFadden 1993/4, 61). If women as whole people as well as men are included in how we define health gender will then be encompassed in our definition of health. Another significant aspect of community life that effects health is economic wealth or poverty of the community. It is often argued that poverty "is the world's most serious carrier of ill health" (Ostergaard 1992, 113). In Canada, poverty is increasing especially amongst single parent mothers and their children and older single women (Reuter 1995, 149). Reuter argues that in light of the well established relationship between poverty and ill health women bear a disproportionate burden of ill health (1995, 149). Other common carriers of ill health associated with poverty are poor sanitation or water supply. It is important to note however that poverty is not always a carrier of ill health.

Paulo Marchiori Buss asserts,

that there is no mechanical, necessary relationship between the level of economic development and community health conditions, which thus contradicts the pathological inevitability of "average poverty." Rather, the determining factor is the social relations of production prevailing in the society (1992, 244).

As evidence to support this point, take the case of the United States and Cuba. Life expectancy at birth between 1985-90 in the United States was 75.4, in Cuba it was 75.2 (Terris 1992, 75). While a true picture of community health cannot be given by one indicator, it is interesting that two countries with such different

social relations of production have such similar life expectancies.

Buss' conclusion is supported by Sanders who writes, *"it is living and working conditions that are most important in determining the health of populations"* (1985,52; italics in original). Sanders also points out that all countries are unevenly developed and asks why it is that underdevelopment is most severe in the Third World (1985, 63). He concludes that the problem is not excess population coupled with inadequate food production in the underdeveloped world, as is often asse₁ted, but rather that the problem is inappropriate production and inequitable distribution (Saunders 1985, 71). In other words, how people live, the means of production in their community, and the level of poverty and wealth are all significant carriers of health.

Having established that social relations are carriers of health, that mental and spiritual health are as important as physical health and that traditional healing systems are as important as biomedical ones, what is the definition of health? There must be as many definitions of health as there are individuals, societies and cultures. David Werner defines health as, "well-being: in body, mind, and community (1979, w7). Nayar tells us that Ghandi defined health as "Body Ease" (Nayar 1987, 6). She also presents the word *Swasthaya* which in English literally means "stability within self" and in her language means health (Nayar 1987, 6).

Holistic health practitioners have another definition of health. One of these practitioners, Richard Miles explains,

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A holistic system may include identification and treatment of disease, as one possible choice among many, but it does not focus on problems and errors, as all the other systems [of health care] do outright (or tend to do). It focuses, instead, on clarity of intention, development of well-being, and enjoyment of life in a system of self-responsibility (Miles 1985, 12).

Other practitioners have slightly different definitions. David Teegarden defines

holistic health as,

not merely the absence of disease. It is a state of well-being and vitality that brings about an optimal level of physical, mental, and spiritual functioning. In this state, you experience a sense of joy, wonder, and love towards yourself and the world. Holistic health also extends to a wider sphere: It may include a high level of social ecological, and political awareness, and a commitment to improve not only your own health and well-being but also that of the surrounding world (1985, 14).

Holistic medicine is defined by Teegarden as,

a system of medical care that emphasises the *whole* person. Rather than focusing only on the malfunctioning body part, it also explores the broader dimensions of the patient's life - physical, nutritional, environmental, emotional spiritual, and lifestyle. In aiming to foster the natural healing process, holistic does not espouse one method over another, but rather encompasses *all* safe methods of diagnosis and treatment - including medication and surgery, when appropriate. Patient and practitioner cooperate to achieve the desired result. Personal responsibility and participation are emphasized (1985, 14).

For the purpose of this thesis I will define health as the full realization of individual physical, mental and spiritual potential within communities that are free of discrimination, stable and safe.

Now that both development and health have been defined, what is their relationship? Defining this relationship is complicated by the existence of two

different approaches to development and to health. For those that accept the definition of development as economic growth improvements in health are "essential for social and economic development" (World Health Organization 1981, 15). For those that accept the definition of development used in this paper, development is health.

As health was defined above it includes the full recognition of human potential. This is consistent with the first of DAWN's five principles of human development, namely, "Human development means supporting the development of people's potential to lead creative, useful and fulfilling lives" (1995, 22).

The second part of this definition of health relates to the second, third and fourth of the DAWN principles. In order to live in communities that are free of discrimination, stable and safe, the economic growth process must be one that is designed with real development in mind, namely one that does not give priority to one group of people over another. Gender based discrimination as well as class, caste, race, sexuality and other types of discrimination and unequal power relations must be eliminated in order for there to be health for individuals and communities. These conditions are also necessary for development as defined by DAWN's principles (1995, 22).

The fifth of DAWN's principles is an increasingly important one, which states, "Human development must be environmentally sound and ensure secure and adequate livelihoods for poor people, especially women" (1995, 22). If the primacy of economic growth continues and real development is ignored then our

environment and our ability to support our population is threatened. In such conditions the attainment of health will be impossible.

When health and development are defined holistically they are so closely linked that it is almost impossible for one to exist without the other. If society works toward real health then we will be working towards real development. If we attempt to pursue real development we will facilitate the attainment of real health.

In the following chapter, the existing literature on HIV/AIDS and development will be discussed. The central issues in the literature will also be examined.

Chapter Three

While the previous chapter presented a definition of development that encompassed far more than economic growth, this is not the most common understanding of development in AIDS and development literature. Likewise a holistic understanding of health is not the most common approach in the literature. This chapter will present current literature[1] and discuss the various influences that the authors' approaches to development and health have on their writing.

It is important to clearly understand that the majority of the literature reviewed in this section accepts either the modernization or dependency frameworks, thus they present analysis from what might be termed the dominant school of thought. The framework presented in the previous chapter is consistent with the alternative school. In other words, to a greater or lesser

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[1] Current literature on the topic of HIV/AIDS and development is quite limited. Most HIV/AIDS related literature is biomedical in nature and therefore not focused on development. A second focus area for literature on HIV/AIDS is education; here again there is little time devoted to development. For this reason "current", in this case, includes literature from the late eighties as well as the early nineties.

degree most of this literature accepts the more narrowly defined definitions of development and health while alternative school writing strives for broader definitions of development and health.

The dominant school understandings are the most widely used, and thus are more influential in forming policy. Approaches which accept the alternative school form policy and take direction from people's experience as is shown in chapter four. One of the main arguments of this thesis is that policy and planning must begin from this alternative school framework in order to be truly successful and responsive to people's needs.

Before proceeding to the discussion of this literature I would like to present a few notes on the extent and status of the AIDS pandemic globally in order to provide a context for the discussion. AIDS has often been mentioned as a central concern when it comes to health initiatives in both the North and the South. International attention has been focused on AIDS through the World Health Organization's (WHO) Global Programme on AIDS (GPA)[2] and through international meetings. The recent Paris AIDS Summit (1 December 1994) saw

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[2] The GPA has recently been replaced by the United Programme on AIDS (which is known as UNAIDS). This programme will unify the various HIV/AIDS related activities of WHO and several UN agencies, specifically; the United Nations Children's Fund (Unicef), the United Nations Development Programme (UNDP), the United Nations Educational, Scientific and Cultural Organization (Unesco), the United Nations Family Population Fund (UNFPA), and the World Bank. For more information on the new programme see, AIDS Analysis Asia 1995, 2; Global AIDS News 1995, 1-2. For an interesting critique of the GPA and of UN AIDS policy
see, Klouda 1995.

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representatives of forty two states gather to discuss the impact of the pandemic and which paths of action their countries wished to follow (Paris AIDS Summit 1994, no pagation). More recently the XI International Conference on AIDS was held in Vancouver, Canada with more than 15,000 people from around the world attending (Picard and Immen 1996, A1).

Although international awareness of AIDS was slow to develop, as mentioned above nations are now working together to face the pandemic. The extent of the pandemic has made this cooperation an absolute necessity. In 1990 WHO estimated that 9 million people worldwide were HIV positive; this could increase to 26 million by the year 2000 (World Bank 1993, 99). The Global Programme on AIDS estimated that there were 14 to 15 million adults living with HIV infection by mid-1995 (Mertens 1995, 8). Yearly deaths from AIDS related illnesses are expected to total 1.8 million in the next decade (World Bank 1993, 99). Eighty per cent of those individuals living with AIDS in 1990 are in the South and this number is expected to increase to 95 per cent by the year 2000 (World Bank 1993, 99). About 70 per cent of people currently having AIDS are in Africa, 9 per cent in the US, 9 per cent in the rest of the Americas, while about 6 per cent are in Asia, 4 per cent in Europe and 1 per cent in Oceania (Mertens 1995, 9).

While the health impacts of AIDS are fairly clear, the development impacts of the syndrome seem to be less obvious. If one considers health as a quality that exists both internally (in a body) and externally (in a society), the

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development impacts of AIDS are more easily established. Dominique David's

understanding of health is also helpful in clarifying this point. David writes,

> Health is simply the manifestation of development in the human
> body. It covers all aspects of life and is not merely a question of
> tackling medical problems. In the development context it is
> becoming increasingly clear that it is not possible to operate health
> and development policies separately in a way that is effective
> (1994, 2)

Unless we understand health as part of development we cannot understand the

magnitude of the impact of AIDS on development. A brief discussion of how

AIDS/HIV is transmitted will illustrate this point.

There are three known means of transmitting HIV, the virus associated

with AIDS. These are through sexual intercourse (chiefly anal or vaginal

intercourse), through an exchange of blood (via sexual intercourse, transfusion,

or the use of unsterilized needles or other medical equipment) and from mother

to fetus or child during birth or while breast feeding. These means of

transmission are significant, since if precautions are not taken, transmission can

occur in a variety of situations. For example, if instruments are not sterile and

are used repeatedly during ritual piercing, scarification, traditional medical

practices, or genital mutilation transmission is possible. Genital mutilation itself

facilitates transmission as bleeding and tearing of the woman's genitals occurs

during intercourse and childbirth. Intravenous (IV) drug use or multiple use of

needles for vaccination without sterilization can also facilitate transmission.

Many aspects of cultures in both the North and the South are traditionally

associated with the activities mentioned above that are facilitators of

transmission of HIV. But the condition that is common across the North and the

South that has been most instrumental in facilitating the transmission of HIV and

the spread of AIDS is poverty. Many statistics can be produced to support this

point, but in essence all statistics reach the same conclusion; as Ankrah states of

one American study, "Having controlled for gender, risk (sexual preference[3],

intravenous drug use) race and age they concluded that poverty is a significant

predictor of HIV seropositivity" (Ankrah 1991, 968).   Poverty encourages

immunosuppression (poor nutrition, inadequate shelter, endemic disease) which

in turn increases the likelihood of contracting HIV and rapidly developing AIDS

(see Hunt 1988, 20 for further discussion).[4] As Palmer and Dorf write on this

point,

> Social discrimination and inequity shape both personal and
> collective vulnerability to HIV/AIDS and health in general.

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[3] Sexual preference is not a risk factor for HIV seropositivity. Certain sexual
practices (ie sexual intercourse without a condom,) are associated with
increased likelihood of HIV transmission. Worldwide the dominant mode of HIV
transmission is through sexual intercourse between men and women;
"heterosexual transmission" (WHO 1993 no pagation). See note 3 for further
discussion.

[4] Poverty and power also influence which HIV/AIDS statistics we hear.
Recently we (in the North) have been hearing AIDS referred to as a chronic, yet
manageable condition. Individuals who have been living with HIV infection for
many years (over a decade in some cases) have been featured in media
coverage. But this hopeful prognosis has been far from usual in the South. As
Kate Dunn writes, "...life is nastier and shorter in the Third World: studies show
Ugandans with HIV progress to full-blown AIDS in six to eighteen months" (1995,
46).

> Epidemiological evidence suggests that vulnerability to HIV is
> inequitably distributed among economic social groups throughout
> the world. Another finding is that discrimination creates group-
> identified vulnerability, influencing significantly the success or
> failure of attempts to change high risk behaviour. HIV/AIDS
> therefore, really cannot be addressed in isolation from social
> inequities which have an impact on health (1995, 20).

In addition, poverty and lack of power enable governments and health

professionals to ignore affected groups, and likewise prevent members of those

groups from obtaining education.

The above makes it clear that AIDS is more than a health issue. Levels

of personal and societal development profoundly affect AIDS. The issues faced

by AIDS activists, people living with AIDS (PWAs) and people affected by AIDS

(caregivers, families, friends) are the issues of development studies. Poverty

alleviation is an AIDS issue. The impacts of structural adjustment programmes

(SAPs) are AIDS issues. Inequity is an AIDS issue. The liberation of women is

an AIDS issue. Racism is an AIDS issue. Sexism, homophobia, racism,

oppression, economic inequity, environmental degradation, all intensely

compound the impact of AIDS on individuals and societies.

People living in poverty often have compromised immune systems and

thus progress from having HIV to having AIDS more quickly. In turn they have

fewer resources to devote to medication, treatment and good food which will

strengthen their immune systems. The increasing marginalization of women by

SAPs and the decreased level of social support contributes to increased poverty

which strongly affects quality of life and impacts on HIV/AIDS as mentioned

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above. For these reasons the literature about AIDS and development is diverse.

The World Bank adds several other concerns to those central to the discussion of AIDS as a development issue. While many activists and authors would agree that there is some relevance to World Bank concerns, much disagreement would arise over Bank priorities. World Bank interest in AIDS is expressed as follows in the World Development Report 1993: "AIDS deserves special attention because failure to control the epidemic at an early stage will result in far more damaging and costly consequences in the future" (World Bank 1993, 99). Other Bank arguments for action include the following: "The HIV epidemic is bad and is getting worse"; "The cost-effectiveness of interventions drops sharply when infections cross from high-risk groups[5] to the general population" and "AIDS has catastrophically costly consequences" (World Bank 1993, 99-100).

As is clear from these points the Bank is interested in AIDS as a development issue in so far as AIDS can impact on national economies. This is

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[5] The term "high-risk groups" has been rejected by many activists and authors as there is no such thing. No one group is any more at risk than the so called "general population". There are high-risk activities, which, when precautions are taken, are rendered much safer. For example, gay men are often called a high-risk group for HIV infection, when in reality only gay men who have unsafe anal intercourse or who share unsterilized IV drug equipment or who had unsafe blood transfusions are "at risk" of HIV infection. Any member of the "general population" who has unsafe vaginal or anal intercourse or who shares unsterilized IV drug equipment or who had an unsafe blood transfusion is similarly "at risk". The term "high-risk group" fosters prejudice against people with HIV/AIDS. It is disquieting to see a member of the United Nations system supporting this kind of prejudice.

a radically different approach than that of many authors and agencies working with AIDS, but is consistent with the Bank's understanding of development as a synonym for economic growth.

The Bank's understanding of HIV/AIDS is part of a larger problem which surrounds the pandemic, and which is highlighted when an economic definition of development is used. Hyde points out the irony of this narrowly applied understanding when he writes,

> Bullets still cost more than condoms, yet governments continue to poor more into the arms trade than into health care when, for many of them, their countries are being torn apart by internal division which no amount of arms will solve. The excuse that HIV/AIDS drugs are far too expensive belies all that market economics teaches about economies of scale - surely with a market potential reaching 50 million by 2000, research and development costs could be amoritized over a longer period, enabling costs to fall considerably (1995, 3).

In spite of the diversity with which various authors conceptualize problems in the field, most writing falls into two main schools. As mentioned at the beginning of the chapter, these schools coincide with the modernization and dependency schools within development studies (Fortin 1989, 198-99). Descriptions of these schools were provided in the second chapter. The modernization school views development in primarily economic terms, and in a very linear or evolutionary way (Fortin 1989 198). In terms of the discussion provided in chapter two, the modernization school coincides with much of WID theory. The central difference is that very often women are marginalized in modernization school writings far more than in WID.

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Those authors that accept the modernization framework believe that the countries that have not "developed" will do so by following the path laid down by the developed countries. Within this school[6] AIDS is seen as a health problem which can be addressed through medical treatment (eventually and ideally through the discovery of a vaccine) and education.

The dependency school, on the other hand, understands development quite differently. As Fortin describes the dependency school's understanding of development, it

> means the breaking of these ties that bind through strategies of revolution, democratization, and regionalism, and the building of a more self-sufficient, indigenous, and culturally relevant social and political order" (1989, 199).

The ties that Fortin refers to are those of the dependency which has been established in the current world order between North and the South. The North exploits the South and the South becomes increasingly disadvantaged. Within the dependency school AIDS is understood as a social problem. In other words, AIDS is seen to occur not only within individual bodies, but also within individual societies. Whom AIDS affects is as much a part of dependency discourse as how they are affected.

The central difference between the two schools is how they seek to answer the question, "How can we best treat AIDS and prevent the transmission

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[6] The modernization school is sometimes referred to as the liberal school within AIDS and development writings; for example see Hunt, 1988.

of HIV?" Members of the modernization school answer this question in almost exclusively medical terms. The dependency school seeks to answer the same question as the modernization school, but adds a second question, "What are the root causes of the AIDS/HIV pandemic?"

When members of the dependency school answer these questions they look to society as well as medicine for answers. This means that dependency school writings are often politically based whereas modernization school writings tend to be biomedically based, often being written by medical professionals, who claim biomedicine is free of politics or bias. Modernization school authors often understand AIDS as a development issue primarily due to the economic impacts of AIDS, while dependency school authors understand AIDS as a development issue primarily due to the social nature of development.[7]

For example, Charles Hunt, a member of the dependency school[8], writes,

If the biological agent of the disease is the same in North America and Europe, and research has proven that it is, then why does the occurrence of AIDS in Africa and AIDS in the U.S. look and act so differently? Why does the same biological cause produce such different demographic and clinical results? The answer lies in the social/historical environment in which the biological cause, the HIV virus, acts (1988, 12).

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[7] Some authors go so far as to call HIV/AIDS a disease of development. See for example Schoepf 1993, 55.

[8] The author's of the various papers discussed in this chapter might not categorise themselves as belonging to the modernization or dependency schools; I am assigning them these designations based on my understanding of their writings.

As Hunt indicates, the different impacts experienced by people living with HIV/AIDS can be explained by the social/historical environment within which people infected with HIV exist. Modernization school writing, on the other hand, sees this question differently. As de Zalduondo, Msamanga and Chen state,

> Differences in the availability of health services, as well as in the spectrum of pathogens in industrialized and developing-country environments, influence the clinical presentation of AIDS and the interaction of HIV infection with other health problems. Together these complicate AIDS diagnosis and care in Africa (de Zalduondo, Msamanga and Chen 1989, 177).

In other words, different medical conditions existing in Africa determine the different impact and epidemiology of AIDS there.

In my experience Hunt's explanation is a more accurate one. If we understand development and health holistically, and as occurring both inside and outside the body then the dependency school provides a much more suitable understanding of AIDS. The situation here in North America provides an example of this. In North America, women, people of colour, gay men and the poor[9] have primarily been those affected and infected by AIDS/HIV (for a

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[9] Any association between class or power position and HIV infection is rejected by many writers in the modernization school. As Chen writes, "That the disease [AIDS] is fatal, attacks healthy adults, favours no class, and is primarily transmitted through sexual contact no doubt adds intensity to the viewpoints." (1987, 189). This is clearly ridiculous as any examination of data on HIV prevalence rates will show. Fortin, who writes in the dependency school recognises this: "almost all commentators on AIDS and underdevelopment recognize that mass poverty in the Third World contributes to the exacerbation of the AIDS epidemic. The poor, they say, are shaping up to be the at-risk group in all countries" (1989, 202).

provocative discussion of this point and the impact of the early characterization of AIDS as a "gay plague" see Abelove, 1994). Research has shown that members of groups that experience discrimination in society (the disempowered) are also those most likely to be infected by HIV (ie. gay men, women, IV drug users, inner city poor) (Overall 1991).

Women, who already provide a disproportionate amount of the personal care work in society, bear most of the burden of caring for friends and family members living with AIDS. In addition, women's bodies are medicalized by the health professions which treat male bodies as the norm and any functions of women's that men can not perform as "deviant" and requiring intervention (ie menstruation, pregnancy) (Chetley 1995, 23; Christensen 1990, 5-6; Godrej 1995, 9). This medicalization leads to non-recognition of women's difference, and excludes us from medical trials and definitions of AIDS/HIV (Christensen 1990, 5-6; Denenberg 1990a, 1990b).

Even when authors write in one school they often express views that would be more commonly associated with the other AIDS and development school of thought. This is a little unusual and might perhaps be attributed to the overwhelming nature of the problems associated with AIDS. Christakis, who is, in most of his writing, firmly within the modernization school, suggests that the nature of HIV/AIDS requires us to view health as a global common (1989, 117). He therefore feels that "Certain aspects of health preservation may now be seen as requiring international attention" (Christakis 1989, 127). The acceptance of

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the global common concept[10], implies a certain resignation of sovereignty to an international body which is hardly a foundation stone of modernization school thought.

Another example of this can be found in de Zalduondo, Msamanga and Chen who write,

> To African countries, the aggregate loss of productive capacity these deaths represent is the principal economic   concern. Illnesses and deaths among women and men in their most productive years mean economic losses and painful decisions at both the family and community level (de Zalduondo, Msamanga and Chen 1989, 180).

This statement is consistent with other modernization school tenets. The departure from acceptable modernization school explanations of the pandemic comes from the recognition that

> Responding to the AIDS epidemic imposes new demands for training, education, and care at a time when national economies have been shrinking under the weight of falling export prices, ecological disasters, and crippling external debt repayments (de Zalduondo, Msamanga and Chen 1989, 180).

De Zalduondo, Msamanga and Chen go on to add that "there are reasons to expect that HIV infection, like other debilitating and deadly health threats, will be found disproportionately among the poor" (de Zalduondo, Msamanga and Chen 1989, 181).

It seems that several authors whose thought seems at first to be firmly

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[10] The concept of the global common was popularised in Our   Common Future. a report written by the World Commission on Environment and Development.

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within the modernization school draw on explanations that are more consistent with dependency school writing (Christakis 1989; de Zalduondo et al. 1989). I would attribute this to inherent weaknesses in the modernization school understanding of the AIDS pandemic.

This lack of clear definition in terms of "the party line" causes me some concern. While I reject the modernization school understanding of AIDS as inadequate, I have some reservation about adopting without modification the dependency school understanding of HIV/AIDS. I, like Fortin, feel that "the official rhetoric of AIDS and underdevelopment gives only minimal voice to the reality of political struggle in which the epidemic is inevitably embedded" (1989, 205). The academic discourse of dependency does not adequately address the concerns of many people infected and affected by HIV/AIDS as will be shown in chapter four it is for this reason that I argue for an alternative framework. In addition, the fact that many modernization school authors include aspects of dependency discourse in their writing points to the cloudy boundaries between the two schools in some cases.

For these reasons I would suggest that while there are two bodies of writing relating to HIV/AIDS and development, they ought to be termed dominant and alternative rather than modernization and dependency school. Writing that could be described as relating to the dominant school refers to the modernization school and includes those authors who use some dependency school analysis. The alternative school refers to the more holistic dependency school writing and

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also includes the analysis of various activists. The alternative school would include all those who write about AIDS holistically either in development or health terms. While I refer to the modernization and dependency schools in this section of the thesis for the sake of clarity, the indistinct boundaries between the two schools should be borne in mind.

As has been seen above, many issues are included under the banner of AIDS and development. The remainder of this paper will be devoted to a discussion of several of these issues with particular attention being given to the approaches of the different schools to the issues. The first of these issues is the position of women in relation to AIDS and development.

Mcfadden, writing about health and gender in Africa, has stated that "If one looks closely at virtually all existing health policies and how they are implemented, the focus is on the child. The woman's health is important only because she is pregnant, and during that period, certain health services are made available to her" (Mcfadden 1993/94, 59). This is also the case for women infected/affected by AIDS. Herdt and Boxer summarize the position of women in relation to the pandemic until now:

> Thus far in the epidemic, women have been primarily viewed as vectors (e.g., as sex partners of IVDU's, bisexual men, or men patronizing prostitutes) or transmitters (e.g., perinatal infection), rather than as a distinct category requiring specialized approaches and culturally sensitive knowledge (Mitchell 1988, as cited in Herdt and Boxer 1991, 178).

Or in the words of Cindy Patton, "Women are considered vaginas or uteruses but

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never both at the same time" (Public lecture 1993). This attitude towards women

is exemplified by writing in the modernization school.

To give one example of this approach, de Zalduondo[11] describes the

modernization school view of women in prostitution (WIP):

> Rather than presenting WIP as links in broader networks of
> heterosexual HIV transmission, women categorized as prostitutes
> have been described as "infecting" their unborn infants, their
> clients, and, indirectly, their clients' other female sexual partners,
> as though HIV originated among WIP (de Zalduondo 1991, 224).

Or, as Usher writes,

> Blinded by the obsessive focus on sex workers as the source of the
> virus, many law-makers overlooked the simple fact that most
> prostitutes (unless they were intravenous drug users) must have
> picked up AIDS through sex with someone; presumably from a
> client or partner (1994, 33).

With this approach the fact that the women are living with HIV/AIDS is rarely a

matter for concern. The focus of attention is on the possibility that women might

pass on HIV. This lack of recognition of sex workers as individuals is quite

common, and is particularly evident at the country level.[12]

Ford points out in his case study of Thailand that "the greatest societal

concern has surrounded infection from prostitutes to their male customers" (Ford

1994, 90). This despite the fact that women contract HIV (or any other STD)

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[11] In this 1991 article de Zalduondo appears to be adopting a dependency
school understanding of AIDS, in contrast to her more modernization school
approach in an 1989 article.

[12] For example see Yole Sills (1994) discussion of prostitution in the
developing world.

from their male sexual partners much more easily than men contract HIV from women.

Also evident in modernization school writing is the sexual double standard and sexism. The double standard is pointed out by de Zalduondo in her discussion of WIP and AIDS research. She writes, "while one standard is applied to men, two are applied to women: one for "good" women and another for women who, for various reasons, are to be denied considerations according to the "good" and/or the powerful" (de Zalduondo 1991, 233).

Other examples of sexism are to be found in modernization school writings, and many are quite subtle. In the case of Christakis, women are ignored in most of his analysis implicitly; indeed we are barely mentioned. We are (presumably) included in his discussion of "people", "individuals" and "patients" but we are noticeably excluded at various points. Take for example the following,

> In addition to moving analysis inward, within the bodies of AIDS victims, we must move outward toward an understanding of the relationship between the patient and his sexual partner, his family, his doctor, his community, and beyond (Christakis 1989, 125).

I reject the suggestion that gender exclusive language is not really sexist, or that arguments for gender inclusion are merely semantics. Christakis purposely used gender neutral words like people, patients, etc. in his paper; was his selection of the male pronoun in the above example any less purposeful? I would suggest that if Christakis understood the position of women infected/affected by AIDS we

would have been included in this example. This lack of understanding is a common thread in the modernization school.

While the modernization school is interested in women primarily as transmitters of HIV, the dependency school is more interested in the role sexism plays in increasing the burden borne by women living with AIDS/HIV. The more radical of the dependency school authors point out the importance of viewing women as individuals, not just as vaginas and uteruses, when facing the AIDS pandemic (or any health concern).

One important area where sexism plays a role is that of research definitions. Women are excluded from drug trials, diseases common to women are excluded from definitions of HIV/AIDS, and double standards in terms of sexual behaviour are widely accepted by researchers (Denenberg 1990a, 72-3; Elbaz 1995, 58). This leads to poor quality research which claims to be universal or at least widely applicable. One example pointed out by Treichler illustrates this point: "Rates [of AIDS prevalence] estimated for all Africans are often based on small studies in urban areas; studies of "prostitutes" may in fact classify all sexually active single women as prostitutes" (1992, 389-90).[13] The double standard here is clear. The lack of reliable statistics hampers useful and realistic planning for the pandemic.

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[13] Defining prostitution in all cultural contexts as it is defined in North America or Europe is another questionable research practice. Cultural attitudes towards sexual activity are many and various. For a discussion of prostitution and the transactional value of sexual acts in Africa see Sills 1994, 28-29.

The sexism experienced by women in our daily lives and its interaction with the affect of HIV/AIDS is also a concern for dependency school authors. Hunt points out that genital mutilation is a dramatic, extreme, and physical manifestation of sexism lived by many African women (1988, 16-17). Many have observed a link between the practice of genital mutilation and increased prevalence of HIV.[14] Edemikpong, for example, writes, "We of the Women's Centre in Eket, Nigeria, have authenticated this research revelation, for of the 98,000 reported cases of AIDS in Africa since 1984, three-quarters are women who are from the areas where female genital mutilation is widely practiced" (in Hunt 1988, 17). While this is not definitive it certainly merits examination, as many dependency school authors assert.

Another aspect of women's lives that increases the effect of HIV/AIDS is our role as caregivers (see Ankrah 1991, 970-71). Agencies as diverse as the World Health Organization and the AIDS Coalition To Unleash Power (ACT UP) have recognised that women do most of the world's personal maintenance work (social reproduction). This inhibits women's ability to care for ourselves and encourages immunosuppression. The stress caused by the illness of a family member also speeds the deterioration of a woman's health. In the case of HIV this means, ultimately, a shorter life expectancy.

Another major issue within AIDS and development is the prominence of

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[14] See for example Philipson and Posner 1995, 840 and additional references cited by them in note 30 page 847.

biomedicine in world medical systems. The dominance of biomedicine is supported by modernization school authors and questioned by the dependency school. If those in the modernization school question anything about biomedicine, it is generally the expense of practicing biomedicine in the South that is of concern.

The PANOS Institute points out that care of a PWA in the United States from diagnosis to death costs US$65,000; in Brazil the average cost is US$21,500, Mexico US$7,345, in Zaire US$816, and in Tanzania US$367 (PANOS 1989, 82). PANOS makes the additional point that a single HIV antibody blood test costs more than the annual per capita health expenditure in many countries of the South (PANOS 1989, 82). The question generally asked by the modernization school is "How can developing countries afford to treat PWAs?"

Another difficulty that biomedicine poses is that it tends to treat individuals, not communities. Dependency school authors see this as a problem due to the limited understanding of health it demonstrates. An additional problem is the lack of understanding of the communities in which biomedical systems are to operate demonstrated by biomedical practitioners.

Modernization school authors see the treatment of individuals as being entirely acceptable. If the community sees this as a problem biomedical practitioners do not agree. As Christakis writes, "biomedicine generally stresses delivery of care to an individual; such individual-based medicine may be

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inappropriate in many settings, especially in Africa, where illness is sometimes viewed as a social as well as a personal phenomenon" (1989, 124-25). The implication here seems to be that a non-individual understanding of health is wrong.

As mentioned earlier, dependency school authors insist that a social understanding of health is necessary, especially in the case of AIDS. As Hunt writes,

> An epidemic, while having biological components, is a social event, not a purely biological one. As a social event it must be addressed socially for its damage to be controlled and its spread to be halted. The simple introduction of Western style medicine, with its individualistic curative approach that ignores social causation, will not succeed in attacking the root cause of this epidemic in Africa while the relationship of dependency continues. An approach that stresses the social structures which shape the epidemic and give it direction, that emphasizes public and social health concepts, is necessary to address social causation - and social cure (1988, 21).

This more complete understanding of health is vital to an understanding of the AIDS pandemic, as the Interagency Coalition on AIDS and Development states, "AIDS is only secondarily a medical issue; it is shaped by the development context, and it impacts upon the development process" (Interagency Coalition on AIDS and Development 1994, 4).

Likewise, an understanding of the class implications of disease is necessary for a full understanding of health.[15] Julie Hamblin states that,

> Increasingly, the global patterns of vulnerability to HIV indicate that

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[15] See also Sills 1994, 34.

the people most likely to become infected are those who, by reason of their social or economic position, are unable to protect themselves against infection (Hamblin 1993, 212).

Fortin feels that to understand the relationship between AIDS, medicine and underdevelopment one must understand "the relation between the reproduction of Western medicine and class" (1989, 208). He writes,

> Vincente Navarro, for example, argues eloquently that the real gap between the "haves" and "have-nots" is "between the capitalist metropoles and the dominant classes of the capitalist periphery on the one side, and the impoverished population of the capitalist periphery on the other. It is these class relations and exploitation that are at the root of underdevelopment, poverty, and the disease of the majority of the world's population" (Fortin 1989, 208).

Biomedicine as an example of capitalist enterprise is, Fortin feels, responsible for the prominence of biomedical systems in the South. In the case of AIDS this means that

> when one puts together the predominant Western model of treatment for HIV infection with all its complex and costly implications with the great need for health care in Africa, one emerges with a spectre of a host of Western business interests seeking to replicate both that system and its demands for expensive and profit-producing medical commodities (Fortin 1989 210).

As the dependency school argues, the root cause of AIDS is not just HIV, but the conditions in which the majority of the world live.[16]

A fourth issue within AIDS and development literature is closely linked to

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[16] For a discussion of the impact of class on HIV/AIDS in the US see Schneider 1992. Her discussion focuses on the interaction of class, gender, race and AIDS in the US, but her conclusions are relevant to the discussion of HIV/AIDS in many marginalized communities.

the question of biomedical systems. This is the question of drug and vaccine trials. The modernization school holds tightly to the belief in a vaccine to cure AIDS, and views this potential vaccine as the solution to the "AIDS problem". The dependency school believes that fundamental change in societal structure will be necessary before a vaccine has any hope of success.

Not only is fundamental change necessary for a just world, but if change is not adopted many people will not be able to afford a vaccine. As Elizabeth Reid has said "Even if a glass of pure drinking water were the cure to AIDS, it would be unavailable to large numbers of people" (in Klouda 1995, 478). Real development as described in chapter two is as essential to an end to AIDS as is a vaccine.

Modernization school authors accept biomedicine and feel that large scale vaccine trials amongst individuals who are "at risk of infection" but currently HIV free are necessary. Further, these individuals must be "pharmacologically virgin" and must not "self-medicate with putative anti-HIV agents" (Christakis 1989, 119). This means that individuals in the North are unlikely to be acceptable due to an unfortunate tendency to be relatively well informed and unlikely to accept the risk of HIV infection (Treichler 1992, 396). This means that medical esearchers from the North look to the South for suitable testing grounds.

Modernization school writers tend to accept this as an unfortunate

necessity, although some raise questions[17]. For example, will it be possible to obtain "informed consent" from participants? Will participants have access to condoms and other means of protecting themselves from infection? If condoms etc. are provided how will this affect trial outcomes? (see PANOS 1989, 102-3).

Despite these concerns, vaccine trials in the South have recently been approved by the World Health Organization (Global Programme on AIDS 1994, 1). In the near future two American companies will begin testing in Brazil, Thailand and Uganda (Global Programme on AIDS 1994, 5). Dependency school authors question how vaccine trials will be conducted, but rarely question their necessity. No mention was made in the WHO announcement whether participant countries would receive special consideration for allowing the trials or whether any resulting vaccine would be subsidised in the South. Subsidization of a potential vaccine by the North has been suggested but has received little attention, although it would seem little compensation for risking infection.

Another important question about the development of vaccines is for which strain of HIV is the vaccine. The Interagency Coalition on AIDS and Development explains that of the thirteen types of vaccine currently under development twelve focus on some version of a North American type while only one focuses on a type found in Africa or Asia (1994, iv). The one vaccine that is being investigated for use in Africa and Asia is of the least safe type of vaccine

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[17] For more discussion of the ethical questions raised by the implementation of HIV/AIDS vaccine trials see, Christakis 1988.

as it uses a whole inactive virus (Interagency Coalition on AIDS and Development 1994, iv). This certainly raises questions about the disinterested nature of scientific investigation and drug companies.

Another issue that should be of concern in discussions of development and AIDS is heterosexism. The assumption that all people are heterosexual and that heterosexuality means a married partnership between one man and one woman is unrealistic and leads to very poor scholarship. The assumption of heterosexuality according to the above model renders all other modes of sexual expression abnormal or deviant. Thus not only are homosexual relationships or sexual activity ignored but so too are polygamous relationships. Or, as was mentioned above, single sexually active women are grouped as sex trade workers because their sexuality is not sanctioned.

Sexual activity outside the heterosexual norm is often criminalized, and those who participate in it discriminated against. This leads to marginalization and poor health for those in communities which are discriminated against. In the case of HIV/AIDS it has also led to fear and blame for homosexuals around the world (Palmer and Dorf 1995, 21).

The widely held association between HIV/AIDS and homosexual men has lead to many authors including a variety of disclaimers when they write about HIV/AIDS in Africa, Asia or Latin America. Philipson and Posner write,

> In sharp contrast to the situation in the United States, homosexual relations and the sharing of hypodermic needles by intravenous

drug users are minor routes for the spread of disease in Africa
(1995, 836).

In a subsequent note the authors state that they are not aware of a systematic

study on homosexuality Africa[18], but that in one study conducted in Ghana there

was very little evidence of homosexuality (Philipson and Posner 1995, 845 note

5). And while this may be true in Africa[19] I would hesitate to make such a

generalization if there has not been a systematic study of modes of sexual

activity in Africa. Further, I would hesitate to make such a generalization based

on one study in one country in Africa. Afterall, Africa is continent with many

diverse peoples and nations.

When authors do write of development and AIDS in relation to

homosexuality it is generally in an aside or as a brief note. All too often the

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[18] It is often claimed that homosexuality is a western phenomena imported
into the South by the media or foreigners (see an example in Jayaseelan 1995,
56). This is far from being the case but a full discussion of this point is beyond
the scope of this paper. The following references must serve to give a superficial
indication of the existence of homosexual activity around the world: on
homosexual infection rates in Korea see AIDS Analysis Asia 1995, 12-13; on
Vietnamese homosexual men's knowledge about HIV/AIDS see Franklin 1993;
on Pink Triangle Malaysia see Jayaseelan 1995; on homosexual male influence
on early AIDS organizing in Chile, Brazil, Malaysia, Singapore, India, Hong
Kong, Japan, Indonesia, the Philippines, the former Soviet Union, Zimbabwe and
South Africa see Altman 1995; for various references to homosexual men in
Thailand see Usher 1994.

[19] In his discussion of community responses to HIV/AIDS Dennis Altman
refers to "gay influence" in community support work in Zimbabwe and in South
Africa (1995, 11). If there were very little homosexual activity in those countries,
it is questionable that there would have been "gay influence" in their AIDS
organizations.

existence of homosexuality of any type is rarely mentioned (Palmer and Dorf 1995, 22). When homosexuality is mentioned it is generally in reference to gay men. Lesbian and bisexual women are hardly ever mentioned in discussions of development or HIV/AIDS.[20] Marginalized groups are frequently a topic of discussion and analysis in development journals and most types of discrimination are discouraged, at least at the policy level, in development studies. This does not seem to be the case in relation to heterosexism and homophobia. It is particularly important in the case of HIV/AIDS, where sexual transmission is so common, that this come to an end.

While these are but a few of the issues central to AIDS and development they are very important ones. We will not be able to slow or stop the spread of HIV/AIDS until we understand it, and we will not understand the pandemic until we grasp its far-reaching complications. Understanding AIDS means more than medical descriptions of a retrovirus and clinical complications, it means understanding the lived experience of people infected/affected by AIDS. This means understanding the experiences of women, men and children in the North and the South. The complexity of these experiences is staggering.

To begin to understand AIDS we need to examine how AIDS interacts with communities. How does a woman in the inner city live with AIDS? How does a business executive in Thailand live with AIDS? How do you or I live with

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[20] For a discussion of the means of transmission between women and the likelihood of that transmission see Stevens 1994.

AIDS? As we begin to understand these realities we will come to understand how to educate our communities about HIV/AIDS prevention. Prevention will include changing the way that people live so that immunosuppression is not an everyday occurrence and so that communities can control the way they experience illness and health.

This change will have to be fundamental and far reaching. It will have to include very basic changes in how we understand health and medicine. It will have to include redistribution of wealth between the North and the South. It will have to include the understanding that not all communities in the North are "developed" and privileged and that not all communities in the South are "underdeveloped" and poor. Change has to begin now in all our communities.

In the following chapter it will be shown that women living with HIV/AIDS are able to perceive and articulate this need for change from their own experiences. It will be argued that this ability is evidence of the need to change to definitions of development and health that are holistic. For only when holistic definitions are used will the real needs and concerns of people infected and affected by HIV/AIDS be addressed.

Chapter Four

It is the purpose of this chapter to examine why it is so important for the concepts of development and health to be applied holistically. Not only is a broad understanding of these concepts required in order to develop policy, but a full understanding of any issue cannot be achieved unless an appropriate framework is applied in its analysis.

When the topic to be considered is one related to health a holistic approach is even more relevant. The experience of having a disease occurs internally and externally. A disease manifests itself through certain physical symptoms. How an individual feels about her or his illness also affects the manifestation of the disease. Likewise, how the family of the individual feels about the illness and whether the family supports the individual affects the experience of disease. Similarly, how society feels about the illness and whether society supports the individual and her or his family affects the manifestation of the disease. Not only body processes, but also social processes will determine the experience of a disease.

In addition, the environment in which the individual lives and works is

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important. Is the environment contributing to the illness, did the environment

cause the illness or influence it? All or these things and many more mediate the

experience of disease.

Susan Sontag has written of these issues at length, in reference to

several diseases including cancer, tuberculosis and AIDS. She illustrates how

disease is given meaning and how that meaning influences understanding and

experience of a particular illness. Sontag writes,

> Nothing is more punitive than to give a disease meaning - that
> meaning being invariably a moralistic one. Any important disease
> whose causality is murky, and for which treatment is ineffectual,
> tends to be awash in significance. First the subjects of deepest
> dread (corruption, decay, pollution, anomie, weakness) are
> identified with the disease. The disease itself becomes a
> metaphor. Then, in the name of the disease (that is, using it as a
> metaphor), that horror is imposed on other things (1990, 58).

If society views a particular disease with horror this will effect an individual's

experience of that disease. Not only may family and friends view affected

individuals in a particular manner but one's view of oneself will be altered. How

could it be otherwise if one feels that corruption, pollution and decay are within?

In North America AIDS seems to have been invested with so much

meaning that real understanding of the disease has been marred. In other parts

of the world AIDS carries other meanings but the power of the North American

media is such that many of our meanings have been exported.[1] Here the

response to AIDS has been a microcosm of all that is ugly in society. Our fear of

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[1] For discussion of this point see Patton 1994, 96 and Altman 1995, 8.

this "new" disease has revealed much of the homophobia, sexism, racism and discrimination directed towards the poor that had been hidden.

As Sontag summarises in reference to AIDS,

Every feared epidemic disease, but especially those associated with sexual license, generates a preoccupying distinction between the disease's putative carriers (which usually means just the poor and, in this part of the world [North America], people with darker skins) and those defined - health professionals and other bureaucrats do the defining - as the "general population": white heterosexuals who do not inject themselves with drugs or have sexual relations with those who do (1990, 115).

As Sontag (1990, 132-148) illustrates, we have long associated disease with punishment and those punished with those who are alien, other, foreign. In this manner those punished by illness can be made distant from ourselves and safely vilified as individuals in some way evil and suitably punished. AIDS has set some individuals apart, bureaucrats have labelled them "risk groups", they have been judged somehow guilty and sentenced (Sontag 1990, 134). If society can distance itself from AIDS by making it a disease of others then the "general public" will be safe and it can be ignored.

The failure to approach AIDS holistically has led to grave misunderstandings and limited our ability as a global society to face AIDS realistically. AIDS is not a living thinking entity. It does not judge each individual on her or his merits and choose those whom it ought to infect. Being HIV positive is an experience that is mediated by social conditions, therefore having HIV/AIDS becomes more than just a condition of the body. Individuals exist in

communities. Therefore that community's understanding of health and of HIV

plays a role in how HIV is experienced and understood. Programming and

planning must consider these various understandings.

As it is understood by the biomedical system AIDS is spread through a

virus, HIV, which is passed to an individual primarily through blood, semen,

vaginal secretions and breast milk[2]. Certain practices facilitate this transmission;

the sharing of blood, the exchange of semen, vaginal secretions or blood during

intercourse, and perhaps the process of childbirth and breast feeding. Other

medical or health systems, such as those mentioned in the second chapter,

understand HIV/AIDS and its causation differently. Regardless, AIDS has not

created innocent or guilty victims; the advent of AIDS means simply that the

global community has another challenge to face, the realities of people infected

and affected by AIDS.

The initial failure of the medical community to appreciate the nature of

AIDS was well demonstrated by doctors in the United States. Early in the course

of the US epidemic most of those infected by HIV were gay men. Doctors came

to associate the disease almost exclusively with men who had sex with men.

Intravenous (IV) drug users were another community that became associated

with AIDS. For some reason, it took quite some time for doctors to realize that

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[2] It is currently open to debate how infectious breast milk may be. The
number of possible cases of HIV transmission through breast milk are limited. In
fact, some argue there have been as few as eight cases; all in special
circumstances (see Garcia-Moreno 1991, 95).

women too could become infected. This belated recognition of women had a significant impact on how women were perceived in relation to AIDS.

When doctors in the US realized significant numbers of women were infected with HIV they created the category "partners of" to refer to women. So if a woman was HIV positive she was a partner of an IV drug user or a partner of an infected man. She was not herself, a woman living with AIDS. On this point Patton comments,

> Hidden within the epidemiological category 'partner of' or referred to in the media as 'heterosexual woman' it seems unlikely that women who might be described in either of these ways actually experience themselves as living in a community defined by their social relationships with men. Few heterosexual women were likely to 'identify' with risk reduction advice which had once been so strongly associated with 'deviance' (1994, 48-9).

Doctors in the US seemed oblivious to the simultaneous development of an African epidemic which included large numbers of HIV positive women.

For women in the sex industry this strange understanding of AIDS was even more pronounced. Patton writes,

> Prostitutes emerged as the hysterical symbol of epidemiological crossover from a perceived nether world of sexual deviance into mainstream society. This misapplication of early epidemiology resulted in increased policing and harassment of women identified as 'prostitutes' in many locals around the world (1994, 53).

In other words epidemiologists were concerned that prostitutes would transmit HIV to mainstream society through the men who hired them for sex. There was little concern for the prostitutes who were infected as individuals, apart from preventing them from transmitting HIV. Indeed it was rarely mentioned that in

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order to transmit HIV the prostitute must herself (male prostitutes were rarely considered) be infected. In addition the biological fact that it is much more likely for a women to become infected by a man than a man to become infected by a woman was not considered (Patton 1994, 53). The question of how these women became infected was never asked.

This failure to approach AIDS in the US holistically has had wide ranging implications. The Centre for Disease Control (CDC) in the US is very influential in setting the accepted medical definition of HIV and AIDS globally. The CDC did not include the diseases common amongst women infected with HIV or having AIDS in its definition until 1993 (Patton 1994, 13).[3] For this reason women died of AIDS in the US and elsewhere without being counted in national AIDS statistics or being able to receive the support granted to those meeting the definition.

As doctors in the US have failed to understand AIDS holistically so has the rest of the global community. For some reason governments and many international organizations have failed to see much that is obvious about AIDS when an unrestricted approach is taken. We must understand that a person infected by AIDS is influenced by more than a virus in her or his body. As Peter

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[3] It is important to note that inclusion of women's diseases in definitions of HIV and AIDS has had little impact on the lives of women in the South. For most of these women gynaecological screening, diagnosis, and treatment are scarce to non-existent: treatment of STDs is expensive and out of reach for many (Patton 1994, 86). More basic inclusion of women's needs in many health care systems will be necessary before changes in definitions will be of use to them.

Aggleton writes, "Indeed, one of the most striking characteristics of the epidemic has been its capacity to reinforce existing inequalities - of gender, of social status, of race, and of sexuality (in Patton 1994, *vi*). If we wish to end, or at least control, the spread of HIV then we must fully understand how it is experienced. To reach this understanding we must use not only scientific research into the medical realm but also social research into the lived experience of people infected and affected by AIDS.

Individuals living with HIV or AIDS understand and express this need for a holistic approach when they are permitted to speak. To illustrate this point and to demonstrate the need for a holistic approach to AIDS the voices of several women from around the world will be quoted in this chapter. It might be asked why women were selected to represent people infected and affected by AIDS. The reason lies both in the number of women infected and affected by AIDS. Women make up the majority of health care providers world wide (Patton 1994, 43). Women are globally less privileged than our male peers. As expressed by Patton,

> Although the status of women varies dramatically in specific locales around the world, when compared to male peers, women are virtually always less well educated, less well nourished, less politically active or powerful, and less economically viable. In most developing countries, the morbidity rate for females of all ages is higher, largely because women receive less health care, and receive it later in a medical syndrome (World Health Organization, 1985). In addition to less access to health care, lower levels of nutrition and calorie consumption result in higher morbidity and mortality for female children (1994, 81).

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As sexual activity is a major means of HIV transmission, the fact that few women have the opportunity or ability to refuse to have sex with their male partners, or insist that a man use a condom even if she knows he is infected, places women in a precarious position. Insisting on condom use or refusing to have sex with a partner may, in many communities, "...invite spousal abuse, rejection and social ostracism" (Canadian International Development Agency 1993, 1). And finally it is possible that globally more women are infected or affected than men.[4] The voices of women are therefore well placed to illustrate the various elements that mediate the experience of AIDS

The following section draws from the collection of women's voices in Positive Women: Voices of Women Living With AIDS (1992). The editors of this work are two HIV positive women, Andrea Rudd and Darien Taylor. All of the women contributing to the book are either HIV positive or have AIDS. Submissions to the anthology were solicited in five languages through an international mailing list to various service organizations. AIDS newsletters were also asked to publish the call for submissions. The editors were afraid that limited literacy amongst women, the need for anonymity and various other

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[4] This statement may seem problematic to many readers, especially those in North America and Europe. What we need to realize is that in most of the world about equal numbers of men and women are infected with HIV. New infections with HIV can be expressed as a ration of 3:2; three infections in women for every two in men (Picard 1996, A1). Already in Africa equal numbers of women and men are infected (Philipson and Posner 1995, 836). When one considers that it is women who do the majority of health care work and thus make up the majority of people affected by HIV/AIDS, this statement seems much more reasonable.

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barriers would prevent submissions from a wide variety of women. For this reason contributors were encouraged to use visual as well as written means to make their submissions. Submissions on audio tape were also welcomed. Women were encouraged to submit materials in their own languages. Submissions were eventually obtained from fourteen countries. The published works were identified by country and by whatever name the creator(s) chose. The editors provide a brief note on all of the contributors.

In this thesis only excerpts from the written portions of the anthology will be referenced. Each quotation will be referenced by the author's name, her country and the page number in the anthology. This collection was selected as the diverse voices it presents give an indication of the lived experiences of women living with HIV/AIDS. Many types of women living with AIDS are not represented here, but the purpose of this section is to illustrate that these women are aware of how many things mediate their experience of AIDS.

The editors efforts to limit bias met with some success, but there were some areas of difficulty. The voices of women from Asia are absent from this anthology. This is unfortunate as their presence would enrich the collection. The editors give no reason for the absence of women from Asia, although it might be assumed that language would be a major barrier. Advertising for submissions might not have been as widely translated and distributed in Asia. Other areas of bias may have entered the collection through the wording of the advertisement or through the types of newsletters in which it was placed.

Many topics were covered by the women in the <u>Positive Women</u>
anthology, but several themes were brought out again and again. The attitudes
held by people about AIDS; lack of control over reproduction and sexuality,
biomedical responses to AIDS; the relationship between the environment and
AIDS; all of these were major themes. One of the most significant
understandings to be drawn from the anthology is that the attitudes held by their
communities have a major impact on how individuals experience AIDS.

One of the most damaging aspects of the attitudes held about AIDS is the
isolation of individuals caused by discrimination. This isolation affects how an
individual feels about her or himself and how the individual is treated by others.
This can lead to early or unnecessary death as was the experience of Yara, a
member of Grupo Pela Vidda (Group for Life), in Rio de Janiero, and her
husband. She says,

> My husband died of both depression and discrimination. He didn't
> die of AIDS. He was HIV positive, had tuberculosis and recovered
> from it. He came back home and started thinking only about AIDS.
> He was a very "macho" man. People think that because he was in
> prison, when he was there he was a woman. But it is not true. He
> did drugs. ... On his medical report, it says that he died of AIDS
> because he had a positive HIV test. But he only had biliary
> tuberculosis that had been treated two months before. He had
> gained weight and he didn't have any other infection. He died of
> depression and discrimination (Yara, Brazil, 43).

Yara is clearly expressing her frustration with societal attitudes that link HIV
infection and homosexuality. Their community thought that if her husband had
HIV he must have contracted it from having sex with another man; for her

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husband this notion was unacceptable and worry about it contributed to his

depression and eventual death.

This perceived link between homosexuality and AIDS is a strong one. For

this reason it does not occur to many people that a woman could have AIDS.

Many women who are HIV positive respond to this attitude by not being open

about their infection. Ill considered remarks reinforce this decision. Maria

provides an example,

> People I know don't know that I have AIDS. They think AIDS is
> exclusively a disease of homosexuals. They make dirty jokes
> about it. Once, for example, there was a disgusting bottle lying
> somewhere, mouldy and grimy. Suddenly someone said, "Put this
> AIDS bottle away" (Maria, Hungary, 213).

As Sontag has written, the use of AIDS as a metaphor for all that is vile and

disgusting, as in this example, is an indication of society's attitude toward AIDS

and the people who live with it.

Another attitude that contributes to the infection of many women is their

impression of who gets HIV and what those individuals are like. People who look

healthy and who they trust are not HIV positive. Kecia Larkin acknowledges this,

> This man contracted the disease in Toronto. Somebody gave it to
> him. He knew about it, but he didn't tell me. I trusted him, so we
> never used condoms and we shared needles. He looked healthy.
> He got into an accident and that's when I found out that he was HIV
> positive. At that point, I knew that I had it. And then it was easy to
> blame myself because I was just another poor little Indian from
> Alert Bay who had run away, gotten into drugs and became a
> prostitute. I felt I deserved it (Kecia Larkin, Canada, 56-7).

Larkin also points out how a poor self image can be detrimental and lead to self

blame or self condemnation. She feels that growing up in the Native community of Alert bay, Vancouver Island contributed to this poor self image as it included sexual abuse and a family history of alcoholism (Kecia Larkin, Canada, 55).

How society treats the ethnic or racial group to which an individual belongs is another type of attitude which mediates an individual's experience of AIDS. Society wide discrimination against African-Americans has strongly influenced how Imani Harrington lives with AIDS. As she writes,

> I have been negated, restrained and repressed as being someone deviant. I have been emotionally strung out and held hostage by the outer laws that have so forcefully governed my existence as a black woman in America. Here in America I am the "alien," the "foreigner" with the AIDS virus. My people have been set apart, divided and damn near conquered in this society. We have been locked away in ships, in jail cells, in cold coffins. We have been ostracized and criticized. Our culture, tradition and languages have never been accepted. If this is not American quarantine, then tell me what is (Imani Harrington, United States, 180)?

The above remarks give an indication of how attitudes affect women who are living with HIV/AIDS. How their communities feel about them affects their actions and attitudes held in their communities affect how they act. If an appropriate definition of development was in use in our communities this would not be the case. That is to say the discrimination faced by Larkin and Harrington would not have occurred. The homophobia of Yara's husband and their community would not have undermined his health. Maria would not be afraid to openly say she was HIV positive because of how her community thinks about AIDS.

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Societal attitudes determine how open people are about their infection as well as other actions they take while living with AIDS. Many women face a number of struggles when they enter a sexual relationship after their infection. First is the question of whether she should tell her partner she is HIV positive. Either decision has many ramifications as Marta's experience demonstrates,

> To the first man, I didn't say anything [about her HIV status]. I only insisted that we use condoms and he accepted this without a problem. But after a short while, he found out that my husband had died of AIDS. Even though he had used condoms, he came looking for me. I heard that he was armed; I heard many stories... (Marta, Brazil, 32).

After describing two other experiences Marta explains how she has decided to act in the future,

> This is the way I try to proceed. I don't tell the truth [about her HIV status] because the truth makes the person run away. But I look for other ways of guaranteeing that the person will not be at risk: using condoms, having safe sex (Marta, Brazil, 33).

It is not only the fear of losing personal relationships that prevents many women from revealing their HIV status, but also the fear of losing their jobs, or fear for their children. As Dora writes,

> I am not open about being HIV positive because of my daughter. I am afraid that she will not get a boyfriend because they will be afraid of her, since her mother has HIV (Dora, Brazil, 38).

The potential loss of employment if it becomes known that they are HIV positive is also a major concern for women. Many women in the anthology expressed this concern. Elizabeth states,

> I am still going on with my job as a nurse, which I am sure I might

be forced to stop at any moment should my employer find out about my situation. I have so far come across many people who are HIV positive since it is spreading here in our country like bush fire. Whenever we meet, we try to comfort each other and it helps one to cope with the situation and the reality (Elizabeth, Tanzania, 67).

Even in North America where AIDS education and human rights legislation should eliminate discrimination based on HIV status, women fear losing their jobs if their HIV status becomes known. Heather explains,

I didn't tell anyone, except the people I had slept with. Absolutely nobody knew for years until three months ago. My family didn't know. It was very alienating keeping it a secret. But when I thought about what would happen if they knew, keeping it a secret seemed less of a stress. My only source of income was running a daycare in my home. And I wasn't willing to deal with what the parents would do if they knew I had AIDS. I was also afraid of losing my childcare licence. This was a very real fear because you can't get insurance when you are HIV positive and you have to have insurance to get a childcare licence (Heather, Canada, 69).

Conditions of health as defined in chapter two[5] cannot exist in an environment of mental distress. Women who must hide a significant aspect of their lives cannot experience mental and spiritual health as they cannot reach their full mental and spiritual potential. If this is the case, real health cannot exist. If in our communities we accepted this broad definition of health and acted on it we would work to end discrimination and thus ensure that people could experience real health. This in turn would facilitate real development, by

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[5] Health was defined in chapter two as "the full realization of individual physical, mental and spiritual potential within communities that are free of discrimination, stable and safe."

enabling people to live to their full potential which is identified as the first point in DAWN's five principles for human development.

Perhaps one of the most frequently mentioned concerns of the women in this anthology is the impact of HIV/AIDS on their children or potential children. Constant themes included: whether to have children; grieving over the decision never to have children; mourning the loss of a child after an abortion or death; and fear for their children's future.

Having decided not to have children M writes,

How much longer will I live? How much longer will I remain fairly healthy? And how long will my s 'ness torture me? I will never have children. To see children I. s me and makes me sad. Yet there is nothing more beautiful tha.. to see laughing, happy children (M, Switzerland, 97).

Dina's fear of infecting her child caused her to have an abortion, a decision that caused her a great deal of pain. She states,

Since I have been living in St. Gall, this is my first real crisis. It started with my pregnancy. The fear that my child would be positive forced me to have an abortion. I do not want to be sad. I have enough of all these depressions. Yet, I suppose this has to be, for I had to prepare myself for the death of my child (Dina, Switzerland, 83-4).

Conflicting advice from physicians and negative views of people having AIDS in the media increased the difficulty of making decisions about having children for Isabel;

Perhaps the greatest blow was the end of our hopes to have a child. Wait a few years, see what happens was the advice of some doctors. On no account have a baby. It will kill you was the advice of others. How can you bring an orphan into the world? Why me?

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Why us? Were we such awful human beings, that we had to be punished like this? All around us the media was stressing the idea that only wicked people carry the AIDS virus (Isabel, Zimbabwe, 129).

Another problem for HIV positive women having children is the lack of control they have over reproductive choices. They are even told when and where to have their children. Their choices are taken away from them. Roseanne provides an example,

> The next day we found out more devastating news. I wasn't going to be able to have my baby naturally, or in town. I was to be scheduled to be induced at a hospital in the city five hours away. I was told when to go to the city and to report to Dr. X to be induced (Roseanne, Canada, 136).

In some countries it is a matter of national AIDS policy to recommend abortion to all pregnant women who test seropositive. This is the case in Cuba where abortion is widely used and where most HIV positive pregnant women do abort (Scheper-Hughes 1994, 997).[6] Some authors, like Scheper-Hughes, claim that the insistence on reproductive rights for HIV positive women is part of an European and North American feminist reality and shows no understanding of reality for women in the South. She writes,

> Brazilian feminist arguments (influenced by North American and European feminist concerns and ideologies) advocating poor women's 'reproductive rights' to risk pregnancy in the face of

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[6] It is interesting to note that much media coverage has been devoted to the human rights problem posed by the use of AIDS Sanatorium in Cuba, while very little is heard about the routine recommendation of abortion as a human rights question On this point and on the operation of the AIDS Sanatoria in Cuba see Scheper-Hughes 1994.

seropositivity are out of touch with the reality of the pediatric AIDS tragedy and its aftermath (Scheper-Hughes 1994, 996).

One might likewise argue the Scheper-Hughes is out of touch with what women in the South want.

Brazilian women and all women are well able to identify their own wants, needs and rights. One of these rights is the control of our own bodies, and this means full reproductive control regardless of HIV status. As was stated in the Beijing Declaration,

> The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. Equal relationships between women and men in matters of sexual relations and reproduction, including full respect for the integrity of the person, require mutual respect, consent and shared responsibility for sexual behaviour and its consequences (World Conference on Women 1995, Paragraph 96).

As expressed by the Beijing Declaration and the women of Positive Women reproductive choice, control and responsibility is part of our full humanity. If we cannot be fully human we cannot have real health, nor be part of real development.

Lack of control over our lives is a major issue for women, and having control over our sexual lives and being able to make sexual choices is especially important for women. In the anthology, it was the women from Africa who most frequently raised this concern. These women were particularly apt at linking their lack of control over their lives with their infection. Rosemary Mulenga explains,

Within a relationship, it is usually the man who chooses his partner and controls when to have sexual intercourse with her. A woman who is worried about HIV infection or sexually transmitted diseases cannot refuse to have sex with her husband or insist that he use condoms. Accommodation supplied by the government or even by a private company usually belongs to the man. So the need for a home and money to buy essentials for her children and herself often forces the wife to stick to a degrading marriage situation (Rosemary Mulenga, Zambia, 29).

Unless they wish to face absolute poverty and social ostracism women in many cultures have few choices when it comes to obeying their husbands. As Elizabeth writes,

Because I was his wife and thus under his command, I had nothing much to do other than just cope with the situation. Our customs demand that a wife be faithful to her husband and accept whatever comes from him (Elizabeth, Tanzania, 65).

Even when their husbands put them at risk of contracting a variety of sexually transmitted diseases there is nothing to be done. Dambudzo provides an example,

After everything was done, I was told that my blood was negative for syphilis. What a big surprise, since I was sleeping with my husband who had all those sores. If I had said no, he would have said, "Pack your things and go right now, at midnight. If you tell anybody that I am sick then don't come back. Stay away forever." Where would I go while I was seven months pregnant (Dambudzo, Zimbabwe, 170)?

Unless women are empowered and thus able to make choices in our sexual lives how can we make other choices about how we will live?

This is yet another example of how lack of self-determination prevents health and development from being realities of many people's lives. As Hamblin

writes,

> For them [women], the obstacles to avoiding the risk of HIV
> infection are particularly great. Their position within families and
> societies means they are often not free to make their own decisions
> about their sexual relationships or to insist upon measures, such as
> the use of condoms or fidelity on the part of their partner, that
> would reduce their risk of exposure to HIV. Cultural expectations in
> relation t^ ..iarriage and childbirth and the absence of means of
> economic support outside the family unit compound the difficulties
> for women to avoid exposure to the virus. For these women, as for
> many poor or disadvantaged people of any gender or race, the
> main risk factors for HIV are inequality and powerlessness within
> their relationships and societies (1993, 212).

It is for these reasons that equality and empowerment form an integral part of

development.

Another example of this need for control comes from women writing about

their interaction with biomedical professionals. Like Roseanne (Canada, 136)

above, Pamela Blaney had little control over her medical treatment when she

became HIV positive. She writes,

> I also continue to see Dr C. I became quite trusting and dependant
> on him. I did what he recommended medically and even had an
> abortion when we found out I was pregnant along with the HIV test
> result. This happened so fast I never even had time to grieve.
> Today I still would have had an abortion, but I might have thought a
> bit more about it (Pamela Blaney, Canada, 220).

The treatment of women by AIDS researchers and society was a theme common

to other women writing is this anthology. As Iris de la Cruz writes,

> And women shouldn't be getting sick and left to die because there
> is no research on women and HIV. Our women are dying
> untreated and without benefits because, although seru-positive.
> PID [pelvic inflammatory disease] is not considered an
> opportunistic infection by the Centre for Disease Control. Women

are going untreated because they can't afford what little treatment there is. As women are the caregivers, if we allow our women to die, we are also condemning society to the same fate (Iris de la Cruz, United States, 116).

Other women found that while there were resources available to them about AIDS, biomedicine itself was inadequate. Lori Lynn Ayers describes her experience,

> The first thing was to learn all I could about this virus, and there are plenty of resources out there for that. What I learned is that no one has the answers; no one really knows about the phenomenon that is human life. Western medicine is good at some things, but limited. I never realized before how medicine in this country [the United States] provides a very narrow pathway to healing under the guise of protecting us from quackery. It is a monster gone out of control and is too heavily and too shamefully chained to the profit motive. Chinese medicine and many holistic modalities offer a different perspective that makes more sense on many levels. But your own mind and spirit centre makes the greatest difference of all (Lori Lynn Ayers, United States, 22).

Through the experience of living with AIDS many women have changed how they view their lives. Some women have found empowerment through living with AIDS. Nicole Follonier is one of these women;

> My goal is to find a "healthy" frame for my life, such as work that I like. Essential for me is to be able to talk openly about being HIV positive. It belongs to me like my feet, my hands. It has become an important part of me (Nicole Follonier, Switzerland, 206).

These women are asking for an acceptance of a definition of health that is not limited to biomedicine. The quality of their lives would have been enhanced if they did not have to struggle for the acceptance of their definitions of health. The recognition of the limitations of biomedicine has been and integral part of

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their experience of HIV/AIDS.

Other women in this anthology have found a broader understanding of the world we live in through having HIV/AIDS. For Fran Peavey this has meant an understanding of the connections between how human life is lived and the environment. She writes,

> We live in a world that is too polluted. There is not enough of an ozone layer left to protect us. Too much radioactivity has been released. New viruses mutate or are manmade; new conditions threaten our species.
>
> ...
> Maybe we people who carry the AIDS virus are the canaries in the mine. Maybe we can whistle such a true and sweet song that our species will see that we must get out of the mine; we must change our addiction to consumption, pollution and mindlessness (Fran Peavey, United States, 255).

Carole Lafavour echoes this understanding,

> It's trying to live life in balance. Without understanding the rhythms and cycles of all life, of Mother Earth and being respectful of them, human life (life of the two-leggeds) becomes disconnected. We live a life of dis-ease. As someone has suggested, we (the world) is suffering from immune deficiency (Carole Lafavour, United States, 265).

Through their voices these women have shown that having AIDS is more than simply having a disease. Having AIDS is living daily life as someone who is disempowered. For those who have been privileged, this means their lives radically change. They experience discrimination in ways they never have before. For those who have lived with sexism, racism, heterosexism or other types of discrimination their oppression is compounded. As Claudia Garcia-Moreno writes,

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AIDS has been used to legitimise prejudices that already exist in societies. It is important therefore to carefully consider our attitudes and even the language that we use when dealing with the subject. The social, political and economic aspects of AIDS are as important as the medical and biological ones in improving the understanding of the disease and in decreasing transmission. Amongst these, gender is an important aspect and all of those involved in this field need to be aware of the existing biases (1991, 97).

Most people having AIDS find new understanding of their lives and some use this understanding to take action. What is needed then is to encourage this understanding and to empower all people having AIDS to take action to change the conditions (whether biomedical or societal) that impede the broad understanding needed to face AIDS. As the women cited from the Positive Women anthology have shown the required actions are many and various. Garcia-Moreno summarises;

Women should be offered appropriate information and education so that they can make informed choices. This should take into account their particular social and economic circumstances, as information is not enough if women are not in a position to have control over their lives and bodies. The messages will be different depending on what women are addressed. Sex workers, women in stable relationships or adolescent girls about to start sexual activities need to be approached with messages that are relevant to their particular situation. In the case of prostitutes it is important not to make them scapegoats. Health education should be aimed at their clients as well (1991, 96).

All people infected and affected by HIV/AIDS should work for the broadest possible definition of health in order that all aspects of AIDS can be addressed. If this approach was taken it would facilitate real development in the global community.

As has been shown in this chapter, achieving gender equality has great importance both for women having HIV/AIDS and in order that real health may be achieved. Likewise, gender equality is an important aspect of real development. Similarly, discrimination against people having HIV/AIDS must cease in order to achieve real health. The end to all types of discrimination is also central to achieving real development. Working towards a holistic approach to health facilitates and reinforces efforts directed at attaining real development.

It has been the purpose of this chapter to illustrate the many impacts on individual experiences of HIV/AIDS. Women are well placed to discuss these impacts as we are placed in the centre of the pandemic; as care givers and as people infected and affected by HIV/AIDS. As Brooke Grundfest Schoepf has written,

> AIDS embodies unequal social relations, particularly gendered inequality in power and access to strategic resources. Throughout the world, patriarchal structures of economic, political and social inequality limit the ability of most women to control independent incomes. These structures also promote women's socialization for subservience to men and limit the ability of most women to say "No" to risky sex (1993, 69).

It has been demonstrated that a wide variety of experiences impact on the health of women living with HIV/AIDS. As this is the case their health is affected. Thus, when discussing the health of people with HIV/AIDS, the definition of health that is used needs to consider all of these impacts. Therefore the definition of health used ought to be a broad one and holistic in nature in order to encompass physical, mental and spiritual health.

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As many kinds of discrimination affect people with HIV/AIDS this too ought to be considered in trying to understand their lives. These types of discrimination include economic, environmental, gendered, sexual and racial discrimination. These are issues of society and the direction in which our communities wish to develop, if we wish to work towards real development as defined in chapter two. Therefore when we as a society consider development we must consider not only economics but also the environment, gender roles, sexual relations, racial discrimination and many other matters. This is why we must use a broad definition of development.

In the following chapter the arguments presented in this thesis will be summarized and the conclusions that can be drawn from them will be discussed.

Chapter Five

It has been the purpose of this thesis to demonstrate that our limited definitions of both health and development have restricted how we understand HIV/AIDS. These limitations have affected HIV/AIDS programming and policy making and thus have impeded successful action to control the spread of HIV and the impact of HIV/AIDS on individuals and communities. If broad definitions of health and development were used to direct policy and programming in health and development greater success would be likely.

At the level of policy, many individuals and agencies recognize the diverse impacts on HIV/AIDS. For example, the Beijing Declaration states,

> HIV/AIDS and other sexually transmitted diseases, the transmission of which is sometimes a consequence of sexual violence, are having a devastating effect on women's health, particularly the health of adolescent girls and young women. They often do not have the power to insist on safe and responsible sex practices and have little access to information and services for prevention and treatment. Women, who represent half of all adults newly infected with HIV/AIDS and other sexually transmitted diseases, have emphasised that social vulnerability and the unequal power relationships between women and men are obstacles to safe sex, in their efforts to control the spread of sexually transmitted diseases. The consequences of HIV/AIDS reach beyond women's health to their role as mothers and caregivers and their contribution to the economic support of their

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families. The social, developmental and health consequences of HIV/AIDS and other sexually transmitted diseases need to be seen from a gender perspective (World Conference on Women 1995, Paragraph 98).

Through the Beijing Declaration the UN system has indicated its awareness that unequal power relationships and gender based discrimination affect HIV/AIDS. While the actions and effectiveness of the UN response to HIV/AIDS may be called into question,[1] at least at the policy level the existence of UNAIDS and statements like those above indicate a high level of awareness of the various impacts on AIDS.

At the international level, there are other signs that there is recognition of the various impacts on and of HIV/AIDS. The Organizing Committee of the XI International Conference on AIDS in conjunction with the National Library of Medicine in the US has provided a searchable index of Programme Abstracts from the conference on the World Wide Web (http://www.cdcnac.org/ nlmabs/index.html). A search of this index reveals that a wide range of topics related to HIV/AIDS were covered at the conference.

For any given search the maximum number of responses is forty, so it was impossible to discover the complete number of papers presented at the conference that relate to development. Of the first forty responses to the search term "development"; four related directly to development as defined in this thesis, twelve were biomedically related, and twenty-four related to the development of

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[1] See Klouda 1995.

statistical or educational tools or project development. Definitive conclusions cannot be drawn from this type of search, but it does indicate at least some discussion of AIDS and development at the policy level.

Further support for this conclusion was given when the following search terms were used: economic development; health development; personal development; political development; social development; spiritual development. Using these terms the search engine would locate any abstracts that contained both words. In all six cases the maximum number of returns was reached. This indicates, at least superficially, that a wide range of issues consistent with broad definitions of development and health were discussed at the conference.[2] It appears that discussions at the XI International Conference on AIDS also demonstrated an acceptance of the many issues that impact on HIV/AIDS.

There are also non-governmental organizations which approach HIV/AIDS programming from broad definitions of development and a holistic understanding of health. Many of the activist originated organizations[3] responding to HIV fall into this category. As Elbaz writes of activists,

[2] An additional search using separately each of the following was also conducted: economic; health; personal; political; social; spiritual. Again, in all cases except "political" and "spiritual" the maximum number of returns was reached. "Political" returned only 38 responses and "spiritual" returned only 21 responses. This may be attributed to a disinclination to discuss politics and spirituality, but definitive conclusions from this sample are impossible.

[3] For a detailed discussion of activist approaches to HIV/AIDS see, Elbaz 1995.

Because activists challenge the state, the economy, and the
autonomous influence of high-powered researchers, theirs is not a
single, but a multiheaded challenge. ... the activists' perspective
and strategies are actually multifrontal, taking on economic,
political, ontological, and epistemological challenges (1995, 47).

This approach starts with an understanding of HIV/AIDS that is multifaceted, and

thus a multifaceted understanding of health. This type of activist organization is

then consistent with the definitions of development and health used in this thesis.

Other organizations also express this broad understanding. The South

African government AIDS programme is one of these. The director of that

programme, Natalie Stockton, has referred to their approach to HIV/AIDS as a

"total paradigm" (cited in Sills 1994, 35). Stockton includes "poverty, violence,

and the powerlessness of women" in that paradigm (cited in Sills 1994, 35).

Individuals have also noticed the need to approach HIV/AIDS in a manner

that recognises the diverse impacts on people living with HIV/AIDS. Usher is

one example of a researcher who writes from this broad based understanding.

She writes,

This essay diverges from conventional ways of thinking that often
focus on a single dimension of the epidemic - AIDS as a public
health problem, or a reflection of racial or sexual or class
discrimination; AIDS as a function of pharmaceutical politics, or a
political priority in competition, say, with military spending; AIDS as
an issue of population control, the sex industry or tourism. AIDS is
related to all of these things, but each seems to illuminate only one
facet of this many-headed beast (Usher 1994, 10).

Usher's approach to HIV/AIDS is informed by her environmental background. In

fact her essay which is quoted here compares HIV/AIDS and forest degradation

in Thailand. It is an important and apt comparison:

> Just as AIDS signals the collapse of human immunity, so
> environmental degradation undermines the resilience of an
> ecosystem. The rain no longer falls in its usual cycles, and the soil
> no longer clings to the hillsides. The streams dry up when once
> they delivered water to lowland villages throughout the dry season,
> only to swell to bursting with the coming of the rains. Forests that
> once provided food and medicine and shelter become waste lands
> or barren timber factories that can no longer sustain communities.
> The self-regulating system that functioned according to its own
> logic as an independent part of the greater whole is suddenly
> overwhelmed by external forces. The slightest shock, a fire, a
> typhoon, a common cold - things which would normally cause a
> minor irritation, but would heal and be quickly forgotten - ravage the
> weakened system, and sometimes destroy it completely (Usher
> 1994, 24).

For Usher HIV/AIDS is as much a development issue as is the environment.

Klouda too sees the need to approach HIV/AIDS with the knowledge that

more than biomedical systems are involved in its management, and that

particular conditions intensify its effect. He states,

> Therefore, taking these areas of comparative analysis, individual
> impact, impact on culture and society, and economic and health
> systems impact, we can say that the impact of AIDS and HIV
> infection will always be greater in poor societies and on the poorest
> and most marginalized people (especially when they are women)
> and that this reflects the unequal impact of other social and
> physical ills (Klouda 1995, 478).

Klouda goes so far as to state that the association between AIDS and social and

physical ills is so strong that HIV could be considered a marker in the situation of

people (1995, 480).

The above individuals, organizations and international agencies all

recognize, at least at some level, that there are many impacts on and of

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HIV/AIDS. While they might not agree that we should therefore broaden our definitions of development and health. I feel that the recognition itself demands just that. How can we form policy and plan action if we do not start from a complete framework? When we attempt to work from other frameworks the result is of limited usefulness as is shown by much of the literature discussed in chapter three.

While it is my opinion and the contention of this thesis that the best approach to understanding AIDS is one that is informed by a broad definition of development and a holistic definition of health there are many reasons for limited acceptance of this opinion. As was demonstrated above, at the policy level this opinion has already gained some acceptance. But it remains to be seen whether it will ever be accepted at the practical level.

Klouda summarizes five of the reasons that make action based on holistic understandings and supportive of change unlikely in his 1995 article. He writes,

> - The lack of interest of donor governments in achieving an
> equitable international and national distribution of resources that
> will allow the development of socially caring policies in all countries
> and societies (1995, 485).

It is very unlikely that any government that wishes to maintain its international position would encourage a redistribution of resources.

Similarly, national power structures are based on power held by a few individuals or families. If all members of a society had equal access to power this structure would be destroyed. Thus the equality necessary for real

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development will never be a priority of those in power, or as Klouda states,

> - The concern of governments with the destabilizing potential of
> providing truly equal access to social services (such as education)
> and rights (including legal support and the concomitant use of truly
> participatory methodologies) (1995, 485).

Again, within nations gender equality and self-determination for women is a

necessary part of real health and development. Many forces, such as custom or

religion, resist this equality As Klouda elaborates,

> - The concern of governments about challenging the influence of
> powerful religions in society which often have very different views
> about, for example, the equality of women (1995, 485).

While nations that lack international power may wish to resist the international

trend towards development as economic growth, they have little choice in which

development path they choose if they accept international aid. Donor

governments give aid for their own reasons. They may wish to encourage

certain political parties or policies; they may wish to open a new market for a

national firm; they may be making a complicated move on the gameboard of

international politics. Klouda has remarked on these points as well,

> - The linking of the provision of foreign aid to commercial or political
> interest.
> - The importance to donors of maintaining a plurality of political
> approaches in the ways in which they provide support (1995, 485).

For these, and other reasons the transformative intent of accepting what I have

referred to as a broad definition of development and a holistic definition of health

renders that acceptance unlikely. At least in the immediate future this approach

will be restricted to theoretical discussions in most cases.

While this thesis has examined the particular example of HIV/AIDS, almost any health issue could have been selected to illustrate the need for changing the commonly accepted definitions of development and health. HIV/AIDS were selected as so many issues have a clear impact on how they are experienced. It is important though, to make the point that AIDS is not a special case.

For most people in the world there are many other diseases that have as great or a greater impact on their daily lives. HIV/AIDS should not be considered a special case. As Klouda writes,

> In terms of the supposedly 'special' nature of HIV and AIDS, perhaps the most we can say in this context is that it adds to (or makes more complex) the burden on the poorer peoples and societies, but to single it out is highly artificial and perhaps unproductive in terms of programming (1995, 478).

Further to this point, Hunter and Chen note that in 1988 in the developing world,

> diarrhea caused about 4 300 000 deaths a year, measles 2 000 000, malaria 1 500 000, tetanus 1 200 000, tuberculosis 900 000, hepatitis B 800 000, whooping cough 600 000, meningitis 350 000, schistosomiasis 250-500 000, and syphilis 200 000 (1992, 324-25).

It is estimated that in the same year 80-90 000 cases of AIDS occurred in developing countries (Hunter and Chen 1992, 325). Mid-range estimates of AIDS deaths as a percent of deaths from all causes world wide in 1995 are 1.8 percent; in 2000 3.2 percent; in 2005 4.5 percent (Bongaarts 1996, 35). This indicates that while the impact of HIV/AIDS is significant and increasing it is not the greatest challenge to health in the world today.

In light of the limited ability to act based on these broadened definitions of development and health how can we begin to implement them at the policy and planning levels? First we, as individuals and communities, must pressure international agencies and our own governments to live up to the commitments they have made in policy documents. Second, and at the same time, we must work from broad based definitions ourselves.

This means that researchers must determine policy based in the knowledge that development has many meanings. Policy must be directed by the people it will affect. Thus the people who will be affected must be consulted. The needs, wants and interests of people must come before the needs and wants of researchers, international agencies or governments. The priorities of individuals and communities must be respected and observed in the formation of any policy.

The importance of consulting people and communities on policy and planning that affects their lives will, of course, complicate existing procedures. But the increased difficulty of such research must not be a reason not to pursue it. If, as has been indicated in this thesis, real development and real health cannot exist without the use of broad definitions, we must begin to use those definitions. The increased difficulty of policy development and project planning will be rewarded by real, useful and sustainable development.

It will be argued by some that planning projects and developing policy from an holistic definition of development will be too costly to be viable. The

logical response to this is that policy and planning conducted from a limited definition of development wastes resources. Long term development and sustainable life on the planet will only be assured if we take all facets of development into account. The priorities of the majority of people must direct this development. Thus wasting resources by spending them on projects that do not fit these goals is a greater waste than investing in development that meets the goals set by the community.

Those of us involved in International Development Studies must be aware of these issues and we too must be careful to act with appropriate definitions and the need for direction by the community in mind. This means that in the classroom students and teachers must be clear in how they define development. The importance of community consultation and direction must be stressed. We must learn how to conduct appropriate research, research that will be useful and consistent with what communities tell us they want and need. We must not try to limit projects by our definitions of development, but rather we should help to plan projects and action based on how the community has defined their development.

The conclusions of this thesis, the demand for a broadening of our understanding of development and health, can be applied to any health or development issue. It has been the intent of this thesis to point out the need for change using the case of HIV/AIDS as an example. While, as indicated above, I am aware that these changes will not happen easily or soon I remain convinced that they must and will occur.

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