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# Access and Belonging in the Age of Viral Epidemic

## Constructing Migrants Living with HIV/AIDS in the Finnish Welfare State



ACADEMIC DISSERTATION

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**ACCESS AND BELONGING IN THE AGE OF VIRAL EPIDEMIC:  
CONSTRUCTING MIGRANTS LIVING WITH HIV/AIDS IN THE  
FINNISH WELFARE STATE**

A DISSERTATION SUBMITTED TO THE FACULTY OF SOCIAL SCIENCE OF  
THE UNIVERSITY OF TAMPERE IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE DEGREE OF DOCTOR OF SOCIAL SCIENCE

**By**

**Kris Clarke**

5 December 2004

## Abstract

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This work examines the social construction of migrants living with HIV/AIDS in the Finnish welfare state through the concepts of postmodern illness, social memory and human rights. Taking a qualitative approach, the study explores how narratives of AIDS have been articulated in public policymaking and social practices concerning HIV/AIDS. Through a close reading of Finnish law and health information texts, the thesis examines how the interaction between cultural practices and social structures articulated meanings and absences on the issue of migrants and HIV in Finland. In-depth interviews of people living with HIV, as well as policymakers and practitioners, are also presented.

The four primary research questions are:

- How has HIV/AIDS been constructed as an exceptional health issue internationally and how has it emerged out of globalized trends in socio-economic development, migration, and the traditions of public health and social work?
- What kinds of stories have been told about HIV/AIDS and how have they been organized as narratives to emplot AIDS in global and local social and health policies?
- How are migrant identities and rights constructed in Finland, specifically in the intersection of legal, social and health definitions for migrants living with HIV/AIDS?
- What sense of cultural identity and belonging is constructed at the core of access to Finnish social and health services for people living with HIV/AIDS and how is it manifested?

The dissertation first examines how the meanings of globalization and accompanying socio-economic transformations have been articulated towards the end of the twentieth century. HIV/AIDS is considered as the first disease of globalization where patterns of the pandemic mirror global inequalities.

The work examines the fragmenting pressures of the neoliberal push for privatization on public health and the welfare state. It then moves on to explore the growth of transnational migration as a consequence of increasing global income inequality and structural violence, which raises new challenges to citizenship, democracy and the basis of the welfare state.

Through a discussion of how the AIDS pandemic was storied, the work suggests that the public policy that emerged in the early days of the AIDS pandemic reflected the complexity of diverse narrative plots. Many of the narrative invisibilities and erasures reveal the inequalities of globalized societies on local levels. HIV/AIDS became an exceptional health issue through the common efforts of community action groups and

public health professionals. Despite these efforts to construct HIV/AIDS as an exceptional disease requiring special care as well as unique prevention and harm reduction interventions, it remains highly stigmatized disease in most societies and very expensive to treat. This presents great challenges to social work with people living with HIV/AIDS.

Finally, the work focuses on the local level of the global story of AIDS. Through an analysis of Finnish texts, such as newspaper articles and academic theses, as well as personal interviews, it traces the chronology and development of the Finnish epidemic. International narratives of AIDS are tied to the shaping of articulations of AIDS policy in Finland. The work moves on to explore how immigration policy in Finland is mediated through social memory. It then locates migrants in Finnish social and health law, arguing that migrants occupy an ambivalent location in constructions of equality in the Finnish social and health care system.

Interviews of Finnish people and migrants living with HIV/AIDS as well as professionals and policymakers in the field are juxtaposed to explore the complex terrain of migrants' social and health needs as well as the realities of social care in Finland. Through a close reading of health information material produced by AIDS agencies, the work explores the invisibility of migrants in these activities and policies of these agencies and their material. It argues that migrants' access to social care can be seen as limited by the lack of recognition of their needs. The paucity of migrant stakeholders and researchers in the development of HIV/AIDS care policy and national prevention strategy can also be seen as a barrier to empowering migrant communities. The interaction between cultural practices and social structures in the Finnish welfare state tends to articulate a culturally normative consensus on care needs. The lack of acknowledgment of cultural competence as an essential element of care and professional training can be seen as articulating indirect discriminatory practices. Finally, the silence and invisibility of migrants in Finnish HIV services is considered through a reflection of two in-depth interviews with migrants living with HIV/AIDS.

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## **I. Points of Departure**

### **1. Introduction**

The founding ideas behind contemporary welfare states in many western societies reflect aspirations to create an inclusive and equitable public system that fulfills the basic needs of the population, guarantees human rights, rectifies drastic socio-economic inequalities, and embodies national and cultural visions of the good life. Welfare states are intrinsically cultural entities that continually reconstruct and reshape identities through shifting definitions of social needs and appropriate public interventions, all of which are constructed within the matrix of power relations in society. Welfare states are national administrative organs sustained by tax collection, controlled by democratically elected political institutions, and articulated through the interaction of experts and communities. They are, nonetheless, increasingly influenced by the ideological and material forces of global neoliberal economics through the prismatic processes of globalization. These trends have important consequences for national democratic processes as well as cultural definitions of identity and belonging.

National identity, no less than personal identity, is a complex and fluid social construction that forms a porous border which comes from within as much as from without. It embodies many elements: emotion, life stories, history, social memory, citizenship, a sense of belonging, tribalism and inclusion as well as alienness, otherness and exclusion. National identity can be seen as incarnating an infinitesimal part of a common national memory story that anchors the past to the present with hopes for the future. Continuously contested, reinterpreted and reconstructed, the national memory story is exceedingly malleable and flexible. National identity is often, though not necessarily, constructed as a form of political citizenship which provides certain privileges or disadvantages.

The affiliation of political with social citizenship in many industrialized countries can be connected to the rise of modern welfare states where entitlement to access to health and social care has been tied to citizenship and residence status. The link between rights to health and social care, on the one hand, and national identity or political citizenship, on the other, sometimes contradicts the basis of many international agreements. The Universal Declaration of Human Rights (1948), for example, asserts that all human beings have fundamental socio-economic human rights regardless of citizenship or national identity.<sup>1</sup> However, as social anthropologist and lecturer in law Marie-Bénédicte Dembour suggests, constructions of human rights have tended to represent political aspirations that privilege civil rights over socio-economic rights (Dembour 1996, 30). Indeed, it would be naïve not to acknowledge the fact that there are no binding higher international authorities at this time that can guarantee or enforce the rule of law regarding the observation of economic, social, political and human rights on a global scale.

The failure to achieve an international normative standard of human rights, which is also legally and morally enforceable, is sadly evident by the fact that tens of millions of people continue to live in conditions of violence and absolute poverty throughout the world. At the same time, the language of human rights is increasingly used as an important tool to justify governmental policies and procedures (Faulks 2000, 140). Nonetheless, there have always been fundamental tensions between the human rights framework, which is based on the rule of law and an end to impunity, and the worldview of political realism, which views the international system as based on the use of power and therefore ultimately amoral and anarchistic (e.g. Bull 1977). The contradictions of these two perspectives on international politics reflect the complexities and inconsistencies of global society. Structural violence, for example, feeds on an unjust

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<sup>1</sup> “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.” (Article 25.1 of the Universal Declaration of Human Rights, 1948)

socio-economic context where impunity reigns supreme. Though it is seen as a basic human right, fair and democratic access to social and health care by citizens of the world is rarely a high political priority in the international arena. This is particularly true in a world where the war against terrorism takes precedence over the fight against AIDS, and where increasing access to guns appears to be more important to many governments than increasing access to anti-retroviral drugs.

This work examines the how migrants living with HIV/AIDS are articulated (or absent) in the Finnish welfare state. It therefore explores constructions of *Finnishness* as an important point of departure towards understanding how the cultural consensus of the Finnish welfare state has developed normative care services and interventions as well as visions of well-being and the good life.

Finland is often described by both Finns and migrants alike as a homogenous country with a fixed and uniform sense of national identity. Yet, like most countries, Finland has been marked throughout its history by migration, diaspora, wars and the effects of foreign rule -- all of which have had a great impact on the transmogrifying Finnish national identity project. The continually shifting constructions of *Finnishness* reveal the fluctuating power relationships and changing definitions between and amongst various social, ethnic, linguistic and other identity groups resident on the Finnish peninsula. The Finnish political scientists Harle and Moisio have pointed out:

When we discuss Finnish identity, many people have the mental image that Finns have always been Finns. The notion that Finnish people have a certain permanent and unchanging identity sits tight; [the idea] that Finns have some special quality which distinguishes them from any other nation [remains]...As Finnish people have striven to realize their national identity project they have been constantly on the move, even though contemporary interpretations insist that they have all this time stayed put at their geographic location, on the beloved Finnish peninsula. The origin of this migration is found in the thought process that one must seek after the right

place to be, as well as to argue in favor of it to both oneself and others.<sup>2</sup>  
(Harle and Moisio 2000, 55).

National identity projects tend to affix foundational and essentialist notions of culture and belonging to place. As Benedict Anderson has pointed out, the randomness of place of birth achieves a ponderous significance in national myths: “It is the magic of nationalism to turn chance into destiny.” (Anderson 1991, 12) To a greater or lesser degree, movement and intermingling has been a constant in human history despite the vacuum-sealed casing of many national memory stories. Yet, for national identity projects to realize their exclusionary distinctness, they must produce a story of purity and uniqueness. In other words, national identity projects must conceptually construct the world through social memory (Pulkkinen 2000, 125).

Though there has always been cultural interchange on the Finnish peninsula, there has never been mass immigration from abroad into the nation-state of Finland. In fact, Finland maintained remarkably low immigration statistics throughout the 20th century. Until very recently, demographic statistics pointed to far greater emigration than immigration in Finland. The balance shifted in the late-1980s, however, as a larger number of migrants began to enter Finland for a multitude of reasons. Moreover, an increasing amount of Finns have intermarried with foreign nationals, producing a new generation of transnational Finns that may challenge traditional constructions of *Finnishness*. In many ways, Finnish society has found the transformation from a nation of emigration to a prospective European multicultural nation of increasing immigration unsettling. Though authorities, politicians and pundits in Finland have begun to recognize the inevitability of further immigration to Finland, and even a necessity, the appropriate measures needed to help integrate newcomers remain a deeply contested issue. The

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<sup>2</sup> Kun puhutaan suomalaisesta identiteetistä, monen mielikuviin nousee ajatus siitä, että suomalaiset ovat aina olleet suomalaisia. Ajatellaan, että suomalaisilla on jokin pysyvä ja muuttumaton identiteettiinsä, sellainen ominaisuus, joka tekee heistä juuri ja nimenomaan suomalaisia erottaen heidät muista kansoista...Pyrkiessään toteuttamaan kansallista identiteetiprojektiaan suomalaiset ovat olleet koko ajan liikkeessä, vaikka ovatkin nykytulkinnan mukaan pysyneet koko ajan maantieteellisellä paikallaan, rakkaalla Suomenniemellä. Liike on syntynyt siitä, että oikeaa paikkaa on jouduttu etsimään ja perustelemaan sekä itsellemme että muille.

ambiguities and anxieties associated with globalizing processes have created an edgy climate of both opportunity and fear in Finland which is reflected in the ambivalent debate on the implications of a small, but growing migrant population within its borders. The impact of diverse cultural identities on the construction of human rights and democratic participation in the welfare state, as well as social memory as a collective story of 'us', remains a fractious point of discussion regarding belonging and inclusion in Finnish society.

### **1.1 HIV/AIDS and migrants in Finland: the focus of this work**

Susan Sontag has argued that each age has a mythologizing disease (Sontag 1988). If tuberculosis was the mythologizing disease of the 19th century, thought to be contracted through excessive sensitivity and feeling; cancer the disease of the 20th century, believed to surreptitiously grow due to emotional and sexual repression; AIDS has emerged at the end of the 20th century as a disease often considered to be a punishment for sexual or social deviance.

Since its identification in 1983, the Human Immunodeficiency Virus (HIV), which leads to Acquired Immune Deficiency Syndrome (AIDS), has taken millions of lives throughout the world. It is thought that AIDS will eventually overshadow the Black Plague as the most devastating pandemic to hit humankind. The socio-political and economic consequences of this disease are broad. They include the social stigmatization that often occurs due to the means of transmission (namely, through sexual contact or intravenous drug use), the types of populations most affected, and the bifurcation of people living with HIV/AIDS (PLWHAs) into 'innocent' (children or those infected through blood transfusions) and 'guilty' (those infected through drug use or sexual contact) victims. These attitudes have an impact on how policies and practices are developed to prevent the spread of the infection. In many developing countries, the impact of AIDS can be seen in the dissolution of social cohesion and public order as well as the breakdown of family structures and traditional community ties. The economic impact of the pandemic is yet to be reliably estimated, though it is thought to affect all

levels of society from the macroeconomic (e.g., labor costs, composition of the skilled labor force, reduced productivity) to the local (decreased family incomes, diminished access to education and

The fact that HIV is often spread by contact that occurs through the process of migration or tourism raises cultural issues, such as popular (and even governmental) fears of AIDS-bearing invaders from foreign countries that seek to infect the purity and security of a nation. Narratives of the plot of ‘African AIDS’, for example, have tended to reinforce racist stereotypes of pathologically sexualized bodies (Treichler 1999, 116; Watney 1994, 109-127). AIDS has also been strongly associated with groups habitually condemned by the mainstream population to be ‘deviant’ outsiders that threaten the health of ‘normal’ members of the nation. HIV/AIDS has thus often been constructed as a disease of ‘otherness’ and strangeness.

The social construction of migrants as well as people living with HIV/AIDS (PLWHAs)<sup>3</sup>, as well as the social phenomenon of the disease itself, has significance in understanding some aspects of how human rights are articulated through institutions and practices in Finnish society. The complexities and contested identities of foreignness and illness raise questions about how social memory produces categories of *Finnish*, healthy or ‘normal’ as well as categories of *outsider*, sick or deviant, and how these categories shape access to care. The multitude of stories that emerge regarding the shifting boundaries between insiders and outsiders in different situations reflect the diversity of public anxieties, fears, hopes and aspirations. These stories can influence the direction of state policies and practices by asserting the presence of a ‘problem’. This is important when we consider the manifold dimensions of democratic access to the social and health care services provided by the welfare state. As British critic Simon Watney has pointed out:

Whilst our experience of HIV/AIDS is always local, it is always important to be able to frame it in relation to the wider national picture,

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<sup>3</sup> This abbreviation is taken from the European Project AIDS & Mobility (see Clarke and Bröring 1999). A complete glossary of the use of terms and abbreviations is provided in Appendix 1.

which includes the great and powerful institutions that determine its course, from elected governments, to churches, political parties, drug companies, university research departments, banks, cinemas, hospitals, television channels, newspapers, and so on. These in turn sometimes need to be viewed in a still wider international context if we are to understand how and where we need to apply pressure for improvements and change when necessary. (Watney 1994, xx)

Hence the issue of PLWHAs in Finland is far more complex than that of a simple question of medical treatment or even national health and social care policy. The impact of stigmatizing attitudes and actions, stories and invisibilities, has a deep and extensive impact on the daily lives of people living with HIV/AIDS throughout the world, though in diverse ways.

Many western welfare states are premised on the notion of equality, yet this notion does not translate transparently into good policy or practice that includes the most vulnerable sectors of society. Equality is not a simple or universal concept but is first and foremost a political concept that reflects social formations (Thompson 1998, 7). Equality is a deeply contested notion intimately connected to power relations and articulations of normalcy, rights and belonging.

The nature of the human immunodeficiency virus disease itself is in the process of change. In the first decade of the epidemic, infection with HIV inevitably progressed to AIDS, a syndrome in which the immune system became so suppressed through the diminishment of CD-4 (T-helper) cells that the body became unable to resist opportunistic infections such as *Mycobacterium avium*, pneumocystis, Kaposi's sarcoma, and toxoplasmosis. Through medical advancements in the early 1990s, the prognosis for HIV infection has shifted in the 20 years of the epidemic from one of certain and rather rapid fatality to that of a long-term chronic disease that may be managed for a relatively long period through the new antiretroviral drug therapies and treatments (ART). However, these new treatments are not effective in every patient and require strict

adherence to prevent the development of drug resistance. Furthermore, we do not know how long these treatments will be successful.

This raises a whole new set of ethical and political questions that intersect with notions of democracy and human rights as well as economic, social, immigration and foreign policy. What responsibilities do national health care services have to provide care and treatment to non-citizens? Should an asylum-seeker, for example, whose status in the host country is not guaranteed, be given antiretroviral treatments that might have to be discontinued if her application for asylum is rejected? Indeed, should an asylum-seeker even be tested for HIV if there is no medical treatment or social support available? What are the consequences of not offering a test to an asylum-seeker? What obligations should the Finnish social and health care system have to foreign residents of Finland holding temporary residence permits? Who should receive the expensive new treatments that require precise adherence to medical regimens? Should the new antiretroviral therapies be given to people who, for various reasons, are unable to adhere to the treatment regimen instructions for use when the interruption of prescribed medications can cause patients to develop a resistance to the new drugs? Should people from different socio-cultural groups who face linguistic and cultural barriers in dealing with medical professionals be excluded from such treatments due to the difficulties in adhering to the drug regimen? Is poverty not an issue, when people who live on a low economic level find it difficult to purchase and prepare healthy, nutritious food to maintain their basic state of health? How do we divide HIV patients into those 'worthy' and 'unworthy' of the new treatments? Is comprehensive medical treatment and psychosocial counseling a social right or personal responsibility? Where is the line drawn between social citizens and outsiders? Indeed, can we draw such a line in view of the intrinsic right of all human beings to health guaranteed by the Universal Declaration of Human Rights? These are some of the complex ethical dilemmas, political quandaries and burning social issues that continue to shape AIDS as a globalized phenomenon in a local context.

## 1.2 Orienting to research in postmodern conditions

Like all contemporary societies, Finnish society has been affected by the significant socio-economic changes of recent decades that have often assembled under the rubric of the postmodern condition (e.g. Castells 1996; Harvey 1990; Jameson 1991). The collapsing of space and time through the Informational Revolution, the global economic transformations of flexible accumulation and labor under late capitalism, new methods and means of governmentality and social organization, as well as the intensifying commodification of culture and subjectivity, all converged in the 1990s to create an historical moment in which theory itself became the central object of theorizing. As literary critic Terry Eagleton put it:

Postmodernism gets off the ground when it is no longer a matter of having information about the world, but a matter of the world as information.  
(Eagleton 2004, 67)

Postmodernist thought emerged in the late 1980s as a series of deconstructions that reflected the shift towards anti-foundational thought. The Finnish philosopher Tuija Pulkkinen has contrasted the aims of modern and postmodern research:

...the modern strips off layers in order to reveal or expose a core or naked truth, whereas in the postmodern, the interest lies in the layers themselves. In the postmodern there is a clear consciousness of the fact that there is no core or naked basis that could be exposed underneath the layers.  
(Pulkkinen 2000, 37)

Postmodernist theories tend to be multifarious and even contradictory, illustrating that they do not seek to prove an ultimate truth, but rather to explore the layers – in Pulkkinen's words – of truths. The deconstruction of grand narratives of knowledge in postmodern theories challenge hegemonic definitions of knowing and represent a crisis of western authority.

Often contrasted with the defining concerns of the modernist period,<sup>4</sup> a period during which western authority strongly emerged as a matrix of relations between knowledge, science, and formations of power, postmodernist thought is perhaps most usefully considered a point of reference to a certain set of problems and issues instead of solely an historical epoch. Political theorist Nikolas Rose puts it in a nutshell:

Rather than conceiving of our present as an epoch or a state of affairs, it is more useful, in my own view, to view the present as an array of problems and questions, an actuality to be acted upon and within by genealogical investigation, to be made amendable to action by the action of thought. (Rose 1999, 11)

Postmodernism can thus be seen as functioning less as a completely consolidated historical category as “a discursive space which *does something*” (Ahmed 1998, 7). In other words, postmodernist thought can be seen as sets of articulations that constitute and formulate meanings.

Implicit in the evolution and development of theories are practices of making claims and verifying true statements. The concept of knowledge, which was often viewed as a static and controllable entity in the modern era, has taken on new meanings in postmodernity, namely, that there is no one privileged perspective, ontology or epistemology, but multiple perspectives, ontologies and epistemologies which obtain meaning or truth value depending on position or context (Lyotard 1984). New theories of voice and narrative, for example, reinforce critiques of modernist grand narratives as well as introduce fresh and diverse ways of perceiving truth and reality. Postmodernist theories have taken up the task of examining the complex ways that we construct our realities, identities, memories and truths (Calhoun 1994, 24-26).

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<sup>4</sup> David Harvey presents several different typologies contrasting modernism with postmodernism (Harvey 1990, 174-179, 224-225, 340-341).

Questions surrounding how truth and knowledge are constructed as valid in postmodern theory, nonetheless, remain a highly contested area. The modernist paradigm tended to connect validity with a realist knowledge orientation and used foundationalism as a criterial question (Lincoln and Guba 2003, 271). In this ontological framework, reality exists 'out there' and can be objectively measured and validated through a set of assumptions about the nature of meaning and knowledge. The postmodern deconstruction of reality and truth, which views them as being 'talked' or 'written' into being (see Potter 1996), militates against a totalizing or teleological ontology.

Following Charles Lemert's definition that postmodernism can be viewed as a social theory of difference that deconstructs the social world by decentering it (Lemert 1992), Patricia Hill Collins points out that critical social theory includes bodies of knowledge as well as institutional practices (Collins 1998, 125-126). This means that as marginality and difference has become the primary focus of much postmodern research, questions regarding ownership of articulating marginalized experiences and their oppositional agenda are crucial. Marginal voices thus have to question whether their voices and experiences are being appropriated to blunt the oppositional aim of their agenda:

Postmodern claims to decentering introduce one important question: who might be most likely to care about decentering – those in the centers of power or those on the margins? By legitimating marginality as a potential source of strength for oppressed groups, the postmodern rubric of decentering seemingly supports Black women's longstanding efforts to challenge false universal knowledge that privileged Whiteness, maleness, and wealth. However, as with changing interpretations associated with Black women's 'coming to voice,' current meanings attached to decentering as a construct illustrate how terms can be continued to be used yet can be stripped of their initial oppositional intent. (Collins 1998, 127)

The constellation of power relations thus remain at the core of articulations of difference. Despite the variety and heterogeneity of much postmodernist theorizing, many postmodernist articulations remain focused on constructions of difference and strangeness, which implies a familiarity from which dissimilarity can be recognized:

...postmodernism involves particular ways of organizing or ordering such concepts and values in the process of constructing itself as an object. These ways of ordering values such as difference have precise political effects – they are not innocent or neutral. The assumption of difference and heterogeneity masks the role of authorization in which postmodernism is itself (ironically) implicated. However, the identification of postmodernism and concepts and values such as ‘difference’ is unstable, precisely because ‘difference’ does not exist as a pure, undifferentiated category. (Ahmed 1998, 12)

Articulations of difference are therefore inherently political and require close scrutiny to consider how power relations are being constructed and manipulated.

In narratives of postmodernity, the seemingly fixed borders of the modern world have given way to the contextuality, fluidity, interconnections and border crossings of the contemporary postmodern condition but this does not necessarily mean that articulations of difference seek to radically alter dominant power relations in society (Ahmed 2000). Arranging the conceptual field into categories of difference and familiarity while decentering the heuristic device of margin/center can subvert the power of resistance embodied in the site of the margin (Collins 1998, 127). Here we can see that the relationship between bodies of knowledge and institutional practices have the potential to converge in articulations that can neutralize marginal resistance and empowerment through a fascination with diversity at the expense of pluralistic engagement and dialogue (hooks 2003, 47).

The dynamics of globalizing processes and the ideology of neoliberalism have tended to create an increasingly individualistic and exclusionary society in many western countries which produces many challenges to the notion of a universal citizens’ welfare state (Amin 1997; Arrighi 1994; Bauman 1998b; Young 1999). New and retrofitted notions of identity, race, gender, sexuality, citizenship, nationality, family, among other social categories, have become increasingly contextualized and often contradict (or are not recognized) within modernist paradigms that have shaped national guidelines for determining eligibility for social welfare and health services. This has brought about the creation of a new vocabulary of subjectivity through which societies attempt to find

means to govern and meet the needs of new and diverse sets of individual and collective identities (Rose 1999, 46). These social, cultural and economic transformations have required a shift in the professional gaze of social and health workers towards themselves as well as their clients/patients and the social welfare and health care system as a whole. Professionals must therefore act amidst the contradictions between criteria set by modernist care systems and the heterogeneous lived realities of clients. The growing socio-cultural diversity that has emerged in many societies due to globalizing processes challenges social memories of nationhood, belonging and inclusion in many host societies, with the accompanying consequences to the development of universal services.

### **1.3 Focusing the points of departure of the study**

This work explores the implications and effects of late capitalism, processes of globalization and articulations of the postmodern condition in connection with the impact of transnationalized migration on public health and social care for people living with illness. The specific point of scrutiny in this study is how migrants living with HIV and AIDS (MLWHA) are constructed in the Finnish social care system. Hence the construction of multiculturalism, migrant identities, and implicit notions of *Finnishness* interwoven in the theory, policies and practices of the Finnish welfare state are examined.

By assessing how care and information are targeted to this highly stigmatized group, I seek to explore the borders and limitations as well as openings and opportunities of the Finnish welfare state. Why take this seemingly circuitous route to the main topic of this study, MLWHA in Finland, via postmodernity and late capitalism? It is my argument here that it is impossible to understand the legal, socio-economic and psychosocial situation of migrants in Finland unless these circumstances are located in the broader context of globalizing processes and postmodernity. It has been suggested that elements of the Finnish welfare state have been constructed on a particular notion of inclusion in an imagined community of *Finnishness* or ‘good’ citizenry (e.g. Anttonen 1998; Clarke 1999a; Satka 1995). The growing visibility of migrants as a social, economic and cultural reality in Finland, a country on the periphery of Western Europe not exactly renowned as

a major crossroads of cosmopolitan cultural diversity, reflects the fact that fundamental shifts are occurring that will continue to have an impact on the Finnish social welfare state and notions of well-being as well as how professionalism and expertise are constructed within the caring professions.

The emergence of HIV/AIDS in the last two decades as a major worldwide epidemic of catastrophic proportions has raised complex issues concerning the relationship between socio-economic position and health and social care. There has been a wide range of responses to the pandemic by governments which include attempts to restrict mobility among certain groups of people to prevent the spread of the disease, discussions of the limits of social solidarity (for example, who is entitled to receive expensive medical treatments and care), as well as complete denial of communities affected by HIV/AIDS. Moreover, the cultural sensitivity of HIV-related issues in increasingly multicultural and ethnically diverse societies poses many challenges to national health systems based on culturally normative standards of care. Dr. Zahra Mohammadzadeh of the Bremen Municipal Health Office in Germany has argued that the treatment of MLWHA is clearly a human rights issue:

The situation, as I see it, still very much reflects the reluctance with which public health systems in the European Union have approached health care for migrants in general. While migrant workers and their families from member states are slowly beginning to be recognized as a group of patients or clients who need special attention, migrants from outside the EU still form a population group that is largely excluded from the benefits of modern health care in Europe. It may seem to be an argument we have repeated too often. But I want to make it quite clear that it remains an issue at the core of what the European Union is all about. It is not just a medical or social services question. It is a human rights issue.  
(Mohammadzadeh 2000, 11)

One of the primary arguments of this study is that health is a fundamental human right and must be considered in all of its complexity. However, we cannot realistically address this matter in isolation from issues surrounding equality and social citizenship on both local and global levels. In other words, to understand how disparities in health continue

to grow despite medical advances and increasing wealth, we cannot remain solely on the level of political aspirations but must consider the how resources are distributed. Factors that maintain poverty and social exclusion not only affect the basic well-being of individuals and communities but also control access to health and social care. It is the confluence of these issues at the point of the phenomenon of HIV/AIDS that is the focus of this study.

## **2. The natural history of the research**

David Silverman (Silverman 2000, 236-237) writes of the importance of including a 'natural history' at the very beginning of a study to explicate the process of the research. Silverman's argument is that the theoretical assumptions, factors that had an impact on the work and the generalizations derived from the analysis, can be better understood in the context of a description of the research process. This chapter therefore outlines the personal context and location of the study through a brief chronicle of the non-linear route of the research process towards its ultimate destination. The purpose of this natural history is to show how the research strategy evolved and why these particular research approaches were chosen. I also provide the basis for the development of theoretical assumptions and generalizations, which are discussed in further detail in the next chapter. Through the explication of the research process, I try to show the development of my ideas on migrants living with HIV/AIDS in Finland and to position myself with regard to the study.

### **2.1 Prehistory and research process**

Migrants are an enormously diverse and rather recent socio-cultural minority in Finland, comprising less than 2% of the total population of the country. As a migrant myself, issues concerning our diverse communities and experiences in Finland have been of great interest for some time – perhaps because it was so very different here than where I originally came from but also, and possibly more importantly, as part of the ongoing process of making sense of the strangeness of the new country in which I lived. When I came to Finland in 1987, it was just beginning to shift from being a country of emigration to one of immigration. The largest number of migrants, or 'foreigners' as we were called (and called ourselves) in the mid-1980s were either the spouses of Finns or university students. We often joked amongst ourselves about how many times a day we were asked by Finnish people why we had come to their country. Indeed, many Finnish people did

not hesitate to approach foreigners at restaurants, in cafés or on trains to ask – in curious and astonished tones – why on earth someone had come here from so far. Those who were ‘obvious foreigners,’ as we used to say, were naturally more likely to be approached by inquisitive Finns; while I found that if I kept my mouth shut, no one would be the wiser that I was actually foreign. The constant inquiries I encountered in Finland represented a big change from the disinterest with which my compatriots tended to meet newcomers in my own country.

When comparing my experiences in Finland with my observations of the experiences of my immigrant grandmother as well as foreign-born schoolmates, I noticed that Americans seemed to have strangely little interest in why foreigners had come to the States because amidst the bombast, self-centeredness and provincialism of American culture, they usually assumed that everyone wanted to come. Moreover, the role of immigration in U.S. society is conceived in a completely different manner than in Finnish society. Since the European invasion of Native American territory (see Zinn 2003, 1-22), the United States has been constructed as a society of immigrants. However, the melting pot that immigrants were expected to assimilate into can be seen in some respects as a deliberate political program to create and preserve a dominant mainstream hierarchical framework of white, Anglo-Saxon American culture that was derived from the founding fathers (Jacobson 2000, 205). Hence while there is a vibrant multiculturalism clearly evident in American society, tensions between group aspirations to speak their own languages and express their own cultures and countermoves to exclude those who do not conform or meet the criteria for inclusion in shifting categories of whiteness have been a prominent feature of the American political landscape.<sup>5</sup>

When I arrived in Finland in the mid-1980s, questions of cultural assimilation or diversity seemed absurd, but by the beginning of the 1990s the population of migrants

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<sup>5</sup> In the 19th century, nativist groups such as the Know Nothings opposed immigration and sought to maintain traditional power structures. At the turn of the 20th century, the English-only movement, which has placed referenda on the ballot in some states, as well as academics, such as Samuel Huntington, have written of the cultural peril of a growing Spanish-speaking population in the US (Huntington 2004).

began to increase and diversify. With the fall of the Soviet Union, there was a rise in Ingrian 'returnees' and Russian immigrants to Finland. Somali, Bosnian and Kurdish refugees started arriving and the number of Finnish-foreign marriages began to increase. Despite the low proportion of migrants relative to the total population of Finland, the actual number of migrants in Finland quintupled between 1987 and 2002 (Pitkänen and Kouki 2002, 105). At the same time, Finland experienced one of the deepest economic recessions in its history. Thus, in a matter of a few years, the socio-economic circumstances and concerns of migrants changed drastically. While, for example, foreign students in the 1980s were routinely issued social insurance cards, increasingly restrictive practices in the 1990s began to limit those entitled to receive such cards which reduced many migrants' access to social and health services. Financial guarantees required by foreign students to study in Finland were more rigorously checked by police and work was harder to come by. As the migrant population diversified and became permanent in Finland, their needs and expectations became more complex. In short, one of the main transformations that I have seen during my stay in Finland has been the shift from migrants' focus on solely bureaucratic-legal concerns to an increasing variety of socio-economic-cultural concerns. This is not to say, however, that the primary significance of legal status, from which entitlements and rights are derived, has diminished in any way.

In terms of my own personal observations, the random encounters with Finns who questioned why we foreigners had come here continued but with a new and more urgently aggressive tone. In the light of such high unemployment and anxiety about the future, foreigners no longer seemed to be exotic or harmless among many in the general public, but rather appeared strange and threatening. Of course, I should point out that I had the advantage of being a 'non-obvious' foreigner which meant certain privileges over my fellow 'obvious' foreigners in occupying public space as well as in reactions to my presence in Finland.

I started my studies in Finland in international relations, with a focus on development studies, because I was interested in the structural factors that affect people's lives. As I lived in Finland longer, I eventually became more interested in the local context and thus

turned to social work and health care, areas where the contested relations of power and inclusion/exclusion seemed to me to be most topical and present. During this time I observed that there seemed to be an attitudinal change in the air. As noted above, I observed that the curiosity and exoticism that many foreign students were initially greeted with in the 1980s appeared to turn increasingly towards hostility in the 1990s amidst the general social anxiety of rising unemployment and cuts in social benefit levels. At the same time, many projects and programs were initiated by the government that aimed at ‘internationalizing’ and ‘multiculturalizing’ Finnish society as Finland obtained membership in the European Union and looked abroad for the future. Multiculturalism as a concept appeared to emerge at the impetus of the government rather than from the grassroots level, and seemed to involve few migrants. In short, it seemed to be constructed as an expert rather than an experiential issue.

In 1993, I started teaching social care subjects at a vocational social care institute that initiated an English language ‘multicultural’ training program for practical nurses and social educators. My experiences at this institute led to a renewed interest in returning to studies in order to make sense of my observations and feelings regarding this national process of internationalization and multiculturalization. To develop my professional skills, I began a postgraduate program in social work in 1997 where I eventually completed a licentiate degree.

In my licentiate thesis, *Breaking the Boundaries of Bifurcation: The Challenge of Multiculturalism in Finnish Social Care Education* (Clarke 1999a), I attempted to understand how the notions of *Finnishness* and multiculturalism were constructed in Finnish vocational social care education courses that advertised themselves as multicultural. Through a textual analysis of the curricula as well as essays and feedback sheets written by the students themselves, I found that there was no clear picture of what multiculturalism meant in Finnish society amongst the educators or the students. An essentialist, bifurcated divide held sway in the classes which dichotomized students into

two camps: Finns and foreigners.<sup>6</sup> These essentialist attitudes were further reflected in the fact that many students felt that they did not experience ‘multiculturalism’ although they were in a group that included people from many different cultures and nationalities (Clarke 1999a, 199). In other words, the process of learning and interacting as a group was not thought to be ‘multicultural.’ Rather, multiculturalism was viewed as a distant augury of things and experiences to come, while the cultural diversity and social difference of the everyday was often overlooked and sometimes disparaged (Clarke 2004).

When I decided to continue with my studies on a doctoral level, I wanted to continue with the themes of *Finnishness*, multiculturalism, and migrants in Finnish society, but I wasn’t sure which direction to take. The atmosphere had changed in Finland by the late 1990s: we no longer ‘went’ to Europe when leaving Finland but were part of it. Finland had climbed out of recession. Globalization was the new buzzword and Nokia mobile phones were an international success story. In short, the change can be summed up in the fact that foreigners were now immigrants.<sup>7</sup>

## 2.2 Why HIV/AIDS?

I came to this specific subject through the backdoor, so to speak. Though HIV/AIDS was a major issue where I came from, and indeed took the lives of many of my friends back home, I had never really thought about exploring the issue. It just didn’t seem so important in Finland where I rarely heard any mention of it aside from the odd public health campaign. I didn’t know anyone in Finland living with HIV or AIDS. However, when I was asked to become involved in a European project on migrants and HIV/AIDS<sup>8</sup> in 1997, I began to think about the silence surrounding AIDS in Finland. I wondered why

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<sup>6</sup> ‘Foreigners’ was generally the term used within these courses to distinguish students who were not born in Finland from native Finnish students, regardless of the actual citizenship or residence permit status of such students. The use of the term ‘foreigner’ thus implied that an individual of foreign origin would always remain outside of the definition of ‘Finnish’ despite having Finnish citizenship.

<sup>7</sup> The shift in Finnish was from *ulkomaalaiset* (foreigners) to *maahanmuuttajat* (immigrants). For an explanation of why I use the term *migrant* in this work (see Chapter 3.7 “On the term ‘migrant’”).

<sup>8</sup> The European Project AIDS & Mobility.

the situation appeared to be so very different up here than in other European nations. In project meetings with people from other EU countries, I knew that what they were describing of their own countries was very different than Finland but I didn't have the facts, personal knowledge or insight to explain why it was so different – and it didn't even seem so different as much as non-existent.

I felt compelled to write about HIV/AIDS and migrants in Finland precisely because though I knew nothing about the topic and could find no information about it, HIV/AIDS nonetheless seemed to be a vitally important subject. Although I spent a lot of time thinking about this issue, I must admit that at the same time I felt reluctant to investigate this topic. From my perspective, particularly as a Californian,<sup>9</sup> it seemed to me to be a narrow field, a morbid topic, a sordid story of governmental neglect, unequal access to treatment and young, useless death – not something that I wanted to spend years researching. Moreover, AIDS seemed to be something that was so 1980s, not something that was on the agenda in western countries at the turn of the millennium. Yet, as time went on, however, I began to realize that in HIV/AIDS all of the issues of migration, multiculturalism, social inclusion/exclusion, global injustice and racialization are crystallized. The challenge indeed was not just to consider AIDS as a terminal disease, but rather to think about what living with HIV/AIDS means globally as well as locally. My involvement with the project raised my awareness of how the discrimination and prejudices directed towards people living with HIV/AIDS by society tends to mirror the evaluations and judgments that people marginalized or socially excluded from the mainstream also face in their everyday lives.

Although the study of migrants in Finnish society has increased dramatically since the 1980s, very little information has actually been produced by migrants or migrant communities themselves. While the recognition of the reality of migrants as members of contemporary Finnish society by Finnish researchers is significant and an important first

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<sup>9</sup> California has relatively high HIV infection rates. San Francisco was the site of a major epidemic outbreak in the 1980s.

step towards the initiation of dialogue and mutual understanding, it is nonetheless important to acknowledge the primary importance of self-expression, self-definition and self-articulation, particularly with regard to notions of well-being. As Rajkumar Sabanadesan, one of the first migrant graduates of a nursing school in Finland, noted in his senior thesis:

It has long been recognized that coping as an ‘outsider’ in Finnish society is one of the most important social and health issues facing migrant communities. Nevertheless, there is little local or national information available on this issue from the point of view of migrants themselves. The development of an effective strategy to promote health and social well-being among migrants cannot take place without adequate information both about how migrants define themselves and what they consider their needs to be. Only by identifying the needs of migrants on their own terms, can adequate solutions be found. (Sabanadesan 2000, 40)

The voices of migrants have yet to emerge as an integral part of the dialogue on multicultural issues in Finland.

In the three country reports I have written for AIDS & Mobility (Clarke 1999b, 2000, 2003a) on the state of affairs of migrants living with HIV/AIDS in Finland, one of the greatest difficulties has been the utter lack of information and discussion on the subject. Non-governmental organizations and social service agencies had little specific information targeted at migrants. As I pointed out in one country report:

Work with culturally diverse communities is not highly developed in Finland as social and health care services have traditionally been viewed as ‘culture-blind.’ The fact that there are very few culturally or linguistically appropriate services available in Finland often serves to exclude migrants from attempting to obtain access to services. (Clarke 2000, 52)

Thus, with a perverse kind of circular logic, discussions in many of the meetings that I attended on migrants and health care reflected a certain blindness about migrants’ needs. The lack of importance attributed to the development of culturally appropriate services was largely due to the perception that there is little need for such services because all services should treat everyone equally. Following this reasoning, differences should not

be recognized or allowed to interfere with the normative construction of equality in the provision of services because such ‘special treatment’ would ultimately further stigmatize people seeking such services. The high threshold that many migrants might face in gaining access to services is left unaddressed. The fact that all social and health services represent cultural notions and definitions of symptoms, health, social needs, help-seeking behavior, appropriate interventions, and so on, is often ignored within the perspective on services as professionally and culturally neutral. Indeed, discussions on the social and health needs of migrants frequently do not involve migrants and they are therefore unable to exert ownership over issues that affect them. Thus, migrants themselves, who would be the best experts on defining their own special needs in services, are like the chalk figures drawn on the pavement at a murder scene: silent, disembodied and powerless. My task in this work, then, was cut out: I was going to try to find out the story behind these chalk figures.

### **2.3 Problems, conundrums and ways toward resolution**

Originally, I intended to write a study that would give voice to migrants and their views on HIV/AIDS. I thought that I could act as a kind of interlocutor or translator and reveal how migrants in Finland felt about AIDS. I initially planned that after interviewing migrants in general, I would move on to talk to migrants living with HIV/AIDS. It was only as the research process progressed that I realized not only was the wrong objective but it was a supremely arrogant endeavor. With all of the stigma, racialization and socio-economic exclusions associated with AIDS, was it really right to place the most vulnerable people under scrutiny? Furthermore, was I really the right person to do this?

At first, I thought that I would track down migrants living with HIV/AIDS and ask them what their situation was like and what they felt that they needed to improve the quality of their lives. After spending a lot of time trying to locate people I realized that this probably wouldn’t be the best method because migrants were not generally forthcoming about their seropositive status and did not want to be identified (sometimes not even anonymously) as living with HIV/AIDS, sometimes especially in the small migrant

communities. Relatively few migrants went to the Finnish AIDS Council in Helsinki for counseling – at least during the period of research for this study (1998-2003) – and none visited the local Finnish AIDS Council office. I thought that my only possibility to contact migrants living with HIV/AIDS would be via hospitals and clinics, which would involve a long process of obtaining research permits through district ethical committees. I wasn't sure that approaching people through their clinics was the best way to make contact. For migrants, many of whom might be refugees or forced to migrate under other circumstances, such inquiries in the context of the clinic might seem intrusive if not downright scary. Thus, I thought that having a researcher descend on migrants living with HIV with a questionnaire or tape recorder during a clinical visit might serve to reconfirm the notion that the confidentiality of the physician-patient relationship was not really true after all.

More specifically, there were four concrete areas that militated against a direct approach to migrants living with HIV/AIDS.

Firstly, I found that my own position as a privileged white female migrant, particularly one who has been in the professional relationship of a teacher to many other migrants, had a negative impact on creating a dialogue in which migrants could feel safe enough to really open up about their thoughts and feelings on the issue.<sup>10</sup> The racialized narrative of the story of African AIDS, as discussed in the third section of this work, has a very concrete effect on inter-personal discussion, particularly when talking across race and gender lines.<sup>11</sup> The deeply stigmatized nature of HIV/AIDS and its association with

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<sup>10</sup> A migrant who did a small-scale qualitative study in Finland for AIDS & Mobility told me that many migrants crossed the street when they saw him coming because they did not want to be asked to discuss the issue of HIV/AIDS (Sabanadesan 2001).

<sup>11</sup> Indeed, the uniqueness and great strength of community researcher Abigail Edubio's qualitative study on the attitudes of African migrants in Berlin to HIV/AIDS lay in her intimate knowledge of the community, its mores and norms. She described how she found the informants for the study: "Initial contacts were made in the usual places of meetings like the churches, African shops, cultural or social meeting places, in hospitals, consulates, buses, the foreign office, in the train stations, at the Reisebank (contains the Western Union money transfer system where most Africans go to send money home), on the streets and in the shops and their homes." (Edubio 2001, 24) It is hard to believe that someone from outside of the African community in Berlin would know the 'usual' places to encounter and gain the trust of community members.

sexuality and race make it a very sensitive topic to discuss which requires a strong bond of trust between the researcher and informant. My role as teacher often means that many of my former migrant students do not relate to me as a peer or impartial researcher. I felt that this would have decisively affected any discussion on deeply personal issues surrounding HIV/AIDS.

Secondly, and perhaps most importantly, many migrants fear that there will be legal implications if they participate in studies, particularly about such sensitive issues as HIV/AIDS.<sup>12</sup> Because many countries (such as the United States) continue to have entry and residence restrictions on immigrants who have infectious disease, some migrants have great fears of being associated in any way with HIV/AIDS.<sup>13</sup> Therefore, the amount of migrants willing to discuss HIV/AIDS appeared to have been very limited. Indeed, my early attempts to test the waters were spectacularly unsuccessful. Many migrants told me that they would be happy to talk about anything other than HIV/AIDS. So, while I did not quite have people crossing the street when they saw me coming, I was told nonetheless politely but very firmly by potential informants that HIV/AIDS was not a subject that people would discuss in interviews.

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<sup>12</sup> As one of Edubio's informants commented: "The project you have explained sounds good, and I know that you will not do anything to harm us, but are you really sure that this is not another way of getting to identify those of us that are not documented? The authorities know that we trust people like you, perhaps that is why they have asked you to come to us, otherwise why are you asking me to disclose my residence status?" (Edubio 2001, 25)

<sup>13</sup> Indeed, for many years there were rumors among migrants in the town in which I live that if a migrant went to an AIDS test, the result would be handed over to the police. Though completely unfounded, these rumors have continued to circulate for years and probably have had an impact on people's decisions of whether or not to be tested. Many of these urban myths developed out of the negative encounters that foreigners experienced in the 1980s. When a friend of mine from Namibia took her sick child to the local clinic in the 1980s, for example, many people refused to sit near her muttering that she had AIDS. Another African friend told me at the same time of an experience in which Finnish students left the sauna at the student dormitory, claiming that he was spreading AIDS. These stories tell a great deal about how AIDS was understood in Finnish society at the start of the pandemic and certainly reinforced to foreigners the extreme stigma they would face if they were publicly associated with HIV/AIDS.

Thirdly, with the recent upsurge in research interest in migrants<sup>14</sup> in Finland, it is becoming increasingly popular to interview and chart migrant communities, but many migrants are not interested in participating in studies that do not appear to benefit them in any way.<sup>15</sup> Finnish-Somali researcher Fatuma Dayib described a ‘research crusade’ in her community, where Somalis were viewed by mainstream researchers as a valuable commodity (Dayib forthcoming). In fact, it may even be possible to talk about a kind of ‘research fatigue’ within many migrant communities that have been approached by numerous researchers, but have had little opportunity to influence or even see the final product of research, let alone recognize concrete benefits emerging from these studies.

Finally, I found that HIV was simply a non-issue in migrant communities because there were so many other issues of everyday survival that took precedence in living in Finland. As one migrant wrote: “Coming to Finland was easy. It was living here that was hard.” (Abdallah 2002) Everyday difficulties, stigmatizing attitudes and legal issues were time and again emphasized by both migrants living with HIV and non-infected migrants as the most significant barriers to achieving a satisfactory quality of life in Finnish society.

Thus, I realized during the early stages of the research process that hunting down migrants living with HIV might not be the right approach because it smacked too much of tabloid journalism. I also began to grasp the mistaken conceit of placing migrants living with HIV/AIDS at the center of the work. I realized that I had to respect the privacy of migrants living with HIV/AIDS and their right to silence. Anyhow, it was not up to me to break this silence because it was not my story to tell.

I saw my ethical responsibility as being towards migrant communities as well as to the community of people affected by HIV/AIDS. Writing a dissertation on this subject of

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<sup>14</sup> In the past year, I have had numerous university and polytechnic students approach me to discuss their undergraduate papers on migrants in Finland. They have expressed a great interest in finding migrants to interview – the response by migrants to such requests varies depending on the specific topic, circumstances and situations.

HIV and migrants had all the potential of attracting undesired and lurid attention to migrant communities already under the strain of racist, ethnocentric and stigmatizing attitudes by many in mainstream Finnish society. On the other hand, I thought that these attitudes could only be challenged or changed by lifting the veil of invisibility on these issues. There is still a great deal of shame and silence surrounding AIDS in Finnish society and within many migrant communities. Few Finnish people living with HIV/AIDS are willing to talk about living with their illness publicly due to fears of discrimination, particularly in employment. Migrants living with HIV in Finland, after all, are really very few in number and few communities have had the time and space to process how HIV/AIDS is affecting them. So, what good would there be in focusing specifically on the most vulnerable, those with the most to lose, those who have had the least opportunity to cope with the implications of HIV/AIDS on their position as newcomers in Finnish society? How could I be sure that raising migrants living with HIV/AIDS as a social issue wouldn't just reinforce negative associations between foreigners and disease? I found this to be a very problematic ethical dilemma and struggled with deciding on the right way to proceed.

This period of deciding which way to handle the research lasted for quite some time. For over a year, I did little more than read. I read everything that I could obtain on globalization, human rights issues, migration and the AIDS pandemic. Most of the material was in English, though I started reading an increasing amount of texts in Finnish for the first time. Memoirs, medical journals, law texts, social work practice guides, microbiology notes – everything seemed to be informative and relevant to the study at hand. Then came the point when I simply had too much information and didn't know what to do with it. My office was littered helter skelter with piles of photocopies, news articles and notes – much to my despair -- and I realized that I had to take action and do something concrete.

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<sup>15</sup> As Edubio noted: “Some of the migrants here have had bitter experiences of constant exploitation, they were not too sure [that] this was not another exploitation and that interviewers were not going to use this interview to make some personal gains at their expense.” (Edubio 2001, 25)

I then sat and began to write the section on postmodernity, globalization and migration as well as the international story of AIDS. This was a very important framing experience and helped me to start thinking about the connections between global and local issues. Furthermore, the process of writing and thinking confirmed my earlier sense that many of the pressing global issues, such as poverty, gender inequality and social exclusion, could be seen through the prism of AIDS.

I also reversed my approach to examine how the system constructed migrants living with HIV/AIDS. When I finally dropped the approach of placing migrants living with HIV at the center of this work, the subject opened up to me. I started to realize that the key issue was that of silence and how it interacted with the system of care. I therefore endeavored to address how migrant identities (as non-Finns) are articulated, represented and categorized in Finnish law and social and health services to explore what that implies about constructions of social memory, human rights and equality. I focused particularly on how official and unofficial constructions of these identities serve to determine access to social and health care services, both in terms of legal rights as well as culturally appropriate care and information. While it is not startling to realize that there are restrictions on newcomers' access to national social and health care services by a host country, what I am interested in is how the definitions of Finnish immigration law and social and health care eligibility criteria construct the migrant as a human being with human rights in Finnish society. I therefore explore the intersection between these definitions and the frameworks of human rights, social work and public health. AIDS has been selected as the specific point of examination.

After all, HIV/AIDS has always been, in Paul Farmer's words, "...a strikingly patterned pandemic." (Farmer 1999, 51) This means that the AIDS<sup>16</sup> pandemic cannot be viewed as separate from growing global economic disparities and the subsequent imbalances in social and health outcomes produced by the local experience of globalization and

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<sup>16</sup> See Chapter 9.4 "On the use of terms", for an explanation of why I sometimes use HIV/AIDS and other times simply AIDS.

national austerity measures. Indeed, health status and levels of personal risk has increasingly become an indicator of economic wealth in the globalized world. While it can be argued that much more must be done to combat the AIDS pandemic, the response to the phenomenon of AIDS cannot be understood without taking into account the extraordinary degree of community organizing on both global and local levels to defend the rights of the most vulnerable in society. AIDS must therefore be viewed in all its complexity.

As I will explore in this work, when the phenomenon of AIDS is reduced to solely a health issue, many of the surrounding, and often more urgent issues to people living with HIV/AIDS are ignored. Questions of power in negotiating safe sex, relations of social exclusion and poverty, degrees of personal risk and vulnerability are all issues that directly effect prevention efforts. One of the main stumbling blocks when it comes to providing care can be that the patient is seen only in terms of her illness and not the circumstances that immediately and tangentially affect her ability to access and adhere to treatment and care. Ultimately, AIDS is also a social phenomenon that is connected to notions of nationhood and belonging, masculinity/femininity, gender roles, sexuality, citizenship, community, and inclusion/exclusion in society.

I began to think about AIDS as myriad narratives and how certain stories, which represent prevailing hegemonies, become accepted as truth and thus influence the action taken by public officials. I became interested in how critical counternarratives and the complexities of diverse perspectives were often silenced or disregarded. Nearly every book I read on the subject of AIDS took the reader through the events of an international AIDS narrative like the stations of the cross (see, e.g. Grmek 1990; Shilts 1987). I do not dispute the veracity of the facts, events or interpretations reported in these books, but I also came to realize that all stories necessarily edit the mass of information available. In this way, they provide a particular perspective that often reflects specific positions in constellations of power. Through reading other works (e.g. Baxter 1997; Cohen 1999; Farmer 1992; Farmer 1999), I became aware of certain absences, omissions and lacunae in many of the prevailing narratives of AIDS. I then decided to explore how this

international AIDS story has been constructed and what impact its elements have had in relation to public responses to the AIDS pandemic.

I then turned to the local context and began hunting down evidence of the Finnish story of AIDS. My aim was to see the relation between prevailing international plots of AIDS and how understandings of local events were forged into a Finnish story of AIDS that, in turn, influenced policy responses. I therefore read master's theses, old newspaper clippings and sought out the few publications on AIDS in Finnish. I constructed a timeline and seemed to have developed some kind of a story. Yet, I had nagging doubts. I didn't know how to evaluate the sources in many ways. I couldn't tell how reliable they were or whether they represented a particular political agenda. I found this very difficult, not only because of the language, but because I wasn't sure where to look for contextual clues or what to make of the information I had. A great deal of the tacit knowledge that Finns have on this issue, regarding reliability or personal or political interests in sources, was simply not obvious to me. Very little, all in all, has been published on the AIDS epidemic in Finland, perhaps because of the small numbers of PLWHAs here. It was therefore hard to flesh out the story from the bare bones of newspaper articles, theses and books aimed at providing information. I had read so many English language sources that I became afraid that I was unconsciously applying an Anglo-Saxon historical and cultural framework to the Finnish context. I then decided that I needed to make a road trip and try to talk to people who knew the Finnish story of AIDS through their own work and experiences.

Most of these people I had met through various activities and events I had attended as part of the project with which I was involved. Previous informal discussions with many of them helped to formulate some of my initial ideas about this research. They represented a diverse group of people ranging from medical professionals to policymakers to people living with HIV/AIDS. All were warmly welcoming and were kind enough to donate their time to explaining the significance of the events of the past 20 years. These interviews were immensely useful because they revealed many of the gaps, misunderstandings and absences in the material I had obtained. Moreover, they also

gave me different viewpoints on the reliability of certain sources. In short, these interviews clarified much of the information that was presented in the Finnish sources that I used in my research and helped me sort out the English language context from the Finnish context, though I alone am responsible for the interpretations presented here.

After the whirlwind of interviews, I then felt ready to make the final push to finish the work. As I was working on Chapter 15, “Silence and Living with HIV/AIDS,” I went to interview two migrants living with HIV. I am very grateful to Justin and Kidane (both pseudonyms), migrants living with HIV, who took the time to share their life experiences with me and explain the difficulties of being a foreigner with HIV in Finnish society. The purpose of these interviews was to discuss the conclusions and meaning of this work, but I found the discussions were much richer and deeper than I ever could have expected. These were the only interviews which I did not record because both Justin and Kidane expressed concerns about the maintaining their anonymity. I also felt that the tape recorder would have made them very self-conscious and been more of a hindrance than a help in the interview process. Instead, by mutual consent, I took brief notes which I copied out in detail about an hour after the interview, so that the details were fresh in my memory. In the brief notes I wrote during the time of the interview, I jotted down many of their comments verbatim which is why I have some actual quotations from them to use in this work. Kidane, in particular, had a very rich use of idiomatic English which provides many of the more colorful comments on being a migrant living with HIV. Justin also sent me follow-up emails to clarify comments and perspectives. These discussions and the later electronic correspondence provided an excellent critique of my work and helped me understand many of the issues related to migrants and HIV/AIDS in quite a different light.

When writing this work, I have been acutely aware that there is currently a struggle in many areas over the ownership of migrant issues in Finland. There are many reasons for this which includes the increased funding offered by the European Union, Finnish government and various foundations for both research on migrants and practical projects working with migrants. Additionally, the desire to establish oneself or one’s organization

as a leader in this emerging field is a further reason to seek to be an authority in migrant affairs. Perhaps even more important than personal or professional ambition is the normal, everyday struggle over defining the future vision of Finnish culture and society. Setting the agenda for how migrant issues are conceived, defined and acted on as well as determining who is included in (or excluded from) the discussion will have a significant impact on how migrants interact with and participate in Finnish society. These debates must be viewed within the international context of migration trends as well as the increasing xenophobia in many western countries in the midst of the so-called global war on terrorism. Indeed, it is no coincidence that immigration has been one of the major political issues in recent elections in Nordic countries. Whether migrants largely remain an amalgamation of marginalized, powerless minority groups or become an integral part of Finnish society will depend very much on whether they can 'own' their own issues.

Therefore, I would like to make explicit at this point what this work is not. In this study I do not write on behalf of migrants living with HIV/AIDS. Their own stories belong to them and are yet to be told. I write as a member of the migrant community, albeit one who has been here longer than many and has seen and experienced many of the changes in Finnish immigration policy. I do not write from the perspective of a visible or oppressed minority group in Finland. I do not write as a person living with HIV/AIDS or as a worker in the field. I do not write with the aim of creating the definitive Finnish story of AIDS. I do write as one of many voices within the diversity of the migrant community. I write with the hope that the silence surrounding HIV/AIDS and migrants can be broken in a way that can empower and benefit migrants as well as other people living with HIV/AIDS so that no one feels the need to hide their seropositive status out of fear of rejection, exclusion or discrimination.

### 3. Theoretical approaches

Social theory strives to provide multiple perspectives on what we know and how we know about our social world. It examines the interaction between individuals, groups and societies in distinct historical periods, and critically explores our assumptions in studying people and communities as well as the structures that define our social worlds in the search for truths about our societies. Social theory thus develops empirical knowledge of our social world by collecting and examining quantitative and qualitative data. As Patrick Baert has defined:

... social theory [is] a relatively systematic, abstract and general reflection upon the workings of the social world. (Baert 1998, 1)

Hence social theory is concerned with conceptualizing and rendering coherent the interaction of human beings through macro and micro-level categories such as social roles, norms and social structures.

When the social sciences emerged in the 19th century, a large body of social theory sought to create foundational social knowledge that could be abstracted and generalized as universal frameworks to explain the social world. Schools of social theory, such as functionalism and structuralism, rejected the interpretive claims of hermeneutics and phenomenology in the search for deeper structures of the social world:

Both [functionalism and structuralism] support a holistic picture of our society in which the interrelationship of sub-systems and practices is central. Both assume that the task of the social scientist is to unravel a deeper reality behind the conscious level of purposive action – for structuralists that hidden realm refers to unacknowledged structures, whereas functionalists search for latent functions. Both functionalism and structuralism minimize the role of agency, attributing importance to broader social forces which transcend the individual. (Baert 1998, 37-38)

Positivist social theories, such as Talcott Parsons's general theory of action, attempted to make social theory a foundational science in which interactions between actors and situations could be objectively understood and predicted in a systematic manner (Baert 1998, 49). Interpretive social theory, on the other hand, which has always co-existed with structural and functional social theories, considers knowledge to be a "complex relational concept" (Harré 1998, 38) that is always metamorphosing. Already in the 1700s, the philosopher Giambattista Vico, for example, linked social construction with structuralism. Literary theorist Terence Hawkes described Vico's worldview:

...man constructs the myths, the social institutions, virtually the whole world as he perceives it, and in so doing he constructs himself. This making process involves the continual creation of recognizable and repeated forms which we can term a process of *structuring*. (Hawkes 1977, 14) [author's emphasis]

Hawkes points out that Vico observes that human society is constantly transforming and of our own making, not simply a static, 'objective' set of structures (Outhwaite 1998, 22-23). The rise of interpretive social theories and anti-foundationalism in the postmodern period thus challenges the positivist basis of how we know the social world by shifting the epistemological and ontological criteria for knowing. Methods of making social theory have come to focus less on measuring how objective explanations and predictions are of social knowledge than on the interpretation of the meanings and actions of agents (Williams 1998, 7). These two tendencies in social theory, empirical and interpretive, have been ascendant in distinct historical periods and demonstrate different ways of knowing, perceiving, representing and articulating the social world.

### **3.1 The postmodernist turn in social science**

Social science emerged with the rationality of the modern era. By radically redefining the epistemological criteria of what could be considered knowledge and truth with man as the maker of objective criteria, modernism firmly rejected theological dogma (see, e.g., Bleicher 1982). Many of the concepts, categories and approaches developed within

modernist social science therefore were grounded in the notion of value-free reason. This conception of knowledge viewed the knower as inconsequential to knowing because the facts, evidence and proof of objective knowledge existed outside of, and separate from, the knower. In this framework, a key criterion for determining what valid knowledge is is the ability to generalize from data. This means that research methods used to fulfill such epistemological standards tend to be based on a notion of ontological reality as unmediated by observers by focusing only on that ‘reality’ which can be measured objectively.

The limitations and contradictions of developing a relationship between social theory and empirical methodology are indicative of the problematics of the concept of theory itself. As British sociologist Ali Rattansi has pointed out, the postmodern turn can be seen as an intellectualized condition that reflects an attempt to theorize the problematics and constraints of modernist ontology and epistemology (Rattansi 1995, 250). The postmodernist turn has brought about a reformulation of the purpose of research itself:

Rather than conceiving of the object of social research as solely that which needs to be illuminated or explained, the very same object also needs to be seen as a central source for inferring theoretical insight. Objects of social research *can* be seen like this because, contrary natural objects, they are re-interpreted by the individuals involved. (Baert 1998, 203) [author’s emphasis]

This indicates a reevaluation and deepening of the object of knowing. If, as Vico noted already in the 18<sup>th</sup> century, our knowledge is shaped by the things that we have made then our society should be seen as a product of our choices, actions and understandings as well as exclusions and absences (Outhwaite 1998, 22). This means that knowledge of our society can never be a simple reflection of reality but always involves interaction between the subject and object of study.

The postmodern turn in social science has an impact on the aim of research because it undermines the possibility, and perhaps even the aspiration, of creating a universal explanatory theory of society. Rather, the postmodern turn has brought new focus to the

relational and mutable quality of social reality through the use of qualitative methodology that seeks to develop an ‘idiographic’ body of knowledge that can make in Malcolm Williams’ terms, *moderatum* generalizations about the social world (Williams 1998, 18). Qualitative approaches come from the interpretive tradition of analysis and are concerned with understanding the meaning of what human beings are saying and doing, rather than proving objective facts about reality within a foundational framework (Lincoln and Guba 2003, 311).

The social theory utilized in this work thus departs from the postmodern turn. I seek to explore how migrants living with HIV/AIDS interact with and are produced (or absent) in the Finnish welfare state. I focus on the legal and social rules that define the needs of migrants living with HIV/AIDS to better understand how the human rights of these migrants are constructed in Finnish society. Hence by taking an attitude of epistemological pluralism, it is my intention to consider the complexity and multifaceted nature of social reality at this particular juncture of historical time, place and situation.

### **3.2 Approaching identity in social theory**

The emergence of modern social theory during the ascent of the nation-state has been shaped by questions of identity and difference, and the individual and the collective (Calhoun 1994, 10). Though identity has often been conceived as a Cartesian act of individual will, increasingly identity is recognized as relational, a process anchored in social interaction (Burr 1997, 51). Identity, sometimes viewed as an irreducible and essential concept, has (as Stuart Hall has termed it) a pivotal relationship to agency and the politics of location (Hall 1996, 2). Identity is thus not solely a matter of self-definition or self-knowledge but also reflects relations of belonging, inclusion, exclusion, centrality and marginalization precisely because it is constructed and develops in complex interaction with others as well as power structures (Hall 1996, 5). Identity exists within contexts, as Avtar Brah points out:

Identity, then, is simultaneously subjective and social, and is constituted in and through culture. Indeed, culture and identity are inextricably linked concepts. (Brah 1996, 21)

Identity is therefore fluid. It embodies both individual and collective aspects and thus can be profoundly ambivalent. There is an extensive body of contemporary literature that deals with the complexity of questions surrounding identity (see, e.g., Brah 1996; Burr 1997; Calhoun 1994; Hall and du Gay 1996; Nicholson and Seidman 1995). My purpose here is not to delineate the intricacy of debates surrounding the contested notion of identity, but rather to introduce how notions of identity and belonging as elements of social theory are used in this work.

Though there is a complex conceptual history of psychological and sociological notions of subject positions, agency, roles and status, many contemporary discussions of identity depart from the distinction between essentialism and social constructionism. In a nutshell, essentialism posits that identity has a basis in nature and is the unique, integral, eternal and harmonious core of each human being (Calhoun 1994, 13). The notion of an essential identity has also often been extended to groups of people, drawing lines between insiders and outsiders. Postcolonial theory, for example, reacted against the reduction of people to essentialist categories (e.g. Said 1978). Some theorists have argued that the colonializing gaze dehumanized communities by making them one-dimensional essences, while others have turned the essential argument on its head, arguing in favor of an authentic essential identity as an important strategy of resistance (see, e.g., hooks 1990, 23-32). On the other side of the spectrum of essentialist notions of identity are notions of constructionism which hold that language, interpersonal interaction and social practices all act together to assemble ever-changing identities (Burr 1997, 1-5). The difference between the two conceptualizations has often been characterized as the difference between nature and culture. However, as Craig Calhoun suggests, it might be more useful to consider essentialism and constructionism as strategies rather than truths in confronting issues concerning identity rather than as mere diametrical opposites (Calhoun 1994, 17).

While much of social theory remains firmly focused on the essentialist/social constructionist debate on identity, following Bauman I would suggest that the more significant issue is how difference functions within the fundamental social fact of mutual dependence (Bauman 2001, 74-88). In other words, cultural, ethnic, sexual, gender or racial difference in and of itself should not be the focus of analysis, but rather the ethical consequences of constructions of difference on equality, the distribution of resources, human rights and social justice within societies should be examined.

The postmodern turn is concerned with how actors function and construct meaning within the web of the mutual dependency. It therefore brings two important elements to contemporary social theory.

Firstly, as noted earlier, it challenges modernist constructions of social theory and concomitant essentializing categories of individual and collective identity. Mutual dependencies are increasingly recognized as extending far beyond the borders of the nation-state through the process of globalization and lived reality of transnational diasporas (Bauman 2001, 97). Notions of cultural order and cultural purity, similar to the grand narratives of modernist science, have given way to the hybridization and border crossings of postmodernity (e.g. Brah 1996; Jameson 1998; Werbner and Modood 2000). Seemingly stable identities and cultural definitions have come under scrutiny as many traditionally culturally invisible groups (often constructed as the Other) have asserted their right to self-definition and visibility on their own terms (e.g. Anzaldúa 1987; Anzaldúa and Kantrowitz 1990; Patton and Sánchez-Eppler 2000; Root 1996). At the same time, the binary opposite to the Other (the One) has become a target of examination and differentiation (e.g. Ignatiev 1995; Jacobson 1998; Walter 2001). In short, the framework of *us and them*, the 'me' and 'muukalaiset' terminology that so often dominates discussions on migrants and cultural minorities in Finland, is becoming an increasingly problematic basis for analysis with its mechanistic implications of stable and unsullied center/periphery relations.

Secondly, postmodern social theory discombobulates the power relations that have undergirded the development of modernist epistemology. As Patricia Hill Collins has pointed out, the knowledge validation process is influenced by those groups of people deemed experts (Collins 2000, 253). These experts represent groups that have access to elite institutions and therefore may have research agendas or perspectives that mirror political interests and hegemonies. The increasing focus on difference and foreignness, on how to know and interpret rather than measure the social world, and to consider how truths are constructed, reflects struggles over the democratization of intercultural knowledge, research ethics and politics of meaning making. Hence which parties have rightful claim to the ownership of issues is not an idle question but reflects the constellation of power relations in society.

In theorizing the significance and ethics of difference in postmodern social theory, many analysts have focused on issues of recognition (e.g. Taylor 1994). Intrinsic to discussions of recognition are contested definitions of group belonging and power, where questions of essentialism/social constructionism are highly relevant as well as issues surrounding citizenship and socio-economic rights. The argument presented by philosopher Charles Taylor, which comes out of the traditions of Bahktinian dialogicality and authenticity, seeks to find a way that the politics of difference and mutual respect can co-exist in the paradoxical community of liberal democracy. With increased migration and transnational citizenship, the implications of questions regarding whether democracy should be representational or participatory, and in which way, have far-reaching significance to the mission of researchers. The relationship and ethics of experts and knowledge makers to constructions of social theory is therefore relevant in how knowing how the social world and expertise are being constructed in studies. Identity is thus not simply a question of curiosity or strangeness, but remains a question of standpoint, power and position. Here the transformation of social theory from the theological hermeneutics of the premodern world to the objective scientism of the modern world has come full circle to the prismatic nature of social theory in the postmodern world.

### **3.3 Theorizing**

In this section, I briefly introduce the three central concepts that constitute the theoretical framework used in this work. The notions of human rights, social memory and postmodern illness are used as a triad of concepts to observe, explain, read and make meaning of the data collected about migrants living with HIV/AIDS in the Finnish welfare state.

#### 3.31 Human rights

Human rights in this work are conceived as the fundamental, indivisible rights of each human being as defined by the 1948 Universal Declaration of Human Rights. These rights include social, economic, health and cultural rights as well as civil and political rights. Though the set of human rights delineated by the United Nations in the years immediately after the genocide of the Second World War are legally binding, as noted earlier, they nonetheless remain in many ways on the level of political aspirations due to the lack of an authority that can hold sovereign states responsible for violations.<sup>17</sup>

Human rights can be conceived in many ways and the intention of this subchapter is not to provide an exhaustive analysis of the diverse definitions of human rights, but rather to explicate how the concept is being used within the theoretical framework of this work.

Human rights can be conceived as having positive and negative aspects. The positive aspects of human rights can be defined as proactive rights to live a free life. These rights can be seen as the constellation of social, economic and cultural rights included in the 1948 Declaration. Negative rights can be defined as freedom from cruelty, persecution and restraints on liberty. Amy Gutmann summarizes a position on the primary aim of human rights:

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<sup>17</sup> Despite the fact that the United Nations held a general assembly in 1998 to establish a convention for the International Criminal Court, which would be intended to end state impunity in human rights violations, the fact that the world's only superpower has not agreed to sign the treaty places a large question mark over the viability and power of such an institution.

...to protect human agency and therefore to protect human agents against abuse and oppression. Human rights protect the core of negative freedom, freedom from abuse, oppression, and cruelty. (Gutmann 2001, ix)

This focus on human rights exclusively as freedom from interference has often been constructed as a pragmatic approach to human rights, while social, cultural and economic human rights have often been viewed as constituting a moral approach. The privileging of one type of human rights over another disregards the intrinsic interconnection of all human rights as the fundamental cornerstones of human dignity. Separating human rights into categories of pragmatic and moral aspirations implies that some rights can never realistically be achieved, because it suggests that human agency cannot affect the socio-economic and political system in which we live. Moreover, rights to health and well-being are frequently intertwined with the freedom to live without fear of oppression.

The concept of human rights used in this work is broad and inclusive. I do not seek to compartmentalize human rights into those which are achievable (pragmatic rights) and those which tend to remain aspirations (moral rights). To differentiate human rights into these types of categories would imply that all human rights are not equally valid and important as well as interconnected. Even if the collision between notions of universal human rights and reality may occur at the level of enforcement and governmental prioritization, this does not provide a case for the privileging of certain rights over others and refusing to see their fundamental links.

This work focuses on the position of migrants in a Nordic welfare state. At this crossroads, issues of citizenship and legal rights are important determiners of how the human rights of individuals are constructed within the community. The concept of human rights used in this work thus functions as set of intrinsic and irreducible universal rights which supercede national definitions and include positive and negative as well as pragmatic and moral aspects, and considers all human rights to be interconnected.

### 3.32 Social memory

Social memory plays a significant role in the way that social reality is constructed through collective stories. Social memory can be defined as the physical embodiment or performance of memory stories. Social memory differs from historical reconstruction in that the latter aims to reconstruct history through an inferential examination of empirical traces of previous existence while social memory preserves the direct testimony of an event through embodying practices (Connerton 1989, 13-14). Documentaries, written histories, art performances, and memorials are among the ways that social memory becomes embodied. The embodiment of social memory legitimates collective histories by recognizing, or denying, historical truths. The disease at the center of this work, AIDS, has been an historical event unprecedented in many ways. As the first disease of globalization, AIDS is epidemiologically fragmented by socio-economic and cultural fissures in global society. Yet, the global response to the disease has often reflected the market forces of global capitalism rather than the interests of public health. Articulations that divide people living with HIV/AIDS into those worthy of gaining access to treatment, and those who are not, reflect the weaving of social memories which privilege the lives of certain people over others, often to the detriment of everybody. The constructions of national social memories of AIDS are therefore important markers of the boundaries of inclusion and exclusion as well as how human rights are practically integrated into welfare states.

Following Paul Connerton, we can say that there are three elements of social memory that are significant to this work (Connerton 1989, 1-5). Firstly, social memory is a dimension of political power that functions via individuals and collectives. Secondly, our present social order is legitimated by constructions of past memories, which can also provide a framework for action. Thirdly, recollection defines who we are. Hence social memory plays an important role in how we define our communities and actions as well as how we seek to shape the future. It also speaks volumes of how policies and services are developed and considered just, fair and sufficient by the community. Cathy Cohen's work on AIDS in African-American communities is a good example of a work that uses the

notion of social memory to draw a clear line between community responses to the AIDS crisis and collective memories of how the U.S. medical establishment has mistreated ethnic minority citizens, especially during the infamous Tuskegee syphilis experiment (Cohen 1999).

Social memory is used as a key concept in this work to explore how Finnish society's vision of '*we-ness*' has served to construct policies and services to support the community's well-being.

### 3.33 Postmodern illness

If we see the world as a social text, resonant with meanings, then illness is one aspect of life that can also be read. As in the Susan Sontag quotation presented earlier suggested, when viewing each historical age as embodying its own mythologizing disease, it is possible to consider illness as intimately connected with culture. This marks a shift from the modernist perspective on illness which viewed it through the biomedical lens of causality and segmentation. Following David Morris, postmodern illness can be contrasted to modernist discourse:

...[while] the long-dominant biomedical model provides one such comprehensive and dubious grand narrative: a theory that reduces every illness to a biological mechanism of cause and effect...by contrast, my argument – that postmodern illness is defined by an awareness of the elaborate interconnections between biology and culture – does not aspire to the stature of a grand narrative. (Morris 1997, 11)

The concept of postmodern illness is thus more extensive than the notion of modernist illness. Located at the interstices of biology and culture, postmodern illness absorbs the multiplicity of narratives, ways of representing and articulating anxieties about illness in the social world. By examining the relationship of meanings and stories to illness, postmodern illness as a concept recognizes that suffering is not solely a private matter, but also a public issue by introducing the notion of social suffering (e.g. Kleinman et al. 1997). If modernist illness relied on the voices of experts to define the discourse on

illness, using postmodern illness as a concept implies a sensitivity to the plurality of suffering voices and the power these voices hold to narrate the lived experience of illness rather than a focus on a professionalized metanarrative of disease (Morris 1997, 200). The concept of postmodern illness links postmodern ways of knowing the social world with the lived experience of illness.

### **3.4 Research questions and research design**

The epistemological and theoretical framework of this work departs from the interpretive postmodern turn in social science and considers the world as a social text that can be read through its stories as ways of constructing and articulating social realities. The methodology of this study can therefore be characterized as qualitative, though elements of quantitative methods, such as empirical data derived from international and Finnish epidemiological statistics, are used as anchors to connect narratives and constructions of social reality to empirically measured statistics on HIV/AIDS. Counternarratives, however, are also presented to problematize the limitations and conclusions drawn from the empirical data collected by epidemiologists and the social policy consequences derived from these findings. The purpose of this use of diverse qualitative methods is to attempt to handle the complexity of issues that constitute the event of the AIDS pandemic as a global and local phenomenon on multiple levels.

The research questions that this work addresses are:

- How has HIV/AIDS been constructed as an exceptional health issue internationally and how has it emerged out of globalized trends in socio-economic development, migration, and the traditions of public health and social work?
- What kinds of stories have been told about HIV/AIDS and how have they been organized as narratives to emplot AIDS in global and local social and health policies?
- How are migrant identities and rights constructed in Finland, specifically in the intersection of legal, social and health definitions for migrants living with HIV/AIDS?

- What sense of cultural identity and belonging is constructed at the core of access to Finnish social and health services for people living with HIV/AIDS and how is it manifested?

I therefore approach the research in the following manner:

First, I briefly map out the socio-economic, political and accompanying cultural changes that have occurred since the economic upheaval of 1974. I examine how these transformations, which have emerged at the same time as the rise of the AIDS pandemic, have been framed in three articulations of globalization. These socio-economic transformations have had a direct impact on the resources and strategies of social welfare states, social and health policies and practices, as well as the developing patterning of the epidemic. Socio-political responses to increasing immigration and cultural diversity on the European level are also touched on to lay a basis for the later analysis of the role of *Finnishness* as social memory in the social and health care context.

Second, I look at connections between migration, public health, human rights, and social issues historically and in the light of globalizing processes. Here I explore constructions of social and health policy lines in the context of notions of multiculturalism, citizenship and belonging, to consider how the development of the AIDS pandemic has been intimately interwoven with these complex issues.

Third, I examine how international plots of AIDS have significantly influenced HIV/AIDS policy development throughout the course of the pandemic. The particular interest in this section is to explore how certain stories of AIDS became dominant and influential, while other critical counternarratives of AIDS were rendered invisible. I focus especially on how identities were molded by AIDS plots, and then move to analyze the local impact of global plots on the interpretation of the Finnish AIDS epidemic by national authorities and the public. I therefore examine the events in Finland from the perspective of the narrative elements of international stories of AIDS as well as critical counternarratives that never reached public discussion. The authority of certain

articulations of stories and plots reveals the constellation of power relations in nations and through globalizing processes. This section thus provides insight into how Finnish AIDS policies were shaped by prevailing stories of the pandemic.

Fourth, I explore how migrant identities and rights are constructed in the social and health care system in Finland through a textual analysis of relevant immigration laws and policies. This discussion links human rights to access to care with the earlier analysis of globalization and its impact on the new face of international migration, increased international socio-economic inequality and the local political ramifications of these phenomena. The notion of equality is thus developed as a contested site of social inclusion through an examination of the rights to access to appropriate care by migrants.

Fifth, through a close reading of available prevention and informational literature on HIV/AIDS, as well as interviews with professionals in the field and PLWHAs, I scrutinize how the needs of migrants living with HIV/AIDS are produced within the Finnish social and health care system, which includes statutory and non-governmental agencies. I conclude by exploring the silence surrounding migrants living with HIV/AIDS through interviews with MLWHAs and examine how issues of belonging and invisibility are fundamentally interwoven with issues of access.

### **3.5 Research approach**

Departing from the notion that the world is a social text means that the research methodology in this work focuses on reading and making meaning of how social realities are produced. The raw material consists of texts and stories collected from various sources, as discussed in the following subchapter. This work sees texts, contexts and readers as coming together to constitute formations of meanings. Articulation as an analytical tool holds that the articulation of meaning takes place in contexts and is therefore processual (Lehtonen 2000, 155). Stuart Hall's theory of articulation, for example, sought to develop an approach to reading texts that could go beyond Marxist determinism in analyzing implacable historical processes. It sought to focus instead on

how the interaction between cultural practices and social structures can come together to articulate new social formations (Hall 1986). Articulation (Weinstein 2004) considers formations of meanings from diverse angles, such as:

- Who is doing the articulation?
- Who is being articulated?
- What is being articulated?
- What is being erased/silenced?
- Are there alternatives?

With this analytical method, articulation raises the process of the contextualization and recontextualization of meanings to the fore and rejects the notion of fixed, essential identities. Narrative and emplotment are therefore used as key tools for reading the formation and articulation of meanings of the AIDS pandemic on both the global and local levels. Narrative as a methodological tool is discussed at greater length in Chapter 9.

Through the examination of multivocal articulations of meanings, this work strives to then explore the social construction of migrants living with HIV/AIDS on a systemic level in the Finnish welfare state. Social construction is used here to refer to the collective articulation of social conventions and reality.

### **3.6 Data collection**

One of the great challenges of writing this dissertation has been the detective work required to try to locate information. Indeed, I often felt a sense of rising panic that I lacked proper data to use in this work. There was almost no information, other than epidemiological statistics or sensational tabloid news articles, which dealt with the question of migrants living with HIV/AIDS in Finnish society. This state of affairs appears to exist for three primary reasons: the desire not to stigmatize migrants living

with HIV/AIDS, the small numbers of migrants living with HIV/AIDS, and an overall lack of recognition of the special needs of this patient group.

As noted in the previous subchapter, the aim of this work is not solely to look at migrants living with HIV/AIDS in a very narrow local context, but to broaden and sharpen the perspective on the situation of these local migrants by integrating globalized formations of meanings on AIDS into the local picture.

To construct the second section on the global context, I set out the groundwork for considering plots of AIDS on the global and local levels; economic, migration, public health and social policy theories are explored in terms of how diverse meaning formations have articulated the role of human rights, social memory and postmodern illness. This bundle of issues is aimed to introduce the complexity of socio-economic and political currents and ways of governing that have given meaning and impetus to action (or inaction) on the AIDS pandemic. The material used for analysis was collected from a wide cross-section of contemporary social, economic, public health and migration theory. The main criteria for selecting material were the relationship of the theories to the contemporary articulations of formations of meanings surrounding the term 'globalization.'

The third section of the work analyzes the role of plots in international and national narratives on AIDS. The published information on HIV/AIDS that I have used includes writings from the fields of social science, epidemiology, medicine, history, contemporary journalism, public health and cultural studies, in both the English and Finnish languages. I sought to throw my net as broadly as possible in order to understand the phenomenon of AIDS in an adequately complex and multidisciplinary sense. This material provided the raw data from which to construct plots of AIDS. It collects material from a wide variety of social, health, epidemiological and cultural sources to construct how narratives were formulated and emplotted to explain the story of AIDS in global and local contexts. These plots are viewed as framing devices that helped to direct the development of policies and reactions to the pandemic.

The fourth section of the work focuses on the local context of the AIDS epidemic. The aim in this section is to explore how migrants living with HIV/AIDS are constructed in the Finnish welfare state. The aim in this area of data collection was to include a diversity of voices that have experienced the Finnish AIDS epidemic from a variety of perspectives, both orally and textually. The data that I collected consists of four main source areas:

- Finnish laws and policies
- Questionnaire data
- Informational material on HIV/AIDS published in Finland
- Interview data

I have tried to collect the most relevant laws and written policies from Finland which have a direct impact on migrants living with HIV/AIDS. The Alien's Act, various public health and social care laws and the recently published Finnish national AIDS strategy have been the cornerstones of the discussion of human rights and equality in the Finnish welfare state. I explore how meanings were articulated in the texts to illuminate how key areas of the social and health care system regarding HIV/AIDS are structured as well as how migrant identities are constructed by law.

I had a questionnaire distributed by physicians (see Appendix 4) to 8 migrant patients at an outpatient AIDS clinic in Finland in 2000. Only two patients responded. Nonetheless, what is perhaps most interesting in these two responses is what is missing: neither person had any complaints about medical care nor were social services users. However, one of the respondents wrote some lengthy comments that provided an interesting commentary on how living with HIV is experienced from a migrant viewpoint in Finland.

I also contacted every agency working with AIDS issues in Finland<sup>18</sup> and requested all of the informational material available in other languages. I received one English language pamphlet, and a photocopied Russian translation, from the Finnish AIDS Council.

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<sup>18</sup> These agencies included the Finnish AIDS Council, the Finnish Family Federation, the Finnish Red Cross, Body Positive and Folkhälsan.

Folkhälsan, as an agency that serves Swedish-speaking Finns, had a great deal of Swedish language information and some English language brochures imported from Sweden.

I interviewed professionals and policymakers from the Ministry of Social Affairs and Health, Finnish AIDS Council, Body Positive and the Aurora Hospital for Infectious Diseases to ask for their views and analyses of the AIDS epidemic in Finland. I also interviewed two Finnish people living with HIV.

Finally, as noted in an earlier chapter, it was only toward the end of the research process that I was able to make contact with two migrants living with HIV. I began to interview them long after I had written the largest part of this work. The decision to start interviewing informants so late in the study was not so much to generate new data as much as to have a commentary and critique of my preliminary findings as well as to discuss the meanings of silence and HIV in Finland. The interviews were open-ended and unstructured. The shortest interview was one hour long, while the longest was four hours long. I have respected the wishes of each interviewee with regard to confidentiality.

In this way, I have tried to triangulate the data by posing the perspectives of published material in contrast to people involved in the field in different ways and other data collected through survey and discussion. This small though very rich source of data has brought out the multiplicity of voices in a rather unknown field. The availability of data nonetheless very much reflects my own research process and my position as an outsider in this field. An insider could probably harvest very different, and perhaps deeper, sources of information and insight from shared experiences. An interesting perspective would be to place migrants living with HIV/AIDS at the center of the work and look at their everyday life, but as I have said before, for many reasons this was not possible for me.

Perhaps the most important lesson during the period of data collection and analysis was to realize just how difficult it is to conceptualize and write about silence and absence.

Silence does not necessarily imply absence, but can contain information in less obvious or visible forms. Silence is not solely a form of self-censorship but can also be embodied as *silencing* which reflects relations of power (Sunderland 2002). An exploration of the meanings of silence thus requires more subtle tactics of observation and theorizing, which I explore in Chapter 15.

### **3.7 On the term ‘migrant’**

At this point, it is important to make explicit how I am using the central term in this work, ‘migrant’. The primary focus of this study is on how MLWHAs in Finland are constructed *by* the welfare state through laws and policies. This is not, however, a straightforward task because cultural and ethnic identity is indeed a fluid and prismatic concept and not an essential characteristic. As Dr. Nicola Schinaia of the AIDS epidemiological unit of the Italian Public Health Institute has pointed out, it is very difficult to collect accurate statistics on migrant health problems when there is no European consensus on how migrants are defined (Schinaia 2003). Several medical articles have stressed the difficulty of constructing scientifically valid social categories of migrants and ethnic minorities that are meaningful to epidemiological research (Fenton et al. 1997; Jones 2001; Kaufman and Cooper 2001a, 2001b; Senior and Bhopal 1994). These complexities lie at the very heart of identity construction and raise the fundamental problem in evidence-based research on migrants, namely, how do we define the target group?

I therefore circumscribe the use of the term ‘migrant’ in this work to people who have moved to Finland from other nation-states and the children born to them in Finland regardless of their residence status. The construction of this categorization is indeed problematic and reflects a framework placed upon what is in reality a very fluid transnational situation. Nonetheless, using the construction of the category of ‘migrant’ is an important heuristic device to explicate the position of those considered to be outside of the Finnish nation. Migrants often remain outside of mainstream Finnish society and social and health care services for many reasons, and thus have special needs due to

differences in culture and language despite the fact that they may have Finnish citizenship. Hence the term 'migrant' in this context is used as a synonym for people from diverse socio-cultural groups who have the experience (or whose parents have the experience) of migration, unlike Finnish Romanies, the Same, gays, lesbians or Swedish-speaking Finns who may also face many socio-cultural barriers in gaining adequate access to mainstream social and health services.

Due to the relatively recent development of in-migration in Finland, I suggest that the term 'migrant' can function in a more limited and clear-cut manner in the Finnish context than other European nations with long histories of migration and colonialism. I use the term 'migrant' rather than the word 'immigrant', which implies a person who has come to a specific country for specific reasons (e.g. to find a job, to marry, to get an education, etc.). I would propose that the designation 'migrant' better reflects the broad spectrum of reasons for leaving/arriving in a country, situations where people often 'end up' in places due to circumstances and for limited periods of time, rather than embarking on a linear journey from point A to point B. The term 'migrant' is also used in this context because it is more restrictive than the notion of 'mobile populations' which would include drug users, commercial sex workers and other such individuals who may not retain a permanent residence and thus may remain outside of mainstream Finnish society for a variety of other reasons. Jeanette de Putter, editor of the first collection of AIDS & Mobility country reports, outlines some of the difficulties in finding accurate terminology:

The main conclusion from the country reports is that mobile groups are no longer always related to mobility. For example, migrants may become residents of a country or be born and raised in a country but still considered to be migrants. They may be restricted in their mobility due to travel restrictions related to their status. Therefore, the term mobility as such cannot be applied to all target groups identified in the country reports...[T]he term 'migrants' has been intensively discussed within the A&M network because it is defined differently in the EU Member States. It usually incorporates diverse ethnic community groups. The definition of these different groups is in accordance with the status people receive when residing in a foreign country. Illegal immigrants or aliens have no legal

rights. The term 'migrants' is often not accepted any more by groups that were born and raised in the country where their parents settled. Groups may identify themselves with another description, e.g. African community. Terminology in prevention policy is important so that specific groups are addressed correctly and not in an offensive or stigmatizing way. (de Putter 1998, 16)

As AIDS researchers Mary Haour-Knipe and Richard Rector point out, depending on their difference to the host population, migrants may eventually become established in a host country and become ethnic minorities (Haour-Knipe and Rector 1996, 6). This mutating definition reflects the great difficulties involved in constructing classifications that accurately mirror the self-identifying categories of communities. Young people, for example, may not view themselves as migrants within the society that they have grown up in, even if many members of that society view them as alien. However, it is the lived experience of migration, travel, and the sense of home being somewhere far away or in-between that distinguishes the migrant from the ethnic minority, whether or not he has ever journeyed himself.

## **4. Finnish research on migrants**

Academic research on migrants that are resident in Finland is a relatively new phenomenon. In this chapter, then, I will map out the terrain of Finnish research focused on migrants to situate the current study. The main guides that I have used to orient myself to the field are a small number of comprehensive bibliographies produced by the Institute of Migration, University of Turku (Domander 1993; Koivukangas 1978) and the Finnish Family Federation (Mattila 1999; Mattila 2000).

### **4.1 Early research on migrants**

The first coordinated effort to study the phenomenon of migration was developed in the 1950s by Professor Vilho Niitemaa who established the Finnish Emigration Project at the Department of General History, University of Turku. The aim of the Project was to collect all relevant research material concerning Finnish emigration into a comprehensive collection for researchers (Virtanen 1979). From its early days as primarily an archive for collected material, the renamed Institute of Migration has evolved into one of the most important research centers on Finnish migration.

As the bibliography compiled by Koivukangas (1978) demonstrates, the vast majority of source material in Finland was related to Finnish emigration abroad, particularly to Sweden, the United States and Canada. Of the twenty works cited in the section entitled 'Foreign-Born Residents in Finland,' only three works were written before 1970. All three of the works were in the form of brief articles. This bibliography reflects the historical fact that few migrants came to Finland before the 1980s and most mobility in Finland took the form of outmigration.

The large bibliography covering the years 1980-1993 that was compiled by Domander (1993) of the Institute of Migration shows a dramatically different picture of migration studies in Finland. While the Koivukangas (1978) bibliography largely classified

information on the basis of destination, the Domander (1993) bibliography focused solely on academic works and constructed 15 different topic categories, none of which focused on national destination. Moreover, a listing on works by scientific discipline was also provided. This indicates that the field of the study of migrants had expanded far beyond the limits set by initial research parameters in the 1970s based on national destination and found resonance in disciplines as diverse as anthropology, language studies and mental health by the 1980s.

The research trends of the 1980s appear to have been largely defined by categories of ethnicity as well as refugeeism. According to the ethnic breakdown of research in Domander (1993, 48), the majority of migration research continued to focus on Finnish migrants to Sweden (e.g. Korkiasaari 1983, 1985a, 1985b, 1989) and Swedish-speaking Finns, along with studies of Karelians, American Finns and Ingrians.

Two of the pioneering researchers in this field were Magdalena Jaakkola and Karmela Liebkind. Jaakkola specialized in examining Finns as an ethnic group in Sweden as well as scrutinizing the relationship of Finns to newcomers (e.g. Jaakkola 1976, 1984, 1991, 1993a). Liebkind, on the other hand, took a social psychology perspective on the issue and sought to understand the factors that created a sense of minority and bicultural identity as well as majority reactions to minorities (Liebkind 1974, 1988, 1994, 2000). Both researchers produced foundational books, in a manner of speaking, that have had a strong influence on the development of Finnish migration research concepts and methodologies.

#### **4.2 Research on migration and multiculturalism in the 1990s**

Many factors affected the shifts that influenced emerging research targets in the 1990s. With the change in Finland as a country from outmigration to one of in-migration, albeit on an extremely small scale, new groups of migrants, such as Somaliss, Bosnians, and people from the former Soviet Union began to arrive and have an impact on Finnish society, particularly as pupils/clients/patients of education, social and health care

services. A steep economic recession at the beginning of the 1990s also served to harden the attitudes of many Finnish people towards newcomers, who were often considered to be 'economic migrants' seeking the benefits of the Finnish welfare state. Political changes, in terms of legislation on migrants and residence permits, as well as membership in the European Union, which has agreements that coordinate the signatory countries' visa policies, also had an impact in the rising importance of migrants and their relationship with Finnish society. Hence two distinct sets of research concerns began to emerge: migration research, which was devoted to studying specific ethnic or cultural groups, and multicultural research, which focused on integration policies and practices.

Migration research in the 1990s saw the development of lines that studied new migrant groups and topics such as specific groups of migrants and their integration into Finnish society, for example, the Vietnamese and integration (Oinonen 1999; Valtonen 1997, 1999), Somali refugees (Virtanen 1993; Alitolppa-Niitamo 1994; Visapää 1997), Kurds in Finland (Wahlbeck 1999), migrants from the former Yugoslavia (Salminen 1997), Muslims in Finland (Sakaranaho and Pesonen 1999), Ingrian and Estonian migrants (Kyntäjä 1998), Iranian refugee women (Turtiainen 1998), and Russian-speaking youth in Finland (Jasinskaja-Lahti 2000).

Among the most significant research on multiculturalism focused on Finns' attitudes towards migrants (Söderling 1998), authorities' attitudes towards migrants (Pitkänen 1999, Salmenhaara 2002), working with migrants (Forsander et al 1994; Ikäläinen 2002; Koskimies 1999; Toikka 2001), educating migrants (Matinheikki-Kokko 1997) along with an increasing number of works on perceptions and experiences of a multicultural Finland on many levels (Anttonen 1997; Clarke 1999a; Haarakangas 2000; Jokela 2001; Liebkind 2000; Pitkänen 1997). Integration became an important theme in research as the Finnish government began to develop integration policies (Berhanu 2001; Ruusunen 1998) and immigration policies (Mbah 2000), particularly in relation to employment as Finland began to climb out of its deep economic recession by the mid-1990s (Forsander 2002).

A great deal of the research on multiculturalism initially came from outside the academy and was largely developed through government policies, project plans and evaluations, as well as vocational education training programs. Indeed, research on the prevalence of multicultural studies in Finland during this period showed an exponential rise in the amount and diversity of publications that dealt with multiculturalism both on the academic as well as the administrative levels (Matinheikki-Kokko 2002).

Multicultural research first became institutionalized in the 1990s and was increasingly commodified as project work, with all of the attendant drawbacks of the transitory nature of such work. This led to the development of a patchwork of multicultural research studies and projects, but with few sustainable programs aimed at grassroots communities.

The measurable products of research are publications, the number of international projects, international relations and further qualifications in the field. This emphasis on commodification has, on the other hand, tended to exclude certain matters of significance from the point of view of social progress in multiculturalism, such as the rise of an academic generation that is familiar with multiculturalism, career development and employment in the sector. Even though the research programmes of the Academy of Finland (1992, 1999) have given researchers engaged in postgraduate studies in the field an opportunity to work in relevant research teams and working collectives, these programmes have not met the need for basic studies and tutoring in multiculturalism. (Matinheikki-Kokko 2002)

Hence there was little connection between the development of research on multiculturalism as a concept in Finnish society and enhancing its practice on a grassroots level. This gap meant that there were few real opportunities to promote intercultural encounter on a personal and community standing. Multiculturalism as a concept, moreover, tended to be articulated from the mainstream as few migrant researchers were involved as writers of the publications or stakeholders in projects. The discourse on multiculturalism thus remained hermetic to some degree, with migrants serving as informants and rarely influencing the findings or conclusions of the emerging field of research.

Very few studies indeed were written from a migrant perspective, a perspective which would have the potential to raise quite different issues than those chosen and defined by Finnish researchers as well as to develop a more balanced dialogue on the notion of multiculturalism in Finnish society. The lack of migrant voices (as articulators instead of solely informants) may reflect to some degree the relative youth of the migrant population in Finland as well as the possibility that there may be institutional and cultural barriers (e.g. the lack of an 'old boy' network, glass ceilings, discriminatory, xenophobic and racist attitudes by employers and colleagues, language difficulties, the potentially differing priorities of funders, power relations within the field of research, etc.) that prevent migrant researchers being hired as well as from participating fully in research networks. Finally, the lack of ethnic enclaves and a critical mass of migrants pressing for community mobilization, as well as the lack of connections and skills to get funding, presented significant barriers to migrant community organizations that could have supported community research.

#### **4.3 Migrant research in the 21<sup>st</sup> century**

With the turn of the 21<sup>st</sup> century, several new studies with innovative approaches have emerged which show great promise for the possible merging of migration and multicultural concerns in migrant studies in Finland. Marja Tiilikainen's rich ethnographic research on Somali women's experience of health and illness in Finland is a very important step towards developing a culturally competent framework for understanding a culturally diverse clientele (Tiilikainen 1999, 2000a, 2000b, 2001, 2003). Petri Hautaniemi's ethnographic study of Somali boys examines the transnational childhoods of 20 boys as they grew to manhood in Finnish society, problematizing modernist conceptions of migration and everyday life (Hautaniemi 2004). Outi Lepola's (2000) study of the political debate on immigration in the 1990s raises the long-neglected issue of who is included and allowed to participate fully in the Finnish political community. Lepola explores the borders of Finnish identity and argues that the development of an inclusive multicultural Finland depends on whether Finnish identity remains ethnically-defined or whether the notion of Finnish social citizenship can be

extended to all who reside here. The study on migrants in the Finnish labor market by Annika Forsander (2002) makes an important contribution to understanding the complexity of discrimination against immigrants in the labor market.

Leena Suurpää's dissertation (2002) raises interesting new perspectives on Finnish constructions of hierarchies of difference and how young people conceive multiculturalism. Laura Huttunen's (2002) work on the understandings and constructions of the idea of home and belonging amongst migrants in Finland demonstrates the transnational and complex nature of identity and perhaps gives lie to the notion that ethnicity is singular, static and all-encompassing identity category. Huttunen's work problematizes the notion of living in Finland as a homeland and raises important implications for a multicultural Finland. These new studies provide a strong impetus towards exploring transnational communities, the increasing global/local context of migration and contemporary postmodern life which will be an important element of future research on migrants in Finland

The decision of the Academy of Finland to launch a large-scale research program entitled SYREENI (Marginalization, Inequality and Ethnic Relations in Finland), which took place between 2001-2003, is an important step towards developing methodological and interdisciplinary work on these very timely topics and demonstrates an official acknowledgement of the importance of these issues. Further published research can be expected to emerge as a result of this. One of the biggest challenges to the development of Finnish research on migrants is the question of whether a dialogue will derive from increased cooperation between Finnish and migrant researchers or whether a bifurcated discourse will emerge.

## **II. The global context**

### **5. Articulating globalization**

As we enter the 21<sup>st</sup> century, it is very clear that our societies are very different than those of a mere century ago. From the technological developments of the automobile, telephone, airplane, computer and weapons of mass destruction to the histories of genocide, famine and holocaust to the polio vaccine and antibiotics, the 20th century has hurtled us forward into a complex and terrifying world of emerging infections, threatening environmental disaster and the war on terrorism (Glover 1999). As Zygmunt Bauman has noted, while the relatively stable era of the Cold War may have been characterized by the doctrine of mutual assured destruction, we now live in a profoundly unstable age of mutual assured vulnerability in all parts of the globe (Bauman 2002, 89). Emerging globalizing trends, which are often filtered through neoliberal ideology of risk and individualism, tend to have a negative impact on the development of international cooperation which is the essential glue that holds public health and well-being together through collective action, development work and legal instruments.

This chapter seeks to establish a socio-economic context in which the construction of migrants living with HIV/AIDS in Finnish society can be examined. Indeed, to approach the issue of migrants in Finnish society, it is important to first consider the how articulations of globalization interact with the material conditions of late capitalism to construct the context for policymaking and practice. Increasing global mobility and growing socio-economic disparities throughout the world, along with the changing nature of national governance, has had a deep impact on the ability and political will of states to organize and provide services for people resident within its borders. Moreover, the notion of inclusion as a recognized legal resident in a country, and the preservation of borders against those deemed not deserving or entitled to equal access to services, has become increasingly contested in many welfare states. This is problematic in the light of the discourse on universal human rights. An increasing amount of international summit

meetings have focused on social and health issues,<sup>19</sup> though there appears to be little progress on this front (Deacon 1999, 213). In short, despite the rhetoric of globalization, few democratic global institutions have been established that have the power to implement concrete solutions to deal with transnational problems.

This work departs from the postmodern commonplace that the local and global are inextricably linked in a multitude of ways that have a vital impact on the everyday lives of people. Hence this section will explore articulations of globalization in late capitalism which are then linked to public health, migration and well-being.

### **5.1 Capitalist hegemonies and the informational revolution: the material basis of globalization**

To approach articulations of globalization, it is important first to explore the material foundation of the phenomenon. This subchapter takes a brief excursion through the major political and economic transformations that have brought us to the current period of late capitalism. Closely following economist Giovanni Arrighi (1994), I suggest that the current global economic metamorphoses represent a further stage of capitalism which can be characterized as late capitalism. The development towards the changes discussed below provides an important background for understanding the economic underpinnings of the AIDS pandemic which added considerably to its rapid increase, particularly in less developed countries.

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<sup>19</sup> For example, the G8 Forum in Genoa in 2001, where a protester was killed by police, had social issues prominently on the agenda. The 2001 UN World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance attempted to raise an international profile for issues related to discrimination. The Earth Summit in Johannesburg in 2002 also discussed the relation of social issues to the environment. The World Social Forum was held in Porto Alegre, Brazil in 2002. AIDS was the first global health issue tackled by a special session of the General Assembly of the United Nations (2001).

### 5.11 Capitalism as a cyclical process: towards late capitalism

Capitalism can be defined as "...[an economic system in which] money is endowed with the 'power of breeding' (Marx's expression) systematically and persistently, regardless of the nature of the particular commodities and activities that are incidentally the medium at any given time." (Arrighi 1994, 8) Capitalism, in Arrighi's view, is dependent on state power and thus is the antithesis of the market economy. As Samir Amin has further defined:

'The market,' a term referring by nature to competition, is not 'capitalism,' of which the content is defined precisely by the limits to competition implied by the monopoly of private property (belonging to some while others are excluded). 'The market' and 'capitalism' are two distinct concepts. (Amin 1997, 15)

It is thus important to distinguish between the market and capitalism. The former is a utopian notion of a state of utterly free competition, often at the heart of neoliberal conceptions of society, while the latter incorporates the notions of state power and hegemonies.

Although there is a tendency to think that the Informational Revolution has brought about an exceptional economic state that is new and unprecedented, I would suggest that the new shift from Fordist-Keynesianism towards what Harvey terms 'flexible accumulation' is yet another stage in capitalism and that each stage of capitalism has indeed been new and unprecedented (Arrighi 1994, 3; Harvey 1990). Each transition between the stages of capitalism has produced new processes that have marked the distinct eras of capitalism, such as the rise of machine technology during the Industrial Revolution. Discontinuous change is indeed typical of the history of capitalism (Arrighi 1994, 1).

As Arrighi discusses, the most important step for the development of mature capitalism was the progression from scattered to concentrated capitalism through the fusion of the state and capitalism (Arrighi 1994, 10-12). In the history of capitalism, we can see that

the transition from one hegemony to another has brought about the further concentration of capital: from the early capitalism of Genoa to the world traders of Holland, and further on to the British Empire of mature capitalism. A significant shift took place after the Peace of Westphalia (1648) in which Western European states formed a political system, created a balance of power and formulated international law (Arrighi 1994, 43). The new set of rules drafted by these powers, combined with the ascent of the Industrial Revolution, laid the foundation for the rise of mature capitalism in the 19th century under the British Empire. These economic transformations provided a basis for the creation of a system of nation-states and the formation of a worldwide capitalist system.

The significance of the shift from early to mature capitalism was the increased role played by nation-states. As political theorist Nikolas Rose has noted:

Economic events were territorialized within a national space, seen as governed by laws and relations whose scope and limits seemed to map on to the territory of political rule. As they crystallized within nations, limited by borders, customs and other restrictions on imports and exports, unified through a single supply of money, characterized by a set of functional relations between their components; these unities were located in an external space within which they could engage in 'foreign trade' with other national economies. (Rose 1999, 142-143)

This union of the territory of the nation-state and economy in the 19th century had broad implications. Arrighi defines world hegemony as the ability of a nation-state to exert moral, intellectual, cultural, political and financial dominance over the world. In Arrighi's own words:

The concept of 'world hegemony' adopted here...refers specifically to the power of a state to exercise functions of leadership and governance over a system of sovereign states. In principle, this power may involve just the ordinary management of such a system as instituted at a given time. Historically, however, the government of a system of sovereign states has always involved some kind of transformative action, which changed the mode of operation of the system in a fundamental way. (Arrighi 1994, 27)

Here we see that the combination of capitalism with the development of the nation-state produced new and complex hegemonies that extended and defined the international system of sovereign states, as well as communities, on cultural, economic and political levels. Hegemony therefore involves methods of governmentality which include managing conflict issues in both global and local contexts (Arrighi 1994, 28).

As Arrighi points out, world hegemonies have not just risen and fallen, but the international capitalist system has been formed and expanded by recurring fundamental restructurings that fall into a pattern of chaos, hegemony and restructuring (Arrighi 1994, 30). Therefore, in approaching the history of capitalism it is important not to concentrate solely on the rise and fall of world hegemonies but to recognize that the modern world system has risen and expanded through recurrent fundamental restructurings (Arrighi 1994, 30). Basic shifts in the international system have come about when the hegemonic role becomes too large for one particular state or organization (Arrighi 1994, 62).

#### 5.12 The postwar economic and political order

The postwar world order was shaped by the US-dominated Bretton Woods agreement and the establishment of the International Monetary Fund which, together with the political upheavals throughout the formerly colonized world, effectively laid the British Empire to rest. Nonetheless, the fundamental crisis that the US corporate world faced in the post-war era was the contradiction between the poverty of foreign markets and the wealth of US markets. This required new tactics and a new ideology:

US corporate capitalism thus was and remained a powerful agency of the destruction of the structures of accumulation of British market capitalism and of the centralization in the United States of the liquidity, purchasing power, and productive capacity of the world-economy. But once the destruction and centralization had become as complete as they possibly could, US corporate business was powerless to create the conditions of its own self-expansion in a chaotic world. No tax subsidy, insurance scheme, or exchange guarantee was sufficient to overcome the fundamental asymmetry between the cohesiveness and wealth of the US domestic market and the fragmentation and poverty of foreign markets. These were

the structural roots of the impasse which after the Second World War prevented the recycling of liquidity back into the expansion of world trade and production. Eventually, this impasse was broken by the 'invention' of the Cold War. What cost-benefit calculations could not and did not achieve, fear did. (Arrighi 1994, 295)

The massive rearmament of the West and Third World during the Cold War through foreign aid and US military expenditures overcame the limitations of the Marshall Plan and provided the world economy with liquidity (Arrighi 1994, 297). Some analysts have even suggested that this led to a permanent arms economy that fuelled the postwar capitalist economic booms (e.g. Kidron 1967). The postwar ideological and political choices outlined by U.S. State Department policy planner George Kennan in the famous national security memorandum of 1948 starkly noted:

...we have about 50% of the world's wealth but only 6.3% of its population. This disparity is particularly great as between ourselves and the peoples of Asia. In this situation, we cannot fail to be the object of envy and resentment. Our real task in the coming period is to devise a pattern of relationships which will permit us to maintain this position of disparity without positive detriment to our national security. To do so, we will have to dispense with all sentimentality and day-dreaming; and our attention will have to be concentrated everywhere on our immediate national objectives. We need not deceive ourselves that we can afford today the luxury of altruism and world-benefaction. (Kennan 1948/1976)

Thus, the Cold War joined economic and ideological purposes on opposing sides with a air rife with fear and distrust. A new postwar world order emerged which, as Amin notes, was structured on a tripartite system:

- a. The West: social democracy, Fordist accumulation, Keynesian national policies
- b. The Third World: modernization and industrialization within the confines of controlled independence
- c. The Soviet Union: attempted to catch up with the West by accumulation, state ownership, centralization of political and economic leadership, the rise of a new bourgeoisie (the nomenclature) (Amin 1997, 46)

American and Soviet hegemony in developing countries was exerted on cultural, economic and political levels. The Cold War shaped the postwar process of decolonization, notions and plans of development as well as newly independent countries' own views of their nations and possibilities for development (see, e.g., Cabral 1970, Rodney 1972).

The expansion of the world economy during the period of 1950-1975 was unprecedented and reflects the hegemonic period in Arrighi's delineation of the stages of capitalism. During this time, there was labor migration from Southern European countries to Northern Europe as well as migration flows from former colonies to the metropolises, which provided labor for the postwar Western European economic miracle. At the same time, there were relatively few political refugees and most of them came from Soviet dominated areas. There were few negative reactions to refugee policies in most European countries until the end of the 1970s (see Brochmann 1996, 25). This period can be characterized as a Fordist regime of accumulation which utilized Keynesian economics to provide a social contract between big business, labor and the state. As David Harvey has described:

...[the state] strove to curb business cycles through an appropriate mix of fiscal and monetary policies. Such policies were directed towards those areas of public investment – in sectors like transportation, public utilities, etc. – that were vital to the growth of both mass production and mass consumption, and which would also guarantee relatively full employment. Governments likewise moved to provide a strong underpinning to the social wage through expenditures covering social security, health care, education, housing, and the like. (Harvey 1990, 135)

The development of western welfare states is therefore rooted in the postwar economic boom.

One important consequence of the boom in world trade was the intensification of competitive pressures between governmental and corporate organizations which resulted in a massive withdrawal of investment in production in the late 1960s and early 1970s

towards investment in financial speculation, especially when exchange rates became flexible rather than fixed and inflation raged throughout world economies. The labor unrest in Western countries in the 1970s was a reaction to the initial pressures on labor to diminish the social contract in the interest of cutting costs among companies in order to make them more competitive. The increase in international financial liquidity, which was often siphoned through offshore accounts, culminated in the fact that by 1979 foreign exchange trading exceeded the total value of world trade by eleven times (Arrighi 1994, 299). These factors laid the basis for the future development of globalization and the growing international division of labor.

### 5.13 The rise of a globalized economy

By the mid-1970s the international geo-political situation began to change. The loss of the Vietnam War had significant implications concerning the limitations of American military might. The Soviet Union under Brezhnev also started its course towards stagnation. The rise of OPEC oil prices in the 1970s accelerated a period of crisis for the postwar capitalist world order under the stewardship of American hegemony. The cycle of stagflation brought about a lack of faith and cynicism on the part of the populace in many industrialized countries towards political leaders. Underlying the economic crisis was the fact that financial speculation and credit-lending continued unabated leading to a financialized international economy that provided little reinvestment in productive capacities. These factors led to the deterioration of industrial capacity in many western industrialized countries. The postwar compromise between labor and capital thus began to unravel in many western industrialized countries. Public investment started its downward trend in many countries throughout the world.

The oil crisis and deep recession of 1974 prompted an 'immigration stop' policy by many Western European countries that had effectively utilized foreign labor to run their economic engines. The recession of 1974 produced some strongly nationalist reactions against immigration and the period of uncontrolled immigration effectively came to an end (Brochmann 1996, 25). By the early 1980s, it had become increasingly difficult to

come to Western Europe legally as a labor migrant. At the same time, the amount of political and economic refugees began to grow dramatically as the impact of globalization was felt in the socio-economic structures and impact on everyday life in many lesser developed countries.

The major restructurings in international capitalism in the 1980s were tied to the recentralization of mobile capital in the United States and other high income areas, the loss of productive industrial and manufacturing capacity in many western countries, the diminished power of governments to control trade through monetarist policies and neoliberal ideologies, the rise of deregulation and privatization, as well as the exponential growth of transnational corporations. In short, the world economy became increasingly financialized, which has strengthened the position of international capital in relation to the nation-state (Mishra 1999, 12). These globalizing trends raise new questions regarding international governance and the role of democracy in policymaking.

The rise of the transnational corporation in as the primus motor of flexible accumulation in the international economy is often considered to be emblematic of globalization, though its significance can be seen from many different perspectives (e.g. Arrighi 1994, 72-74; Barnett and Cavanaugh 1994; Friedman 2000; Kennedy 1993; Stiglitz 2003).

The lack of local control over transnational corporations as well as the fact that they are not necessarily obligated to contribute to the well-being in local communities makes it difficult (though not impossible) to find a means of influencing the economic development of globalization in late capitalism. As investigative journalist and social activist Naomi Klein has noted: "(transnational corporations) are the most powerful political forces of our time." (Klein 2000, 339) Despite the fact that there have been a variety of responses within diverse western welfare states to the economic pressures of global trends (Mishra 1999, 102), many developing countries have found themselves in a far more vulnerable position when negotiating trade agreements and debt relief, particularly in the light of the political and economic power of regional associations such as the European Union and the North American Free Trade Association (NAFTA). The

economic power of transnational corporations thus poses many challenges for international governance and public accountability. The failure of nation-states and international bodies to prevent corporate abuses of human rights and the environment or to formulate an effective and enforceable code of conduct for transnational corporations reflects an inability to construct a working model of the social in a global context. This incapacity might simply reflect the sheer economic might of TNCs in the global arena.<sup>20</sup> Ultimately, the consequences of deteriorating social cohesion in communities with little economic power and few resources contribute to increasing transnational social and health problems.

Capitalism as a phenomenon has not developed along a singular linear trail. Rather it has developed as a 'spiral' (to use Arrighi's phrase) or a 'virus' (in the words of Jameson). The impact of the current stage of late capitalism together with shifting patterns of hegemony can be seen in significant transformations in contemporary global socio-economic life which are explored in the following chapters. These transformations are intimately entwined with reactions to AIDS as the first disease of globalization.

## **5.2 Articulating globalization**

There is broad consensus that the world is in the midst of a fundamental change which appears to be as significant as the socio-economic and political changes that accompanied the Industrial Revolution of the late eighteenth and early 19th centuries (see, e.g., Arrighi 1994; Bauman 1998a; Bauman 1999; Beck, 1992; Castells 1996; Mishra 1999).

Globalization has become the new buzzword to describe a mass of emerging interwoven phenomena from accelerating migration and compressed spatial relations to the new technology to new patterns of work to the increasing global gap between rich and poor to global public health threats. Reams of scientific literature have sought to define the

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<sup>20</sup> To illustrate this point, Canadian journalist Murray Dobbin reports: "General Motors is larger than Denmark, Ford is bigger than South Africa, and Toyota surpasses Norway...The largest ten corporations had revenues in 1991 exceeding the combined GDPs of the hundred smallest countries. Put another way, the two hundred largest corporations have more economic clout than the poorest four-fifths of humanity." (Dobbin 1998, 10)

phenomenon from diverse perspectives producing such a plethora of viewpoints on globalization that one economist has characterized the discussion on the concept as ‘chaotic’ (Jessop 1999).

The Informational Revolution, which has its roots in the economic hegemony of the United States after the Second World War and the massive spending by the American government to support the development of new technology during the Cold War, has transformed economic production and international finance. Concomitantly, the cultural reification of individualism and risk has become an increasingly important element of political decision-making. The contemporary global political order has stepped beyond the constraints of the modernist framework of bipolarity towards a multipolarized and postmodern world (dis)order in which time and space have seemingly collapsed into one another (Castells 1996, 41-60). Through the analytical framework of Arrighi (1994), I have argued in the previous subchapter that this immense metamorphosis represents less the ‘end of history’, as some observers have commented (Fukuyama 1993), than a further and transformative stage of capitalism which has as wide-ranging effect on our being in time and space, as well as the sharing of resources, as did the Industrial Revolution.

Technology as such does not embody a political agenda, but its significance is determined by the socio-cultural context from which it is born and nurtured, as well as the meanings that are constructed for it, and the direct effects it has on the lives of people. The cultural, economic and societal shifts that occur due to advancing technology are embedded within the fabric of various hegemonies and power factions that seek to control developments in their own best interests. However, dissent and counterreactions to the direction of such changes, especially when perceived to result in the disempowerment and exclusion of large segments of the population, also has an impact on the direction of social and technological change.

One of the most common ways to describe the contemporary changes in international society is by the term ‘globalization.’ Globalization is often discussed as if it were a known and singularly understood concept, but its significance is often disputed. In the

following subchapters, I explore how globalization has been conceptualized and articulated from three different perspectives.

### 5.21 Approaching the universal and the global

Finnish political scientist Ari Nieminen (Nieminen 1997) has pointed out that the notion of the ‘global’ must be differentiated from the notion of the ‘universal.’ As Nieminen notes, the notion of the universal was a basic concept of idealist modernist social theory. Referring to Kant, Nieminen argues that the modernist concept of the universal holds that there are certain intrinsic moral and ethical codes that apply to all human beings regardless of whether they have relations with one another or not (Nieminen 1997, 3). Universalism is thus one of the cornerstones of modern concepts of human rights, public health and social well-being.

The notion of the global, however, is far narrower. It refers to the end station of the globalization process in which all states are unified in a single closed social system:

What, then, differentiates [the] global condition from all other human conditions, or from all other social configurations? The answer to this question seems to lie in the totalitarian character of the notion of [the] global: in a fully globalized world, all social subsystems are tied into [a] comprehensive global social system. So, the fully globalized world consists of one closed social system. This means that the global social system lacks [a] social environment, every social phenomenon belongs to it, and there is nothing social outside it. (Nieminen 1997, 2-3)

The notions of the *universal* and the *global* are therefore distinct. The aims of the universalizing mission of the 19th century, tied to the historical period of modernity, embodied an idealistic vision of moral and ethical betterment, an all-embracing and all-inclusive social space under the rule of reason. The universal sought to raise all human beings to an (albeit) ethnocentrically defined and gendered notion of reason and humanity, in an attempt to transcend the Hobbesian brutality of the human condition. Thus, the frameworks of human rights and international law are firmly grounded in the

concept of the universal. The universal implies a sense of self-awareness and consciousness of one's being in the world.

In contrast, the global lacks social content and is driven by the logic of the market. The global reflects more the idea of a planetary existence as a series of episodes, as a perpetual present, which is interlinked, fragmented and disorganized. It is not introspective but instantaneously reactive, not engaged but aloof and ironic. If the universal can be characterized as a hegemonic notion of reason and progress that linked discrete elements into an international system, then the global can be seen as fragments that lack a compelling unifying idea other than the expansion of the market. The global thus militates against the development of collective solidarity by focusing exclusively on individual choice, which is often constructed through the framework of consumerism and privatization, rather than the social, community and the public.

#### 5.22 Conceptualizing globalization

Notions of globalization have often been articulated as new phenomena that are composed of several themes. Globalization has been conceived as “the compression of the world and the intensification of consciousness of the world as a whole.” (Robertson 1992, 8) Many of the descriptions of the phenomenon of globalization focus on the changing socio-economic and cultural relationship to time and space in the Informational Revolution (Harvey 1989). Castell’s theory of ‘flows’ sees information technology as creating a network society that extends flows of finance, technology and technology as the new architecture of the global economy to all corners of the world (Castells 1996, 1997, 1998). Many sociologists focus on the view of globalization as a process and set of practices (Albrow 1997, Robertson 1992). Other observers link globalization to neoliberal ideologies and monetarist policies (Cox 1996). The theme of globalization has grown exponentially in social science literature: in 1980, there were 89 sociological abstracts dealing with the theme of globalization, while in 1998 there were 1009 (Guillén 2001, 239).

### 5.23 Three articulations of globalization

In *Global Ethnography: Forces, Connections and Imaginations in a Postmodern World* (2000), Michael Burawoy argues that the analysts of globalization can be divided into three camps: skeptics, radicals and perspectivalists (Burawoy et al 2000, 337-350; also Held et al. 1999). I use the terms introduced by Burawoy to explore three different articulations of the phenomenon of globalization and their political implications. The purpose of this section is less to give an exhaustive view of the diversity of perspectives on globalization than to sketch out three different articulations on the concept that can serve as an opening to consider perspectives on AIDS as the preeminent disease of globalization.

Skeptics hold that much of the discussion about globalization is ahistorical and finds phenomena unique, such as transnational capital and migration, which in fact have existed in various forms for centuries. They suggest that international trade was far more interconnected in the era before the First World War than now. Indeed, many consider the interwar and postwar period to be an interlude of trade and migration barriers between periods of internationalization. Skeptics argue that there is very little difference between the notions of internationalization and globalization (e.g. Boyer and Drache 1996; Hirst and Thompson 1996, 18-98). Many economists have argued that the economy is indeed becoming more international, but not necessarily more global (Guillén 2001, 243; see Krugman 1994; Wade 1996). In other words, transnational corporations continue to locate most of their assets and research and development in their own countries. This means that we cannot speak of a globalized economy in the sense that capital is equally distributed throughout the world. Moreover, similar to political realists (e.g. Morgenthau 1954), skeptics argue that the role of national sovereignty remains primary in the international arena. Inequality is viewed in terms of the North/South divide and the imperial trade policies of western governments (e.g. O'Connor 1998). In short, skeptics believe that globalization is more hype and ideology than a completely new reality (Burawoy et al 2000, 338).

The skeptical articulation of globalization remains unconvinced by the claims of the inevitability and irreversibility of the process of globalization (Guillén 2001, 243-244). The myths and assumptions underlying much of the hoopla surrounding globalization are viewed as promoting an uncritical vision of a network society that ignores the significance of international economic and political power relations. These articulations have thus tended to come from frameworks of analysis that tend to use totalizing theories, such as Marxist economics. However, this line of thinking on globalization has increasingly transformed in the direction of the perspectivist school.

Radicals, such as Anthony Giddens who introduced the bifurcation between skeptics and radicals in his Reith Lectures (Giddens 1999); believe that globalization does indeed represent a fundamental shift in world history:

The radicals argue that not only is globalization very real, but that its consequences can be felt everywhere. The global marketplace, they say, is much more developed than even two or three decades ago, and is indifferent to national borders. Nations have lost most of the sovereignty they once had, and politicians have lost most of their capability to influence events... The era of the nation state is over. (Giddens 1999, lecture 1)

Radicals tend to view the significance and singularity of globalization as self-referential. As Giddens stated: "The global spread of the term [globalization] is evidence of the very development to which it refers." (Giddens 1999, lecture 1). The inevitable process of globalization in this framework is thus seen as the cause of social change which obscures the relationship between cause and outcome (Yeung 2002, 286). Radical views of globalization consider it to be a force for positive social change that will eventually eradicate extreme socio-economic inequalities throughout the world:

Along with ecological risk, to which it is related, expanding inequality is the most serious problem facing world society. It will not do, however, merely to blame it on the wealthy. It is fundamental to my argument that globalisation today is only partly Westernisation. Of course the western nations, and more generally the industrial countries, still have far more influence over world affairs than do the poorer state, but globalisation is

becoming increasingly de-centred - not under the control of any group of nations, and still less of the large corporations. Its effects are felt just as much in the western countries as elsewhere. (Giddens 1999, lecture 1)

Here Giddens divorces growing inequality from human agency. The wealthy in this framework do not cause inequality, and are perhaps best characterized as lucky bystanders within this new process. Globalization is constructed as an inevitable force that is not tied to any hegemony or cultural location, not even the financially powerful transnational corporations. Indeed, in this conception, globalization lacks social content and context. Globalization in this sense grows like kudzu but is not associated with hegemonies.

Many radicals also tend to reify the notion of global culture, which they construct, like Giddens above, as lacking hegemonies. This contributes to a perspective on the meaning of cultural difference as neutral or a consumer choice, rather than collective efforts by identity groups to subvert oppressive and dominating relations. As David Theo Goldberg has pointed out:

...racelessness is at once a product and purveyor of globalized neoliberalism. While the ethnoracial and gendered shaping of global markets is crucial to globalization historically and contemporarily understood, heterogeneous sensitivities entail that the marks of race can no longer be quite so explicit or intentionally imposed...Racial configurations are no longer thinkable as moral or political imperatives, natural or historically evolutionary social conditions because the implications of such thinking are seemingly irreversible. (Goldberg 2002, 257-258)

To summarize, radical conceptions of global culture often separate the socio-economic and significance of constructions of differences through a harmonious vision of equalizing, acultural and irreversible globalization.

This totalizing view of history, which posits that the world is in the midst of vast and unprecedented change, is often described in somewhat simplistic and optimistic broad strokes. The construction of globalization as a universally positive force that is bringing

the world together is perhaps more reflective of the perspectives of those who are privileged to hold acceptable passports that remove barriers to mobility and include them in social welfare schemes (Sassen 1998). The nation-state, however seemingly superfluous to globetrotters, is nonetheless a very real entity to most of the world's citizens through its enforcement of border controls and sovereign rights to decide on asylum applications. Globalization may have become the buzzword of the chattering classes, but how much networking and instant access represent the experience of the vast majority of people in the world is questionable. Globalization in this interpretation conceives of the ideology as a reality, a force majeure, an inevitability, something that businesses and peoples cannot oppose or even influence, and which will be beneficial to all people of the earth, despite evidence that contemporary forms of globalization have exacerbated global inequalities.

Articulations of the radical view of globalization tend to position themselves as apolitical and view the spread of the network society as a positive force. By naturalizing globalization as an inevitable process of development, radicals largely view the process of globalization as benevolent (Yeung 2002, 294). As James Mittleman has pointed out:

A political agenda of inevitability overlooks the fact that globalization was made by humans, and, if so, can be unmade or remade by humans.  
(Mittleman 2000, 7)

By denying or ignoring human agency in the process of globalization, radicals tend to present few critiques of the status quo. In this sense, it is a profoundly political view of the process of globalization. By conceiving globalization as without agency as well as natural and inevitable, the radical view implicitly accepts current relations of oppression and submission, and it diminishes the important role of democracy. Furthermore, notions of global culture and detraditionalization through increasing globalization tend to underestimate the significance of local cultures as communities of resistance to relations of domination.

Similar to Zygmunt Bauman's notion of tourists, locals and vagabonds in a postmodern world (Bauman 1998a), the perspectivalists, according to Burawoy, "...are quite at home with the idea that we create images of globalization in accordance with our own global location." (Burawoy et al. 2000, 340) In the perspectivalist view, globalization is not an inevitable and unchallenged course of events that affects all people in the same way, but reflects the divisions and hegemonies of global wealth and power relationships. In this sense, perspectivalist views can be seen as a unification of sorts of the skeptical and radical views outlined above (Burawoy 2000, 340). Globalization here is not considered a singular or harmonious process but rather as a complex and multifaceted process that has specific local consequences whose effects are often contradictory, bewildering and diverse.

Unlike skeptics, the perspectivalist view on globalization accepts that globalizing processes are indeed occurring. Following Appadurai (1996), political scientist James Rosenau has defined globalized space:

...a space that is not disaggregated in terms of specified geographic territories so much as it consists of a wide range of fast-moving, boundary-spanning actors whose activities cascade erratically across amorphous ethnoscaples, mediascaples, ideoscaples, technoscaples, and financescaples. For the foreseeable future, therefore, I view this disaggregated system of diverse transnational collectivities as a multicentric world that competes, cooperates, or otherwise interacts with the state-centric world and, as such, constitutes the new world order, an order that is so decentralized that it does not lend itself either to hierarchy or coordination under hegemonic leadership. (Rosenau 2000, 172-173)

Globalization in this line has created a hybridized space where traditional actors coexist with emerging actors. A central concern of perspectivalists is the significance of the increasing privatization of public resources and arenas (e.g. George 2003). A central challenge of the process of globalization is considered to be the development of increased public accountability to promote global democracy and equality. This challenge is firmly viewed as being within the bounds of human agency and not a pilotless, inevitable process.

Articulations of perspectivalism often focus on the fragmented interests and implications of global power and governmentalities on various local levels (e.g. Soja 1989). They therefore tend to recognize and examine the role of political and socio-economic hegemonies as a means of analyzing processes of globalization. Cultural difference and diverse identities are considered to be expressions of lived experiences located by socio-economic circumstances and opportunities (e.g. Bhattacharyya et al. 2002). In other words, a singular global culture of diversity does not exist, but rather there is a transnational chaotic mosaic of heterogeneity with varying relationships to the center and margin, as well as oppression and domination, which intimately shape the multiplicity of cultural roles and forms.

This work departs from a perspectivalist viewpoint on globalization. I suggest that the patterning of the AIDS pandemic can be best understood through a perspectivalist view of the impact of global changes. The regional influence of globalizing processes in diverse nations – such as, the local impact of the debt crisis and the privatization of public infrastructure on social cohesion and communities -- is a significant reason why HIV/AIDS is more prevalent in certain areas than others. Poverty, social exclusion and vulnerability all play decisive roles in increasing the risk of being infected by HIV. The role of culture as a translator of risk management in diverse transnational settings is also significant. Finally, this global location has an epidemiological influence on the HIV infection rates of host nations that receive migrants from countries of high prevalence. Hence one's position in the globalized order strongly determines one's chances being infected as well as opportunities for care and treatment. Poverty and social exclusion thus remain the greatest risk factors for human rights violations.

### **5.3 The significance of globalization in this study: articulating frameworks for policy narratives**

For the purposes of this study, globalization is defined as an international economic process with cultural implications. The globalization process can be characterized by rapidly advancing technology in which the financialization of the global economy has

become dominant. Production has become increasingly globalized through the growing hegemony of transnational corporations that combine various resources to ensure the protection and dominance of their cost-effective networked horizontal organizations. Globalization has often been seized as an ideological and practical tool by hegemonic transnational corporations and supranational entities, such as the World Trade Organization (WTO), to increase economic profit and global dominance through the strengthening of monetarist policies, the privatization of public assets, and the weakening of state regulatory agencies and labor unions. These phenomena have produced a prismatic experience of the globalization process in which certain groups of people in particular locations tend to benefit more from the fruits of globalization than others.

The three articulations of globalization outlined above lend frameworks to creating narratives on the experience of globalization and possible solutions to social and health problems. If the skeptics deny the novelty of the phenomenon of globalization, then the policy implications to deal with social and health issues clearly aim at solutions that construct a world which remains largely similar to that of a century ago. Skeptical narratives thus tend to focus on national solutions to problems that are viewed from a modernist perspective. Radicals articulate narratives, on the other hand, that construct globalization as an apolitical and cutting edge phenomenon that benefits all. The network society and technology are hailed as engines of new policies and practices in a postmodern world. Hence radical narratives are often constructed from the optimistic point of departure that technology can solve social and health care problems. Often missing from radical articulations of globalization is the different significance of hegemony and power in people's everyday lives which serves to limit their access to the network society. Finally, perspectivalist articulations recognize the newness of the phenomenon of globalization but also emphasize the important role of hegemonic power relations in the daily lives of people. Perspectivalist narratives thus explore the possibilities, as well as restrictions, presented by transnational social and health care policies. Solutions are presented as complex and intimately tied to local lived realities of entangled hegemonic power relations.

In perspectivalist articulations of globalization, the increasing centralization of economic power into the hands of a few transnational corporations, along with the drive towards privatizing public assets, has a great impact on the political capacity of societies to make their own democratic choices (Minow 2002; Mishra 1999, 15). Perspectivalists consider that the drive for increased competitiveness in a global economy thus has many social and health consequences which include diminished solidarity when workers must contend for jobs in a competitive environment that puts downward pressure on wages, the growing inequality of income, and the difficulty of developing public accountability and transparency in governmentality in political systems increasingly dominated by special interest groups and determined by unelected international rulemakers, such as the IMF and WTO. In many narratives by perspectivalists, lower investment in social protection and public health systems are one of the first results the impact of globalizing processes in nation-states (e.g. Wilson 1996). This sets the stage for the rise of poverty, social problems and infectious disease and tends to limit the international coordination of responses to such community threats.

In summary, globalization is a complex process that includes many contradictions and is viewed from a diversity of perspectives. The socio-economic and technological transformations characteristic of the material basis of late capitalism have been collected into the notion of globalization. The significance of these changes has been constructed along a spectrum from minor (skeptics) to major (radicals and perspectivalists) societal transformations. These articulations of globalization have created frameworks for narratives that construct the possibilities for social and health policymaking in very different ways.

Though many of the radical analysts of globalization have reported the demise of the nation-state, this may be premature. Globalization brings a new geography of centrality and marginality, of power and presence, and practices of global and local control but it is still the nation-state that exerts law enforcement control, regulates borders and to some extent controls financial markets (Sassen 1998, xxv). Functioning structures of democratic global institutions that provide the mechanisms for public accountability and

transparency have yet to emerge. The nation-state remains one of the primary units of loyalty and identity for millions of people and a central site of contestation in multiculturalizing communities, though these national identities are increasingly stretched across borders through diasporas and migration flows. Globalization perhaps poses the greatest threat to communities, if we understand 'community' as a term used to express the direct, informal relationships that undergird an immediate and emotional sense of belonging which is linked to place (or the absence of place in the case of many migrants) (Williams 1977, 65-66). Communities provide norms and social controls against destructive behavior. The unravelling of communities through post-industrial economic displacements, poverty, forced migration, environmental degradation and increasingly unfair terms of trade has significant implications for social well-being and public health as epidemics and anti-social behavior tend to flourish in the midst of social disintegration.

## **6. The construction of public health in infectious disease control**

Human history has been shaped by disease. From the destructive path of the Black Plague that took millions of lives in medieval Europe to the influenza pandemic of the early 20th century, human history can be characterized as an ultimately losing struggle against life threatening disease. This struggle has nonetheless always been embodied by unequal health outcomes which have been directly related to social class position and status in society. Disease has often been used a weapon of domination and oppression. For example, the annihilation of indigenous Native American populations by conquering Europeans, who deliberately infected them with smallpox (Zinn 2003, 16), can be seen as intimately connected with the prevalence of substance abuse by the impoverished and disempowered descendants of the same indigenous peoples in 20th century America. The embodiment of power relations, in other words, can be seen as evolving and transforming over the years.

Disease is not solely a physical event but can also be read as a social and cultural text. Though our basic needs for food, shelter and safety are universally the same, how biology interacts with culture to manifest distress and risk as well as find solutions to problems is evidence of the fact that human beings are social animals (Morris 1997, 8-9).

Departing from a perspectivalist viewpoint of globalization, health issues can be viewed as having a direct and diverse social, economic and geo-political impact on individuals, communities and populations. Hence the significance of AIDS as a global phenomenon is emphasized by medical journalist Laurie Garrett in her book on emerging diseases:

It wasn't until the emergence of the human immunodeficiency virus, however, that the limits of, and imperatives for, globalization of health became obvious in a context larger than mass vaccination and diarrhea control programs. From the moment it was discovered in 1981 among gay men in New York and California, AIDS became a prism through which the positive lights by which societies hoped to be viewed were fractured

into thousands of disparate and glaring pieces. Through the AIDS prism it was possible for the world's public health experts to witness what they considered to be the hypocrisies, cruelties, failings, and inadequacies of humanity's sacred institutions, including its medical establishment, science, organized religion, systems of justice, the United Nations, and individual government systems of all political stripes. (Garrett 1994, 10)

AIDS has been characterized as the preeminent disease of globalization, of which people have been conscious from the start (Barnett and Whiteside 2002a, 347). AIDS is a disease that is deeply interwoven with the socio-economic, political, cultural and biological forces of the late 20th century. Indeed, the prevalence and infection patterns of HIV/AIDS largely follow the outlines of global wealth distribution and social marginalization. HIV infection can be seen as emblematic of the borders between inclusion and exclusion in the global society as Paul Farmer has pointed out:

...AIDS has always been a strikingly patterned pandemic. Despite the message of public health slogans – 'AIDS Is For Everyone' – some groups are at high risk of HIV infection, whereas others clearly are shielded from risk. Furthermore, although the terminal events have been grimly similar across the board, the course of HIV disease has been highly variable (Farmer 1999, 51)

Thus the dominant frameworks for constructing, understanding and conceptualizing the AIDS pandemic reveal hegemonic absences and invisibilities, as well as a varying degrees of thickness or thinness in narratives, which have influenced the direction of policymaking both on national and international stages. Moreover, the current neoliberal tendency to view health as an individual matter, rather than a community issue, reflects what development researchers Tony Barnett and Alan Whiteside term a 'medieval' view of disease (Barnett and Whiteside 2002a, 348-349). In this sense, Barnett and Whiteside argue that relying solely on traditional public health measures, such as quarantine, is not a realistic in a globalized world:

...[quarantine] was a sensible risk-avoiding response in a small village or town. It will not work in a global society. The flux of the globalized world of the twenty-first century is too porous, too flexible, too changeable and

capricious to permit us to avoid risk. We live in a world of global risks; disease is only one of them. (Barnett and Whiteside 2002a, 349)

This chapter briefly explores the rise of public health as a science in the modern age before examining how articulations of the body and health changed in the postmodern era. The concept of postmodern illness is therefore an underlying theme of this chapter. I examine the question of why traditional public health measures face special challenges in a globalized world. The purpose of this chapter is to provide a context for analyzing the emergence of stories of AIDS and the accompanying development of policy, prevention and health promotion tools discussed in the next section.

### **6.1 A brief history of public health**

The theory of modernization was the dominant model of development in the postwar period until the oil shock of 1974. Constructed in a sequential fashion, the theory of modernization held that development would occur as newly independent nations followed a linear line of progress through successive stages that would culminate in the achievement of industrialization along the lines of western developed countries. During this process, developing countries would shed their traditional cultures and become modern, self-sustaining and high-growth economies (e.g. Rostow 1960). The problems of underdevelopment were thus considered to be internal (e.g. the lack of capital investment) rather than external (e.g. relations of dependency). The process of modernization was conceived to be inevitable and singular. In the field of public health, the health transitions model mirrored modernization theory. This model sets out the notion that as living standards improved in a country, the general state of public health would also improve. In short, as they went through the modernization process, developing nations would undergo an epidemiological transition that would transform the leading causes of mortality from communicable to non-communicable diseases (Fetter et al 1997; Farmer 1999, 41-42).

Since the discovery of antibiotics during the Second World War, which vanquished venereal infections as a significant public health problem in most developed countries, the modernist belief in the ability of the power of science to conquer the threat of microbes through the creation of ‘magic bullets’ appeared to be boundless (Brandt 1987, 174; Garrett 1994, 62). It was broadly accepted in the scientific community of the mid-20th century that the challenging diseases of the future were to be chronic (such as heart disease, diabetes, and various cancers) and that the ‘basic’ diseases of measles, tuberculosis and diarrheal infections would disappear in the face of the advance of modern medicine. Indeed, the final case of variola minor (smallpox) was found and the scourge was eradicated in 1977, proving that it was possible to annihilate one of humankind’s great plagues<sup>21</sup> (Garrett 1994, 46). The development of modern medicine in the 20th century, with the miracles of antibiotics and polio vaccinations among other technologies, helped to establish the notion of disease as a conquerable object in the public mind. The discoveries of medicine and success of public health were constructed as milestones along an unalterable narrative of progress, similar to modernization theory.

The enormous rise in life expectancy among people in western countries took place largely in the early 20th century as a result of the development of public infrastructure (e.g. sewerage systems that led to increased sanitation), better public health information and education (more hygienic everyday practices and food safety practices), social improvements (bringing better nutrition and less poverty) and the reduction of infant mortality. All of these factors preceded the era of ‘magic bullets’ and high technology in medical procedures (Garrett 2000, 10). The 19th century public health movement, in particular, contributed to the vast advances in both quality and length of life. Laurie Garrett has noted:

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<sup>21</sup> It is important to note, however, that neither the United States nor Soviet Union could ever come to terms on eradicating the remaining stockpiles of the smallpox virus. As the security surrounding the Moscow storehouse has been questioned, it is suspected that stockpiles of the virus may have fallen into the hands of various terrorist groups. It is thought that an outbreak of smallpox in the world population would kill approximately two billion people due to its high mortality rate, the lack of smallpox resistance in the general population, and the deficit of smallpox vaccine (Garrett 2000, 524). The controversy over the preservation of the smallpox virus and its handling by governments demonstrates the fact that the interests of public health are often at cross purposes with the perceived interests of governments.

It is a matter of considerable academic debate which factors were most responsible for the spectacular improvements seen in life expectancy and infant mortality in the United States and Western Europe between 1700 and 1900. A constellation of the following were key: nutrition, housing, urban sewage and water systems, government epidemic control measures, swamp drainage and river control engineering, road construction and paving, public education and literacy, access to prenatal and maternity care, smaller families, and overall improvements in society's standards of living and working. In the early twentieth century elimination of urban, overcrowded slums that lacked plumbing and toilet facilities clearly improved the health of tens of thousands of Americans and Europeans. (Garrett 2000, 10)

The expanded role of medical authority, and community action in the shape of government initiatives and enterprises to better the lives of its citizens and residents through environmental improvement, was instrumental in reducing mortality and the spread of infectious diseases. In short, by the end of the 19th century it was widely recognized that only by improving the basic living conditions in cities and towns, through improved housing, streets and reduced pollution, could a better quality of life and decreased risk of infection be available to all people regardless of social class. As the medical historian Charles E. Rosenberg has noted:

This new area was public health, in particular, the shaping of an interventionist social agenda. These reformist and environmentally oriented guidelines seemed no more than appropriate responses to the findings of contemporary epidemiology. Sickness was repeatedly connected with poverty and deprivation. The conclusions seemed obvious to reformers. An enlightened society should purify its water, provide pure milk for its children, inspect its food, and clean its streets and tenements. The expansion of public medicine was connected in a score of ways with the style of self-consciously and self-righteously enlightened government we have come to associate with progressive reform. (Rosenberg 1992, 270)

Crucial to the development of the public health movement was two essential discoveries in 19th century medical science: contagion and germ theory. Though there were many who initially rejected the emerging theory of contagion, this was largely because miasmatic theory dominated notions of public health in the early 19th century.

The shift from miasmatic theory to contagion and germ theory therefore reflected a deepening knowledge of the role of pathogens and paths of transmission. One famous case of epidemiological detective work was John Snow's finding that the users of a certain London water pump had a higher incidence of cholera than the users of other pumps. By removing the handle of the water pump, Snow reduced the incidence of cholera in the area thus demonstrating the scientific validity behind contagionism and the need for societies to ensure sanitary conditions to protect their populations from epidemic outbreaks of disease (Rosenberg 1992, 117-119). Building on the work of the physician Rudolf Virchow, among others, Louis Pasteur published his landmark *Germ Theory of Disease* in 1880 which argued that all contagious diseases were caused by microscopic organisms (Garrett 2000, 292). Soon thereafter, the main bacterial agents responsible for diseases such as tuberculosis, syphilis and cholera were discovered. The significance of these advances in medical science was the recognition of the multifaceted nature of disease and rise of epidemiology as a recognized branch of medical science.

If disease was understood in the early 19th century by medical practitioners as a combination of individual volition and pathology, an interaction between mind and body; then the rise of modernism witnessed the dawn of conceptualizing disease through rational, scientific methods which increasingly focused on the role of pathogens in disease incidence, rather than individual will.

With the rise of the Industrial Revolution in the 19th century, many western countries faced rapid urbanization as people migrated from the impoverished countryside to cities in search of work. Lacking a proper infrastructure, large sections of western urban centers at this time became a morass of filth and disease (e.g. Prunty 1998). As epidemics swept through cities, and with the growing scientific knowledge of theories of contagion and germs, it became increasingly clear by the middle of the 19th century that public health laws had to be enacted to protect the health and well-being of the general population.

By the middle of the 19th century most western countries had begun to draw up and enforce public health laws. Public health, however, was far broader than the enforcement

of quarantine and surveillance laws, it also involved the betterment of living conditions for all residents. These laws were intended to protect the health of the general population by improving the sanitation of cities through sewerage systems, paving, better ventilation, food inspection and safety, developing an epidemiological system of surveillance with disease notification and reporting which could facilitate a rapid response to disease outbreaks, and requiring vaccinations as well as sanctioning behavior considered to be a menace to public health.<sup>22</sup> Between the mid-19th century to the mid-20th century, public health efforts culminated in a great advance in both the quality of life and rapidly decreasing mortality rates throughout the western world. As Dr. Vicente Navarro has pointed out:

Not even public health interventions (such as immunizing against childhood diseases), which have been far more effective than have medical care interventions, can be considered the main reasons for the mortality decline in the twentieth century. Social, economic, and political interventions are the primary reasons for this decline. (Navarro 2000, 1599)

The objective of public health, therefore, is the prevention of the spread of disease and the promotion of health. In the public health framework, health and disease are conceived in terms of communities, with all of the surrounding cultural issues. Public health experts have long recognized the significance of good governance and the important role of socio-economic factors in reducing vulnerability. From its origins as an emerging science in the 19th century which united bacteriological studies with sanitary science, public health shaped the development of epidemiology as a social and health tool to examine and improve the health of the community at large. As Charles Edward Amory Winslow, chairman of the Department of Public Health at Yale University between 1915 to 1945, put it:

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<sup>22</sup> The story of Typhoid Mary has been an archetypical public health lesson. When Irish immigrant cook, Mary Mallon, was found to be the common link for dozens of typhoid cases in New York, she was incarcerated on an island in the East River. Public health officials released her from custody on the condition that Mallon no longer work as a cook. Mallon nevertheless returned to cooking after being released despite her promises to stay away from the profession. Eventually, New York public health officials tracked her down and returned her to the island where she lived out her remaining days (Garrett 2000, 300).

[Public health is] ... The science and art of preventing disease, prolonging life and promoting health and efficiency through organized community effort. (Institute of Medicine, 1988)

This community effort works through the constellation of power relations in society and is premised on the notion of social inclusion. It recognizes that the welfare of all population groups is important to promote the health of society in general.

## **6.2 Shifting views of the body and public health**

In the previous chapter, we have seen how the power relations surrounding globalizing processes have enhanced inequalities throughout the world. The privatization of public assets, for example, is the result of multiple global processes such as the financialization of the world economy, the exponential growth of powerful transnational corporations, and the attendant neoliberal ideology of individualism. These trends indicate a shift towards a global context, which lacks social content, rather than an inclusive, universal social space. This means that a greater emphasis has come to be placed on the rights and responsibilities of the individual as consumer at the expense of the community (see, e.g., Minow 2002, 1-6).

This increasingly individualistic view towards society can be seen in shifting views of the body and health. Emily Martin suggests in *Flexible Bodies: The Role of Immunity in American Culture from the Days of Polio to the Age of AIDS* that the object of public health endeavors in the mid-20th century shifted from a concern with the community at large to the individual as a body:

...by the 1940s and 1950s, the focus of public health thinking had narrowed. Whereas in earlier decades the conditions of the whole city, for example, would have been of concern, by this time people were more apt to think in terms of the cleanliness of their own immediate environment, their house and their bodies. (Martin 1994, 24)

The body was thus constructed as a castle that was laid siege to by various microbes, and health care providers emphasized the need to maintain the ‘outer fortifications’ (skin and mucous membranes) through cleanliness (Martin 1994, 32). In other words, individuals, rather than communities became responsible for their biological defenses through an intensified focus on the importance of personal hygiene within all levels of society from educational institutions to the hints for housewives published in women’s journals.

By the 1970s, however, the image of the body and its defenses against infection had changed from a system of external barricades to one of the strength of internal networks:

What we see emerging through the immunologists’ eyes by the late twentieth century, then, is a body that actively relates to the world, that actively selects from a cornucopia of continually produced new antibodies that keep the body healthy and enable it to meet every new challenge...All these transitions take place within the context of the assumption, which gradually grew more clearly articulated over the 1960s and 1970s, that the various parts of the immune response form a single, interconnected *system*. This framework resides entirely within the body, where it links the body to its changing environment. (Martin 1994, 37) [author’s emphasis]

This shift in the conceptualization of the body and its defenses in many ways mirrors the social transformation from modernism to postmodernism. Bodies, in other words, were no longer viewed as mechanical entities that functioned in a machinelike fashion requiring proper maintenance but rather as complex flexible networks wired with intricate genetic material that interacted with environmental and individual factors to produce wellness. In a certain sense, concepts of disease had come full circle with the notion of individual volition creeping back into the picture again, this time utilizing a different, consumerist terminology.

As Martin has noted, this metamorphosis in the view of the body recognized inherent genetic differences in susceptibility to illness and placed an increasing personal burden on individuals for their health while minimizing the role of community public health:

I find this development troubling because, for all the beguiling attractions of this way of positioning oneself in the world, it also has disturbing implications. There is the propensity to extol harmony within the system and reliance on the group while paradoxically (and distractingly) allotting individuals a dynamic, ever-changing, flexible role... Concealing conflict between those who have different amounts of resources and power for the sake of the appearance of harmony usually hurts the disadvantaged... This propensity plays its part in an emerging form of neo-social Darwinism, which again has unfortunate consequences for the disadvantaged. (Martin 1994, 247)

Paul Farmer has termed this view of health as the 'exaggeration of personal agency,' which he says fails to account for the fact that personal agency is constrained by structural inequality (Farmer 1999, 86-87). As Farmer points out:

Technology has often been presented as the remedy for social ills, and the development of effective tuberculosis chemotherapy was hailed as the beginning of the end of the disease. But the poor remained much more likely to become infected and ill with *M. tuberculosis*... One place for diseases like tuberculosis to 'hide' is among poor people, especially when the poor are socially and medically segregated from those whose deaths might be considered more significant. (Farmer 1999, 186-87)

At the same time that increasingly sophisticated medications and bio-medical technologies were rapidly developing towards the end of the 20th century, the standard of living in many less developed countries began to collapse. The optimism of the modernization efforts of the 1960s faded as visions of industrial progress continued to remain a distant dream by the 1980s. The increase in environmental degradation caused by poorly designed projects, political corruption and Cold War power politics, as well as socio-political disruption engendered by inadequate development policies, had serious repercussions for developing countries.

Perhaps emblematic of this period has been the resurgence of malaria. As Laurie Garrett has pointed out, malaria was 2.5 times more common in 1975 than it was in 1961. One of the main reasons for this rise was the deterioration in living conditions in many countries as well as the emergence of drug resistant types of malaria (Garrett 1994, 52). By 1980,

the World Bank concluded that the malaria eradication campaign had failed, with malaria increasing on the Indian subcontinent by 230 percent (Garrett 1994, 205; Henderson 1998). With the increasing number of 'emerging' diseases (the Ebola virus, Lassa fever, Legionnaire's Disease, the jump in the number of Guillen-Barré Syndrome cases after swine flu vaccinations, etc.), the post-war victory over the microbe has appeared to be less certain than earliest predictions.

Pathogens have become the embodiment of socio-economic and political inequality at the dawn of the twenty first century. It is important to note that a huge amount of people throughout the world continue to die of preventable diseases caused by unclean water (Garrett 1994, 203). This demonstrates the vast disparity in health care between rich and poor countries. Even within wealthy countries, such as the United States and the United Kingdom (see, e.g., Fein 1995), the difference between the average lifespan of people on a low socio-economic level compared to those in high income brackets, as well as gender, race and ethnic differences, is a growing cause of concern in many countries (e.g. Byrd and Clayton 2000). This can be seen in the rise of national and transnational research programs dedicated to examining health disparities. Indeed, the rapid decline in health during the Russian post-Soviet transition period can be directly attributable to the community disintegration, political instability, the lack of investment in health, structural readjustment programs demanded by the World Bank, and plummeting economic situation of the vast majority of the population. Cardiovascular disease, for example, has dramatically risen and life expectancy in Russia continues to decline (Farmer et al. 2003).

This raises the question of whether it is possible to conceive of health transitions as an inevitable process without considering the retrograde socio-economic effects of globalizing processes, particularly in terms of the privatization of public assets such as water, education and health care. As medical experts in the field themselves have noted:

The changing nature of the financing of medical procedures and public works linked to mortality reduction has been neglected in the transition literature. (Fetter et al. 1997, 236)

A nation's state of health is intimately connected with prevailing socio-economic conditions. Moreover, divergences in health among particular groups often suggest marginalization, social exclusion, or the lack of access to appropriate health care. As Paul Farmer has written: "...fundamentally social forces and processes come to be embodied as biological events." (Farmer 1999, 14) In other words, large income differentials can be seen in health disparities.

The explosive increase in mobility and rapid changes in the environment have also influenced the development of disease. The growth of massive urban areas, population depletion in rural areas, and disruption of traditional lifestyles due to poorly planned modernization development projects have contributed to a rise in urban poverty in many developing countries which lack basic sanitary infrastructures. Research has also demonstrated clear links between health outcomes and poverty in terms of the preconditions of health (such as, preventive medicine, education, gender equality, child and maternal health) and outcomes (such as, infant mortality rates, reproductive health, and infectious disease) (see, e.g., Byrd and Clayton, 2000). Moreover, cuts in public health budgets in many western countries have provided the opportunity for previously controlled diseases to grow.<sup>23</sup> Furthermore, it can be argued that the rate of AIDS orphans in many African societies, for example, has increased due to the inability of the traditional extended family unit to cope with the vast socio-economic and cultural changes sweeping the continent.<sup>24</sup>

Hence several significant factors concerning health coalesced globally in the 1970s to produce the structural preconditions for the international HIV/AIDS pandemic:

- An increasing amount of international migration and tourism

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<sup>23</sup> The rise of tuberculosis is a good example: "By the end of the 1990s the world would be facing a massive tuberculosis pandemic, with drug-resistant strains of the microbe spreading from one corner of the planet to another. Fully 20 percent of all TB in the world would have some degree of drug resistance and more people would die of the disease in 1999 than in 1899." (Garrett 2000, 418)

<sup>24</sup> This point was made to me in an email from Dr. Patrick O'Sullivan of the Eastern District Health Board, Dublin.

- A growing international socio-economic division between the haves and have nots thereby exacerbating the structural violence of poverty and incidence of disease, diminishing the effectiveness of public health efforts, and escalating the exploitation of impoverished people by sex tourists as well as blood companies.
- A greater amount and higher quality of sophisticated medical treatment increasingly restricted to those who can afford it.
- An increasing emphasis on personal responsibility for wellness to the exclusion of socio-economic causal factors, which in essence blames the victim for her own poor health.

The transformation of conceptualizations of the body, from a holistic unity of mind and body to the biomedical model to an individualistic view, reflect broader trends in ways of looking at the relationship between societies, communities and individuals. The apotheosis of the interventionist community in the modern age reflects universal values. The current focus on health as an individual concern demonstrates a growing association between individual agency and health, often at the expense of the community.

### **6.3 Epidemiology as the science of social construction**

Epidemiology, the study of epidemics, is the detective squad of medicine. It is a cluster of scientific methods that is used in cooperation with national public health systems to assess the distribution of health-related conditions in various populations as well as to control the outbreak of health problems in the population. Through complex surveillance, notification and sentinel systems, epidemiologists seek to achieve the early detection and control of disease in society. The emergence of diseases can present themselves as riddles. Therefore, one of the primary virtues of a good epidemiologist (similar to a good detective) is the ability to take all factors into account and to question underlying assumptions when approaching disease causation. Clues to solving the enigma of disease incidence are both biological and social.

It is, however, possible to raise two critical points regarding the traditional understanding of epidemiology. This criticism is perhaps best understood in the context of the epistemology of the postmodern condition. If, as noted earlier in this work, we are witnessing a shift in conceptualizing knowledge from the modernist framework which emphasized objectivity and order towards a postmodernist structure which stresses the discontinuities and hegemonies of knowledge, then the social understanding of epidemiology as a science that flourished under the modernist framework becomes increasingly problematic. Firstly, as Paul Farmer points out, it is not a question of whether epidemiologists recognize the sociogenesis of disease emergence. The multifactorial model ensures that social relations and communities are considered to be the basic building blocks in determining the transmission of disease. The critical question is rather how such conceptual frameworks are constructed and understood (Farmer 1999, 40). As discussed in the next section, the construction of ‘risk groups’, used to indicate population groups that have a statistically greater risk of contracting a specific disease, can be badly misconstrued, as in the case of Haitians in the early days of the AIDS epidemic. In this example, the designation of Haitians per se as a risk groups by epidemiologists reflected a stigmatizing labeling of ‘otherness’ which was based less on a clear and unbiased understanding of the health issues facing marginalized communities than epidemiologists’ own assumptions about them. The labelling of Haitians as a risk group reflected the inscription of disease upon the bodies all of people with that nationality regardless of risk behavior or even period of residence in the country. In short, a postmodernist framework, which examines the implicit assumptions and hidden invisibilities in allegedly objective social science, is an important perspective to bring to traditional, modernist understandings of epidemiology.

Secondly, many traditional conceptualizations in epidemiology ignore the important role played by poverty and social exclusion. They thus imply a certain cartography of the world, often based on a colonialist diagram of the globe, with particular geographical areas designated as diseased while others are not. Yet as Paul Farmer points out, despite overwhelming evidence that poverty plays one of the most significant roles in disease emergence, it is often attributed to a geographic rather than social topography (Farmer

1999, 41). This often leads to the stigmatization of people from areas labeled as diseased. A critical epidemiology would therefore be important to better understand the sociogenesis of disease.

The science of epidemiology traces and finds the origins and transmission routes of outbreaks of disease. As bodies and their behaviors is the focus of the epidemiologist's craft, epidemiologists must use multifactoral models to understand the complexity of social and biological causation in the spread of disease and recommend means to contain it. In arguing for a critical epidemiology, Paul Farmer states:

*A critical (and self-critical) approach would ask how existing frameworks might limit our ability to discern trends that are related to the emergence of diseases. Not all social-production-of-disease theories are equally alive to the significance of how relative social and economic positioning – inequality – affects the risk of infection. For example, neither poverty nor inequality appears as a 'cause of emergence' in the self-described 'catalog' of emerging infections compiled by the Institute of Medicine. (Farmer 1999, 44) [author's emphasis]*

In other words, Farmer's call for a critical epidemiology can be seen as a call for a return to the public health movement and social medicine of the 19th century. Pioneer scientists of that time, such as Rudolf Virchow and Henry Sigerist, clearly made the connection between disease causation and living conditions.

Hence epidemiology cannot be viewed as a 'pure' science separate from its role as a cornerstone of national public health efforts and its task to socially construct nosological and causal categories of disease. These definitions and tasks, in turn, are affected by the prevailing socio-political winds. Questions of whether certain diseases should be considered to be 'emerging' or 'endemic' depends to a great extent on how the health needs of the population are framed. Thus, the degree of access that the general population has to medical practitioners and facilities affects how categories are constructed and knowledge obtained about their state of health. As we will see, it can be argued that the early construction of AIDS as a disease of white American gay men could be partially

attributed to the greater access of these men to health care than, for example, medically marginalized African-American intravenous drug users. Indeed, marginalized populations often tend to be underrepresented in national statistics simply because they lack access to proper care and therefore cannot be counted.

Research funders often have their own agenda, which may reflect priorities that are of concern only in certain, powerful segments of society. The massive funding mobilized in the US medical establishment to find the cause of Legionnaire's disease in the late 1970s as opposed to the meager funding allotted to HIV/AIDS research in the early 1980s is a case in point. Moreover, the massive increase in HIV/AIDS research funding in the 1990s, when breakthroughs in the development of protease inhibitors and drug cocktails began to construct HIV as more of a chronic condition rather than a rapidly terminal event, can be attributed, at least partly, to the fact that pharmaceuticals for chronic diseases are highly profitable in markets where the population can afford such medications.

The majority of epidemiologists in the world work within western institutions, such as the World Health Organization (WHO), which often view disease as an isolated phenomenon that exists outside the prevailing global inequality.<sup>25</sup> This may result in the articulation of causal and nosological categories based on a limited narrative of health needs. If disease is seen as largely unrelated to socio-economic living conditions, such as poverty, thought to be solely a culturally constructed category, then the primary structural causes for disease may go unnoticed.

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<sup>25</sup> For a critique of the "Assessment of World Health Report 2000" published by the WHO, see the article by Dr. Vicente Navarro in *The Lancet*. (Navarro 2000) As Navarro argues: "The principal values reproduced in the WHO report are those that sustain the dominant conventional wisdom in the foremost medical, financial, and political arenas in the USA and other major more developed countries, based on two assumptions. The first is the belief that one of the most prominent health problems our societies now face can be resolved by technological-scientific medical bullets or interventions, without reference to changes in the social, political, and economic environments in which these problems are produced. The second assumption is that the supposed 'failures' of health care systems are due to an excessive reliance on public interventions without allowing for the development of the (assumed) great potential of the private sectors." (Navarro 2000, 1601)

Paul Farmer's analysis of HIV/AIDS in Haiti is of relevance here (Farmer 1992). In the early days of the AIDS pandemic, the popular press and even in the *Journal of the American Medical Association* accused Haitians of bringing AIDS to the United States and spreading it through voodoo rituals (Farmer 1992, 3). These accusations, which were based on myth and speculation and lacking historical and socio-economic analysis, meant that the context of the rise of HIV/AIDS in Haiti was ignored. Indeed, the fact that development projects had devastated many rural communities in Haiti forcing peasants into the city to find work as well as the increasing dependence of Haiti on tourist dollars, particularly sex tourists, provides a compelling but often invisible frame of reference to understand the rise of this pandemic. Unfortunately, these structural causes have often been neglected in the literature surrounding HIV/AIDS incidence and prevention.

### 6.31 State intervention and stigma

One important aspect of managing epidemics is the role of state intervention. Intervention has broader implications than mere health management because it directly affects the use and control of the body, and is expressed through social and cultural matrixes, particularly in matters such as hygiene and sexuality. Among the intervention tools at the disposal of epidemiologists are quarantine, surveillance and contact tracing.

Linda Singer has introduced the notion of *sexual epidemic*, which she defines as a range of theoretical and political questions that have emerged around the regulation of bodies and sexuality, two highly contested subjects (Singer 1993, 27-29). As Singer explains:

[...] as metaphors of sickness and health come to dominate the representation of the social, we are confronted by an ever increasing number of cancers, viruses infecting the body politic through mechanisms of contagion and communicability. In order to represent a phenomenon as socially undesirable, be it divorce, drug use, single motherhood, teenage pregnancy, one need only call it epidemic. In doing so, one not only engages in a kind of rhetorical inflation, but also mobilizes a certain apparatus and logic, a particular way of producing and organizing bodies politically. An epidemic is a phenomenon that in its very representation calls for, indeed, seems to demand some form of managerial response,

some mobilized effort of control. To the extent that epidemics come to function as a ground for the mobilization of social resources, they operate as more than metaphors of the social. They also function as political logics, forms of social rationality. (Singer 1993, 27)

An epidemic thus makes it acceptable to intervene into people's lives, as Singer points out, precisely because an emergency calls for a strong managerial response. The connection between selectively causal explanations of disease and social intervention in the lives of people living with a disease can often lead to stigmatization. Epidemics that involve aspects of life that are culturally sensitive can also raise strong public reactions. As Allan Brandt shows in his study of the American response to sexually transmitted diseases (Brandt 1987), the fear of sexuality and contagion led to 'social hygiene' regimens that led to an implicit public link between disapproved forms of sexual expression (such as sex outside of marriage) and constructions of disease.

Erving Goffman defines the stigmatized individual as

...reduced in our minds from a whole and usual person to a tainted and discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap. It constitutes a special discrepancy between virtual and actual social identity...The term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed. (Goffman 1963, 12-13)

The stigma attached to certain diseases and health conditions can often hinder efforts to provide help and support to individuals and communities. Goffman's theory of stigma, which conceives it as occurring in three stages as the abomination of the body, a blemish of individual character, and the stigma of the race, nation or religion, can be seen in many early articulations of AIDS identities (Goffman 1963, 14-15).

The struggle of AIDS activists to attack negative attitudes and humanize people living with HIV/AIDS in the early days of the pandemic was explicitly focused at diminishing the stigma of the disease. The rise of AIDS exceptionalism, which is discussed in the next

section, as a series of anomalous exceptions to traditional public health interventions, also facilitated the reduction of the stigma associated with HIV/AIDS. However, it would be overly optimistic to argue that AIDS exceptionalism, which emerged in the mid-1980s, succeeded in overcoming the structural barriers that continue to medically marginalize and exclude people throughout the world. As Allan Brandt has commented:

The way a society responds to the problems of disease reveals its deepest cultural, social, and moral values. These core values – patterns of judgment about what is good or bad – shape and guide human perception and action. This, we know, has most certainly been the case with AIDS; the epidemic has been shaped not only by powerful biological forces, but by behavioral, social, and cultural factors as well. (Brandt 1988, 147)

With the advent of globalizing processes, societies face many new challenges regarding how they respond to emerging diseases. The privatization of public assets and care as well as the dominance of neoliberal ideologies of individualism and risk has an impact on state interventions in public health. AIDS is a prismatic example of the first global disease and its incidence and prevalence could be seen from a perspectivalist viewpoint on globalization.

### 6.31 Treatment as the end stage of public health

It is important to make a distinction between public health and medicine. Much of the debate about HIV/AIDS has focused on the availability of new treatments to people in less developed nations. However, it is important to recognize that by the time treatment options are discussed, a more serious stage of the disease has begun as medical professionals then take over the management of the disease. The focus of public health is on the preconditions of health and containment of epidemics. It therefore has a significant social dimension because it concerns prevention:

To always think about treatment is to remain distanced from the social and economic origins of illness and ill-being. Illness and ill-being are not only or most importantly about individual risk. Rather they are ‘systemic

events, which are accordingly in need of general political regulation.’  
(Beck quoted in Barnett and Whiteside 2002a, 364).

As treatment regimens are often defined by the capacity to access care, the poor, the vulnerable and the marginalized are often disproportionately excluded from treatment. Many times this exclusion is justified in the name of cost effectiveness (e.g. certain patients are defined as non-compliant) or culture (e.g. stereotypes about cultural notions of time and responsibility that are thought to lead to non-compliance) while fundamental issues of the lack of access to health care remain unaddressed.<sup>26</sup> If cost effectiveness and high technology solutions are considered markers for ‘good health care’ without taking into account questions of access and affordability, then the structural violence of poverty ensures that in the name of cost effectiveness, certain lives are implicitly considered to be more valuable than others because they have access to (and can afford) treatment (Navarro 2000). The field of medicine, which often does not adequately take into account the role socio-economic factors in compliance, thus sometimes constructs a narrow vision of treatment options for marginalized populations.

To summarize, infectious disease and illness have shaped human history. With the rise of industrialization and rapid urbanization in the modernist era, public health became an essential tool to enforce adherence to health laws and create healthier environments through the improvement of living conditions, particularly in rapidly urbanizing areas. The role of poverty in disease causation was a central concern for the early public health movement. The science of epidemiology uses social categories, as well as other variables, to understand the outbreak of epidemics. In the age of globalization, these issues are increasingly entwined with global and local socio-economic and cultural forces. Hence the practice of epidemiology and public health, which exists in a global context, must

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<sup>26</sup> ”The steep grades of social inequality in Lima meant that second-line antituberculosis drugs necessary to treat MDRTB (multi-drug resistant tuberculosis) were available on the market but that the people most at risk for MDRTB were unable to purchase these drugs in a reliable manner. And surely valuation of human life underpinned the public health community’s ready acquiescence to cost-effectiveness models that made MDRTB a treatable disease in some communities and ‘untreatable’ in others.” (Farmer 1999, 33-34)

negotiate between universal concepts of the fundamental human right to health and the perspectivalist realities of globalized socio-economic inequities.

#### **6.4 Health as a human right and the challenge of migration**

One of the rights enshrined in the Declaration of Human Rights is health as a fundamental human right. Health is conceived broadly in the Constitution of the World Health Organization:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

This definition emphasizes a holistic view of health that includes the preconditions for disease prevention and well-being.

There are numerous international conventions and treaties that recognize the right to health (Hendricks 1998). This definition of health has wide-ranging implications regarding social well-being. As legal expert Aart Hendricks has written:

Here it should be recalled that the contribution of the health protection measures and health care services to health, while undeniably important and sometimes vital, is quite limited. In fact, the vast majority of research into the health status of individuals and groups has identified the so-called societal factors, and notably a person's socio-economic status, to represent the single largest determinant of health. It is therefore of crucial importance to recognize that the right to health also entails a duty for States to undertake measures aimed at the creation of conditions favorable to the achievement and maintenance of the highest attainable level of health, notably by gradually improving the socio-economic conditions which may hamper the realization of his right, and is not confined to ensuring adequate health promotion measures or guaranteeing a comprehensive health care insurance and delivery system (Hendricks 1998, 391)

States therefore have an obligation to protect health not only through the provision of health care but also by ensuring the preconditions of health by improving social

conditions. This construction of health is an extension of 19th and early 20th century public health theories and militates against the increasing individualization of health in which public responsibility and accountability has been reduced (e.g. Minow 2002, 121-141). Health as a human right is thus based on the notion that states have a fundamental obligation to protect health and provide equal access to care for all of its citizens.

Often health issues have not been discussed in terms of human rights due, to a large degree, to the differing scientific vocabularies (Mann et al. 1999, 8). The human rights framework in regard to health can be conceptualized following Mann et al. (1999, 7-21; Feitsma 2001, 9) through the following points:

- Health policies, programs and practices have an impact on human rights
- Violations of human rights have an impact on health
- Health and human rights are therefore inextricably linked

Underlying this conception of the relation of health and human rights is the notion that social justice is inextricably linked to health. As medical psychologist Nancy Adler (Adler et al. 1999, 181) has pointed out, health issues throughout history have been linked to socio-economic status. Though health and social policies have tended to be formulated on a national level, the logic of globalization increasingly affects state governance. The globalizing trend of growing socio-economic inequality not only between nations but within nations has had a negative impact on health and social rights, particularly in the area of HIV/AIDS.

As the articulation of the perspectivalist view discussed earlier, globalization is experienced very differently according to class, gender, race, place of residence and type of passport. Unfair global economic relations have plunged many nations into deep poverty. Many poor countries have had to spend scarce public money to service expensive debt repayments to wealthy nations rather than invest in public health structures, health promotion programs as well as education and social investment. The pressure of

international trade organizations to privatize public assets in many less developed nations has led to public health threats.<sup>27</sup> The privatization of water, for example, often forces impoverished populations to seek other sources of water from disease laden streams, rivers and lakes, which has resulted in a higher prevalence of water-borne disease.<sup>28</sup> Diminishing standards of living in many countries contribute to social disintegration, greater risks to public health and social well-being, and increased migration as people move in search of better survival opportunities.

The migration experience itself can present many risks to health. Migrants fleeing from war, environmental degradation and poverty may face all of the deleterious effects of poor infrastructure, lack of health care provision, unchecked exposure to infectious disease and poor nutrition. Migrants may also face significant risks during the journey with regard to personal safety in during migration. Migrant women in particular often face gender-specific risks, such as rape and reproductive health problems. Due to the prevalence of air travel, migration occurs at an accelerated rate in the 21<sup>st</sup> century. This high rate of rapid mobility can present new problems with the traditional tools of communicable disease prevention, tracing and treatment.

The rights of migrants in host societies have a great impact on the preconditions of health for all. State health and welfare policies determine eligibility criteria of inclusion and exclusion, which determine how individuals gain access to care and treatment. Conceptions of the nation, state and citizenship also strongly affect how newcomers or strangers are viewed and treated in a society, which can have an impact on outreach and information efforts. Moreover, notions of transnational identity influence how people construct their sense of home, community and belongingness. As Professor Manuel Carballo has pointed out:

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<sup>27</sup> Unfair trade arrangements often include items such as the Government Procurement Agreement (GPA), worked out by the World Bank, that make the privatization of public services and the open offer of these contracts to international corporations a precondition for trade and development aid. This further diminishes the power of any state to guarantee a safe and healthy environment for its citizens.

<sup>28</sup> See investigative reports by the Center for Public Integrity on links between water privatization as a loan condition and General Agreement on Trade in Services (GATS) (Center for Public Integrity 2003).

Despite its positive features migration has nevertheless always presented complex health and social questions. Even when migration is planned and structured around well calculated national labor needs, the entry of new human resources into a society often prompts unforeseeable health and social problems that are difficult and costly to manage. Health and social services, together with housing and employment, for example, are sectors that are immediately challenged by the process of mass in-migration. (Carballo 2001, 270)

The impact of migration on health and well-being, in all of its manifold expressions, is an important human rights issue. In recent years, there has been growing discussion of the position of denizens or long-term residents who live much of their lives in countries where they may have few democratic rights. Many national social and health care services exclude those who do not have the requisite permits and papers accepted by authorities. The lack of culturally and linguistically appropriate health promotion policies and practices, as well as interventions planned with communities, can result in significant health disparities among migrants living on the margins of society. Poor living conditions and poverty also have a negative impact on the preconditions for health. In short, health and human rights challenges for migrants do not end when they arrive in their new host countries. States have an obligation, according to the body of international law, to create conditions that are favorable to the achievement and maintenance of the highest possible level of health (Hendricks 1998, 389). These conditions and rights are not limited solely to citizens, but are a fundamental human right of all people.

## **7. The changing concepts and dimensions of migration**

There are widely varying accounts of the amount of contemporary migration. According to UNAIDS, there are an estimated two billion people on the move throughout the world each year (UNAIDS 2001, v-vi). Some estimates claim that in 2000, there were 150 million people living in a country other than their own (Martin 2001, 2). The United Nations High Commission for Refugees (UNHCR) currently has approximately 21 million people under their mandate, of whom 8 million reside in western industrialized countries. Approximately half of these refugees are women and children. Despite western media images of floods of asylum-seekers and refugees flowing into industrialized countries to take jobs, as migration experts Hammar and Tamas clearly point out, more than 98% of the world's population does remain at home (Hammar and Tamas 1997, 1). The vast majority of refugees never make it to western shores. According to UNHCR data, 40% of refugees are in Asia, 27% in Europe, 25% in Africa, 5% are in North America and 3% in Latin America (Russell 2002). While global population has grown 1.7% per year between 1985-1990, the total population of international migrants has risen by 2.59% per year (Martin 2001, 2). These statistics show that while international migration is indeed increasing, particularly forced migration, images of western countries being 'swamped' by armies of refugees have little basis in fact.

The changing demographics of highly industrialized countries, such as falling birthrates and the graying of the population, has led to both a rising need for certain kinds of labor, particularly in the service and high technology sectors (Ehrenreich and Hochschild 2002; Sassen 1998). The public perception that migrants and refugees are flooding into their countries to take advantage of social welfare and take jobs is often manipulated by politicians seeking to use these fears and underlying anxieties about national identity for their own advantage (Steiner 2000). The phenomenon of migration can be seen, in Zygmunt Bauman's words, as a prismatic concept: what you see depends on which side of the prism you are looking through (Bauman 1997). Many people in the industrialized

countries of the North believe that their communities are being inundated by opportunity seeking migrants that threaten national identity, economic bounty, and social cohesion. Increasingly restrictive immigration laws and policies have therefore been enacted in many countries. From the perspective of migrants from the South, migration is often considered to be the only option for survival despite the fact that it is fraught with risk, social exclusion and the possibility of permanent socio-economic marginalization.

Though migration has been one of the most enduring hallmarks of human existence, the amount and diversity of people, as well as the speed by which they travel today, is truly astounding in historical perspective. The complexity of migration as a geopolitical phenomenon is being increasingly recognized (e.g. Brah 1996; Zolberg et al. 1989). Traditional neo-classical theories which conceive of migration as a rational individual choice based on push-pull factors tend to obscure rather than illuminate the multifarious nature of mobility. Notions of transnational communities further challenge customary views of borders, national identity and the process of acculturation. Indeed, psycho-spatial concepts of 'home', for example, are often not as crystal clear as imagined: does 'home' signify the place one lives, the place one was born and raised, somewhere in between or something completely different? (see, e.g., Brah 1996; Fitzpatrick and LaGory 2000; Huttunen 2002)

This chapter briefly explores the development of theories of migration and then moves on to discuss how concepts of migration have shifted and become increasingly complex in the midst of contemporary globalizing processes. The notion of transnational communities is discussed in relation to immigration regimes.

## **7.1 Theories of migration**

Modern neo-classic theories of migration have developed out of the sciences of geography, demography and economics. The 19th century geographer E.G. Ravenstein delineated certain 'laws of migration' which classified motivations for migration through the model of gravity. In this mechanistic model, geographical places, like planets in the solar

system, were conceived as exerting pull due to favorable socio-economic circumstances. Individuals were thought to respond to economic opportunity spatially. The conceptual basis of Ravenstein's laws of migration is thus similar to Adam Smith's view of man as an agent<sup>29</sup> who rationally pursues his economic self-interest. This perspective is based on a modernist framework of dualism whereby 'individual rational man' is viewed atomistically, as detached from his community and separate from his cultural and historical context.

Ravenstein's ideas have been very influential in the development of migration theories (Malmberg 1997, 22). Most explanatory models of migration up until the latter part of the 20th century were conceptualized in terms of push-pull factors. In other words, certain factors, such as poor economic prospects or living standards, political repression or environmental limitations, 'push' individual migrants out of their homelands while other factors, such as economic opportunities, available land or political freedom, 'pull' individuals to particular places.

The neo-classical 'push-pull' explanatory model of migration has come under increasing criticism for many reasons and is no longer considered to be sufficient to explain the contemporary phenomenon of migration, if it has indeed ever been an accurate reflection of it (see Sassen 1999). The 'push-pull' model is thought to be ahistorical, mechanistic, overly static and doesn't take into account the great diversity of migrants and complex reasons for migrating. It does not explain why people decide to stay at home. Furthermore, it does not differentiate between national, regional and international migration and underestimates the important role of the extended family and community as well as cultural links on migratory decisions. The role of the state and restrictive immigration laws are also ignored. Finally, 'push-pull' geographical explanations, which tend to focus on space, often ignore the importance of social factors, such as age, gender,

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<sup>29</sup> I deliberately use the term 'man' rather than 'human being' to more accurately reflect the worldview of the time.

race, professional qualification, involved in the decision to migrate (see Malmberg 1997, 29-30, for a critique).

Modern theories of migration have tended to analyze the phenomenon on one of three levels:

- macro (structural, socio-economic factors)
- meso (community, family, ethnic group, occupational factors)
- micro (individual, motivational factors)

Until the 1980s, most theories of migration continued to use modified versions of the traditional modernist ‘push-pull’ model and focused on global structural or individual factors that influence the decision to migrate (Faist 1997b, 187-88). When applied to migration, rational choice theory, for example, focuses on the micro-level of the individual, assuming that people act in purposeful, rational ways to maximize their own benefit. One shortcoming of a rational choice theory of migration is that, similar to the critique of ‘push-pull’ factors, it views individuals primarily as self-sufficient units that are motivated largely by economic gain. In dual labor theory, the need for labor in industrialized countries was thought to act as an inevitable magnet to attract labor flows from less developed countries (see, e.g., Harris and Todaro 1970; Sjaastad 1962). World systems theory, with its stronger Marxist orientation, emphasized the role of the international capital in producing labor migration flows (see, e.g., Wallerstein 1974, for a classic source; Massey et al. 1998, for an overview of economic theories of migration). These theories thus tend to construct a dichotomy between explanatory frameworks, with the micro-level emphasizing the agency of the migrant and the macro-level stressing the structural causes of migration.

As a consequence of this heuristic impasse, what Faist terms the ‘crucial’ meso level became increasingly recognized as an important analytical area in understanding migration in the 1980s. As the impact of the postmodern turn began to be felt in the social sciences, a growing number of interdisciplinary approaches undermined the more mechanistic and segmented modernist views of migration that attributed mobility only to

economic reasons. When applied to migration, social network theory emphasizes the role of chains of migrations, communities and personal networks and views migration as a self-sustaining process (see, e.g., Faist 1997b; Portes 1997). Social network theory provides a means to examine the complexity and interrelatedness of reasons that cause people to migrate.

There has been research on the family unit and household as the center of migration decision-making for many years. However, a gendered approach to families and decision-making emerged only in the late 1980s and 1990s at the same time that a growing proportion of refugees, asylum-seekers and migrants in general were made up of women and children (see, e.g., Kofman et al. 2000). These researchers tended to criticize the focus on migration as structural or personal-motivation causes of migration because it has often served to obscure gendered relations within the household.

## **7.2 Nations and citizens**

In many ways, the specter of cultural diversity has become the hobgoblin of contemporary industrialized nation-states. Fearful of losing the security of social memory stories of national identity in the face of threatening images of globalization, many of the positive images of internationalization and multiculturalism that characterized early visions of globalization have soured into a focus on border control and fear of asylum-seekers (see, e.g., Steiner 2000). As Benedict Anderson has argued, nation-states require narratives of origin create the imagined distinctive qualities of their citizens, rendering them different than other nationals (Anderson 1991). The nation-state, however, can also be considered as embodying a unique position from which it claims to be post-ethnic through articulations of it as a patriotic civic religion (see Baumann 1999, 136). The notion of the nation-state as civic religion, however, shows evidence of fraying at the corners as ethnic, racial and religious communities, as well as hybrids of these, increasingly question the exclusiveness of the nation-state to determine group loyalty (Gilroy 2000).

There are three important concepts embedded in many of the discussions and debates surrounding the phenomenon of migration and notions of multiculturalism: the state, the nation and citizenship. All three are distinct concepts with different, and exhaustive, histories and genealogies. In this subchapter, I briefly discuss a few relevant dimensions of each concept and then tie these concepts to contested notions of multiculturalism. This will lay the foundation for a discussion of the emergence of *the migrant*, as opposed to immigrant, through a delineation of the notion of transnational communities.

The state is a legal-political concept, as distinct from a nation, which refers to a certain social organization that is located in a particular territory which has authority, a monopoly on force, and administers a government as well as institutions. The idea of the state is linked to the notion of sovereignty. Early theories of sovereignty by Jean Bodin and Thomas Hobbes placed ultimate authority and the right of force in the king. Due to human nature, the world is, in Hobbes' immortal words, *bellum omnium contra omnes*. Therefore, in the interest of self-preservation, individuals entered into a covenant as subjects to the king/state for protection. This view is based on a view of human nature as inherently selfish. The Enlightenment hailed the dawn of the modern era. Through Rousseau's notion of the social contract and the general will, an alternative view of human nature took shape which underlined the role of the community and consensus in adhering to the rule of the state. In the modern era, the notion of sovereignty was transformed from the person of the sovereign into one of the fundamental aspects of a state, namely the right of states to independence and self-determination.

The state is the sole legitimate authority that can exert force within its territory as well as determine policies, laws and enforcement in the form of institutional practices. Whether a state is recognized as legitimate, however, is connected to its relations with other states in the international community and not solely determined by the people resident within the boundaries of the territory.

The nation, distinct from the state, is an entity often defined or described by ethnicity that shares a common sense of socio-cultural identity. It was only in the 19th century that the

rise of the nation-state united the two concepts. The nation is not necessarily synonymous with the state. In Benedict Anderson's analysis, nations are imagined

...because the members of even the smallest nation will never know most of their fellow-members, meet them, or even hear of them, yet in the minds of each lives the image of their communion. (Anderson 1991, 6)

Hence a nation exists as a concept or image in the minds of its members. The construction of narratives of social memory, in this sense, is a significant dimension of political power because it legitimizes the social order by defining a sense of who we are as a nation (Connerton 1989, 1-5). The nation is thus constructed as embodying spiritual and irrational qualities attached to it that bind its members emotionally together as well as to the idea. Biological or genetic ties, socially constructed through a belief in a common ancestry or ethnicity, often underline the alleged connection of the people of the nation (Baumann 1999, 20). According to Anderson, a nation is also necessarily limited or bordered in order to distinguish it from other nations and to create a sense of uniqueness. Finally, nations are conceived as communities which, though they may embody inequality and stratification, nonetheless posit the fraternity of all members of the nation (Anderson 1991, 5-8).

There are two distinct political interpretations of the concept of the nation: the concept derived from the French Revolution and the German-Romantic idea of the nation (Ahmed 1997, 161-162).<sup>30</sup> In the former, the nation is conceived of as a collective of citizens that freely, and implicitly, choose to consent to the authority of the state. The basis of citizenship is therefore residence and membership in the collective of residents. In this conception, all people born in the territory of a state are automatically granted citizenship [*jus soli*] (examples of such nations include the United States and France). Hence, civic education in *jus soli* nations encompasses the notion of inculcating common values and

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<sup>30</sup> Indeed, the English word *citizen*, derived from Anglo-French, originally meant resident of a city possessing civic rights and duties, in other words, a freeman. (OED 1979, 442) The Finnish word for citizen, *kansalainen*, is derived from the word *kansa*, meaning people or folk with all of the connotations of blood that this entails (Nyky-suomen sanakirja 1992, 187).

ethics amongst all members of the state, making the state greater than its nations. Education is valued as a means of achieving democracy, passing on social memory and reinforcing civic identity.

The German-Romantic idea of the nation, however, is founded on an ethnic, organic conception which does not necessarily have to include a state. Based on the idea of blood or ethnic uniqueness, membership in the nation in this conception is derived from biology. Examples of this nation idea include Finland and Germany, countries which can grant citizenship on the basis of ancestry [*jus sanguinis*]. The nation can occupy a space that is not enclosed by a state (such as the Kurds), or a part of a state (such as the Catalans) or an imaginary place that is not necessarily connected to a specific space. Belonging to a nation can be a matter of the acceptance of its values through socio-cultural assimilation and integration or can be constructed as solely an issue of blood.

### **7.3 The development of the principle of citizenship as a legal marker of inclusion**

Concretely defined, citizenship refers to membership of a nation-state. In this subchapter, I will not delve too deeply into the multiple meanings of the concept of the citizenship, which has been a vigorously debated academic topic in recent years, but just briefly outline its significance to provide the basis for the development of the notion of multiculturalism and its relation to migrants.

As Saskia Sassen notes, the use of a passport as an essential document to prove citizenship became common in western nations only during the First World War when the system of an international community of states became increasingly bureaucratized and rationalized through the strict enforcement of border controls. Indeed, Sassen argues that a new conception of foreigners/outside dates from the initiation of border control during this time and continues to reverberate in current controversies over immigrants, refugees and migrants (Sassen 1999, 77). As Sassen points out:

The nationalism associated with states seeking sovereign control over their territories and the strength of the interstate system transformed the whole notion of ‘foreigner’, compared to its rather lighter connotations in earlier centuries...The coupling of state sovereignty and nationalism with border control made the ‘foreigner’ an outsider. The state was correspondingly able to define refugees as not belonging to the national society, as not being entitled to the rights of citizens. (Sassen 1999, 78)

If foreigners had previously been relegated to the margins of society on a par with other outsiders, such as tramps (e.g. Cresswell 1998), then the newly rationalized bureaucratic systems of passports and permits at the beginning of the 20th century created a new form of marginalization. This marginalization was based on state approval and definition of acceptable and unacceptable foreign residents in the nation. Echoing the Napoleonic era linguistic differences between refugees (Protestant Huguenots subject to intolerant religious persecution) and émigrés (aristocrats forced to leave France during the Revolution), state definitions emerged which classified foreigners in terms of their relationship to the citizenry of a nation-state. Citizenship was a series of legal protections (life, liberty, etc.) and political rights (enfranchisement) that developed, with many striking gaps, in many western industrialized countries at the same time as the rise of the nation-state. Indeed, as historian Matthew Frye Jacobson points out in the example of the United States, “...[in republicanism] inclusions and exclusions based on whiteness did not contradict, but rather *constituted* republican principles...” (Jacobson 1998, 26) [author’s emphasis]. Citizenship, in short, cannot be seen as a culturally-neutral category separate from the racial and ethnic constructions that characterize the nation-state.

Citizenship is therefore intrinsically connected to recognized membership in a state. As *Black’s Law Dictionary* (1993), the standard reference for legal professionals in the United States, defines:

‘Citizens’ are members of a political community who, in their associated capacity, have established or submitted themselves to the dominion of a government for the promotion of their general welfare and the protection of their individual as well as collective rights. (Black’s Law Dictionary 1993, 166)

Citizens are therefore different than *denizens*, the older term used to denote residents of a place that has recently been revived (Fischer et al. 1997, 82), due the fact that they enjoy civil rights and duties. One of the basic civil rights of citizens is equality before the law (also known as equal protection). Equal protection means

...that no person or class of persons shall be denied the same protection of the laws which is enjoyed by other persons or other classes in like circumstances in their lives, liberty, property, and in the pursuit of happiness. (Black's Law Dictionary 1993, 371)

If certain groups of citizens feel that they do not receive equal protection, then they may resort to a civil rights approach to challenge discriminatory practices (Baumann 1999, 7). The struggles for equality led by Dr. Martin Luther King and Nelson Mandela were premised on the notion that citizens of color were denied full equal protection *as citizens*. Denizens (or resident foreigners) therefore are not necessarily entitled equal protection because they are not citizens. An important question in the future will be whether it is feasible to have a democracy where a large proportion of the population are denizens and therefore disenfranchised.

As noted earlier, people are increasingly on the move. Demands for skilled and unskilled labor, civil or communal violence, poverty, family ties, environmental devastation, among other reasons, cause people to migrate to other countries. When people migrate, they do not necessarily lose their emotional or financial ties to their homeland. The globalization of production and finance brings a very new social context to labor migration in the 21st century (Grillo 2001). As Sassen has commented, migration is one of the constitutive processes of globalization (Sassen 1998, 5-30). Often migrants develop complicated and multifaceted relations to communities in the host country. Many guest workers have had the experience of living many years in a foreign country where they have worked to save money for their return home, where they may have actively participated in diasporic national politics or voted in elections. As the findings of the expanding field of cultural studies has clearly demonstrated, identities as well as communities can be very complex and fluid (Bhattacharyya et al. 2002; Brah 1996;

Werbner and Modood 2000). There can be a sense of being ‘neither here nor there’ or of being both ‘here and there’ (Grillo 2001, 17) by many migrants. There can be loyalty to a diasporic homeland that is not a recognized sovereign country (such as Kurdistan or the Basque country) (Walhbeck 1998) or membership in identity groups (e.g. the Muslim Brotherhood).

The notion of *transnational identity* has developed in the last two decades to reflect the multiplicity of national identities that may or may not be covered by citizenship. As Grillo defines:

Transmigration entails manifold socio-economic, political and cultural linkages across boundaries, raises questions about identity (and identification), and rights and entitlements, and problematizes ‘bounded conceptualizations of race, class, ethnicity, and nationalism [we should add culture] which pervade both social science and popular thinking.’ (Glick Schiller et al. 1992, x; quoted in Grillo 2001, 8)

Because identity in the nation-state is seen as transcendent and privileged, above and beyond tribal or ethnic loyalties, the transnationalization of identity poses many basic challenges to traditional ways of conceptualizing identity (Baumann 1999, 136). The notion of being loyal to two nations at the same time, or to no nation in particular, runs counter to the basic formulation of most modernist ideas of national belonging that tend to rely on narratives of unique origin and constructions of social memory.

Citizenship is a problematic and highly contested concept that has been the subject of countless debates and discussions, especially with regard to migration (see, e.g., Ahmed 1997; Castles and Davidson 2000; Dwyer 1998; Faulks 2000; Lister 1997, 1998; Young 1999). There is little room here to go into the specifics of the complex debates on citizenship, but I will briefly draw a broad outline of the some of the main ideas surrounding the concept. As the renowned British political theorist Quentin Skinner has pointed out, the development of notions of citizenship are intimately tied to the rise of the liberal state towards the end of the sixteenth century and the emergence of non-sectarian state bureaucracy (Skinner 1978). With the dawn of the modern era, notions of

citizenship evolved as a series of individual privileges, duties and rights towards the state. These ideas represented a seachange from philosophers such as Hobbes who viewed citizenship as a form of surrender. In the Hobbesian world, citizens exchanged their personal freedom for the guarantee of security by the state. Thinkers such as John Locke later underlined the inviolability of individual rights with regard to the state, particularly with concern to property. Lockean ideas became the basis for liberal conceptions of citizenship.<sup>31</sup> The French Revolution of 1789 introduced a language of inalienable civil rights (for male citizens) embodied in the Declaration of Rights of Man. These philosophical ideas, which has become the commonsense foundation of notions of liberal democracy, provided the basis for the emergence of the framework of human rights in the 20th century.

The rise of the bureaucratic, rational state, which intruded ever further in the private lives of its citizens through the enlargement of social administrative governance, embodied many of the social changes that occurred in western industrialized countries through the struggle for social rights and equality. The multiplicity of forms western welfare states emerged in different cultural contexts out of the struggle between labor and capital, as a key means of social control through new types of governmentalities, and as a device to define shifting boundaries of inclusion and exclusion in society (Rose 1999, 123). Citizenship, in short, can be defined as the attempt to impose rules on a chaotic human environment (Castles and Davidson 2000, 44).

As British political scientist Keith Faulks notes, citizenship was ambiguous in modernity (Faulks 2000, 29). The construction of various forms of the universal welfare state came out of the struggles of social movements, ideological influences and economic factors (Faulks 2000, 26-27). Modernist ideas of citizenship reflected the conflicts between national and minority group identity, liberalist views of the emancipatory power of the market versus socialist demands for an end to wage slavery, as well as disputes of the

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<sup>31</sup> The U.S. Constitution is a good example of Lockean thought with its claim that "...life, liberty, and the pursuit of happiness" are fundamental rights of citizens.

notion of society and belongingness, rights and responsibilities (see, e.g. Esping-Andersen 1990, 41-47). One of the major themes of the modernist period in western history is the drive towards standardization not only in industrial production (which will eventually find its zenith in 20th century Taylorism and Fordist methods of mass production), but also in terms of culture and language. Indeed, the emergence of the public school as an institution and rite of passage in the late 19th and early 20th century served to standardize languages and narratives of national origin. Citizenship thus developed as a cluster of civil, political and social rights endowed by the state to members of the nation. It is important to note, however, that not all residents in a state qualified or were viewed as members of the nation. Dichotomous and exclusionary constructions of the public and private sphere in addition to race, gender and ethnicity had a great impact on ideas of citizenship (see, e.g., Yuval-Davis 1997).

The modernist notion of citizenship in a singular inclusive nation as a mark of distinct identity is increasingly under challenge by the globalizing processes of late capitalism (Castles and Davidson 2000, 156). The terms *transnational identity* and *transnational space* have surfaced in recent years to better define ways of being amidst changes in migration patterns, globalizing socio-economic and political trends in late capitalism and their concomitant effect on ideas of citizenship and belonging (Castles and Davidson 2000; Grillo 2001; Martin 2001; Portes 1997; Sassen 1998; Wahlbeck 1998).

There is a growing acceptance of dual citizenship in many western industrialized countries.<sup>32</sup> The increasing recognition of transnational identities raises issues that go to the core problems of democratic theory. If the democratic process is limited to the borders of a particular state, for example, how is participation in the democratic process then defined? Should exiles or expatriates from a country be able to participate in the democratic process from afar or should it be limited to those actually living in the

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<sup>32</sup> There is an increasing amount of discussion on extending dual citizenship in Germany, for example. The Finnish government has also recently changed the citizenship law. It now allows Finns who have lived abroad for many years, and who have often had to give up their Finnish citizenship due to pension laws in their new country of residence, to reacquire their Finnish passports.

country? What about residents who do not have formal citizenship, but who pay local taxes and use local services? These questions have been resolved, at least for the time being, in a variety of ways according to local tradition, history and culture.<sup>33</sup> These are complex issues that reflect the difficulties of translating modernist systems into postmodern conditions.

#### **7.4 Multiculturalism as a national phenomenon**

Nation and citizenship remain furiously debated issues in many countries today, particularly in the guise of the role of multiculturalism in the nation-state. These debates can be seen as reflecting the collision of the modernist aspirations to national identity versus the fragmentation and chaos of postmodernity. Notions of multiculturalism have often been the lightning rod of debates on ethnicity, blood and civil, community and social rights. A large body of literature has built up on multiculturalism in many different disciplines (Baumann 1999; Blommaert and Verschueren 1998; Butler 2001; Connolly 1991; Gilroy 2000; Kymlicka 2001; Martinez-Brawley and Brawley 1999; Okin 1999; Pitkänen 1997; Soysal 1994; Takaki 1993; Taylor 1994; Williams, Soydan and Johnson 1998). There is no space here to enter into the multifarious twists and turns of various debates on multiculturalism, but I mention some brief points in the context of this discussion on nation, state and citizenship.

As noted earlier, citizenship includes civil, political and social rights that are usually attached to a sense of national identity and shared social memory. Membership in the nation can be constructed as a civic fraternity of equals or an ethnic sense of common descent. The nation can be identified with a state, but it can also exist without one (Palestine is a good example). In a collection of polemics on multiculturalism (Okin 1999), the following definition emerged:

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<sup>33</sup> Permanent residents in the European Union, for example, have the right to vote in local elections regardless of country of origin. Only citizens can vote in US elections and expatriates can vote by absentee ballot, a factor that proved to be of great significance in the 2000 presidential election. Expatriate Irish citizens, however, are not allowed to vote by absentee ballot as residency in the Republic is a key requirement for the franchise.

Multiculturalism, according to one especially compelling formulation, is the radical idea that people in other cultures, foreign and domestic, are human beings, too – moral equals, entitled to equal respect and concern, not to be discounted or treated as a subordinate caste. Thus understood, multiculturalism condemns intolerance of other ways of life, finds the human in what might seem Other, and encourages cultural diversity. (Cohen et al. 1999, 4)

Multiculturalism in this framework tends to be constructed as a universalist political aspiration. Implicit in this definition, as the authors themselves note, is a culture-blind assumption of what equality means. Indeed, this type of equality closely mirrors western liberal notions of individual rights. Collective rights to equality, however, are quite a different issue. As Jürgen Habermas has underlined, the fundamental integrity of the individual is one of the great achievements of liberal democracy:

The political achievements of liberalism and social democracy that are the product of the bourgeois emancipation movements and the European labor movement suggest an affirmative answer to the question [of whether collective rights can be reconciled with a theory of rights that is individually designed]. To be sure, both attempted to overcome the disenfranchisement of underprivileged groups and with it the division of society into social classes; but where liberal social reform came into play, the struggle against the oppression of collectivities deprived of equal social opportunities took the form of a struggle for the social-welfarist universalization of civil rights. (Habermas 1994, 108)

Here Habermas clearly draws the connection between the consolidation of principles of individual rights and the achievements of the social welfare reforms. Underlying this discussion, however, is an implicit assumption that such rights are for citizens because it is only the state that can guarantee such social-welfarist universalization of civil rights through its own laws, policies and practices. In other words, the historical context out of which western social democracy, and accompanying ideas of equality, emerged cannot be considered as universally applied, accepted or understood in the same way as a culturally-neutral set of prescriptions. A fundamental argument that surrounds notions of

multiculturalism, then, is who defines intolerance, and how far should intolerance be tolerated?

One of the problematic issues in many discussions of multiculturalism is the tendency to view culture groups as essentialist categories. Indeed, the very notion of what constitutes a culture group (ethnicity, race, traditions, heritage, community) many times tends to be blurred and unclear. The construction of culture communities as static entities that embody specific social characteristics that persist in the same forms down the years, despite the reality of continuous cultural dynamism and fluidity, serves two purposes.

First, essentializing culture communities makes it easier for the mainstream culture (and the accompanying power structure) to objectify, control and implicitly disregard the implications of difference without having to personally or structurally cope with the complexities of cultural identity (particularly with regard to the sharing of resources). This is sometimes the purpose of multicultural policies which

...propose a mosaic of fixed essences glued to the to their historical past, part of an *époque* which assumes that these essences never change and never encroach on or challenge each other. To do this is not to deny pluralism or diversity. This course is that of conservatives who wish to return to a nostalgic world of consensus and conformity. (Young 1999, 108)

As Zygmunt Bauman underlines, this type of multiculturalism, which is built on a complex structure of essentialist identities, tends to use traditionally liberal inclusivist discourse to exclude and deny change or hybrid transformations (Bauman 1995, 188).

Second, culture communities can be constructed as essential from within communities themselves as a strategy of resistance to the tendency of mainstream power structures to render them invisible, their experiences meaningless and silence their voices. In this sense, identity politics can be an important element of affirmation of the survival of a people. Examples of this can include the development of a Sabra Jewish-Israeli identity after the Holocaust and the creation of an Afro-American identity in the wake of the civil

rights movement in the 1960s. In these examples, the use of an essentializing cultural identity proves the survival and pride of people oppressed and denigrated for embodying precisely these essential identities. In other words, the essentialized cultural identity can be turned against those who would 'other' them as an act of resistance.

When considering the role of different culture groups within the nation-state, Charles Taylor (1994) has raised the dilemma of recognition by posing the question of whether all cultures are equally valid and valuable. Taylor argues that recognition can only be granted as a moral presumption of equal value or the right to respect and dignity. This, Taylor rightly notes, makes it difficult to have any subjective judgments of value. Dutch researcher Gerd Baumann has criticized Taylor as conceptualizing cultures in far too abstract terms which can have the consequence of exclude the recognition of certain cultures on rather arbitrary grounds (Baumann 1999, 112). Yet, as educational researcher Mark Mason has emphasized:

If we accept, then, that we are morally obliged to treat others with respect, and that we are bound to accept the force of that which has been justified in reason, then we are committed to honoring the principle of multiculturalism. A commitment to multiculturalism (from which we cannot escape if we accept these premises) commits us to the universal applicability of its associated principles, which commits all to the transcultural normative reach of its principles. This means that we are bound to respect the right of all citizens to live in accordance with their own beliefs and practices, but only in so far as these beliefs and practices are consistent with the principles associated with multiculturalism itself, primary among which is the principle of respect for the rights of others. (Mason 2003, 21)

This recognition of the rights of others within the framework of mutual respect underlines Zygmunt Bauman's notion of postmodern ethics as relational rather than a solid set of immutable prescriptions.

Zygmunt Bauman has further noted that an exclusive focus on the issue of recognition tends to overshadow the often more fundamental issue of socio-economic equality:

Ostensibly, multiculturalism is guided by the postulate of liberal tolerance and by care for the communities' right to self-assertion and public recognition of their chosen (or inherited) identities. It works, though, as an essentially conservative force: its effect is a recasting of inequalities, which are unlikely to command public approval, as 'cultural differences' – something to cherish and obey. The moral ugliness of deprivation is miraculously reincarnated as the aesthetic beauty of cultural variety. What has been lost from view in the process is that the bid for recognition is toothless unless sustained by the practice of redistribution – and that the communal assertion of cultural distinctiveness brings little consolation for those who, courtesy of the increasingly unequal division of resources, have their 'choices' made for them. (Bauman 2001, 107)

Bauman's critique goes to the heart of globalized late capitalist postmodern relations. Questions of recognition, respect and the inherent dignity of different identity groups in a society are not merely cultural phenomenon but also reflect the power of economic and political relations through marginalizing practices. These issues cannot be discussed in a vacuum but are linked to conceptions of the nation and citizenship which also limits those who is included and allowed to participate in the community.

### **7.5 The matrix of identity and the migrant experience**

Migration is becoming an ever more significant focus of study and its inherently interdisciplinary nature is increasingly recognized (Brettell and Hollifield 2000). In many ways, contemporary trends in migration can be seen as the embodiment of globalizing processes. One important feature of these processes has been the emerging sense of simultaneous globalization and localization. Despite the fact that the vocabulary of globalization can sometimes been seen to erode the language of race and class, it is important to recognize that these elements are intimately connected and reconstructed in the creation of a new world social order albeit in new cultural configurations (Bhattacharyya et al. 2002, 35).

Many modernist theories of migrant identity in the 20th century tended to view the construction of migrant identity as the collision between two intact and essentialized cultures. Generally, social adaptation among migrants was conceived of as assimilation

or cultural pluralism. In assimilationist theories, migrants were thought to acculturate and integrate into the new society by adapting the language, culture and customs of the host country and eventually intermarrying with members of the dominant group. Sociologist Milton Gordon (1964) held that after personally adapting to the new culture, migrants would then integrate into the structures of the new society. Hence after a generation, there would be little cultural difference between the members of the original migrant group and citizens. Notions of assimilationism were thus largely based on the assumption that host societies would have fair and impartial social systems that would not discriminate against newcomers on the basis of race, ethnicity or religion. In other words, assimilationism is premised on the supposition that personal identity acculturation inevitably leads to social structural inclusion.

Where assimilationism sees migrants' cultural identity as gradually melting through acculturation, cultural pluralism views migrants' own cultural identity as an essential core that never entirely disappears. In cultural pluralism, migrant communities retain their own culture and never completely acculturate. Migrant cultural identities therefore remain primary through generations and are a significant element in societal power relations. Cultural identity, in the pluralist view, is an important element of mutual aid networks, self-image and political organization (Glazer and Moynihan 1970). The migrant group's desire for cultural separation is often taken for granted in the cultural pluralist view of identity. However, as Castles and Davidson point out, the flip side of this can be termed 'differential exclusion' whereby the migrant group is not accepted in as permanent residents in society despite the fact that they might live there over generations (Castles and Davidson 2000, 61). Castles and Davidson cite the example of the *Fremdarbeiter* in Germany in this connection.

In theory informed by the postmodern turn, however, both the concepts of identity based on assimilationism or cultural pluralism appear overly essential and restrictive because they frame identity as a singular, and often immutable, entity that is commonly tied to location. As noted earlier, identity has become increasingly problematized in postmodern theory. It has been generally recognized that identity is not simply a static receptacle

anchored in place and filled with identifications based on social status, class, gender, ethnic group and nationality. Rather, as Baumann points out:

...all identities are identifications in context and...they are thus situational and flexible, imaginative and innovative – even when they do not intend to be. (Baumann 1999, 138)

Identity exists within a complex network of relations and therefore is not solely tied to place but is also about dislocation and displacement. The notion of transnational identity has gained prominence in the postmodern world and is acknowledged as an integral part of the process of globalization. A group of social anthropologists have defined transnationalism as:

We define ‘transnationalism’ as the processes by which immigrants forge and sustain multi-stranded social relations that link together their societies of origin and settlement. We call these processes transnationalism to emphasize that many immigrants today build social fields that cross geographic, cultural, and political borders...An essential element is the multiplicity of involvements that transmigrants sustain in both home and host societies. We are still groping for a language to describe these social locations. (Basch et al. 1994, 6; quoted in Portes 1997, 4)

Transnational identity therefore reflects the fact that migrants often feel both ‘here’ and ‘there’, or sometimes neither ‘here’ nor ‘there’ (Grillo 2001). In short, the conceptualization of transnational identity challenges traditional modernist concepts of immigrant identity which have tended to draw a definitive line between location and self-definition.

Many people and structures in host societies harbor the perception that migrants embody a singular and essential identity. This can be seen in the complex categorizations used in administrative procedures that slot migrants’ identities into one-dimensional compartments. Often this reinforces the fact means that there is little recognition accorded to the equally complex nature of migrants’ identities. It becomes increasingly

easy to stereotype or 'other' migrants, particularly when there is little personal contact between members of the host society and migrant communities.

As nursing care expert Geri-Ann Galanti points out in her handbook to cultural competence in health care, the basic difference between a stereotype and a generalization is that the former is an ending point while the latter is a point of departure (Galanti 1997, 2). The use of stereotypes reflects a view of migrants as embodying a contained and known singular identity. The exercise of generalizations, however, reflects the use of cultural information as a guide to enhance the process of getting to know about the complex identity of the migrant. Stereotyping migrants into singular identity categories contradicts the increasing reality of transnational identities in the globalized postmodern world.

When stereotypes are invoked, migrants are often solely characterized solely in terms of deficits, especially if they are in a vulnerable socio-economic status in the host society. Theories of assimilationism continue to be strongly tied to notions of belonging in the national community. Indeed, to assimilate means to remove the deficits of difference and become one with the new national community. Cultural pluralism may be seen as more supportive of migrants, particularly those who come from already established minority community enclaves that have community based organizations, because it recognizes the right of minority groups to define aspects of their own social reality within the nation.

The rise of the post-colonial critique in the late 20th century has focused attention on the 'conjuncture' of geopolitical forces in local conditions (Frankenberg and Mani 1993, 292). In other words, the 'othering' or 'invisibilizing' of certain identity groups often represents the crystallization of globalized socio-economic relations. Edward Said's exploration of the binary division of the 'one' and 'other' in colonialist discourse through the notion of orientalism (Said 1978) underlined the fundamental point that it is impossible to separate the experiences of colonizer and colonized. Using the terms 'overlapping territories' and 'intertwined histories', Said underscored the fact that people

share histories, albeit from very different perspectives, memories and experiences, throughout the world (Said 1993).

Edward Said's notion of orientalism provides a good opening to understanding the position of vulnerable migrants in industrialized societies, many of whom originated in former colonies. As pointed out in Chapter 5, many globalizing trends in late capitalism have sharpened international socio-economic inequality, which has been manifested in the growing divisions of labor by nationality, race and gender. These phenomena have a strong impact on the development of migrant identities and opportunities for social mobility and integration in host societies (see, e.g. Portes and Rumbaut 2001).

Migrant identity is thus a complex amalgamation of socio-economic and geo-political forces in addition to specific cultural, ethnic or racial group, social class and personal factors. It is therefore a dynamic embodiment that is affected by many more elements than other than simply location. Traditionally mechanistic models of acculturation often do not take into account the complexity and fluidity of migrant identity. Lindsay and Booth (1998) have used the metaphor of 'layering' to reflect the complexity of migrant identity:

Differences in actions between peoples and places can upset the established ordering of layers and act to challenge identity. Migrants who were part of a dominant culture in their homeland find themselves assigned to a marginal place in the new culture. This results in questions about where they fit in and how *long* they have to *be* here to *belong*. Significant disruptions to the layering of experiences are equivalent to this experienced movement from one patterning of situation to another... Long after they think they have been in the new place long enough, incidences will occur to remind them that they come from somewhere else. (Lindsay and Booth 1998, 9-10)

Among the many complexities inherent to migrant identity are elements specific to the migration experience. As noted earlier, migration is often not simply a linear journey from one point to another but can involve multiple crossings and re-crossings of borders which can create new identity communities (Anzaldúa 1987). Social class and status have

a significant impact on migration opportunities and levels of vulnerability (Bhattacharyya et al. 2002). These multifaceted factors form an intricate background to identity issues that are specific to migrants.

One of the greatest challenges to many migrants is the sense of perpetual dislocation. As pointed out earlier, nations are defined by their borders and exclusions, as well as social memories. Interpretations and national integration policies dealing with belonging to the national community can vary widely from those who favor assimilation to the cultural plurality standpoint on acculturation. Moreover, racial and ethnic difference from the dominant population of the host country can have a great impact on the development of a sense of belongingness through the prevalence of discriminatory practices no matter how much a migrant has acculturated. This means that belonging is a far more complex issue than the individual choice of migrants. Power relations within the national community, societal constructions of the nation and its history as well as family, gender and individual constraints all play a role.

The migration experience itself challenges the continuity of identity development. As Lindsay and Booth have termed it, the migration experience produces ‘states of liminality’ (Lindsay and Booth 1998, 1) in which migrants exist in the interstices of nations and cultures. This sense of dislocation can be seen in the everyday experiences of migrants:

The necessity of learning a new language acts as a continual reminder for migrants that they no longer live in their homeland. Even when the language of the homeland is the same as the language of the new land, the daily patterns and practices of usage are usually different enough to cause sporadic disruptions to everyday life. Shopping for food is often fraught with difficulty, particularly if there are no signs or goods that can be pointed at. When one is a visitor in an alien place, it is easy to shrug off the inconveniences because next week, or next month, you’ll be home again among familiar things. When one has no alternatives and no where else to go, the situation can be much more traumatic. (Lindsay and Booth 1998, 2)

The confusion and disorientation of living in a foreign culture can force migrants to continually remake or relayer their identities. This can result in deeply ambivalent feelings towards both the new country of residence and the country of origin. Fitzgerald and LaGory (2000, 37) suggest that all human beings have a fundamental need for a sense of place and rootedness as a precondition for health. The sense of rootlessness and not belonging to place can therefore have a serious impact on health. Finally, social memory plays a significant role in shaping migrant identity. Migrant identity is therefore forged in the experience of migration, an experience which does not necessarily follow a linear pattern with a specific beginning and endpoint.

## **8. The nation and the universal social welfare state: Well-being to social exclusion**

The universal welfare state<sup>34</sup> is one of the major achievements of the modern era in Nordic countries. The cornerstone of the universal welfare state is the inclusion of all citizens in a common social safety net through the promotion of societal well-being and forging of a social compromise between the polarizing forces of capital and labor (Amin 1997, ix-x). Constructions of the welfare state brought together notions of the nation as a territorial and economic space with aspirations for the good life and community. Articulations, narratives and constructions of welfare states thus reflect positions within the specific socio-cultural and economic circumstances and power relations in each society.

The universal welfare state can be characterized as a multiplicity of societal organizations that intervene in and support the lives of all citizens regardless of income level. The origin of universal welfare states was thus premised on a modernist belief in the controllability of the social environment, the importance of social integration into the nation, and the possibility to enhance the ‘good life’ for citizens. Universal welfare states nonetheless often embody a high level of ambiguity because notions of the social good are not self-evident categories, but rather reflect constellations of power in how they are constructed and managed.

The aim of this chapter is to explore the intersection of the nation and citizenship in the Nordic universal welfare state. As the focus is on this specific point, I do not attempt to outline the manifold formations and models of welfare states nor exhaustively trace the complexity of welfare states. Though it is important to approach generalizations about

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<sup>34</sup> The universal welfare state that is discussed on a general level here should be qualified as referring exclusively to western industrialized welfare states. The term ‘universal’ emerges from the Eurocentric philosophical framework defined in chapter 5.21 and refers to the inclusion of all citizens in the national welfare state.

welfare states cautiously, this chapter has the limited aim of synthesizing previous arguments and defining certain issues that are important in this work. By presenting a blueprint of the Nordic welfare state, I attempt to make a bridge to the next section which explores stories of AIDS and their impact on policymaking. The Nordic welfare state and its tasks, which are sketched out in this chapter, are examined in detail in the fourth section of this work.

The 20<sup>th</sup> century welfare state can be seen a set of governmentalities that emerged out of the ‘moral technologies’ of the 19<sup>th</sup> century. The 19<sup>th</sup> century can be characterized as the era of disciplinary technologies with the development of modern asylums, prisons and public schools, which served to shape and control the character and moral conduct of certain citizens in relation to constructions of the socio-cultural norm (Rose 1999, 103; Satka 1995). The 20<sup>th</sup> century welfare state represented a shift towards the development of social well-being strategies informed by experts which promoted the social good through responsible citizenship in a social state (Rose 1999, 133). Welfare states can be viewed as both the modernist apogee of social solidarity and inclusion through the notions of social rights and social citizenship, as well as the pinnacle of social control through the disciplinary control of individuals’ subjectivity by rendering bodies docile. These contradictions have always coexisted within universal welfare states and are realigned and reevaluated according to the prevailing political winds and social changes.

Despite the many differences among western welfare regimes, which embody specific historical, cultural and local contexts ranging from the corporatist tendencies of Germanic nations to the residual systems of Anglo-Saxon nations to the universalist welfare states of Scandinavian countries, social citizenship forms the core idea of inclusion in the 20<sup>th</sup> century welfare state (Esping-Andersen 1990, 21). According to the classic text by T.H. Marshall, social citizenship emerged historically after civil/legal and political citizenship. In Marshall’s view, social citizenship was a status, rather than a sign of virtue, to which all citizens were entitled (Marshall 1950). This notion of citizenship was therefore strongly linked to commitment to the idea of social inclusion for all

nationals (Katz 2001, 344). Citizenship in this formulation was strongly tied to membership in the nation.

Yet, many theorists have contested the notion of social citizenship as a synonym for social inclusion (Young 1999, 198). Emphasising the role of gender, class, racial and ethnic difference as significant barriers to access and equality in societies constructed on class-based, cultural and andro-/heteronormative systems of merit, social citizenship has been problematized as a universalistic concept. Social citizenship can be seen as the product of compromises and power sharing amongst various groups in society that is realized through systems of social stratification and social exclusions shaped by the forces of the welfare state, rather than an eternally universal and immutable concept:

The welfare state is not just a mechanism that intervenes in, and possibly corrects, the structure of inequality; it is, in its own right, a system of stratification. It is an active force in the ordering of social relations.  
(Esping-Andersen 1990, 23)

The Nordic welfare state can be characterized as embodying a certain definition of what the good life is through a welfare model based on explicit communitarian goals (Sunesson et al. 1998, 19). Hence the Nordic welfare state represents specific cultural constructions of social and community values as well as the policies and practices created to define and realize them. Nordic universal welfare states arose as structures that sought to mitigate the most drastic effects of the commodification of the individual (the subjugation of human beings to the cash nexus), to create a social compromise among groups competing for position and resources, and to build a ‘people’s home’ for all citizens.

### **8.1 Social memory, the nation and the universal welfare state**

The idea of the universal welfare state is strongly tied to narratives of the nation. The nation is premised on social memory stories of national unity, uniqueness and eternity. The birth of the nation-state at the dawn of the modern era represented a new

consciousness of being in the world and the creation of a new set of unifying social memory stories. The cultivation of a national identity and culture, as opposed to a patchwork of local identities and cultures, thus involves some degree of edited social memory to produce the imaginative leap of an exclusive identity, unity, standardization and similarity. Among the processes involved in developing a national identity is the codification of a national linguistic grammar, the designation of eternal national symbols, and a common social memory which is continually constructed on strategic amnesias that reinforce or shift power relations and hierarchies in society.

Zygmunt Bauman links Anderson's 'imagined community' of the nation to the 'imagined entity' of modern society (Bauman 2002, 43). Ideological narratives of the nation are reflected in articulations of society, which are then operationalized in the institutions, policies and practices of the universal welfare state, and territorialized in the economic space of the state. Social memory narratives of the nation, and its institutionalized form, the society, thus evoke the naturalization of hierarchies which extend down to the community and family levels. Yet, the nation itself is a Janus-faced construction: simultaneously friendly and bellicose, inclusive and exclusive (Bhabha 1990, 3-5). The welfare state thus reflects the hierarchies and normative relations constructed within the nation-state and rationalized by social memory stories. The people's home therefore offers security and a sense of belongingness, but often at the cost of conformity to prevailing ideas of the good life.

If we look at the history of Finland, we can see a sparsely populated and rather culturally and ethnically homogenous country with a strong agrarian tradition. It has been argued that Finnish notions of citizenship can be described as communitarian (*gemeinschaftlichkeit*) unlike the civic-republicanism of the French or western political liberalism of the British. This means that Finnish citizenship was constructed in the context of a community:

Citizens were not regarded as autonomous individuals, but rather as members of communities. Accordingly, the legal system based on

individual rights and liberties has had as its background the collective identity of the nation. (Anttonen 1998, 356)

The nation was thus identified with the community, though the metaphorical borders of the nation and concomitant meanings with it were constantly shifting. Underlying this bond was the Nordic Lutheran Church which has had a strong impact on shaping a culturally homogenous political and mental culture in Finland (Stenius 1997). As social policy expert Anneli Anttonen has summarized:

...the unification of state and church has fostered a culture of belonging to one religion, to one community and to one nation. (Anttonen 1998, 357)

The Finnish universal welfare state is thus largely based on specific cultural notions of solidarity and equality, informed by a common religion, which have defined social citizenship. As Esping-Anderson has defined:

...the universalistic system promotes equality of status. All citizens are endowed with similar rights, irrespective of class or market position. In this sense, the system is meant to cultivate cross-class solidarity, a solidarity of the nation. (Esping-Anderson 1990, 25)

The equalities and conceptions of the 'good life' mapped out by the Finnish welfare state reflect constructions and social memories of *Finnishness*, with accompanying exclusions, political definitions and legitimations. The construction of the universal welfare state was intended to alleviate the greatest inequalities of capitalism by creating a social security net that would include all citizens. It can nonetheless also be seen as a means to legitimate an inherently unequal system (Cochrane 1998, 254).

The universal welfare state has been constructed through the values of solidarity, inclusion and the common good, which in turn are defined through shifting constructions of the social memory of the nation. One of the major challenges to conceptions of the universal welfare state is the growing cultural diversity within national populations. This diversity may bring a multiplicity of narratives of social memory which can problematize

notions of the nation and inclusion in the community. While some observers consider emerging cultural diversity to be a threat to notions of 'the social,' (e.g. Rose 1999, 136) others view multiculturalism as an opportunity to question the fixed values of experts in the social welfare state and increase democratic participation (Young 1999, 198-199).

## **8.2 Social policy and social work: towards professionalization**

Social policy and social work are two professional fields that emerged in the 20<sup>th</sup> century as expert disciplines on the modern social welfare state. These disciplines are unique in the sense that their mission is explicitly the promotion of social justice. Therefore, they must engage in dialogue with democratic institutions to continuously define the best ways to achieve a higher quality of life for all citizens. If social work focuses more on practical interventions with individuals, groups and communities, then social policy seeks to set strategies to achieve negotiated societal aims.

Diana DiNitto defines social policy thus:

(S)ocial welfare policy involves a series of *political* issues about what should be done for the poor, the near-poor, and the nonpoor--or whether anything should be done at all. The real problems in social welfare are not problems of organization, administration, or service delivery. Rather, they involve political conflicts over the nature and causes of poverty and inequality, the role of government in society, the burdens to be carried by taxpayers, the appropriate strategies for coping with social problems, the issues posed by specific social insurance and public assistance programs, the relative reliance to be placed on providing cash rather than services to the poor, the need for reform, and the nature of the decision-making process itself. In short, social welfare policy is a continuing political struggle over the issues posed by poverty and inequality and by other social problems in society. (DiNitto 1995, 1-2) [author's emphasis]

Articulations of social policies reflect diverse views of what we are and what we want to be as a society. They embody the results of our collective negotiations over the notions of fairness, justice, equality, belonging and rights. In the current stage late capitalism with its accompanying characteristics of highly mobile capital, neoliberal ideologies of

individual responsibility, and the deterritorialization of production, discussions on the fate of liberal democracy and the sovereignty of the state has raised many of the old debates on fairness and economic rights, but perhaps with a new urgency. Definitions of belonging, with their associated social citizenship rights, are closely tied to collective narratives of social memory which can be very exclusive. The growing cultural diversity within urban centers can be seen, along with prismatic globalizing processes and neoliberal ideologies, as challenges to the modernist definition of social welfare values (e.g. Sassen 1998). As Zygmunt Bauman has noted:

One of the most seminal consequences of the new global freedom of movement is that it becomes increasingly difficult, perhaps altogether impossible, to re-forge social issues into effective collective action. (Bauman 1998a, 69)

Modernist definitions of the universal welfare state which have been linked to the intimate connection between the nation and social inclusion are thus becoming increasingly problematic in a more mobile and globalized world.

The growing shift from social rights-based to duty and personal responsibility-oriented lines of social policy in many countries mirror contemporary political currents (UK Prime Minister Tony Blair's 'Third Way' can be seen as emblematic of this approach). This shift can be seen as parallel to Nieminen's discussion of the difference between the universal and the global, discussed earlier in Chapter 5.21. A universalist social-rights based notion of citizenship appeals to modernist social theory which raised the role of moral and ethical codes that transcended time or place. A global notion of citizenship, on the other hand, lacks a social content and is based on the idea of the citizen as consumer. The postmodern condition of social fragmentation can be understood as the subversion of universalizing grand narratives, such as a universal moral or ethical code, with all of the implications that entails towards the shrinking of a common public arena. At the same time, the postmodern turn leaves open the possibility for further democratization through the articulation of diverse voices through the emergence and empowerment of previously invisible identity groups.

Social work as a profession implicitly seeks to alleviate human suffering, protect and support the vulnerable, and promote the general well-being of the population. Social work itself has been defined as

(T)he applied science of helping people achieve an effective level of psychosocial functioning and effecting societal change to enhance the well-being of all people...Social work practice consists of the professional application of social work values, principles, and techniques to one or more of the following ends: helping people obtain tangible services; providing counseling and psychotherapy with individuals, families and groups; helping communities or groups provide or improve social and health services; and participating in relevant legislative processes. (Barker 1995, 357)

Originally derived from church charity work and poor relief, western social work developed as a secularized, state-supported professional activity in the 20th century which sought to mitigate the worst effects of poverty and social deprivation as well as a means of providing a modicum of social control through the definition of normality and correction of deviance. From the earliest poor relief laws that restricted assistance to legal residents of a county to the demonization of the tramp and vagrant to the granting of relief to the 'deserving poor,' social work itself has been the site of many debates and negotiations over its implicit definition, purpose and breadth as a field (see, e.g., Katz 1996; Piven and Cloward 1993, 1997; Satka 1995). Premised on a strong ethical basis of advocacy for the weak and excluded members of society, social work as a statutory activity has nevertheless reflected national policies that fix the limits of inclusion and social citizenship in the nation-state through the definition of eligibility for social assistance and the prioritization of social needs. Thus, in many senses, social workers have served as the border guards of inclusion in the welfare state and, in Foucauldian terminology, have been agents of social control by wielding the disciplinary control of eligibility criteria (see, e.g., Chambon et al. 1999).

Social policy and social work are the two expert disciplines that define, plan and implement interventions in the social field and are often part and parcel of the state administration. These disciplines are uniquely tied to specific national and socio-cultural

contexts. Indeed, there are great diversities in the way that social work as a profession is defined and practiced in different countries. The social memory of nations has a strong influence on how social values are shaped and viewed as intrinsic to communities. Hence social work and social policy can be seen as professions that involve continuous negotiation between understandings of social memory and aspirations for inclusion and the general good.

### **8.3 The transition from well-being to social exclusion**

The primary aim of the creation of the universal welfare state was to prevent the multidimensional negative effects of poverty and include all citizens in a universal system of social welfare that would ensure citizens' human rights. One of the fundamental concepts that the modern social welfare state utilizes is the notion of well-being. Well-being can be defined as a state of being which is more than the absence of negative impacts such as disease, poverty and violence. Well-being can be defined in a positive sense as having a good quality of life, and having opportunities and rights. Well-being, moreover, is a relational concept and differs according to the constellation of power relations in society, culture and national context. Hence there is not a singular or culture-free definition of the term.

The nation-state was combined with the modern welfare state to create societies of disciplinary inclusion, with those who did not meet the changing standards for inclusion tended to be relegated to the margins. One of the primary aims of creating modern nationhood was to mold the diversity of the local into the singularity of the nation, though it must be noted that this has been an ongoing social memory process with ever-shifting rules. The welfare state served as a means of socializing diversity into the national whole by defining and treating deviance and enforcing discipline. Policies of assimilation, for example, can be seen as a hallmark of the modern welfare state. Social inclusion, often at the expense of individual and group rights, was therefore one of the primary characteristics of the modern nation-state.

Social exclusion is a relatively recent term (Sen 2000, 1) which was developed to describe the new challenges of late capitalism, globalization and postmodernity. Social exclusion has been defined as "...the process of becoming detached from society." (Heikkinen 2003, 2) Social exclusion is therefore tied to issues of marginalization and disempowerment. The notion of social exclusion thus attempts to take into account the multitude of factors that prevent individuals or groups from participating in mainstream society, rather than focusing solely on more quantitative factors such as poverty.

In his groundbreaking study on social exclusion, Jock Young argues that the transition from modernity to postmodernity (or late modernity as he terms it) can be seen as a shift from an inclusive to an exclusive society (Young 1999, 7). Young suggests that the transition to a late capitalist, post-industrial society has brought with it an ideology of individualism that is based on exclusion. He points out that the focus on assimilationism and incorporation so characteristic of the modern state has been superseded by the concentration of segmentation and individualism distinctive of the postmodern state. This marks a significant shift from the inclusive basis of the modern national welfare state.

#### **8.4 Transnational well-being**

The changes in conceptions of the nation-state, citizenship and nationality that have accompanied globalizing processes in late capitalism have also affected the contemporary planning, practice and theorization of social work. Social work projects in European countries, for instance, are increasingly turning to funding available through the European Union. The structure of these projects tend to encourage the treatment of social issues that manifest transnational concerns and require several partners in different nations to form a network, rather than to exclusively national sources of income. This shift in sources of funding and new criteria for funding carries a fresh set of assumptions in social policy regarding inclusion and social citizenship. Moreover, a new social memory of European identity is being forged (and resisted) to solidify a sense of commonality among actors. If the concern was earlier for social work projects that addressed the needs of Finnish citizens, for example, then one current concern could be

characterized as the promotion of social work undertakings that deal with common European interests and posit the existence of an overarching European citizenship. At any rate, exclusionary practices remain, though perhaps on a more globalized basis.

There can be little doubt that social issues, needs and problems cross borders and do indeed require transnational responses. However, the nation-state is still the primary organizer and funder of the provision of social services in each country. States can also still determine national policies on the acceptance or rejection of foreign residents by the definition and application of immigration law. Though European Union law is increasingly being harmonized, states can still determine the conditions of foreigners' residence through financial eligibility requirements, restrictions on social and health services, and labor market regulations.

Social work thus treads a difficult line between empowerment and control. Though it explicitly positions itself as client-centered, it is nonetheless subject to the definitions and financial restrictions of policy planners as well as the contradictory pressures of outlining both the common and individual good in increasingly fragmented mobile societies. Undocumented foreign residents or foreign residents that do not fulfill eligibility criteria can pose challenges to the development of inclusive state-funded social programs that seek to extend positive human rights to all people in society. The field of social work, which has often operated in rather exclusively nationalistic terms, thus faces new challenges in responding to issues and problems that transcend borders.

Thus, the increasing social fragmentation and the deconstruction of grand narratives of universalism in social welfare provision through neoliberal ideologies can be seen as one of the hallmarks of late capitalist insecurity. Social citizenship has always been conditional, particularly when we consider the position of women and minority ethnic groups in many societies, despite narratives of universal inclusion in the welfare state. When certain diverse socio-cultural identity groups are considered to be outside of the mainstream socio-cultural identity group, and excluded from social memory, then they are often thought to be less deserving of inclusion into the parameters of universal

national social rights through eligibility restrictions. The lack of social services that are culturally sensitive and appropriate can be seen as marking a line between those included within cultural definitions of the universal welfare state and those excluded. It can also be seen as a form of enforcing cultural normativity. In other words, an implicit monoculturalism in social services reflects exclusionary practices that tend to render the needs of members of diverse socio-cultural identity groups invisible.

### **8.5 HIV/AIDS as a transnational social and health care issue**

Increasing global mobility and growing international income disparities, as well as the changing nature of national governance and governmentalities, have had a deep impact on the ability of states to organize and provide services for people resident within its borders. The role and definitions of social memory in constructing a sense of belonging and ‘we-ness’ are also becoming more problematized as competing narratives of the nation vie for dominance and recognition. Finally, both the notion of inclusion as a recognized legal resident in a country and the preservation of borders against those deemed not deserving or entitled to equal access to services have become increasingly contested issues, particularly in the light of the postwar tradition of universal human rights.

HIV/AIDS is an acutely stigmatized illness. Although human rights arguments hold that all people have a right to social and health care, millions of people living with HIV/AIDS throughout the world remain unable to gain access to treatment and care. Despite vast efforts by many organizations to put a human face on HIV/AIDS, there is still a great deal of work to be done to include and recognize marginalized and vulnerable people affected by HIV/AIDS as human beings equally entitled to receive appropriate care and treatment. Moreover, attitudes towards people affected by HIV/AIDS continue to be subject to nationalist, racist, heterosexist, and classist biases. These attitudes can be reflected at the highest government levels, as a recent report by the Central Intelligence Agency states:

New and reemerging infectious diseases will pose a rising global health threat and will complicate US and global security over the next 20 years. These diseases will endanger US citizens at home and abroad, threaten US armed forces deployed overseas, and exacerbate social and political instability in key countries and regions in which the United States has significant interests. (Central Intelligence Agency 2000, 2)

This statement clearly demonstrates the bifurcation between the humanity of ‘US citizens’ who are ‘endangered’ by the faceless infected masses that menace US interests and merit no mention as human beings, but are merely relegated to the category of ‘disease’. Unlike epidemiological conceptions of HIV transmission through risk behavior, the ‘global health threat’ in this report appears to exist outside of the borders of the United States stalking US citizens and there is no mention of a global community response nor a sense of solidarity with those non-Americans affected by HIV/AIDS, let alone a discussion of the basic human rights of people living with HIV/AIDS regardless of nationality. As George J. Annas has noted:

Metaphors matter; they make all the difference whether, in adopting a global AIDS strategy, nations adopt the war-containment or escalation discourse, in which control is viewed as an end in itself and the infected body becomes a battlefield, or the human rights discourse, in which our collective futures and the values of human flourishing and the right to humane treatment are paramount. (Annas 1999, 37)

The CIA report clearly demonstrates that in an age of viral epidemic, infectious disease can easily be construed as a menace to national security. In many quarters, health has increasingly viewed as the rightful possession of the privileged to be defended against potential threats, not a human right for all. The threat scenario presented by the CIA thus easily translates into a policy of exclusion for those non-citizens or non-nationals suspected to have infectious diseases.

The war-containment way of considering infectious disease control militates against the lessons of public health. As René and Jean Dubos argue in their seminal book on tuberculosis, *The White Plague*, the improvement of living conditions has time and again proved to be a far more effective public health measure against the spread of disease than

quarantine (Dubos 1952, 208-228). The predominant construction of societal responses to infectious disease can therefore be characterized as the dualism between war containment and human rights. Thus, despite the fact that the virtues of border crossing and internationalization are frequently trumpeted as a core element of the process of globalization, questions of transnational equality and well-being remain the fundamental human rights issues that are most effective in containing epidemics and promoting health.

### **8.6 Summary: Trends of globalized late capitalism and their impact on transnational health and well-being**

Health and well-being are strongly tied to national policies and practices. Economic trends and globalizing processes have a strong impact on how services are developed and the people who are included. The following points summarize some significant trends in globalized late capitalism and their impact on transnational health and well-being:

- *The deterritorialization of capital and flexible accumulation in late capitalism creates prismatic globalizing processes*

New economic developments in the era of late capitalism have produced the phenomenon of globalization. This phenomenon has been articulated in diverse ways and its meaning is disputed. However, there is general agreement that capital has become increasingly flexible and deterritorialized as financial markets have been deregulated and information technology has facilitated horizontal networks of production. The benefits of globalization have not been equally shared. A new international division of labor has intensified poverty and social exclusion in many countries and social classes. Globalization can therefore be characterized as a process which is prismatic.

- *Different articulations of the significance of globalizing trends represent different political orientations to the changes*

The significance of globalization remains strongly contested. How the significance of globalization is articulated is strongly tied to political orientations of current socio-

economic change. There are generally three articulations of globalization that can be discerned in contemporary literature: skeptics (who deny that there are radical changes in the contemporary socio-economic and political order), radicals (who view globalization as a unprecedented era in human history which will ultimately provide great benefits to the world) and perspectivalists (who consider the processes of globalization as being prismatic and therefore experienced differently in diverse locations and social classes).

- *Globalizing processes pose serious challenges to the development of democratic global institutions that can provide solutions to transnational problems*

The implementation of prismatic globalizing processes has generally been led by private transnational corporations and other international organizations, such as the WTO, which have no democratic representation. The power of finance capital in relation to many nation-states has raised increasing questions about responsibility for transnational environmental, social and health issues. As neoliberal ideology has had a stronger influence on political discourse, the democratic and inclusive aim of public health institutions has faced significant challenges to provide solutions to health problems.

- *The migration process brings many challenges to health which are often not recognized in modernist systems of health care*

Globalizing processes bring a greater degree of international mobility. Though migrants represent many different social classes and nationalities, there is a growing amount of clandestine migrants taking great risks to flee environmental disaster and political oppression as well as to obtain better socio-economic opportunities in life. Migration has thus become a complex geo-political phenomenon which is experienced differently depending on nationality, location, gender and social class, among other factors. As the borders surrounding rich regions and social inclusion in wealthy nations have become increasingly strict, many migrants are condemned to lives without social rights. Systems of social and health care developed during the modernist period of the universal social welfare often have few mechanisms to reach out to undocumented migrants and people with special social and cultural needs.

- *Growing multiculturalism and immigration challenges modernist conceptions of citizenship and rights*

The universal welfare state is premised on a cultural consensus within the nation-state regarding the values that support the good life for the individual and community. This cultural consensus is created through social memory which constructs the community as a nation. Constructions of cultural consensus and social memory are nonetheless infinitely malleable and subject to shifting socio-political constellations of power. Multiculturalism and increased immigration tend to challenge constructions of belonging in the nation and provide diverse narratives of social memory. Strong counternarratives of national social memory can result in exclusionary social policies and practices.

### **III. Unfinished Plots and Stories of AIDS in a Global/Local Context**

#### **9. Constructing unfinished plots in stories of AIDS**

Storytelling is one of the most fundamental elements of human culture. It is an implicitly social act because it involves communicating information from one person or people to another through textual, visual or oral media. Telling a story conveys information, makes sense of experience, and communicates feelings and understandings to others. Stories construct and reconstruct the world through representation, social memory and making meaning. Stories render fragmented incidents into an integrative, sequential narrative that convey the deeper significance of the events. Alternatively, stories can reflect the chaos of discrete events and leave meanings ambiguous. Hence stories can persuade or confuse. There may be multiple stories about the same events which can reflect complex, and sometimes even contradictory, meanings. Stories change and transform in the telling in accordance with shifting impressions, interpretations, and meanings. They have an impact on our actions and how we organize our societies. Indeed, experiences or events can be restoried in retrospect and in view of changed circumstances, understandings or meanings. Stories are therefore intimately entangled with power relations, particularly the power to tell the 'truth' and to act on this truth. By telling how we remember our past, we reflect much of our present as well as aspirations for the future. The construction of social memory is thus intimately connected to the construction of our identity (Dienstag 1997, 2).

As an important point of departure in this work is the notion that the world can be read as a social text. The social theory used here is strongly influenced by the postmodern turn, which means that social knowledge is considered to malleable and capable of being perceived, interpreted or 'known' in diverse ways. This section explores some of the stories and narratives told about AIDS that, in turn, were articulated into plots that defined conceptions of the pandemic as well as the policies and practices to cope with it. In this section, I concentrate on how these stories were shaped into narratives which

served to emplot articulations of AIDS identities in global and local social and health care policies.

There are many versions and types of stories about the AIDS pandemic, all of which are highly contextualized by the location, teller, position and perspective. AIDS as a disease has been uniquely associated with certain stigmatized identities. There are multiple points of entry into AIDS stories, thus providing many variations within the plots of AIDS. AIDS stories have been articulated in many ways, for different reasons and through various guises over the two decades of the pandemic. How these stories have been represented (or rendered invisible) in public discourse is important because the hegemonic position of particular stories and plots has had an influence on public opinion, policy decisions and the information presented as scientifically accurate. This, in turn, has a decisive impact on the quality of lives of people affected by HIV/AIDS through the formulation of definitions of socially acceptable and unacceptable attitudes, policies, services and access to treatments.

In many ways, plots of AIDS can be said to have shaped patterns of the pandemic through by global hegemonies and local cultures that have influenced access to services, patterns of social denial, health education, and health promotion information. This work seeks to challenge many of the official versions of the story of AIDS. It examines the role of power and scrutinizes whose stories were articulated in the narratives on AIDS and whose stories remained marginalized and silenced.

### **9.1 Narrative, discourse and unfinished plots**

Narrative studies has become a major area of research in recent years (see, e.g., Bal 2002; Dienstag 1997; Mattingly and Garro 2000; Törrönen 2000) as increasing attention has been paid to how truths are constructed by narrative stories. In this subchapter, I explore some of the basic notions surrounding the concepts of narrative, stories and discourse to clarify how I am using these conceptual tools in this chapter. I will therefore simply

define a few of the basic concepts that guide my analysis of the construction and articulation of plots in stories of AIDS.

For the purposes of this work, I make a distinction between narratives or stories and discourses. In this analysis, I consider narratives to be synonymous with stories, though I recognize that this is a highly contested territory (Mattingly and Garro 2000, 12-13). I view narratives as compelling stories that can include emotions and drama in addition to cognition. Narratives and stories progress through time. Discourses, on the other hand, consist of groups of statements that follow certain rules and practices. Discourses construct meanings and truths by drawing lines between acceptable and unacceptable ways of talking about or representing a certain matter. Discourses are synchronic, meaning that they describe a subject as it exists at a certain period in time.<sup>35</sup> In short, discourses can be characterized as a dissection rather than a temporal rendering of events.

I approach the subject by extracting three unfinished plots derived from various stories and narratives of the AIDS pandemic. I analyze these plots utilizing the perspectives of epidemiology, virology, history, sociology as well as the popular press and memoirs. My aim, in short, is to examine the inclusions and exclusions constructed by the articulations of these multifarious stories through the device of plot, rather than to perform a linguistic analysis of the data. In this way, I explore how the meanings of AIDS have been articulated through the years of the pandemic which, in turn, have influenced the action (or inaction) of governments, scientific institutions, practitioners and communities.

In the traditional Aristotelian conception, all stories or narratives exist in time and consist of a beginning, middle and end. If we accept the premise that the chaos of everyday life presents few opportunities for neat and tidy beginnings and endings, then narrative structures can be seen as a violence committed on the phenomenological turmoil of real life. As David Carr has noted:

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<sup>35</sup> Clearly, a good topic for a dissertation would be an examination of the various discourses on AIDS, and the concomitant power relations amongst them, which could then elucidate the various national and disciplinary representations of the disease and those affected by it.

Narrative structure, particularly the closure and configuration given to the sequence of events by a story's beginning, middle, and end, is a structure derived from the act of telling the story, not from the events themselves. (Carr 2001, 8)

Hence my aim in this section is not to 'tell' the story of AIDS with closure nor to explore ways of telling AIDS stories, but rather to chart bundles of articulations of multifarious open AIDS stories organized through the device of unfinished plots, plots that may have no 'ending.' Along with Dienstag, I consider the narratives and stories used in this section as articulations grounded in diverse ontological structures of the world, rather than simple reflections of human experiences (Dienstag 1997, 12).

The unfinished plots in this section thus reflect partially coherent worldviews as well as specific geo-political, cultural and socio-economic perspectives on the AIDS pandemic. It is important to remember that there are many stories of AIDS that have not been told. There are few widely recognized counternarratives to AIDS plots that challenge prevailing global socio-economic structures and dominant articulations of globalization. The influence of authoritative articulations of AIDS has had a significant impact on funding decisions which, in turn, directly affects the lives of many living with HIV/AIDS. As we will see later in Chapter 14.7, plots are also an important way of explaining HIV/AIDS in many health information brochures which has an influence on the public's awareness of the disease itself.

HIV/AIDS is a thickly storied disease. AIDS continues to exert a strong presence globally, though articulations of the disease and its social implications have transformed over the years. As Wittgenstein wrote metaphorically:

The strength of the thread does not reside in the fact that some one fiber runs through its whole length, but in the overlapping of many fibers. (Wittgenstein quoted in Dienstag 1997, 199)

In this section I therefore explore articulations of AIDS through unfinished plots that have been an intrinsic organizing element in many stories of AIDS. My focus is initially on international unfinished plots and their articulations, which reveal the prismatic global socio-economic power relations through the politics of location, deviance and belonging. I then turn to explore the local Finnish context with the aim of examining how international and national plots of AIDS have had an impact on the development of AIDS awareness, policy and practice through a chronological exploration of the events of the Finnish story of AIDS.

I use the term ‘unfinished plot’ to describe the central organizing principle for stories in this section. Unfinished plots are an ordering device used to imply a causal or sequential relationship between events, although this relationship is constructed and does not offer closure. Plots can be seen as the landscape through which the story moves (Kirmayer 2000, 171). Unfinished plots are not incomplete, but rather a different type of structuring which does not bring closure (Dienstag 1997, 20). Emplotment is “...the construction and interconnection of events in such a way that meaningful structures are developed.” (Hermans and Kempen 1993, 22) Clearly, emplotment is a problematic process which involves making choices about inclusion and exclusion as well as exploring gaps between ‘historical’ and ‘narrative’ truths (Hinchman and Hinchman 2001, 1). At the same time, when I construct unfinished plots of AIDS I also explore ‘counter-stories’ that challenge many of the fundamental premises of these plots. Indeed, the plots that I discuss are implicitly unfinished and open and thus subject to reconstruction. Hence the unfinished plots explored do not simply reflect past events but also project visions of the future and perceived needs for action (Dienstag 1997, 19).

These unfinished plots are based on collections of stories that employ a variety of pending narratives. Researcher Jukka Törränen has explored the notion of pending narratives through semiotics. Törränen has defined pending narratives as

... a semiotic macrostructure that is used to inspire passion toward a specific goal of action and which, therefore, is applied in polemical and

persuasive texts...The rhetorical force of the pending narrative comes from its sudden interruption: as soon as the motivation for an action has been created, and as soon as identities have been established for the actors involved in the action, the story is interrupted, brought to a halt. (Törrönen 2000, 81-82)

The stories and narratives explored in this section involve actors, anti-actors, heroes, villains, objectives and purposes enmeshed in a complicated matrix of meaning.

Articulations that have emplotted AIDS stories have had a very direct and diverse impact on the development of social and health policies and practices towards those affected by the AIDS pandemic. My interest subsequently centers on how these stories exert power as articulations through their emplotment rather than how these multifarious stories have been constructed narratively or discursively. After briefly outlining how terms are used, this chapter moves on to discuss the role of power in storytelling. I then explain how the unfinished plots discussed in Chapter 10 have been constructed. In the previous section, I introduced three articulations on globalization, as well as conceptual maps of international migration, public health and the universal welfare state, to anchor discussions of AIDS as a cultural phenomenon to the network of social and health services and policy traditions. A multiplicity of community interventions and power struggles have emerged from these frameworks that have resulted in the development of methods of practical assistance for people affected by the disease. I suggest that it is essential to keep these perspectives in mind to understand how diverse articulations shape societal actions and responses to the events and socio-cultural understandings of various AIDS epidemics.

## **9.2 Power and stories: postmodern illness**

HIV/AIDS is one of the most analyzed diseases in history. From considerations of its cultural meanings and political implications to its clinical and scientific aspects, AIDS is a phenomenon that has produced a mountain of written material. Coming at the time it did, the emergence of the AIDS pandemic coincided with conceptual shifts in social science

research. In terms of the ‘historical moments’ outlined by Denzin and Lincoln (2000), social science in the early 1980s decisively broke away from modernist traditions which emphasized empirical natural science methods of proving the validity and objectivity of evidence-based findings or totalizing truths. According to Denzin and Lincoln, social science went through a period of ‘blurred genres’ between 1970-1986 which obscured the boundaries between different disciplines and provoked a crisis of representation and legitimation (Searle 2002, 100-101). The use of totalizing language was criticized as assimilating or appropriating the diversity of the world to one limited worldview or truth (Cheney 2001, 331). With the emergence of the linguistic turn in the 1980s, the complex role of language in constructing reality became an area of great interest in terms of discourse analysis, social constructionism and other methods of analysis. What Holstein and Gubrium (2000, 231) term ‘the moral significance of the local’ is now a focal point of much research. As Holstein and Gubrium argue:

...the moral significance of the local derives from ‘where people are,’ as Dorothy Smith reminds us. This is not meant to resurrect a positivistic naturalism, nor to romanticize a deeply hidden, genuine self. Instead, it points us in the direction of the *working* horizons of identity. As such, the moral significance of the local rests on the methods people themselves apply to construe who and what they are. It entails a concerted alertness to the many and diverse ways that self can be assembled and articulated in the midst of its always compelling operating locales. (Holstein and Gubrium 2000, 232) [authors’ emphasis]

The increased emphasis on the importance of how the local constructs the self and community indicates a growing recognition of the diversity and fluidity of identities throughout the world. There are complex relations between the ‘big and little stories’ of who and what we are (Holstein and Gubrium 2000, 232). This scientific reorientation drew increased focus on the individual experience of illness.

The concept of postmodern illness reflects the notion that disease can also be ‘read’. It sees an intimate relationship between knowledge, power, voice and the body (see Foucault 1977; 1984; 1979). This reflects a very different viewpoint on illness than the

modernist perspective, which raised the medicalization of disease to the center. As Arthur Frank has defined:

The *postmodern* experience of illness begins when ill people recognize that more is involved in their experiences than the medical story can tell.[...]What is distinct in postmodern times is people feeling a need for a voice they can recognize as their own. This sense of a need for a personal voice depends on the availability of the means—the rhetorical tools and cultural legitimacy – for expressing this voice. *Postmodern times are when the capacity for telling one's own story is reclaimed.* (Frank 1995, 6-7)  
[author's emphasis]

In this conceptual framework, the person with the illness becomes the embodied subject rather than the object of medical interventions. In other words, postmodern illness considers sickness from a thickly narrated and individual perspective which consists of myriad stories and resonant with meanings, rather than an 'objective' and scientific metanarrative which excises the patient's voice from the event of illness.

Yet, all stories are not assigned the same amount of truth value. The power of truths to make themselves true through ways of representation and ways of structuring meaning lies in the hegemonic position of their author function<sup>36</sup> in the constellation of societal power relations (Hall 1997, 48-49).<sup>37</sup> In other words, it may be so that the postmodern turn in social science has enhanced appreciation of the fact that there are many truths that coexist at the same time, but some truths do nonetheless have more power than others.

Interpreting Foucault (1979) and Sawicki (1991) in a discussion of empowerment and social analysis, Beth Humphries offers a model of empowerment informed research based on three basic elements.

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<sup>36</sup> Here 'author' is not only understood as a persona but also as a function. It thus refers to a particular set of writings that exists within a discourse. The strategic location of authors' works demonstrates hegemonic relations within and amongst competing discourses.

<sup>37</sup> For example: "'Truth' is to be understood as a system of ordered procedures for the production, regulation, distribution, circulation, and operation of statements. 'Truth' is linked in a circular relation with systems of power which produce and sustain it, and to effects of power which it induces and which extends it. A 'regime' of truth." (Foucault 1984, 74)

- Power is exercised in situations rather than possessed.
- Power is not primarily repressive, but productive.
- Power is analyzed as coming from the bottom up. (Humphries and Truman 1994, 186)

This triad rejects totalizing assumptions about power as a possession, recognizes the multiple dimensions of power and acknowledges the possibility that dominated groups can exert power through resistance and everyday struggle – indeed, by telling their stories. Stories resist erasure. Witnessing demands recognition. Telling a story in a different way than the dominant hegemonic discourse can be a significant act of resistance to invisibility or, more importantly, denial. Sociologist Stanley Cohen points out in his exploration of denial, atrocities and suffering in the 20th century that we cannot go to the point where all truths are relative and all stories have equal moral weight. Instead of emphasizing the role of truth, Cohen focuses on the terrible price wrought by denial:

Personal denial can be tolerated, because dignity and privacy are also important. Compromises are possible; no one else may be harmed; knowing (and telling) the truth does not set you free. It is your human right not to have to face the truth about yourself; you can create your favorite fiction and live in blissful self-deception and bad faith. At the political level, though, we simply cannot tolerate states of denial. There is no room for compromise. Even if truth telling is not a value in itself, denial *must* always affect others. (Cohen 2001, 295) [author's emphasis]

Resistance to denial and silence has been a very conscious strategy of many AIDS awareness campaigns, not only as a way of helping individuals cope with illness but as a way to resist marginalization and influence policymaking. If storytelling constitutes an act of imparting the meaning of an experience, an implicitly social act, then on a societal level the emergence of counter-stories can force a reassessment of accepted truths or ways of acting. Resistance to totalizing discourses thus means the recognition of the innate complexity of the relationship between truth, power and the construction of

identities. Perhaps even more significantly, resistance to such discourses reflects the power of individual agency to name one's own reality. Addressing these alternative stories as a researcher can provide a means of challenging dominant assumptions and constructions of power as well as bringing out the contested nature of social issues. My purpose in focusing specifically on plots in stories of the AIDS pandemic is to explore the complex terrain of meaning making and policymaking and the role of power in these negotiations.

### **9.3 The stories that construct the unfinished plots**

Chapter 10 examines three unfinished plots of the AIDS pandemic organized as they emerged chronologically through a textual analysis of the multiple stories of the disease and illness, and their concomitant social ramifications. This chapter emphasizes the metamorphosing views of the disease over the past two decades by exploring how the following three significant unfinished plots emerged in stories, were debated in the international arena, embodied pending narratives that called for action, and thus had a decisive impact on the development of care and treatment of people living with HIV/AIDS. These three plots were selected due to their focus on the construction and articulation of 'AIDS identities,' a main focus of this work.

The examination of these unfinished plots therefore focuses on the local level of how these stories have been 'lived out' and what subject positions have been created through the unfolding of these unfinished plots. By exploring key local stories which embody global hegemony through the construction of unfinished plots, I examine how the AIDS pandemic has been constructed and personified. The three unfinished plots analyzed in this section are:

- The plot of gay plague and the lifestyle hypothesis
- The plot of African AIDS
- The plot of AIDS exceptionalism

Due to the extraordinarily complex character of the AIDS pandemic, there certainly are many more plots than these three. However, my aim is to use these three as a heuristic device to explore how AIDS stories have had an impact on policy, particularly in the Finnish context, rather than to provide a definitive account of the variety of emplotment in global stories of AIDS.

The texts<sup>38</sup> selected to construct these plots include all of the major historical works written on the AIDS epidemic (Garrett, 1994; Grmek, 1990; Shilts, 1987), as well as an oral history of key figures in the US epidemic (Bayer and Oppenheimer, 2000), personal histories of physicians specializing in HIV/AIDS (Baxter, 1997; Gallo, 1991; Selwyn, 1998; Verghese 1994), cultural, political and social science analyses of the epidemic (Barbour and Huby, 1998; Browning, 1998; Cohen, 1999; Crimp, 1989; Fitzsimmons, Hardy and Tolley 1995; Moatti et al., 2000; Nelkin et al., 1991; Patton, 1996; Singer, 1993; Sontag, 1988; Treichler 1999; Watney, 1994), social medicine and public health histories and analyses (Barnett and Whiteside, 2002a; Farmer, 1992, 1999; Fee and Fox 1988; Fee and Fox 1992; Garrett, 2000; Gong and Rudnick, 1987; Haour-Knipe and Rector, 1996; Leinikki and Löytönen, 1993; Mann et al., 1999; Martin, 1994; Rosen, 1993; Rosenberg 1992). I have also assembled a sample of news stories, which are mostly retrospective views of the impact of AIDS on society through the years of the pandemic, (Altman, 2001; Attaran et al., 2001; Herbert, 2001; Le Monde, 2000; Villarosa 2000), medical articles (Centers for Disease Control, 1981; Durack, 1981; Fetter et al., 1997; Geddes, 1988; Von Krough et al., 1987), and policy statements and analyses of the situation in various countries and among particular groups (Central Intelligence Agency, 2000; Clarke and Bröring 1999; Clarke 1999b, 2000; del Amo et al., 2001; Hendricks, 1991; Pollak, 1994). The personal stories testimonies, and speeches written by people affected by HIV/AIDS are also used (Cameron, 2000; Doty, 1997; Johnson 1996; Kramer, 1989; Monette, 1988).

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<sup>38</sup> It must be noted that the texts are largely limited to those available in the English language.

Certainly this analysis betrays a western bias, specifically a North American point of departure, due to both my background and the enormous amount of documentation that has been produced in the US on the AIDS epidemic. However, I have thus constructed the unfinished plots used in this study on the basis of an extensive review of the written material available on AIDS in both English and Finnish. Hence the availability and volume of material about AIDS, which is largely produced in western countries, perhaps most clearly demonstrates the domination of the discourse on AIDS by people and organizations in countries which have access to the means of disseminating information. Throughout the analysis, I attempt to point out the invisibilities and gaps in the conceptualization and discussion of the effects of AIDS on diverse, and often socially excluded, populations. While much of the analysis focuses on early events in the United States, this is due to the preeminent role of the CDC (Centers for Disease Control) in international epidemiology as a defining force for disease, the fact that the first explosive outbreak of HIV-1 is thought to have originated there. The strong influence of American AIDS activism in Western Europe is another reason to focus on the early development of this unique health and human rights campaign. Moreover, it is in the United States that most narratives of the development of the AIDS pandemic begin thus providing a logical starting point for analysis (Altman 1988; Brandt 1987, 183-185; Grmek 1990).

This section approaches the development of the 'AIDS crisis' as a series of unfolding and complex stories that have been shaped by hegemonic discourses fostered by the mass media, medical and political establishments in the developed world as well as a countervailing resistance to dominant discourses on AIDS by activists and others excluded and marginalized from globalized society. The many struggles to socially reconstruct and give meaning to AIDS, often in resistance to hegemonic representations and discourses, reflect the deep fissures that exist in global society regardless of national borders and, indeed, within nations themselves. As Barry Smart has noted, hegemony can be defined as the power embodied in the ability to manipulate and control the relations of both consent and force that are incarnated in the social (Smart 1986, 159). As he continues: "The concept of 'the social' refers not to that global abstraction 'society' but to a series of methods, techniques, and practices which have effected a particular form of

social cohesion.” (Smart 1986, 159) Hence the disparities in the levels of care and visibility of those affected by HIV/AIDS, and by implication the difference in the valuation of lives, can be linked not only to prismatic hegemonic globalizing processes but the dominant discourses which often implicitly justify unequal treatment.

It has often been said that narratives of the development of AIDS as a pandemic have been written many times. This study does not aim to create a totalizing concept of the history of AIDS. Rather, the research interest focuses instead on how stories of and by those affected by the disease have appeared, been portrayed or been rendered invisible and how these stories have had an impact on policymaking and the development of practice through the device of emplotment. Are Africans or drug users affected by HIV/AIDS, for example, more likely to be represented as less significant or human (or simply absent) in the story of AIDS than a western senior citizen infected by a blood transfusion? This is not to diminish the suffering of any individual who is seropositive, but it has important implications with regard to how we perceive the value of life in our societies, the basic human right to receive proper care and treatment, as well as the type of HIV/AIDS prevention and care policies that we promote. Through an analysis of three plots that can construct a framework to consider stories of the AIDS pandemic, the borders between the included and excluded, ‘innocent’ and ‘guilty’ victims, those deemed worthy and unworthy of treatment, and visible and invisible sufferers can be seen. Moreover, this analysis provides the background to the examination of the basic question that this work seeks to investigate: How are migrants living with HIV/AIDS constructed in the Finnish social and health care system? The answer to this question, however, can only be understood through the back story of *Finnishness* and its relation to the narrative elements of AIDS stories. Despite its specifically local context, the Finnish social and health care system, as well as the Ministry of the Interior -- which is specifically entrusted to define and enforce immigration law -- has developed in interaction with the global socio-economic order. Hence the question of how the story of the global AIDS pandemic has been framed and emplotted is of great significance when considering how this new scourge was understood and handled from a Finnish perspective.

#### 9.4 On the use of terms

At this point, it is important to clarify how terms are used in this section of the work. The distinction that I have made between the terms HIV/AIDS and AIDS is borrowed from Treichler (1999), namely that I use *AIDS* to refer to the international pandemic as a social and cultural phenomenon of crisis, while I use *HIV/AIDS* to refer to public health and clinical conceptualizations of HIV-related conditions. The HIV/AIDS *epidemic* refers to the emergence of HIV/AIDS among a large number of people in a certain locality, while HIV/AIDS *pandemic* refers to the broadly transnational nature of the epidemic (Black's Medical Dictionary 1999, 181 and 409). Finally, using Kleinman's definition, I make a distinction between *illness*, meaning the social and subjective experience of sickness, and *disease*, as a medically identifiable disorder of the biological system (Kleinman 1988, 1-5).

## **10. Unfinished Plots in Stories of AIDS**

### **10.1 Risky identities and lifestyles**

AIDS was initially associated with North American male homosexuals by international health organizations as well as the global mass media in the early 1980s (Treichler 1988). The first plot of AIDS, the gay plague or the gay lifestyle, constructs AIDS as a mysterious, grotesque and deadly disease with an intrinsic connection to the essentialist category of western male homosexuality. The unfinished plot of gay plague and the gay lifestyle is not as resonant today as it was a decade ago because of the emergence of counternarratives of gay pride, as opposed to gay shame, and the rise of AIDS awareness as a human rights issue. Advances in medical and social knowledge of HIV/AIDS have also reduced the palpable ignorance and fear of the early days of the pandemic and increased understanding of the illness. Nonetheless, the sense of dread that this plot evoked continues to be associated with AIDS in a way unlike other terminal illnesses.

Stories within this plot tend to emphasize terror, panic and a sense of doom, with the frequent use of 'plague' metaphors. The 'infected' in this plot tend to be constructed as an essential category, with AIDS directly connected with homosexuality or the individual choice to live such a lifestyle, and they are stigmatized by society. Medical experts in this plot are baffled by the emergence of the new disease. The plot of gay plague is thus composed of pending narratives constructed within a certain context that sought to stir the public into action against stigmatizing attitudes. Other communities and nations affected by AIDS, but which did not have access to medical care and were therefore excluded from epidemiological statistics for the most part, remain largely invisible in the plot of gay plague or the gay lifestyle which constructed AIDS as a unique disease that solely affected North American gays. The silenced counternarratives of ethnic minorities, women and drug users in many ways reinforced their socio-economic marginalization

and lack of access to social and health care by rendering them invisible in early discussions of the impact of the disease (Cohen 1999, 149-185).

### 10.11 The initial discovery

The plot of gay plague emerged in the early 1980s when HIV/AIDS first was recognized by American medical authorities. The first indications that something atypical was occurring in the health of Americans came at the beginning of the 1980s. In June of 1981, a report was published in the CDC's *Morbidity and Mortality Weekly Report* (MMWR) concerning the highly unusual fact that five gay men living in the Los Angeles area had been diagnosed with pneumocystis carinii (PCP), a rare condition caused by parasitic protozoa that engenders opportunistic infections in the lungs (MMWR 1981b). Moreover, orders for pentamidine, a drug used in the treatment of PCP which was distributed to physicians solely by the CDC, had doubled during the first half of 1981 (Brandt 1987, 183; Garrett 1994, 285).

In August of 1981, *The Lancet* published a study of eight particularly severe cases of Kaposi's sarcoma diagnosed in men living in New York City in the spring of 1981 (Marmor et al. 1982). Kaposi's sarcoma, an extremely rare autoimmune disease largely found among older men of Southern European or Middle Eastern origin, causes malignant skin tumors and is usually a benign, chronic condition. The striking aspect of these newly diagnosed cases was that the patients did not fit the general profile of people suffering from Kaposi's sarcoma: None of the eight patients fulfilled the 'ethnic' criteria, they were young, suffered from particularly acute cases of the disease, and all were homosexual (Grmek 1990, 6-7). Finally, a report in the July 4<sup>th</sup> issue of the MMWR linked Kaposi's sarcoma, PCP, and male homosexuals in New York City and California (Garrett 1994, 286; MMWR 1981a). By the end of August of 1981, 107 reports had been made to the CDC of cases of Kaposi's sarcoma, PCP, or a combination of the two in 95 homosexual men, six heterosexual men, five men of unknown sexual orientation, and one woman (Garrett 1994, 288). The appearance of a remarkable increase in cases of thrush, toxoplasmosis, PCP, and Kaposi's sarcoma indicated a serious disorder that was causing

the collapse of the immune system, and according to reports, it seemed to be presented largely in young, white, American homosexual men.

By the end of the year, *The New England Journal of Medicine* published an editorial along with three articles on this new unknown syndrome (e.g., Gottlieb et al. 1981). The thrust of the theory surrounding this emerging disease was that it was perhaps caused by a combination of drug use, genetic predisposition, and infection by sexually transmitted diseases (such as CMV) among gays. In short, the ‘homosexual lifestyle’, as many scientific researchers put it, was the root cause of the epidemic (Treichler 1999, 6). Hence the predominant thinking on AIDS among medical scientists at the beginning of the epidemic, which was quickly seized upon by the media, was that it was primarily a homosexual disease. Early descriptions of the emerging disease of AIDS were thick with reference to male homosexuality as a causative agent. Homosexuality was discussed as a completely consolidated biological category of sexuality thought to be equivalent to certain social behaviors (such as having multiple sexual partners and using drugs which implied the value judgments of promiscuity and degenerate behavior), rather than a complex social sexual identity with multiple manifestations and a diversity of behaviors. The key point here is that homosexuality was positioned as an essentialist attribute. Later, we see how homosexuality became articulated as a lifestyle. In social constructions of AIDS (i.e. AIDS as a gay disease and AIDS as a gay lifestyle), the social dimensions of the disease were central to directing the material basis of the emerging science (Treichler 1999, 25).

From the beginning of the epidemic, epidemiologists also used sociogeneic methods to attempt to discover the root cause of the disease. Many speculated that AIDS transmission was due to a ‘lifestyle hypothesis’ as the first cases reported to the CDC involved young, gay men (CDC 1981). The early days of the epidemic were a difficult time to assess the totality of the situation as early figures regarding infection rates and populations affected by the new disease were probably skewed due to factors concerning access to health care and the lack of diagnostic criteria. In examining the cases of gay men who had contracted AIDS, researchers noted that they tended to have

multiple sexual partners, use ‘poppers’ (amyl nitrate), and have contracted cytomegalovirus (CMV), one of the herpes viruses that is often transmitted sexually, but they had few other leads.

The ‘lifestyle hypothesis’ posited that there was some aspect in the ‘homosexual lifestyle’ that predisposed gay men to infection with the new disease. This plot therefore represented a slight shift from the plot of gay plague. In the plot of the lifestyle hypothesis, the focus was on behavior rather than identity as an attribute. As Oppenheimer has argued, one reason that the CDC quickly leapt to the conclusion that a ‘homosexual lifestyle’ must be a causative factor in the emergence of the new disease on the basis of only five reported cases was the fact that the CDC had recently completed a large-scale study of homosexual men and hepatitis B (Buchbinder et al., 1994; Oppenheimer 1988, 271). This study was conducted in the midst of numerous studies that found a general rise in reports of sexually transmitted diseases among gay men. The subjects of the CDC hepatitis study, however, tended to be young, urban, sexually active gay men who were attending sexually transmitted disease clinics. Hence, as Oppenheimer notes, “...(the subjects) were not necessarily representative of homosexual men.” (Oppenheimer 1988, 271) Finnish sociologists Grönfors and Stålström further explain:

All available research shows clearly that homosexual persons do *not* constitute a uniform cultural or social minority with a common culture or lifestyle, not even within one country. Sexual preference itself – whether heterosexual or homosexual – does not entail common group characteristics. Individuals choose their frame of reference on an entirely different basis, whether it be political belief, religious conviction, social background, or whatever. However, homosexuality, which is often feared, hated and felt to be wickedly attractive, induces stereotypes which disguise reality. These stereotypes are of paramount importance for the legitimation of social control. (Grönfors and Stålström 1987, 54) [authors’ emphasis]

The early social categories thus presented by epidemiologists were thick with a specific view of homosexuality which elevated the construction of a particular ‘lifestyle’ as synonymous with the category of a biologically causal agent. Among the adjectives used

to describe the 'homosexual lifestyle' were promiscuous and drug using, which implied negative value judgments as such behaviors were thought to be confined to and generalized among homosexual men.<sup>39</sup> These representations of gays thus tended, as Stålström and Grönfors note, to legitimize heteronormative social control and stigmatizing attitudes. Early conceptualizations of risk, transmission and the AIDS pandemic underlined that 'deviance' from the sexual social order would almost automatically lead to disease and death. It is interesting to note, by way of contrast, that IV-drug users remained largely invisible in these social constructions of risk, though their behaviors were certainly as risky as unprotected sex. Their absence in this discourse perhaps reflects the medical marginalization of these groups in epidemiological studies as well as in accessing care and treatment facilities (Cohen 1999, 129).

#### 10.12 The sexual revolution and medical categories of sexuality

One of the important aims of the gay liberation movement since the 1950s in the United States, but also in many other western countries (see, e.g., Stålström 1997), had been to demedicalize homosexuality, which had long been considered to be a deviant psychological or physical condition in the medical field (Loughery 1998, 422). Hence early efforts by medical professionals to label AIDS as a 'gay cancer' which required sexual continence was often met with outrage by gay men, particularly in large urban centers, who had just struggled their way out of the closet into public space and were gaining a sense of gay pride, and were now being told that their 'promiscuous lifestyle' was causing them to be infected with AIDS. The social memory of sexual repression remained strong in many gay communities, leading many to believe that 'gay cancer' was just another tactic to stigmatize them (e.g. Shilts 1987).

During the fall of 1981, information about the new 'gay cancer' began to hit the American newspapers. This association between homosexuality itself, as a supposedly

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<sup>39</sup> "Gay liberation and AIDS had called forth large-scale representations of a gay community, but the pictures and spokesmen tended to be achingly uniform." (Loughery 1998, 442)

causative factor, and AIDS remained a dominant discourse for years. Indeed, the initial naming by epidemiologists of AIDS as GRID (Gay Related Immune Disorder) had a strong effect on maintaining this image in the general public due to the tremendous respect and power of definition wielded by the profession. Despite the fact that MMWR ran five articles in an eighteen month period (9 July 1982-7 January 1983) on the epidemic which clearly indicated that it was a sexually transmitted, blood-borne disease that also affected women, heterosexuals, hemophiliacs and others, the thickness of description in contemporaneous media accounts tended to equate the growing pandemic with male homosexuality thus minimalizing the susceptibility of women, the poor, socially excluded and other medically marginalized groups to the emerging disease (Bayer and Oppenheimer 2000, 20-21).

The sexual revolution of the 1960s had a great impact on the normalized framework of the nuclear family in many western countries (see, e.g., Weeks 1989, 249-272). Due to a multitude of factors far too complex to go into here, fundamental changes occurred in family structures and sexual behavior in many western countries. Through the pressure of feminist and gay movements along with other liberation movements of the 1960s, the dominant societal discourse in most western countries, which relegated women's sexuality to the province of the institution of marriage and stigmatized other forms of sexuality, was challenged by newly empowered women and sexual minorities who had often faced punishment, shame, stigmatization and exclusion for expressing their social and sexual identities. Changes in sexual behavior due to greater independence and the decreasing social power of restrictive moral codes resulted in a general increase in the number of sexual partners individuals had as well as a rise in experimental drug use. The escalation in the number of sexual partners, combined with the higher prevalence of injecting drug use, in addition to the development of blood products and transfusion technology, created fertile ground for the emergence of a sexually transmitted and blood-borne virus.

Despite the sexual revolution of the 1960s, western medical models of sexuality tended to set clear behavioral dichotomies between genders (female and male) and sexual

orientations (gay, straight, bisexual). The rigidity of these definitions in epidemiological population categories often rendered the diverse reality of sexual behaviors invisible. As Paula Treichler wrote:

An enormous body of research at this point makes clear that sex and sexuality are complicated, with no fixed or fully predictable correspondence between sexual desire, past practice, current practice, self-perceived identity, and official definition. How much more complex this becomes when cultural and linguistic differences are also present, and how futile to make facile generalizations about whole populations (Treichler 1999, 256)

The emergence of the AIDS crisis can be seen as forcing a rupture in narratives of the western sexual revolution at least in part because in the early years the epidemic was defined in terms of deviant, disease-causing sexuality. Narratives of free love and the diverse expressions of sexuality that were prevalent in western societies the 1960s and 1970s no longer seemed innocent or acceptable in the face of a deadly unknown disease, indeed 'deviant' sexuality was increasingly constructed as dangerous (Bhattacharyya et al. 2002, 97). Yet, the categories of sexuality remained fixed in most medical literature which limited the multifactorial information available to researchers (see, e.g., Ramos 1997). Moreover, these fixed categories presented barriers to creating accurate and appropriate health promotion and prevention information as well as outreach efforts amongst people with diverse sexualities.

Although AIDS was initially considered to be a marginal phenomenon confined to middle class white gay men, epidemiological narratives that constructed homosexuals as a consolidated social group, with similar habits and behaviors, this later led to a problematic situation when it became apparent that AIDS was not confined to a single type of gay man. Further research showed that there was a diversity of sexual expression within the constructed category of gay men, including married men who had sex with men, as well as heterosexual injecting drug users. A further consequence of this narrow epidemiological focus on white gay men was that it excluded many other groups, mostly notably women, from emerging medical narratives of AIDS. Indeed, AIDS was initially

branded as an identity rather than a behavior (Goldstein and Manlowe 1997, 8). The silenced narratives of racial, ethnic and sexual difference and diversity thus had a very negative impact on the spread of the virus. This narrow construction of a ‘risk group’ was to prove costly later.

### 10.13 Early epidemiological constructs

Epidemiology is a unique biological science because it has a very strong social dimension. The task of epidemiology is to analyze the emergence of epidemics through the social matrix presented by the population (Oppenheimer 1988, 267-68). Hence epidemiologists generally use a ‘multifactorial model’ in which all possible circumstances, causative factors, and connections in the social matrix of the affected community are outlined to produce an explanation for the origins of epidemics. Moreover, the multifactorial model holds that there may be a ‘web of causes’ and opportunities to intervene at various points during the course of an epidemic, recognizing the fact that all diseases go through multiple stages as they develop.

Here we can see that Oppenheimer makes the link, discussed in the theories of Michel Foucault, (Foucault 1973, 1977, and 1979), between the power of the scientific establishment to define the social discourse on illness and the subsequent scientific findings regarding the disease through the use of metaphor and ways of conceiving and categorizing. In other words, researchers tended to see what they were looking for. As Paul Farmer has pointed out, the delimitation of analytical categories used by researchers to examine HIV/AIDS, for example, has influenced the societal view of the disease, its sufferers, vectors of transmission, and even treatment protocol.<sup>40</sup> Here it is worth recalling Susan Sontag’s insight that the metaphors used of illness often function to characterize and stigmatize individuals suffering from disease.

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<sup>40</sup> “On a trip back to the United States, I turned to the massive and expanding literature on AIDS. A search of a computerized AIDS database revealed that more than one hundred thousand references were instantaneously available. But when I restricted the search by adding the term ‘women’ to ‘AIDS,’ I found only two thousand references. Seeking to further restrict my search by adding the word ‘poverty’ as a third qualifier, I was informed that there were ‘no references meeting these specifications.’” (Farmer 1999, 60)

The epidemiologists and physicians monitoring the early development of AIDS in the United States remained, for the most part, outside observers of the culture of gay communities. Dr. Mirko Grmek summarized the attitude at the CDC in 1981: "If there was a danger, it seemed confined to a marginal group." (Grmek 1990, 9) Nonetheless, it is important to note that although the CDC had extensive experience in working with the mainstream gay community, particularly in the area of sexually transmitted diseases; this did not necessarily mean that there was cultural sensitivity to the plight of the gay community in the midst of a devastating epidemic. The tendency to use impermeable categories to define human sexuality and place informants in rigid classifications reduced deeper scientific understandings of the flexibility of sexual categories.

Hence the lack of sensitivity towards the humanity of gays combined with the dearth of inside knowledge on the complexities of gay culture served to help construct a climate of suspicion and fear amongst many gays towards public health officials. The fact that until 1973 homosexuality was considered to be a medicalized deviant condition also underlined the cynicism that many gays felt towards the medical profession. Indeed, in the early days of the AIDS crisis many gays rejected the reality of AIDS, claiming that the infection scare was a homophobic conspiracy to silence them and once again render them invisible (see Shilts 1987).

#### 10.14 The construct of the gay lifestyle as deviance

Epidemiologists sought to refine initial constructs of homosexual identity as a risk factor per se in the mid-1980s. The lifestyle hypothesis thus arose as an attempt to distill the susceptibility to HIV into a manageable epidemiological concept. The lifestyle hypothesis constructed an image of a male homosexual which was thick in negative behavioral terms and presented homosexuality as a completely consolidated identity category that inherently embodied the behaviors of promiscuous sex and the copious use of drugs (Oppenheimer 1988, 279). Rather than focusing on solely on behaviors regardless of social identity, the lifestyle hypothesis mixed essentialist and constructionist elements, to create the image that gays were the only people susceptible to

AIDS because implicitly they were the only ones engaged in such behaviors. Due to their highly marginalized status, intravenous drug users, as noted earlier, were largely excluded from studies of the new illness in the early 1980s. Moreover, the notion of the lifestyle hypothesis contained a strong element of stigmatization and blaming the victim as it was based on the idea that people with AIDS were responsible for their own condition through bad behavior defined as promiscuity or drug using (Oppenheimer 1988, 279). The early reliance on the model of the lifestyle hypothesis as an analytical tool to understand the emerging illness may have also delayed scientific research by overemphasizing the role of ‘promiscuity’ and ignoring factors that linked intravenous drug users, gays, and heterosexual men and women (Berer and Ray 1993, 38).<sup>41</sup>

The semantic and conceptual shift from the lifestyle hypothesis to the notion of ‘risk groups’ came in 1983 when the March edition of the MMWR referred to high risk groups for the first time. As Oppenheimer defines: “High risk groups were those whose members were at greater risk of infection *and* of infecting others.” (Oppenheimer 1988, 282; author’s italics) This meant that as knowledge of the transmission increased and could no longer be linked exclusively with a ‘homosexual lifestyle,’ a new replacement concept had to be developed. The notion of high risk groups thus implied people who lived dangerously and were different and threatening to the general public. On a scientific level, however, the shift to the concept of high risk groups meant that the emerging illness was beginning to be understood as a transmissible agent and not merely a byproduct of a deviant lifestyle.

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<sup>41</sup> “Would investigations of heterosexual patients, paralleling those done of gays, have offered a different cast to the lifestyle model? We will never know for certain. The model probably would have placed less emphasis on multiple sexual partners, on ‘promiscuity.’ Perhaps chemical toxicity or the immunosuppressive power of heroin, nitrites, and other drugs might have had more significance, at least at the start. But inasmuch as women – some of whom were *not* intravenous drug users – were among the earliest patients, investigators might possibly have hypothesized much earlier on that a microbe was *the* direct cause, explaining the appearance of the new disorder in all affected groups.” (Oppenheimer 1988, 279) (author’s emphasis)

### 10.15 The 4-H club

The predominant scenario produced by the emergence of AIDS as an epidemic was one of moral panic. High risk groups were initially defined as the so-called 4-H club (homosexuals, Haitians, hemophiliacs and heroin users), groups that were generally marginalized and stigmatized in society.<sup>42</sup> This definition of groups was again a curious mix of social constructionism and essentialism. Homosexuals as a group, as noted above, can be characterized by a sexual preference or orientation towards the same sex, but do not necessarily demonstrate the same sexual or social behavior. The designation of Haitians as a risk group, moreover, categorized all people holding Haitian passports as potentially infectious. This was the first time that the CDC had designated a nationality as a risk group. As Paul Farmer explained:

Indeed, U.S. public health officials were faced with the task of tidying up the nongroupable cases. In order to accurately assess risk among Haitian immigrants, a sound knowledge of the size of the population was necessary. However, no such data were available. Instead of acknowledging its inability to make an assessment of risk, the official – and spuriously low – figure of 200,000 recent Haitian entrants was initially used as the denominator. The resulting conceptual round-up officially brought together *all* Haitians together in a ‘risk group.’ The CDC had inferred that Haitians *per se* were in some way at risk for AIDS. (Farmer 1992, 211) [author’s emphasis]

One difficulty implicit in the designation of the 4-H risk groups was the fact that no degrees of risk were outlined. Moreover, each risk group was seen to be a completely consolidated category with no diversity recognized within the group, signifying that membership in the group defined by the CDC was considered to be sufficient grounds for risk of infection, despite behavioral variations. As Paula Treichler commented:

This list (the 4-H group) structured the collection of evidence for the next several years and contributed to the view that the major risk factor in

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<sup>42</sup> “‘This disease,’ said a woman interviewed at the time, ‘affects homosexual men, drug users, Haitians, and hemophiliacs – thank goodness it hasn’t spread to human beings yet.’” (Grmek 1990, 40)

acquiring AIDS was being a particular kind of person rather than doing particular things. (Treichler 1988, 198)

Though it is indeed the task of epidemiology to collate groups as a basic element of understanding and examining epidemics and vectors of transmission, there are enormous difficulties in translating social groups into biological categories particularly when the groups in question are underrepresented or invisible in the defining process.

The use of the concept of risk groups, combined with growing fears of casual transmission, resulted in the stigmatization of people belonging to the 4-H group as ‘carriers’:

A further consequence of creating ‘high risk groups’ was to reinforce the relationship between the disease and the ‘marginal’ members of the population...In the case of HIV, although each of the groups ostensibly threatened the remainder of the community through the medium of blood or sex, public health recommendations were intended to inhibit such contamination. Consequently, the disorder could be contained at the boundaries, among people who were ‘different’ from the majority but undifferentiated within each of the ‘high risk groups.’ (Oppenheimer 1988, 283)

Randy Shilts’ identification of a gay Canadian airline steward as ‘patient zero’, the contemporary version of Typhoid Mary, demonstrated the need to put a face on a scapegoat. In his controversial book on the AIDS epidemic, Shilts portrayed the steward as a man concerned with being ‘the prettiest one,’ (Shilts 1987, 21) who needed to ‘satisfy his voracious sexual appetite’ (Shilts 1987, 22) and ‘seemed quite pleased with himself as he rattled off his sexual exploits.’ (Shilts 1987, 136) Furthermore, Shilts constructed the figure of the steward as an amoral, dangerous carrier threatening to society at large.

Note the two following passages:

“It’s probably some virus,” said Conant [the doctor]. “If you do have sex, make sure to avoid anything where you come inside somebody or

exchange body fluids.” [The steward] looked wounded, but his voice betrayed a fierce edge of bitterness. “Of course, I’m going to have sex,” he told Conant. “Nobody’s proven to me that you can spread cancer.” [The steward] cut Conant’s rebuttal short. “Somebody gave this thing to me,” he said. ‘I’m not going to give up sex.’” (Shilts 1987, 138).

And:

It was around this time that rumors began on Castro Street about a strange guy at the Eighth and Howard bathhouse, a blonde with a French accent. He would have sex with you, turn up the lights in the cubicle, and point out his Kaposi’s sarcoma lesions. “I’ve got gay cancer,” he’d say. ‘I’m going to die and so are you.’” (Shilts 1987,165)

This image of the AIDS carrier/outlaw as predator seeking revenge would repeatedly emerge through various guises representing the deep-seated fears in societies towards difference, whether of sexual orientation, race, religion, social class or nationality.

The first news stories about AIDS that appeared in the United States were largely reported in 1982 (Cohen 1999, 160-171). These stories emphasized the lifestyle hypothesis which was interpreted to implicate gay men in having been infected (Cook and Colby 1992, 89). Generally absent from the coverage, however, were medically marginalized groups such as intravenous drug users and people of color who were also rather invisible in the CDC statistics. However, when the shift from the lifestyle hypothesis to the concept of risk groups took place in 1983, a new perspective on the epidemic emerged. As Cook and Colby argue, the AIDS story was not broadly covered in the American press when it was thought to be a disease of the marginalized, but once the figure of the AIDS carrier/outlaw appeared a new angle to the story developed: the division between innocent and guilty victims of AIDS emerged.

People living with HIV/AIDS were thus divided into innocent victims (hemophiliacs, children, unwitting wives, usually of Anglo-American heritage) and those paying the wages of sin and dangerous to the general public (homosexuals and intravenous drug users), with people of color invisible for the most part in the media coverage. Significantly, unlike married women or hemophiliacs, gay and drug using people living

with HIV/AIDS were rarely shown in the context of their families by the media, but rather in public places such as clinics and parks, which further emphasized their marginalized outsider status (Cook and Colby 1992, 98). HIV/AIDS thus became strongly linked with social exclusion and all of the associations that it entailed, most significantly the construction of borders and boundaries between the individual suffering from the illness and the rest of the community. This social exclusion can serve to naturalize the difference between healthy ‘us’ and suffering ‘them’ (Helne 2003, 117-119). Many early AIDS counternarratives thus emphasized the loneliness and isolation of living with the illness, or as Paul Monette described it – “living on the moon.” (Monette 1988, 83)

#### 10.16 Invisible counternarratives

At the beginning of the AIDS crisis in the early 1980s, the focus remained tightly on white male homosexuals and little attention was paid to other affected groups. Politically, many western countries (most prominently, Reagan in the United States and Thatcher in the United Kingdom) were in the midst of a conservative revolution that sought to roll back the social advances of the Keynesian-Fordist regimes and further privatize services. As many inner cities deindustrialized, the poor and vulnerable throughout the world found themselves in an increasingly stigmatized and precarious situation by the 1980s (Cohen 1999, 86). As the CDC remained concentrated on the association of the new syndrome with largely white, North American male homosexuals, the notion that transmission of this syndrome could be possible among other population groups was initially strongly rejected.<sup>43</sup>

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43 [A physician] began noticing that cases of unexplained immunodeficiency and unusual infections were beginning to surface among intravenous drug users, with features very similar to those described in gay men... When [the physician] went to attend a conference in Manhattan given by an official of the Centers for Disease Control (CDC) who had come to give a talk on this new immunodeficiency syndrome. He tells of running down the hall to catch the CDC speaker after the meeting and describing the clinical features of cases such as [a patient’s] that were appearing in the Bronx. When [the physician] suggested that this could be the same phenomenon being found in gay men, he was promptly rebuffed. This syndrome, the CDC official assured him, occurred only in homosexual men: our drug-using patients must be affected by something else. One year later, in late 1982, CDC released its first report specifically identifying intravenous drug users as an AIDS risk group. (Selwyn 1998, 2-3; author’s emphasis)

The possibility of infection among drug users was largely neglected by epidemiologists at the CDC for several reasons. Firstly, there was not adequate communication between public health agencies and agencies dealing with marginalized drug users, a fact which indicates a normalized division of health concerns between ‘the public’ and marginalized populations (Oppenheimer 1988, 279). Secondly, the CDC discourse on those susceptible to AIDS had been clearly defined as male homosexuals and the vast majority of fieldwork and research was directed towards this end. Thirdly, and most significantly, the CDC did not have adequate surveillance procedures to monitor the health of those who lacked access to health care and were thus medically marginalized. As Cathy Cohen has noted:

However, the problem is not simply that the CDC overlooked the development of HIV and AIDS among injection drug users and thus entirely mischaracterized the nature of this epidemic for the general public and more specifically for communities of color...[the question is] not why the CDC did not know, in the first few years of the epidemic, that AIDS was emerging among injection drug users, but instead if and why, with infection rates nearing 50 percent in this population in urban areas like New York City, there seemed to be a severe, possibly systematic, undercounting of their cases of AIDS. (Cohen 1999, 128)

Cohen’s impressive study of the impact of the AIDS epidemic on African-American communities, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*, points out that HIV apparently appeared in the American injection drug using community as early as the 1970s, but was not noticed due to the marginalized status of injection drug users who had little access to health care (Cohen 1999, 128).

The first emerging plot on AIDS thus linked white male gay identity with disease; however it was an unfinished plot because it never attained closure. Moreover, the plot of gay plague can be characterized as a pending narrative in Törrönen’s framework because it produced the impetus for action and then disappeared. The first narratives of AIDS in the early 1980s were strongly marked by the CDC definition had an enormous impact on the development of worldwide AIDS prevention and management policies due to the singular position of the CDC in international health. To summarize, all of the early information about the new disease came from the CDC. The thick definitions presented

by the CDC, namely HIV/AIDS as a 'gay disease', were to influence the future trajectory of conceptualizations of HIV/AIDS. The fact that transmission through blood, injection drug use, and heterosexual contact were not considered initially had an influence on the slow response to protecting national blood supplies, advising intravenous drug users not to share or to use clean needles, and designing appropriate safe sex campaigns. The thickness of description in official narratives about the emerging pandemic focused on male homosexuals, particularly those who were affluent enough to seek proper medical care. We can see that there was a thinness of description about socially excluded groups, such as people of color and intravenous drug users as well as women as a whole (see Goldstein and Manlowe 1997). The strong influence of the CDC on international epidemiology meant that this conceptualization of HIV/AIDS as a gay disease was disseminated throughout the world.

The earliest cases of AIDS in Western Europe originated in Denmark. The WHO reported 36 cases of the unknown illness in 1981, the majority of which were in France (Grmek 1990, 23). However, as the official CDC case definition focused on the 'homosexual lifestyle' as a diagnostic criterion of AIDS, many European cases among people who were not gay were misdiagnosed or only recognized later.<sup>44</sup> Though Western European media coverage of the disease did not really start until 1983 when the notion of risk groups was a concept that was firmly entrenched in American epidemiological circles, the earliest reports stressed the marginal status of people affected by the disease (Grmek 1990, 31).

Many pressure groups protested against the use of the term 'risk groups' because of its stigmatizing implications. Indeed, the notion of a risk group raises the question of who is at risk (people in the designated group themselves or others?). The notion of 'risk behavior' was preferred because of its emphasis on actions rather than social identity.

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<sup>44</sup> "Thus, for example, in the case of the woman who died in Copenhagen in December 1977 and whose clinical picture corresponded to that of gay Americans, no one dared make the connection until 1983 – that is, until well after the publication of American observations on heterosexual patients." (Grmek 1990, 23) Regarding this issue, see also Grmek's discussion of physicians' lack of awareness of AIDS among intravenous drug users in Italy. (Grmek 1990, 23-24)

The first guidelines for ‘risk reduction’ were issued by the U.S. Public Health Service in 1983 (Shilts 1987, 243). As an increasing amount of evidence of the heterosexual transmission of HIV/AIDS began to surface, the notion of risk behavior became much more prominent among epidemiologists who began to recognize that they were dealing with a microbial agent. Nonetheless, as Cindy Patton point out, despite the change in terminology, the implicit association of AIDS with the 4-H club continued:

As soon as the emerging syndrome was linked with a perceived subgroup, homosexuals, AIDS epidemiology and educational efforts generated from the Public Health Service employed a risk-based approach. Rapidly changing attitudes about sexuality and drug use rendered the notion of risk groups highly equivocal because it referred to subcultures that were already labeled socially deviant and were presumed to be virtually autonomous from the perceived mainstream population. Ironically, gay people’s battles to reclaim once stigmatized social labels as positive cultural identities meant that there was an uncomfortable convergence between groups’ hard-won notions of community and epidemiologists’ labeling of risk groups. Despite efforts among activists to shift terminology from risk group to risk behavior, AIDS education information concerning risk *reduction* was directed almost exclusively toward gay men, and soon (though much less consistently) toward injection drug users. (Patton 1996, 26)

The strategy of providing health education material for risk reduction behavior regarding HIV/AIDS significantly differed from other risk reduction campaigns concerning, for example, coronary heart disease. Whereas health promotion material in many countries in the 1980s stressed the need for proper low fat eating habits and regular physical exercise to prevent coronary heart disease, material was generally targeted towards the general public rather than particular groups. An important part of the development of health promotion efforts was the involvement of the food companies in marketing ‘healthy heart’ foods prominently in supermarkets. As Cathy Patton has noted of HIV/AIDS prevention efforts:

Attempts at condom marketing might have helped shift HIV prevention education to a population-wide strategy; however, social mores (television wouldn’t air ads, it was difficult to get the product sold at likely outlets – schools, vending machines, publicly funded clinics) thwarted even capitalism’s attempts to enter a new health promotion market. (Patton 1996, 160)

Thus, it was difficult to market AIDS awareness in the same way as other public health awareness issues precisely because of its highly stigmatized construction. Despite the semantic shift from risk groups to risk behavior, the implication that ‘certain’ people were liable to be infected with HIV persisted. People living with HIV/AIDS tended to be marginalized and divided between the categories of innocent and guilty. Many gays feared that the AIDS crisis would be used as an excuse to push them back into the closet. Indeed, stigmatizing attitudes towards HIV can be seen in the prioritization of funding on health. U.S. government spending on the AIDS crisis demonstrated the value placed on the lives of members of the so-called risk groups.<sup>45</sup>

Goffman’s definition of stigma can clearly be applied to the early sufferers of AIDS. Those judged to be among the ‘guilty’ victims of the disease were embodied by the figure of the AIDS carrier/outlaw while the ‘innocent’ victims were pitied for their gullibility and bad luck. The ‘guilty’ victims were thus often characterized as physically repulsive and morally flawed on the rare occasions that they were shown in the media and they were habitually presented in public places bereft of friends and family (Cook and Colby 1992)

#### 10.17 The gay plague and gay lifestyle as a pending narrative

It could be argued that the thick descriptions of the impact of AIDS on gays were due not only to epidemiological interpretations, but also because of empowered gay communities. Determined not to be marginalized by the mass media or medical establishment, courageous gay activists raised the issue of AIDS despite its unpopularity both among the general public and in many quarters of the gay community itself. The plot of gay plague thus acted as a pending narrative in Törrönen’s characterization:

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<sup>45</sup> According to a Congressional Report, the National Institutes of Health (NIH) spent \$36,100 per death during the Toxic Shock Syndrome, \$34,841 per death during the Legionnaire’s Disease scandal, but only \$3,225 was spent per AIDS in 1981 which rose to a meager \$8,991 in 1982 (Shilts 1987, 186).

The rhetorical force of the pending narrative comes from its sudden interruption: as soon as the motivation for an action has been created, and as soon as identities have been established for the actors involved in the action, the story is interrupted, brought to a halt. (Törrönen 2000, 81-82)

Once the plot of the gay plague coalesced in the face of a rapidly spreading fatal disease of unknown cause and created a largely united front to fight back against gay stigma and for increased research and treatment funding, the rhetorical force of the plot was spent. Coming at the same time as new discoveries about the virus, new pending narratives were created to promote action in different areas affected by the pandemic.

The plot of gay plague brought the cause of gay liberation into the limelight because many prominent gay communities, such as San Francisco and New York, were simply devastated by the epidemic. Larry Kramer, the prominent New York activist, used the metaphor of the holocaust to describe the AIDS pandemic (Kramer 1989). The plot of the gay plague helped to raise the profile of AIDS activism which eventually became effectively organized and well funded.

AIDS activist groups in many western countries tended to follow the model of 'new social movements' (NSM). NSMs can be defined as activist groups that decisively broke from modernist ways of organizing, such as through labor union membership or socialist political beliefs (Calhoun 1994, 22). NSMs have been characterized as largely middle-class movements organized around the specific identity themes that use a variety of cultural instruments to influence decision-makers (Gamson 1989, 354). The use of blood as a symbol by AIDS activists, for example, was creatively and effectively utilized by artists and activists, and even companies such as Benetton, to challenge the stigmatization surrounding AIDS (see, e.g., Giroux 2001). However creative many of these NSMs were, they often had difficulty in reaching out to marginalized populations, particularly across racial and gender divides. Indeed, the internal structure of many new social movements mirrored dominant power relations in society which tended to exclude members of disempowered groups from having their concerns prioritized (Cohen 1999, 116). In regard to AIDS, activist groups' association or dissociation with various

essentialist or constructionist views of homosexuality, with all of their social and cultural implications, often made for complex contradictions, particularly when resisting the notion that AIDS was solely a gay disease (Gamson 1989, 363).

However, participation in AIDS activism tended to reflect the exclusions practiced by epidemiologists. In the plot of gay plague, mainstream white gay communities were at the center while women, ethnic minorities and people with diverse sexualities largely remained invisible (Cohen 1999; Goldstein and Marlowe 1997). Women and ethnic minorities were thus largely absent from organizations and demonstrations. At the same time, many ethnic minority communities did not want to face the threat of AIDS due to stigmatizing attitudes within its own members. (Cohen 1999, 341) This would have an important impact on the development of prevention information, outreach work and medical treatment because the important viewpoint of other groups was absent as AIDS awareness policies and practices were formulated.

To summarize, medical categories of sexuality tended to be rigid and did not take into account the diversity of sexual expression. We can also see that the thickness of descriptions of AIDS during 1981-1982 primarily focused on North American male homosexuals. However, this thickness was nonetheless restricted to the portrayal of gays from a particular perspective. The thickness of description employed two tactics, one of gays as sexual carriers/outlaws; and second, the counterreaction by the gay community towards politicization and empowerment. Women remained largely invisible in the early discussion of risk groups or were discussed as mere 'vectors' of the disease. As Segal notes:

Women, as we know, rarely exist as equal partners in their sexual encounters or relationships with men, in the way gay men mostly do. It is harder for women to feel the self-confidence required to make demands in situations of dependence, where they may be trading sex for security or money, or simply be subject to sexual coercion by men. (Segal 1990, 165)

The fissures evident in broader society, in terms of socio-economic and racial/ethnic differences and marginalization, rent many people affected by AIDS apart and prevented the development of a unified grassroots movement to fight AIDS. The shifting boundaries and constructions of social exclusion further stratified and disunited movements against AIDS on sexual, ethnic, racial and class lines.

## **10.2 Scientific narratives of the disease**

When scientists began studying the new mysterious illness that was affecting gay men in metropolitan centers in the United States, they were baffled by the causative agent. Doctors treating patients who arrived at clinics with suppressed immune systems had no remedies or protocols to consult because they had no idea what was causing the problem. The main framework for understanding HIV/AIDS in the early 1980s was the plot of gay plague which labeled gay identity itself as an epidemiological risk factor. It is important to recall that the link between ‘a gay identity’ and AIDS was initially based on a case study consisting of five subjects (Oppenheimer 1988, 271). This meant that many people who did not fit the description, most notably women and drug users, were underdiagnosed and often medically marginalized. The strength of the plot of gay plague, and its counternarratives, tended to render other stories and narratives of AIDS invisible. Representations of people with HIV/AIDS have therefore had an influence on the development of accurate epidemiological and health promotion information. As Paula Treichler accurately points out:

Representation significantly limits access not only to ‘data,’ in other words, but also to the subject positions, narratives, and identities that could make sense of information and act on it. (Treichler 1999, 235)

Scientists were therefore also affected and limited by the representations of behavioral information available to them. As the dimensions of the AIDS pandemic grew, there were varying responses by the different levels of the international medical community though the initial plot of gay plague was not displaced for many years into the pandemic. These

responses were influenced by local socio-economic contexts, cultural dynamics, and perhaps most importantly, the politics of funding.

There was broad agreement within in the scientific community by 1982 that the causative agent for AIDS must be a virus, probably a retrovirus. The increased focus on HIV as a virus by bench scientists had the effect of reducing the stigma placed on AIDS as a consequence of ‘risky’ behaviors (Oppenheimer 1988, 285). The plot of the retrovirus thus reflected a new era in scientific discovery and understanding of the body. The modernist fortress-like view of the body that Martin describes as common in the 1950s, gave way to a vision that more closely resembled a computer circuit, with its complex interactions and links. It took scientific research to a new postmodern level where mechanistic views of the body could not follow. The realization that the human immunodeficiency virus was fundamentally different than previous viruses was also connected to the emerging methods of scientific research.

A shift in the conceptualization of the body had occurred with the discovery of retroviruses by Howard Temin and David Baltimore in 1974, which was a result of advances in genetic manipulation. Viruses are infective agents that are capable of multiplying within an organism but cannot be treated by antibiotics (Black’s Medical Dictionary 1999, 583). Some of the most devastating diseases in human history, such as influenza, polio and smallpox, are caused by viruses. A retrovirus, however, is a virus that contains ribonucleic acid (RNA) which is able to change its genetic material into deoxyribonucleic acid (DNA). DNA is the fundamental, and uniquely individual, genetic material of all cells in the human body. Thus, when a retrovirus gains entry to the human body, it makes a reverse transcriptase (a mirror image in reverse) of itself. What this means is that the previously healthy DNA is integrated with the new virus which becomes an intrinsic part of the genetic material of the body. The notion of retroviruses has great importance, suggesting that cancer and other illnesses could be the result of a virus. This discovery signified a new conceptual system for the functioning of the body.

When the HIV retrovirus was discovered, it became increasingly possible for medical professionals to recommend prevention and treatment measures. Most importantly, however, the discovery of HIV shifted a great deal of attention from the construction of risk groups to the virus itself, thus thickening the leitmotiv of faith in and hope for a magic bullet. Many new international magazines featured the human immunodeficiency virus on their covers and the scientific race began to find a cure for AIDS. Though many thick descriptions in popular and fundamentalist religious discourses considered AIDS in a neo-Darwinist light, as a plague sent to eliminate the sinners or deviants; for the most part, the contemporary media had thickened descriptions of the scientific aspects of HIV which reflected a modernist impulse to control the uncertainty of the environment as well as to restore faith in the medical establishment in the face of this raging and highly virulent disease. The plot of the retrovirus and politics of treatment thus conceived the virus as something entirely new and requiring new methods to control. Further, AIDS was not constructed as a threat to the general public but as a property of certain, limited identities.

Closely linked with the emergence of the retrovirus and politics of science were treatment issues. Treatment was contentious from the very first days of the illness. The fact that there was little that doctors could prescribe or do to alleviate the symptoms of the unknown virus, let alone provide a cure, was very frustrating to both patients and care providers (Bayer and Oppenheimer 2000). In countries lacking national health schemes, such as the United States, access to treatment often depended on health care insurance and personal financial means. In other countries with comprehensive national health systems, access was often tied to citizenship or residency status. Many other nations with crumbling (or non-existent) public health infrastructures had no hope of obtaining expensive, experimental drugs. From the very start, then, HIV treatment was intimately tied with citizenship, social inclusion and access to financial means.

Participation in clinical trials became the only possibility for many people living with HIV to gain access to any kind of treatment. Ethical dilemmas also surrounded the traditional design of clinical trials. Eligibility for clinical trials was not only often

dependent on access to health care, but also on the criteria for the study. Research protocols were often designed for men, excluding women of reproductive capacity or requiring sterilization as a precondition for participation due to possibility of fetal damage and consequent litigation. Hence women with HIV faced the predicament that they were disqualified from using experimental drugs, the only hope for a remedy, in order to protect a potential fetus from a potential risk (McGovern et al. 1994, 102). According to the US AIDS Clinical Trial Group, only 9% of participants in 1993 clinical trials in the US were women (McGovern et al. 1994, 102). This gender disparity had many implications for the development of appropriate medication regimens for men and women. Children also remained largely unrepresented in clinical trials, though this was largely due to age-related ethical concerns.

The legacy of unethical medical experimentation on members of minority groups in the 20th century has tended to raise mistrust in many minority communities towards clinical trials. The revelations of medical experiments in Nazi concentration camps gave impetus to the creation of the 1947 Nuremberg Code (Lifton 1986). This convention expressly stipulates that all participants in a study must give informed consent to participate, unnecessary suffering must be avoided, and the experiment must be terminated if the subject so desires. Nonetheless, racist studies such as the Tuskegee Syphilis Study, in which US Public Health officials systematically deceived African-American males suffering from syphilis about their actual diagnosis and denied treatment on the grounds that the progression of the disease was being studied, continued until 1972 (Jones 1993). The association of government-sponsored clinical trials with racist unethical medical experiments ran very deep in many ethnic minority communities. The lack of minority physicians and decision makers in many countries contributed to the sense that the mainstream medical establishment had little interest in the well-being of minority communities.

### 10.3 African AIDS

If AIDS came to be defined as the property of certain deviant bodies (or ‘risk groups’), then the specter of ‘African AIDS,’ so frequently invoked in the media and public discourse, signified a spatialization and racialization of the disease. As cultural critic and AIDS activist Simon Watney has noted, the western media generally talks about ‘African AIDS’, in which AIDS is an attribute of Africanness, rather than the more impartial ‘AIDS in Africa’ (Watney 1994, 116-117). Indeed, the western media commonly paint a one-dimensional picture of a mass of Africans, undistinguished by any individual human characteristics, squatting in a decaying hospital.<sup>46</sup> Watney, following Edward Said’s ideas in *Orientalism* (Said 1978), argues that these representations tell us more about ourselves and our culture than about Africans (Watney 1994, 117). This subchapter explores constructions of African AIDS as an important plot of AIDS stories. African AIDS has been a prominent plot not only in cultural representations of AIDS but, and perhaps more significantly, in scientific conceptualizations of the disease.

Stories of African AIDS have persisted throughout the two decades of the pandemic as narratives of racism and as symptomatic of xenophobic and racist anxieties targeted in complex ways at the African diaspora.<sup>47</sup> Stories have rarely been told by Africans themselves, hence African AIDS remains a narrative element largely articulated by non-Africans. African AIDS stories tend to have two focal points: the construction of a dark continent and fears of contagion embodied by the African diaspora. Consequently, AIDS stories have often unlocked new dimensions of mainstream fear and invective at home towards threatening images of ethno-racial and cultural diversity. Though it is not a new phenomenon, stories of AIDS have associated notions of health and control with race, migration, less developed countries and sexuality. Yet representations and articulations of African AIDS are different than AIDS in other less developed countries because no other continent has been so closely identified as part and parcel of AIDS. As Treichler has

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<sup>46</sup> See, for example, the series of articles published on African AIDS by The New York Times in 1990 (Treichler 1999, 205).

<sup>47</sup> On the complexity of conceptions of African diaspora and identity, see Davis (1999) and Roberts (1999).

noted, AIDS inevitably has a political subtext which is articulated within a local context. Stories of African AIDS are not monolithic but have complex genealogies and thick descriptions that are directly related to questions of colonialism, urbanization, modernization, development, poverty, disease and race albeit through diverse local perspectives (Treichler 1999, 115). The plot of African AIDS consists of stories that focus on race and often omit the significant role that poverty and social exclusion also play in such stories, with the latter often meriting much thinner descriptions.

There are a wide range of attitudinal, cultural, historical and structural socio-economic matters connected with the AIDS pandemic and issues of race and the African diaspora. Underlying these themes is the complex relation between exclusion, language and the construction of reality, particularly in how stories of African AIDS have come to be a central theme of many AIDS narratives. What is significant in stories of African AIDS is who has been privileged to tell these stories and how lived reality is missing in most stories. In short, African AIDS can be seen as a political issue articulated by outsiders (Treichler 1999, 210).

As we have seen, stories of AIDS have generally been marked by a series of dualisms (gay/straight; guilty/innocent; white/black; risky/not risky). These categories have often been defined by epidemiologists and represent an attempt to impose order and control by categorizing complex phenomena, as is the primary task of epidemiology (Treichler 1999, 115). The subtlety, fluidity and multiple meanings of identity and behaviors can therefore be lost amidst the attempt to create consolidated and predictive categories. This is one of the fundamental dilemmas embedded in the construction of an epidemiological multifactoral model. More important, perhaps, is the power implicit in the ability to define and designate something as a fact because this is the foundation from which all policy is developed. Stories of AIDS tend to depart from a western perspective and are often couched in North American terms. The voices of those affected by the pandemic in non-western countries are frequently silenced or filtered through a western outlook and this can be seen most clearly in stories of African AIDS.

As Rosenberg has suggested, the social construction of the meaning of disease frequently involves the quest for origin or assignation of blame in response to the seeming randomness of infection, in short, a search for scapegoats (Rosenberg 1992, 284).

Western scientific authorities AIDS initially connected with the so-called 4-H club (Haitians, homosexuals, hemophiliacs and heroin users). AIDS was thus stigmatized as a venereal disease derived from deviant sexual practices or illegal drug use. The origin of the disease, however, was thought to have come from a primeval source, the heart of darkness in Conradian terms: Africa. Indeed, it has largely been assumed that HIV originated in Africa, as Randy Shilts casually wrote:

It was the end of 1980...a new virus was now well-entrenched on three continents, having moved easily from Africa to Europe and then to North America. Later surveys would show that in the United States fifty-five young men had been diagnosed with some infection linked to the new virus by the end of 1980. Ten others had been diagnosed in Europe, while many more were ailing among the uncounted sick of *primitive* Africa. (Shilts 1987, 49) [my emphasis]

Here we can see the construction of Africans as ‘other.’ Whereas there are American ‘young men,’ and even Europe rates the human-sounding ‘others,’ the picture of Africa is rich in colonialist images. Unlike Europe or America, the teeming mass of Africans lack humanity and individuality in their ‘primitive’ land – they are simply the ‘uncounted sick’. Unlike their North American or European counterparts, narratives are very thin regarding people from lesser developed nations living with HIV/AIDS. AIDS is not portrayed by the western media as having a human face in Africa. Furthermore, there are no voices from these faceless groups to challenge their representations. Thus Africans, similar to Haitians and other members of the African diaspora thus became a threatening mass of AIDS carriers, not individuals affected by a disease.

Theories of causation, and by implication blame, were traced back to Africa from the start of the pandemic.<sup>48</sup> Professor Geddes of the Department of Medicine at the University of Birmingham argued in 1988:

How did the infection get from Africa to Europe? It seems most likely that it started to break out of Africa when laborers from the Caribbean island of Haiti went to work in Zaire, contracted the infection heterosexually, and took it back home to a country which, by great misfortune, happened to be the playground of the promiscuous North American man. In that way it got back to North America and then across the Atlantic to Europe. (Geddes 1988, 14)

These theories involved a great deal of speculation. There was little factual evidence or ethnographic knowledge to support such conclusions, which were often redolent of racist or colonialist perspectives. As the Chirimuutas have shown in their review of medical literature on African AIDS (Chirimuuta 1989), many prominent scientists framed their findings within racist explanatory models that were historically inaccurate. Prominent American researcher Dr. Robert Gallo, for example, who first received the credit for discovering the HIV retrovirus, only to later acknowledge that his sample originated in the Pasteur Institute in Paris (see Crewdson 2002, for a discussion of the controversy), wrote several articles in *The Lancet* in which he claimed there was a connection between HTLV (an early acronym for HIV) and Africans and the indigenous people of Japan via Portuguese seafarers (Gallo et al. 1983; Gallo 1986). This speculation, as the Chirimuutas correctly point out, is based on a selective reading of history. In Gallo's theory, the minimal contact between Portuguese, Africans and the Ainu people of Japan is placed front and center, while the centuries-long slave trade between Africa and the New World is not considered worthy of mention. What is common to this type of speculation is the link between constructions of race and disease. As Gallo wrote:

Our more recent studies show that HTLV is prevalent in Africa...In most other areas of the world, and notably in healthy Whites of Western Europe and North America, HTLV infection seems to be very rare, except in

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<sup>48</sup> They continue to do so, see Hooper and Hamilton (1999).

persons with acquired immunodeficiency syndrome. (Gallo et al. 1983, 962-963)

In this way, medical evidence and causation was interpreted according to racist frameworks. These articulations of race and AIDS were powerfully difficult to dispute because they were published in the top medical journals.

More importantly, little information from those actually involved, namely people in Africa, was included in the analysis. Hence African origin theories can be largely characterized as constructing a geography of danger, an illusion of control amidst a growing pandemic that provided a safe assurance that such diseases could not be produced in western countries and, by implication, that westerners (particularly whites) could only be affected by HIV through contact with Africans or those who have had contact with Africans. Like Joseph Conrad's *Heart of Darkness*, fables of African AIDS show the continent as inscrutable and unknowable where statistics cannot be kept (numbers of infected people are 'uncountable') and the greatest danger for whites is 'going native'. African AIDS as a sexual metaphor must be considered within the context of a long genealogy that extends back to colonialist stereotypes of the savage and sickness (moral and physical) (see, e.g., Gilman 1985, 1988). Hence, stories of African AIDS are not simply spatial (located in a particular geographical place – Africa) but they are also embodied (in Africans wherever they reside) as Watney points out:

It is as if HIV were a disease of 'Africanness', the viral embodiment of a long legacy of colonial imagery which naturalizes the devastating economic and social effects of colonialism in the likeness of starvation-bodies reduced to 'bundles of acute angles.' (Watney 1994, 112-113)

Because the pandemic in Africa has largely been manifested through heterosexual contact, unlike the first information from the United States, initial reports speculated that HIV was spread by exotic sexual practices, voodoo rituals or green monkeys (Watney 1989, 187). Other theories constructed people affected by HIV as lacking agency and the victims of western gay tourists (in the case of Haitians) or promiscuous husbands (Africa). Indeed, African men were often constructed in the mold of the sexual

carrier/outlaw. Hence the equation of race with disease and dangerous sexuality played a role in inscribe attitudes on the bodies of the African diaspora as a repository for disease.

Professor Susan Craddock noted a similar tendency in her study of syphilis and Chinese people in San Francisco:

Social and medical interpretations of smallpox and syphilis utilized ideological notions of Chinese habits, morality, and hygiene to construct a pathologized Chinese body. Constructs of the 'depraved Mongolian' were in other words remapped as etiological explanation. In the case of syphilis, racialized notions of gender informed both the interpretation of the disease's epidemiology and the production of the female Chinese body. The Chinese body, both male and female, became virtually metonymous with smallpox and syphilis, dangerous symbolic and material entities that threatened the body of the city with their infectious emanations. The framing of these epidemiologies thus illustrates the degree to which medical knowledge informed, and in turn was produced by, social values and political imperatives, and the importance of bodies to this process. (Craddock 1998, 1)

Like the Chinese bodies described by Craddock, African bodies are often represented as synonymous with AIDS. In this sense, then, African AIDS can be seen as socially constructed as a contagion, rather than an infectious disease, in which any kind of contact with African bodies could be potentially dangerous.

In stories of African AIDS, the continent of Africa is constructed a site of disease and decay. The proliferation of visual images of nameless people wasting away and sitting in desolate unequipped clinics as well as armies of AIDS orphans have entwined socio-cultural judgments and the apparent imperatives of globalization in such a way that has constructed Africans as expendable and even redundant. The problem of AIDS in Africa has thus often attributed to denial rather than to growing socio-economic inequities which have been accelerated by the processes of economic globalization, political instability and increased mobility. These economic factors have placed terrific pressure on public health and social infrastructures. As noted earlier in Chapter 4, the improvement of living conditions and reduction of poverty in western countries in the 19th century has been

considered to be the single most important factors in enhancing life expectancy, reducing mortality and preventing disease. Development specialists Tony Barnett and Alan Whiteside link the enlargement of the AIDS pandemic in Africa to the legacy of colonialism, economic exploitation and misguided decisions by inexperienced and corrupt governments:

Africa's history is one of abnormal normality. It differs from all other regions of the world in the sustained nature of disruption, exploitation and bad government – and the fact that Africans, in contrast to the indigenous populations of other world regions, have survived these experiences. In the last 30 years the misfortunes of this history have been compounded by a long period of economic crisis. The oil price hike in 1974 was soon followed by economic collapse. (Barnett and Whiteside 2002a, 156)

Growing global income gaps and the ascent of the individual over the community, which accelerated in the 1980s and 1990s, have substantially contributed to the spread of HIV/AIDS, particularly in less developed nations.

African AIDS has raised fears in highly developed countries because it is socially constructed as contagious rather than infectious. As the cultural studies researcher Barbara Browning has pointed out, AIDS in Africa became a concern precisely because it had the potential to affect western countries:

...as devastating as AIDS is in the Third World, there are other diseases which represent an even greater public health threat – malaria, in particular. While the West has shown a morbid fascination with other viruses, such as Ebola, which could theoretically have an 'outbreak' here, little attention is given to deadly and virulent diseases that represent little or no risk to First World populations. (Browning 1998, 52)

When stories of the African origin of AIDS became the accepted wisdom in the late 1980s, moral panics ensued in many western countries regarding foreigners, particularly members of the African diaspora, which stigmatized foreigners as AIDS carriers that could potentially threaten national health. With many of the socio-economic changes described in the first section taking effect in many western countries, migrants often began to be perceived as rivals for social welfare entitlements and employment,

particularly in many European countries experiencing higher unemployment rates due to the transition from an industrial to a post-industrial economy.

Migrants resident in highly developed countries faced a particularly difficult situation during the period that the AIDS pandemic really took hold in many western countries. As the numbers of refugees and asylum-seekers burgeoned in the late 1980s and early 1990s, the borders to highly developed nations were being tightened, for example through the harmonization of European Union immigration laws, which prompted increasingly desperate migrants to go to ever greater extremes to enter wealthy countries illegally. Fears of racial contagion were an important subtext in many public debates on immigration and multiculturalism, and were particularly focused on African AIDS in many countries (see, e.g., Browning 1998, Farmer 1992). In 1996, for instance, the Norwegian Board of Health issued a warning to Norwegian women that having unprotected sexual relations with African men carried a significant risk of exposure to HIV (Norwegian Board of Health 1996).<sup>49</sup> In the wake of this statement, there was a frenzy of speculation in Norwegian newspapers regarding the actual percentage of Africans resident in Norway that were infected with HIV, with estimates ranging from one in ten to one in fifty. African community organizations protested the statement claiming that the Board of Health had launched a stigmatizing AIDS campaign against their communities (Organization against Official Discrimination 2002). The marginalized position of much of the African diaspora globally has made it difficult for community organizations to have the resources and influence to challenge stereotypes and discourses on African AIDS. These stereotypes must be understood within the context of colonial images of the primitive and savage as well as moral panics about national purity. As the sociologists Goode and Ben-Yehuda define:

A moral panic is characterized by the feeling, held by a substantial number of the members of a given society, that evil-doers pose a threat to the society and to the moral order as a consequence of their behavior and,

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<sup>49</sup> In this context, it should be noted that having unprotected sexual relations with anyone (regardless of nationality) carries a significant risk.

therefore, 'something should be done' about them and their behavior.  
(Goode and Ben-Yehuda 1994, 31)

Fears of African AIDS were thus intimately linked with fears of immigration overwhelming distinct national identities in many, particularly European, societies. The plot of African AIDS distilled the enormous diversity of the African diasporic community into a monolithic construction of threatening AIDS blackness which received many thick descriptions in tabloids, scientific journals and often public health reports.

There have been few counternarratives to African AIDS for a multitude of reasons. First and foremost is the simple lack of access to the means of disseminating stories through various media by many disempowered communities. Secondly, the African diaspora is an enormously diverse population of communities and individuals that span the continents of the world. There is no singular consensus of what the African diasporic experience has been or means. Further, there is no clear-cut definition of membership (see, e.g. Collins 2000, 22; Gilroy 2000). Perhaps most important, though, are processes of globalized racialization that perpetuate imbalanced power relations, stereotypes and racism (Bhattacharyya et al. 2002).

To summarize, in HIV/AIDS, many of the deepest fears and taboos societies had regarding sexuality, criminality and otherness coalesced around the persons of Africans who were then associated with AIDS as a disease. Represented as a faceless mass, sexual outlaws or diseased bodies, thick descriptions of African AIDS were embedded in many mainstream accounts of the African diaspora. Indeed, throughout modern history members of the African diaspora have often been quite invisible to policymakers and health practitioners. As the physicians Byrd and Clayton have written in their landmark history of race and medicine in the United States:

...when journalists and health policy makers mention poor Black health outcomes at all, they continue to project them as stemming almost exclusively from a 'culture of poverty' perspective that presumes defective health habits. Indeed, many erroneously attribute aspects of the 'dual' health crisis to the Black community's highly publicized problems

with drug abuse, violence, and AIDS [...] The reality is that poor African American health status and outcomes are not aberrations – they are pervasive and systematic. They are reflections not only of the poor performance of the health system but also of poor nutrition, being forced to live in toxin-exposed environments, poor housing, poor health habits, and health-risky behaviors. (Byrd and Clayton 2000, 16-17)

Here we can see how implicit (and individualized) blame is constructed which characterizes members of the African diasporic community as culturally defective rather than examining the structural factors, including poverty, that contribute to negative health outcomes. This affinity can often be seen in thick descriptions of African AIDS. As a writer in a journal on African culture noted:

It is the political economy of underdevelopment, not sexual intercourse, that is killing Africans. Poor harvests, rural poverty, migratory labor systems, urban crowding, ecological degradation and the sadistic violence of civil wars imperil and destroy far more African lives. When essential services for water, power and transport break down, public sanitation deteriorates and the risks of cholera and dysentery increase. African poverty, not some extraordinary sexual behavior, is the best predictor of AIDS-defining diseases. (Gesheketer 2001)

From the perspective of many Africans, it has been difficult to challenge the reigning AIDS orthodoxy on the origins of the virus, analysis of reasons for the pandemic, treatment options or ways to disseminate prevention information without being labeled as a denialist. There are also extremely few stories of HIV/AIDS from an African or black perspective in the United States, for example, though there are a significant amount of narratives written by white westerners who have put a human face to the illness (see, e.g., Johnson 1996; Monette 1988) As cultural anthropologist Arthur Kleinman has pointed out, there is no universal or singular language of suffering. Suffering is both a collective and intersubjective experience:

Cultural representations, authorized by a moral community and its institutions, elaborate different modes of suffering. Yet, local differences – in gender, age group, class, ethnicity, and, of course, subjectivity —as well as the penetration of global processes into local worlds make this social influence partial and complex. (Kleinman et al. 1997, 2)

The truths of African experiences of AIDS have been mediated by westerners just as many migrants have little opportunity to tell their own stories. The plot of African AIDS has reinforced many of the ethnocentric and racist associations of disease and ignorance. Most devastatingly, these stories have silenced and rendered irrelevant the diversity of experience and perspectives by crunching Africa into a monochromatic and one-dimensional category. Blackness, in short, has often been rendered as equivalent to disease in many stories. The fact that African perspectives have been largely rendered invisible suggests that stories of African AIDS (rather than AIDS in Africa) have been more an image of white anxiety rather than a logical response to a public health issue.

#### **10.4 AIDS exceptionalism: shifting identities and priorities**

When HIV/AIDS emerged as an infectious disease in the 1980s, perhaps the most emotional and difficult political, social and medical debates concerned whether traditional public health measures, including routine testing, name reporting, partner notification, contact tracing and even quarantine, should be implemented to contain its spread. As HIV/AIDS was first reported among urban gay, and largely white, males – as described earlier in the plot of gay plague – AIDS quickly became associated with this specific identity group despite the fact that other medically marginalized groups (such as intravenous drug users, ethnic minorities and women) were also affected. As previously discussed, the designation of risk groups by epidemiologists reflected the construction of categories of social groups by scientists who often knew very little about the complex identities or flexible border crossings amongst the groups they were studying. The invisibility and silence of marginalized groups, particularly in early statistics and stories, revealed the fissures in the alleged objectivity and comprehensiveness of data collection and analysis. Moreover, the racist and sexist frameworks of many mainstream scientists became apparent through the construction of interpretive frameworks that associated racist or sexual attributes to disease. At the same time that the complexity of these diverse groups was growing apparent, the identification and progression of HIV disease became increasingly familiar to clinicians along though both experience and breakthroughs in medical knowledge about treatment options. As scientific knowledge

increased about HIV transmission and communities mobilized to challenge discrimination against PLWHAs, HIV/AIDS became increasingly normalized as a disease. Yet, AIDS remained exceptional in many ways. This subchapter explores some of the plots that constructed AIDS as an exceptional disease.

The plot of AIDS exceptionalism constructed AIDS as a uniquely stigmatized disease that required special measures, unlike other diseases that endangered public health. Due to the fears raised by the early plots of AIDS, a battery of criminal sanctions was employed in many countries with to prevent the spread of the disease and penalize people living with HIV. AIDS exceptionalism thus emerged as a contested term. Stories that viewed AIDS as the just desserts for deviant behavior were hostile to exceptional public health measures and tended to favor punitive and compulsory procedures to deal with people living with HIV. Stories from a harm reduction viewpoint, however, tended to promote the notion of AIDS exceptionalism as the most rational means to limit the spread of the disease (for an outline of the Finnish AIDS strategy, see Chapter 14.5) A specific constellation of political, social and medical forces thus came together to construct AIDS as an exceptional disease.

When AIDS surfaced in the early 1980s, it quickly became a highly stigmatized disease strongly associated with 'deviant' behavior, such as homosexuality, sexual promiscuity and the use of illicit drugs. Hence AIDS developed as a double stigma: it was frightening, disfiguring and incurable, and often interpreted as a moral judgment on those who were infected. There was a thick texture of stories with different perspectives on the meaning of AIDS from fundamentalist religious views of AIDS as the fruit of sin to conspiracy theories of CIA collusion in the spread of AIDS to millennium fears of emerging diseases in an increasingly hostile ecosystem..

AIDS exceptionalism can be defined as a bundle of interconnected policies and practices that construct HIV/AIDS as anomalous health concern. First, a battery of legal protections emerged in the 1980s to protect PLWHAs from stigmatizing behaviors (Klein et al., 2002). Many of these legal protections defined HIV as a disability, thus associating

HIV with the framework of disability law that barred discrimination in housing, employment and other areas of life (Annas 1997). Second, AIDS exceptionalism consists of policies that focused on respecting the privacy, confidentiality and social rights of people at risk by emphasizing non-coercive measures to encourage testing and non-risky behaviors. Finally, AIDS exceptionalism consists of social and health care practices that empower patients. The underlying notion of AIDS exceptionalism is to promote healthy behaviors and increased testing by underscoring human rights, the reduction of social exclusion and the elimination of stigma.

From the very start of the epidemic, however, there was tremendous resistance by gay activists and even many public health figures to the implementation of traditional public health measures, largely due to implicit and stigmatizing connections that were made between abnormality and infectivity. These connections were thought to have a negative impact on outreach work to encourage people to get tested and take precautions. Public health measures were also interpreted by some gay activists as pursuing an anti-sex agenda by attempting to push gays back into the closet (see, e.g., the discussion of bathhouses and San Francisco public health department in Shilts, 1987) or as intruding on the civil rights and privacy of individuals. These conflicting pressures presented many challenges to the diversity of forms and concerns that epidemiological efforts and health promotion information had to address. The social stigma and discrimination that many people living with HIV (or suspected of living with HIV) faced in the 1980s was intense and included incidents such as exclusion from school, the loss of health insurance, eviction, loss of jobs and rejection by friends and family.

Unlike the United States, where the president did not publicly address the issue of AIDS until a brief mention at a press conference in 1985 after thousands had died, discussion about the ramifications of the disease started early in Europe. The Council of Europe was one of the first international bodies to express concern over discrimination against PLWHAs in a 1983 resolution. Declaring that "...each individual is entitled to have his privacy respected and to self-determination in sexual matters;" the resolution condemned inaccurate and sensationalist images of PLWHAs in the media and called for ethics in

research on PLWHAs (Council of Europe 1983). This resolution confirmed the exceptional nature of AIDS and recognized its close connection with stigmatizing the gay community. From the beginning of the pandemic, governmental organizations in Europe tended to design policies from a public health perspective rather than a criminalizing instinct, though criminal law has been strategically applied in certain cases.

Many of the gay groups that took up the cause of AIDS from the very beginning recognized that AIDS represented a new kind of disease. Using the pending narrative of the gay plague and gay lifestyle, gay community groups began forming to fight back against official indifference and social stigma. Framing the struggle against AIDS as a struggle for existence and recognition, AIDS activism became strongly associated with gay rights groups. Battle lines grew between activist groups and the medical establishment and governments that were thought to be dragging their feet with funding and making new medications available. Assertive new groups, such as ACT-UP (AIDS Coalition to Unleash Power), founded in New York City, demanded the right to access to medical treatment and medications and developed an inventive method of ‘zaps’ to draw attention to the plight of people living with HIV and profits made by pharmaceutical companies. By the time that the retrovirus for AIDS was discovered in 1983, an effective AIDS bureaucracy had started to develop through gay community organizations throughout the western world. These groups provided a variety of services, such as home care, meals on wheels, and counseling on a range of issues specific to AIDS. These types of services were not necessarily specifically available and sensitive to people living with HIV through other agencies. The profile of AIDS rose through the design of the red ribbon symbol, the remembrance quilt and various celebrity-studded fundraising events.

AIDS awareness and activism did not grow in all communities at the same pace. For example, the New York-based Gay Men’s Health Crisis (GMHC), which was started in writer Larry Kramer’s living room in 1981, controlled a \$10 million budget and had 100 employees by 1988. However, the Minority Task Force on AIDS, also based in New York, had less than one-tenth the budget and staff as the GMHC (Stoddard 1989, 96-97). The plot of the gay plague had a strong impact on how information about HIV was

disseminated and understood, particularly in marginalized communities which had negative experiences with the medical establishment or were excluded from treatment and care (Cohen 1999). Moreover, access to funding depended on community capacity, political power and health awareness.

In 1985, the ELISA test was developed to screen blood. Data presented at the 1986 Atlanta AIDS Conference definitively clarified the fact that HIV was not casually contracted. These findings raised many new complex issues regarding the acceptability and appropriateness of testing and confidentiality issues. While it was indeed welcome to have a definitive method of ascertaining seropositivity status, there were many ethical fears about how this knowledge would be used. It was thought that if people had fears that they could be discriminated against, or their identities or risk behaviors effectively 'outed', then people would be discouraged from being tested. Methods and protocols for test counseling grew at this time as it was increasingly recognized that coercive measures tended to be counterproductive in getting people to tests. Many organizations tried to lower the threshold for being tested by offering the possibility to take an antibody test anonymously. This has become a core element of good practice in HIV/AIDS awareness work. The plot of AIDS exceptionalism thus developed as a public health approach to effective preventive measures as well as reaction to the stigmatizing plots that dominated the early stages of the AIDS pandemic. AIDS thus began to emerge as a human rights issue, though the national responses to the crisis reflected different articulations of socio-economic, ethnic, gender, citizenship and cultural status in societies.

Political scientists Darius Rejali and Thomas McElroy have compared the development of HIV testing policies in Europe and the United States (Rejali and McElroy 1997). They identified two types of testing regimes: preventive and diagnostic regimes. Preventive regimes viewed testing as a first contact point which can initiate behavioral modification. Diagnostic regimes, on the other hand, saw behavioral modification interventions and contact with communities prior to testing as vital (Rejali and McElroy 1997, 2). As Rejali and McElroy define:

These two ideal types embody different assumptions about the kind of disease AIDS is. A preventative regime treats AIDS in the same spirit as any acute infectious disease, whereas a diagnostic regime treats AIDS as a chronic disease like cancer. The logic of preventative testing is to reduce infection and keeping those who are healthy from getting sick. The logic of diagnosis is to help those who have a chronic condition, and who will have it for the rest of their lives, to live with their condition. (Rejali and McElroy 1997, 3)

These regimes therefore show two different ideas of the disease. Rejali and McElroy further argue that the development of HIV testing policy had less to do with the severity of the epidemic or the strength of gay community movements than the administrative culture within countries (Rejali and McElroy 1997, 10-12). Countries tending towards a corporatist model (e.g. Sweden, the UK, and US) "...the government recognizes a single group as having a monopoly in representing interests of a certain social sector." (Rejali and McElroy 1997, 10). The corporatist government thus creates policy on this basis of the advice given by the designated group of experts. Pluralist administrations, on the other hand, have weak control over the rank-and-file and must negotiate policies and decisions with a patchwork of competing interests (e.g. The Netherlands, Denmark and France). Pluralist administrations are therefore subject to more debate and dissent over how policies are formulated and implemented.

Plots of AIDS exceptionalism can be seen as undergirding one of two articulations. Articulations of AIDS exceptionalism can be tied to the two lines of policy on AIDS prevention: criminalizing and harm reduction. Those who articulate AIDS exceptionalism in negative terms, consider it to 'coddle' PLWHAs. Many times these articulations seek to restore the stigmatized status of AIDS. Articulations of AIDS exceptionalism that view it in a positive light, consider the exceptional measures used to protect confidentiality as part and parcel of public health.

At the end of the first decade of the epidemic, the framing of AIDS began to subtly shift. During the first ten years, AIDS was largely defined as a disease of white, male homosexuals despite health promotion efforts to the contrary. Gay communities

throughout the world rallied to provide support services and defend the human rights of those affected by HIV/AIDS. The highly successful efforts of gay health promotion efforts resulted in a general trend towards diminishing incidence of HIV/AIDS in gay communities throughout the West.<sup>50</sup> AIDS fell from the headlines and there were fewer stories of AIDS. Though it was popular to advertise the notion that ‘everyone can get AIDS’ this was somewhat facetious. HIV/AIDS disproportionately affected the poor and issues surrounding AIDS began to shift from questions of recognition and awareness to equity and fairness. Criminal justice issues also became more prominent in debates on AIDS towards the end of the 1980s.

The high financial costs of the new treatments often brought about an erosion of alliances among different groups as class interests tended to overwhelm solidarity. The term ‘AIDS exceptionalism’ thus became a contested concept, particularly when the pandemic became endemic among drug users, migrants, the poor and most vulnerable in societies. Impulses to contain the AIDS pandemic through coercive measures of containment mirrored other trends in globalized societies where the socially excluded were increasingly relegated to spaces outside gated communities and labeled as social outcasts (see, e.g., Helne 2003 and Young 1999 on the exclusive society).

One metaphor that has uniquely stamped AIDS is the connection between access and transmission. Though AIDS exceptionalism became the norm in most medical and health care throughout the world, this exceptionalism did not extend to social issues, particularly where foreigners were concerned. Hence fears of disease transmission often raised debates on the necessity to tighten borders, and limit the mobility and contact between certain people designated as ‘risk groups’. In 1987, the US banned non-citizens with HIV from entering the country without a special waiver, though this ban was challenged by delegates attending an AIDS conference in 1989 (Goldberg 1998). Despite protests the US ban remained largely in effect as visitors to the US were asked on the visa application

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<sup>50</sup> It is important to note here that some new evidence suggests that the new generation of young gay men lack information (or information is not appropriate to their generation) on HIV/AIDS because of rising rates of infection in areas (such as San Francisco) which have been decreasing for many years.

form whether they have ‘a communicable disease of public health significance.’ US citizens with HIV, however, are allowed to freely travel to and from the US. In 1995 Yelstin required HIV tests of foreigners but not Russians returning from abroad (Williams 1995). From Saudi Arabia to Taiwan, there have been reports of government policies to expel foreigners with HIV. These types of policies tend to draw a line between nationals with HIV, who may be stigmatized but are nonetheless accepted as part of the nation, and foreigners with HIV, who are excluded.

AIDS exceptionalism was important to those who had mobility and access to health care. Yet, the role of AIDS exceptionalism remained more unclear in immigration regulations, for example, that could further stigmatized and excluded non-citizens living with HIV/AIDS. This raised the question of whether seropositive status should be used to exclude refugees or asylum-seekers. As immigration restrictions tightened in the European Union and other western countries, a debate grew over the acceptability of using HIV testing as criteria for entrance. Entry and residence requirements regarding HIV vary from country to country. The human rights of people living with HIV/AIDS emerged with testing, though migrants remained a lacuna. Lacking political rights, as well as access to social and health services, migrants were largely an invisible and vulnerable group in the plot of AIDS exceptionalism.

The vulnerability of migrants is closely linked to their relation to power in the host society and the degree of discrimination they experience. Household and community characteristics influence migration, which can be considered an economic or political risk-reduction strategy for many households. Throughout much of the world, residues of colonialism influence the patterning of HIV transmission. (Sabatier 1996, 90-91)

Social welfare and national health systems constructed on ethno-political concepts of social citizenship often did not take the specific needs of vulnerable migrant populations into account. At the same time, it was very difficult to raise AIDS awareness within many ethnic minority communities in the western world due to the stigma and possible legal and social consequences of being identified as HIV positive.

AIDS exceptionalism as a plot views constructs HIV/AIDS as a unique and special disease which requires extraordinary public health measures based on the special needs of certain communities. However, there are absences in this plot. Indeed, AIDS exceptionalism largely did not extend to the most vulnerable members of global society, namely those in lesser developed nations and migrants who lack social rights in highly developed countries. The paradox of AIDS exceptionalism continues to have an influence on the different valuations of people living with HIV/AIDS. The lack of solidarity can be seen especially with regard to migrants. The thin, and often unvoiced, counternarratives of MLWHAs are commonly subsumed in migration issues, such as residence permit requirements and work regulations. In many respects, HIV/AIDS has been viewed as a stigmatizing issue amongst migrant communities which have feared the ramifications of 'African AIDS' stories. Raising AIDS awareness within many ethnic minority communities has faced special challenges. Hence pending narratives to organize migrants living with HIV/AIDS have not emerged and have indeed often been denied or repressed within migrant communities. The plot of AIDS exceptionalism has therefore had a rather nominal impact on communities struggling for the recognition of fundamental human needs and rights.

### **10.5 Summary: The significance of plots of AIDS**

AIDS has been one of the most storied diseases in recent memory from the very beginning of the pandemic. The Spanish influenza pandemic of 1918, for example, which was estimated to have killed over 20 million people globally, has largely remained a gap in history until recently (Kolata 2001). AIDS has received an enormous amount of attention, though there is not one story but rather a thick, richly textured terrain of stories which embody a thicket of plots. Some narratives have had greater influence in explaining the story of AIDS than others, while other stories have remained untold.

In analyzing black feminist thought, Patricia Hill Collins has pointed out the significance of storytelling as a means of dialogically sharing experience in the African American community (Collins 2000, 260-261). Collins argues that this mutual sharing of

experience through stories produces a sense of connectedness, which has been a cultural characteristic of many African American communities. Following French philosopher Michel Foucault, it can be argued that stories can exert power through drawing boundaries between what can be spoken and what cannot, by defining differentiations that allow dominant people direct and react to the actions of subordinate people, to institutionalize power relations and to rationalize such power relations (Dreyfus and Rabinow 1983, 208-226). In short, when stories are not shared dialogically, then they can be seen to function as a form of social control rather than liberation.

The processes of globalization combined with neoliberal ideologies of individualism have created increasingly exclusive societies (Young 1999) in which dialogical relationships between groups is becoming ever harder to attain. At the same time, the yearning for community and security has perhaps never been stronger than in the midst of the uncertainties of postmodernity (Bauman 2001). As Tuula Helne rightly points out, no one wants to be relegated to the camp of the socially excluded, a designation which tends to construct a 'double exclusion' through the stigma associated with the expression as much as the social processes that are ascribed to the term (Helne 2003, 1-15). Viewed as separate from society, the socially excluded are thus often described through the attributes of passivity, isolation and hopelessness and implicitly scapegoated for their circumstances. The growing spatial and communal gap between the included and excluded in fragmented global society makes dialogue ever more problematic.

AIDS arrived as a 'master illness' (Morris 2000, 59) at the end of the 20th century which mirrored the risks of the postmodern age. Though constructed as a stigmatized disease through the initial plots of AIDS, such as the gay plague and the gay lifestyle, empowered activists in many western countries managed to take back the stigma of the disease and fight for access to treatment. These activist movements, however, embodied many of the contradictions of new social movements. By simultaneously attempting to 'own' the issue of AIDS as a gay issue and deny that the virus was exclusive to homosexuals, many AIDS activist groups reinforced racialized, gendered and class relations of power by overlooking the concerns of marginalized groups in defining

priorities in the AIDS struggle. AIDS exceptionalism reconstructed the status of people living with HIV/AIDS as ‘outsiders-within’ (Collins 1998, 231) and removed some of the more stigmatizing public health, legal and social policies towards PLWHAs. The dominant AIDS plots discussed in this chapter nonetheless reflect a selective view of the development of the AIDS pandemic. Many stories are simply not represented in these plots because the experience of those who lived invisible stories have not had the political power to ‘come to voice’ in the AIDS pandemic (Collins 2000, 100-101).

AIDS has increasingly become a story of poverty and disempowerment. As cases decline and combination therapies become more prevalent in western industrialized countries, the most conspicuously absent story is that of those excluded from care and treatment options due to their residence status. Moreover, there are other thin counternarratives that have yet to come to voice which relate to the personal experience of globalizing processes and AIDS through the lens of the migration experience. As noted earlier, in Chapter 7.5, the layering of migrant identity produces loss as well as gain, dispossession as well as a new sense of cohesion. These stories are indeed absent from unfinished plots of AIDS.

As Mattingly and Garro have pointed out, the meaning attributed to emplotted events reflect the expectations and understanding of specific social worlds (Mattingly and Garro 2000, 3). We can see in the plots outlined in this section that socio-economic status was a decisive factor in whether stories were able to exert power in the form of a pending narrative or whether they became objectified as a target of stigmatization (e.g. ‘African AIDS’). The social worlds thus embodied in the plots reflected a relatively exclusive gated community, which barred the poor and disenfranchised.

According to the most recent AIDS epidemic update issued by UNAIDS, in 2002 three million people died of AIDS, five million people were infected by HIV, and 42 million people were living with HIV throughout the world (UNAIDS 2002c, 7). Furthermore UNAIDS now reports that women now make up half of the HIV cases in the world. The 2000 statistics on HIV infection are 50% higher than the projections of the WHO Global Program on AIDS (UNAIDS 2000, 2). Moreover, the statistics show, in Paul Farmer’s

words, a strikingly patterned epidemic in which poor people suffer from HIV disproportionately. At the same time, AIDS is increasingly falling off the agenda in many information societies. AIDS is thus increasingly becoming a disease of those denied the right to narrate their own stories (Bhabha 2003). As citizenship and social integration reemerges as one of the most significant markers of inclusion in society, the traditional aim of public health as the well-being of all people is in danger of being lost. The silence of counternarratives to dominant AIDS plots is thus profoundly dangerous.

## **11. Contextualizing Finnish Stories of AIDS**

This chapter analyzes how the unfinished plots of AIDS discussed in the previous chapter articulated societal understandings of HIV/AIDS both as an epidemiological disease and social phenomenon in Finland. I therefore take a linear focus based on the chronological events of the Finnish AIDS epidemic to explore how global plots of AIDS shaped the growing epidemic in Finland. Starting with a discussion of how notions of *Finnishness* have been articulated, the socio-cultural, epidemiological and political issues related to HIV/AIDS are then briefly outlined to contextualize the Finnish situation. The unfinished plots discussed in the previous chapter are incorporated into the analysis to show the global/local nature of the pandemic. A timeline of the major events concerning the development of HIV/AIDS in an international and Finnish context is provided in Appendix 2. Finnish academic research on the non-clinical aspects of HIV/AIDS, particularly social science and mass media studies, is introduced to explore how Finns themselves have analyzed the phenomenon of HIV/AIDS in their society.

### **11.1 Articulating nationhood and disease**

Notions of the nation are almost always associated with images of health, virility and strength. The nation as an identity category naturalizes goodness, belonging and health by structuring hierarchies and relationships between members through the customs of cultural deference and behavior, the institution of the family and gender roles, among other issues. Through these social and cultural codes of behavior, the nation is constructed as a positive identity category for its members. However, notions of the nation do not remain static. They shift and change according to competing articulations of goodness and health.

The societal reaction to the onset of an epidemic tells a great deal about nations and their socio-cultural and political structures. Epidemics by definition represent a threat to the

health and safety of a nation. In Rosenberg's theory of epidemics as dramaturgic events, the crucial window of opportunity for moral panic and stigmatization sets in between the first act of an epidemic (progressive revelation) -- when it becomes apparent that an uncontrolled disease is loose in society -- and the second act of an epidemic (managing randomness), in which a managerial response is initiated. As Rosenberg notes:

Accepting the existence of an epidemic implies – in some sense demands – the creation of a framework within which its dismaying arbitrariness can be managed. Collective agreement on that explanatory framework may be seen as the inevitable second stage in any epidemic. (Rosenberg 1992, 282)

The sense of panic, threat and fear that often accompanies the seeming randomness of an epidemic thus tends to lead to public calls for, in Linda Singer's words, a strong managerial response (Singer 1993, 27). The way that a managerial response is constructed and articulated often reveals the constellation of power relations within a society, as well as divisions between members and non-members of the nation, through the fissures, hegemonies and exclusions of policies and practices.

In her social constructionist study of the cultural meanings of TB and AIDS in Finnish society, sociologist Tiina Hautamäki discusses two central discourses related to health and identity: the individualistic and collectivistic discourses (Hautamäki 2002, 140-143). Hautamäki claims that in the collectivistic discourse, a nationalist slant prevailed in much of Finnish literature on health until the 1960s. Hence, it was considered to be the duty of citizens as part of the nation to be healthy. This emphasis later shifted to focus on population-based risk management (Hautamäki 2002, 159-161).

As we saw in Chapter 6, public health has long been associated with notions of the nation. Initial efforts at public health represented collective action in western societies to raise the income level and living conditions of all people in order to improve hygiene and sanitation. These shifts had a tremendous impact on mortality rates and sickness rates throughout the western industrialized world. The shift pointed out by Emily Martin

(1994) from collective responsibility for health to individual responsibility can be seen in the increased emphasis on individualized explanations for illness. Hautamäki's finding that the nationalistic-collectivist discourse on health began to disappear in the 1960s to be replaced by a more individualized view. In Frank Mort's (1987) historical study of the development of health policy in England, he shows how medico-moral systems of knowledge and power were connected with the surveillance of sexuality. Hence health, knowledge and power, as Foucault clearly demonstrates, are interconnected. This shift would become particularly significant with AIDS where 'risk groups' (gays, migrants, drug users) would be singled out as separated from the Finnish nation.

## **11.2 The background to the Finnish context**

Many of the Finnish reactions to the onset of the AIDS pandemic can be linked to the international plots discussed in the previous chapter. However, there are certain features that were specific to the Finnish context. The socio-cultural context of Finland supported the hegemony of medical expertise in AIDS stories which, in some ways, contributed to heightened tensions regarding homophobia and racism. As we will see, despite some mention of migrants and AIDS, usually in the form of African AIDS, very few migrants themselves have ever been involved in the discussion. If the first decade of AIDS in Finland can be characterized, it is one of moral panic in the public at the same time that there was a growing consensus amongst experts of the need for non-judgmental public health and counseling services in the form of AIDS exceptionalism.

As we have seen in the previous chapter, HIV/AIDS was initially characterized as a 'gay disease' which linked a socially constructed homosexual identity with AIDS. In the early years of the pandemic, transmission of the disease was thought to be associated with a 'gay lifestyle.' This was true also in Finland as most scientific information concerning HIV/AIDS came from sources such as the CDC which labeled AIDS as a disease of male homosexuals. The Finnish context was not immune to virulently homophobic attitudes that had rapidly engulfed many western countries in the wake of the first signs of a major epidemic. The plot of gay plague posed deep threats to constructions of Finnish

masculinity. These attitudes can be tied to the fact that between 1983 and 1986, reported AIDS cases in Finland doubled annually, only to plateau in 1987 (Lähdevirta 1999), which tended to increase fears an impending plague. Moreover, the socio-cultural, political and legal circumstances of Finland surrounding attitudes towards homosexuality reinforced many homophobic biases which were then firmly associated with AIDS.

Another emerging plot in the late 1980s, African AIDS, coincided with increased migration into Finland, the start of a deep economic recession, and a growing xenophobia in Finnish society. Along with the general sense of moral panic in Finland, fears of AIDS borne by foreigners were often inadvertently reinforced by public service and news items that connected HIV/AIDS with images of a threatening outside world. The subliminal message sent by this type of information was to raise fears of sinister outsiders menacing the existence of the Finnish nation. These fears were similar to stigmatizing societal attitudes towards Finnish gay men who were sometimes constituted as threats from within to Finnish masculinity, and by implication ‘healthy sexuality’, in the early days of the epidemic.<sup>51</sup> Indeed, in many of the stories of AIDS in the first decade of the pandemic, we can see a convergence between traditional ideals of Finnish masculinity and fears of threatening of outsiders.

#### 11.21 A background sketch of the Finnish context

The plots of AIDS discussed in the previous chapter might provide an overall framework for organizing the events of the pandemic and assigning significance to them, but narratives and stories of AIDS exist within specific cultural histories and contexts and thus receive tacitly cultural meanings. It is impossible to discuss AIDS without considering issues related to blood, sexuality and death – all highly sensitive cultural matters – that are understood and viewed through a myriad of cultural and religious taboos, mores and norms. Hence it is worth making a brief thumbnail sketch of some

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<sup>51</sup> I am grateful to Tommi for this insight.

aspects of Finnish sexual and gender history preceding the arrival of HIV in 1983 in order to contextualize the Finnish story of AIDS.

In many ways, Finnish society has been very progressive in terms of gender equality in comparison to many other western societies. By the turn of the century, for example, Finnish women had the right to vote, rights for children born out of wedlock were guaranteed, and inheritance rights were equal between men and women. As the Finnish welfare state expanded in the mid-20th century, a comprehensive system for child and maternal care was set up after the Second World War which was provided free of charge to all citizens (Hermanson et al. 1993). Many social benefits, including maternity leave and child allowance, were established to secure women's economic position in Finnish society, though women's wage levels have remained less than men. A comprehensive family planning strategy was adopted in Finland in the late 1960s which expanded the right to legal abortion, reproductive health counseling and sexual health information in the school health services (Rimpelä et al. 1998).

Perceived sexual and social deviance had been criminalized in Finland for many years, but also became increasingly medicalized in the 20th century. The practice of eugenics, for example, reflected an attempt to improve the 'quality' of the Finnish population by removing those considered to be 'unhealthy'. The forced sterilization law enacted in 1935 was largely targeted at women and justified on medical grounds while the 1950 castration law was aimed at men and rationalized as criminal policy, though it often administered to the mentally disabled or mentally ill (Hietala 1996, 240-241). In both cases, eugenics policy was implicitly used to 'purify' the Finnish population. Moreover, though infidelity was no longer a crime by 1948, sexuality that was deemed to be 'deviant' continued to be criminalized: In the 1950s, an average of 55 people; and in the 1960s, 23 people, were criminally accused of being fornicators ('haureuden harjoittajaa') each year (Månsson 1984, 336).

The 1960s were a period of sexual revolution in Finland, as in many other western countries, as students agitated to change attitudes and overturn archaic laws, such as one

which prohibited unmarried people from sharing a hotel room. There were also many debates in the public arena regarding sexual policy in Finland. In 1970, the laws on involuntary sterilization and castration were overturned, and the abortion law was also reformed. Nevertheless, the difficult implications of the eugenics policies would not be widely discussed until the 1990s when information about the numbers and reasons for sterilizations in Scandinavia were brought out in academic publications which created a storm of controversy, particularly in Sweden (Broberg and Roll-Hansen, 1996).

In a nutshell, up until the late 1960s Finnish criminal, medical and social policies on sexuality and related issues therefore can be characterized as reinforcing and supporting a normative notion of heterosexual family life and sexuality. Sexual and gender deviance was gradually constructed as a medical issue. Health promotion played an increasingly prominent role in reproductive health policy by the 1970s (see Rimpelä et al 1998). As Finnish sexual health experts Ilsa Lottes and Osmo Kontula have argued that in the last three decades Finns have increasingly viewed sexual activity as an important part of health and well-being:

The positive attitude of Finns towards sexuality are a result of the combination of characteristics of Finnish society. One is the general acceptance of an egalitarian ideology, and another is the lack of strong religious forces that associate sexual health problems, and sex in general, to morality and sin. (Lottes and Kontula 2000, 331)

This description, however, overlooks the many erasures and absences in the broad Finnish definition of ‘healthy sexuality’ which has often been a byword for heteronormativity.<sup>52</sup>

Sex education was started in Finnish schools already in 1944, with the formal training of teachers at summer training sessions in sex education becoming common by the 1960s (Papp 1997, 17). In the 1970s, attempts were made at reform and a Sex Education

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<sup>52</sup> It should be emphasized, though, that other articles in the book do explore underrepresented sexual minority cultures.

Working Group was formed, but it was not until the 1980s and the discovery of HIV that a great effort was made to improve the knowledge of pupils (Papp 1997, 17-18). The notion of ‘healthy sexuality’ underlying the teaching of sex education, however, was normative heterosexuality. The law banning the public encouragement of incitement to homosexuality made the publication of information on gay sexuality and relationships virtually impossible.

There was very little systematic research was conducted in Finland on issues related to sexuality aside from one large-scale survey of adult sexual behavior that was conducted in 1971 (Sievers et al. 1974). Indeed, Rimpelä et al. suggest that the emergence of the AIDS pandemic made clear the glaring lack of research on sexuality issues (Rimpelä et al. 1998). Several research projects on a variety of issues were initiated in the late 1980s and sex research eventually achieved a permanent position at academic institutions (see, e.g., Kontula and Haavio-Mannila 1993, 1995; Lottes and Kontula, 2000).

### 11.22 Towards gay rights in Finland

It appears that attitudes towards homosexuality have traditionally been more conservative in Finland than, for example, its neighbor, Sweden. Homosexuality was decriminalized in Sweden in 1944. Yet, it was not until nearly thirty years later (in 1971) that Finland removed homosexuality from the list of criminal offenses after 82 years on the law books. Nonetheless, certain restrictions remained in the law books. A law (RL 20.9.2) prohibiting the public encouragement or incitement to homosexuality was only repealed in 1999.<sup>53</sup> As sociologist Olli Stålström points out:

The Finnish situation was further aggravated by lack of factual information about homosexuality up to the 1980s. Distributing information had for long been impeded by a censorship law unique in Western countries, the so-called prohibition of public encouragement or

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<sup>53</sup> “Any person who publicly encourages sexual relations between persons of the same sex shall be sentenced for incitement to homosexuality as provided for at which offence shall be punishable by up to six months imprisonment or a fine.”

incitement, [of homosexuality] which was passed on the basis of the illusion that homosexuality could be transmitted through information. Moreover, discrimination and stigmatization against homosexuals had long lived in Finland on the grounds of religion and medical science.<sup>54</sup> (Stålström 1988b, 22)

At the start of the AIDS pandemic, the important consequence of this law, coupled with the lack of research on sexuality, was to hinder the dissemination of accurate and factual information concerning homosexuality and sexual practices (Stålström 1983, 50). This lack of information combined with the prevalence of medicalized heterosexist attitudes contributed to the lack of sensitivity and blatant prejudice with which some medical professionals viewed gay men in the early days of the epidemic.

Until 1981 homosexuality was officially considered to be an illness in the Finnish diagnostic manual. The Finnish National Organization for Sexual Equality (SETA) was founded in 1973 with the aim of including people of all sexual orientations and genders to create an umbrella organization to change social attitudes and laws. The gay liberation movement in Finland differed from many in other western countries in its emphasis on inclusion of all people, regardless of sexuality or gender, in the attempt to repeal repressive laws and attitudes. As Olli Stålström wrote in 1983:

An interesting aspect of the Finnish gay rights movement has been the great emphasis on the integration of people in the movement regardless of age, gender, sexual orientation or political opinion. SETA is one of the few gay rights organizations where women work side by side with men in spite of occasional differences of opinion about the strategies and structure of the organization... A unique aspect of SETA is that it has always actively welcomed straight people to support its cause and work in it. Several of its board members have been straight and one of its chairpersons has been a straight woman Member of Parliament. [Now President of Finland] (Stålström 1983, 53)

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<sup>54</sup> Suomen tilannetta vielä kärjisti asi tiedon puuttuminen homoudesta aina 80-luvulle saakka. Tiedottamista oli pitkään haitannut länsimaissa ainutlaatuinen sensuurilaki, ns. kehottasmiskielto (RL 20:9.2), jonka säätämisen taustalla oli kuvitelma homoseksuaalisuuden tarttumista tiedottamisen kautta. Suomessa oli myös pitkään jatkunut homouden syrjintä ja leimaaminen uskonnollisin ja lääketieteellisin perustein. (Stålström 1988a, 22)

This way of organizing closely mirrored the Finnish cultural tradition of consensus and integration to provide social cohesion, one legacy of Lutheranism (Clarke 1999a, 82-89). On the one hand, homosexuality was stigmatized in society because it was neither considered to be ‘normal’ *Finnishness* nor the embodiment of the traditional Finnish masculine or feminine ideal; on the other hand, its gay liberators united by creating an all-inclusive national organization, rather than a narrowly defined identity group, to challenge dominant beliefs. Change was therefore organized, as Stålström points out above, through the *integration* of Finns of diverse sexual orientations and genders into a *national* movement. As we will see below, it will be precisely this point – the integration into a national movement to advocate social change – that proves problematic for migrants in Finnish society. The ambivalence with which migrants are encountered in Finnish society, and their construction as outsiders and therefore not part of the nation, means that the traditionally inclusive methods of organizing used by homosexuals and the disabled, for example, under the banner of a unified national movement for social change may not be applicable to ethnic minority and migrant social movements.

The 1980s was therefore a decade in which gradual changes in laws and attitudes towards homosexuality in Finland began to occur. At the same time, homosexuality was just being struck off the list of psychiatric disorders and the public encouragement or incitement to homosexual relations remained a crime. Significantly, the 1980s was also a period in which the number of migrants entering Finland increased along with xenophobic and racist attitudes within the host society (see, e.g., Jaakkola 2000). Hence when Finnish stories of AIDS are explored, it is important to recognize that while sexual minorities began to receive a modicum of greater acceptance and human rights in mainstream, heteronormative Finnish society in the late 1980s, immigration was just starting to increase with the corresponding societal reactions of curiosity, fear and dread.

### **11.3 AIDS arrives in Finland: The 1980s**

The first information about AIDS in Finland was given to the general public by SETA. In the autumn of 1982, SETA published the first article on HIV/AIDS. At the same time, a

social worker, Jussi Nissinen, started health education groups which created and disseminated what little information was known about HIV/AIDS. Many members of SETA apparently felt that they needed to instigate activities because they felt that no one else would do it for them. SETA took action in 1982 by making an initiative to the Helsinki City Social and Health Care Services STD clinic to enhance cooperation and to particularly target the area of HIV, though as Stålström noted: "...specialists in venereal diseases were reluctant to cooperate."<sup>55</sup> (Stålström 1996, 5) The STD clinics were good places to contact gays because they formed a distinct clientele that was familiar to clinic staff. As the AIDS epidemic progressed in Finland, it would be initially more difficult for hospitals, which had to cope with boyfriends for the first time, to adjust to culturally appropriate ways of providing support and care to members of the gay community (Tommi interview 2002). In short, even if their social or sexual identity was not always recognized by practitioners or the health care system itself, gays, like other population groups of Finns, remained part and parcel of the national social and health care system.

The plot of gay plague was the primary framework for understanding AIDS in a Finnish context in the first days of the epidemic. As noted in the previous section, the plot of gay plague focused on constructions of gay identity as the main risk factor of contracting HIV. This plot became deeply entrenched as an explanatory factor in the Finnish context partly because social factors, such as the fact that homosexuality remained illegal and medically defined as a sickness until the latter part of the 20th century. Hence the cultural preconditions of heteronormativity provided the foundation for the labeling of AIDS as a disease of deviance largely because gays continued to be constructed as outsiders within the Finnish national community.

By the time the first case of AIDS in Finland was confirmed by physicians and SETA, in June of 1983, there had already been over 50 articles in the evening tabloids, often with screaming headlines that played on people's fears. One example from the evening tabloid

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<sup>55</sup> Sukupuolitautilääkärit suhtautuivat kuitenkin vastahakoisesti yhteistyöhön.

*Ilta-lehti* was: “AIDS devours its victims before your very eyes AIDS.”<sup>56</sup> (Stålström 1996, 8; Stålström 1988a, 119) Reporters prowled outside hospitals hoping to get the opportunity to catch a photo of a person living with AIDS. The lurid coverage of AIDS was traumatizing to many people seeking help and raised an atmosphere of moral panic in Finnish society that continues to reverberate in the fears many people living with HIV/AIDS still experience in having their seropositive status revealed.

In 1983, as the first AIDS case was officially diagnosed in Finland, the medical field began to slowly focus on the issue of AIDS as a potential health crisis. As AIDS was initially defined within the plot of gay plague, there was, nonetheless, a considerable gap between social knowledge of the gay community in Finland and medical research. Controversy surrounded one of the first medical studies on HIV and gay men as evidence suggested that ethical considerations regarding ensuring the privacy of clients was not maintained. More significantly, from the perspective of developing research on AIDS, similar to the CDC as seen in the previous chapter, some of the Finnish medical researchers in the early days of the AIDS pandemic demonstrated little knowledge of the gay community. In a written complaint to the national medical science committee of the Academy of Finland, the chairman of SETA, Jorma Hentilä, stated:

During the research project it has become apparent that those conducting the research do not have adequate knowledge about the lifestyle, personal relationships or meeting institutions of homosexual men and women, nor about the objectives and activities of organizations that seek sexual equality... This deficiency in basic knowledge may lead to incorrect conclusions and generalizations about the lifestyles of homosexuals on the basis of medical research.<sup>57</sup> (Hentilä 1983)

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<sup>56</sup> AIDS syö uhrinsa silmissä.

<sup>57</sup> Tutkimusprojektin aikana on käynyt ilmi, ettei tutkimuksen tekijöillä ole riittävää tietoa homoseksuaalisten naisten ja miesten elämäntavasta, ihmissuhteista tai tapaamisinstuutioista tahi seksuaaliseen tasavertaisuuteen pyrkivien järjestöjen tavoitteista ja toiminnasta...Perustietojen vajavaisuus saattaa johtaa virheellisiin homojen elämäntapa koskeviin johtopäätöksiin ja yleistykseen lääketieteellisen tutkimuksen tulosten perusteella.

The point made by Hentilä was very significant because it drew a clear line between the power of medical research findings and the social construction of identity. Hentilä indicated that there were potentially serious consequences of medical research on an emerging disease which were based on false interpretations of the behavior of the target community. This dispute reflects the fact that the sociogenesis of disease is often neglected or not recognized by many epidemiologists and bench scientists (Farmer 1999, 40). The lack of insight into the meanings of social practices among a particular group can cause scientists to come to erroneous conclusions regarding the transmission of a disease. Consequently, these conclusions can be used to further stigmatize groups whose social practices are not widely understood in mainstream society.

Though the main medical researcher in this project later wrote that the ‘gay movement’ was responsible for creating a subculture that created the preconditions for the spread AIDS (Valle 1987, 48), there were important grounds for Hentilä’s complaint, namely that homosexuality tended to be constructed as other and dangerous, notion which were based on misinformation or misguided conclusions. A consolidated, essentialist category of gay men, in other words, appeared to be posited as a risk identity per se. The association of ‘gay identity’ with the new emerging disease thus became the predominant plot of AIDS in Finland in the early 1980s. However, at the same time, resistance to the stigmatizing of gay identity and AIDS gained greater impetus in some sections of the gay community.

HIV/AIDS statistics in Finland began to increase in the mid-1980s due to the progression of the international pandemic, growing awareness of HIV and the development of a reliable HIV test. Moral panic about AIDS began to peak in Finnish society in the mid-1980s in the wake of the first reported death from AIDS and growing debate over the what would constitute a proper approach by authorities to the emerging epidemic. Many medical experts weighed in with opinions in the newspapers. One physician, for example, suggested in the main Finnish daily newspaper that Moses may have had good medical reasons for prohibiting disease-spreading behavior like homosexuality (Vaheri 1985). There were divisions within the Finnish medical community on the most appropriate

approach to HIV/AIDS. One vocal camp believed that a strong managerial response, which could potentially include quarantine, was necessary. Another camp in public health, which had a lower profile, recognized the importance of community involvement from the beginning of the crisis.

HIV/AIDS was first understood in Finland through the plot of gay plague and the plot of the gay lifestyle. Finnish society turned to medical authorities to formulate an appropriate response. This reflects the fact that Finland tends to have a corporatist orientation, in Rejali and McElroy's framework, to towards public problems (Rejali and McElroy 1997). In this sense, a corporatist orientation reflects a reliance on administrative expertise rather than community negotiation to define and intervene in social and health issues. This had a strong impact on the development of policies as well as decisions regarding which parties were to be included in the discussion on AIDS. Michael Pollak noted in his 1994 comparative study of European response to the AIDS pandemic:

In contrast to The Netherlands, the Swedish and Finnish AIDS state committees and advisory committees (created in 1984 and 1985) were rather medically dominated with no gay representatives. Intensive contacts between health services and gay organizations exist at the regional and local level. In both countries, HIV was defined legally as a venereal disease. This opened the avenue for state intervention including the closing of gay saunas, anonymous registration and surveillance of HIV+ people, compulsory partner-tracing programs and, in Sweden, the possibility of isolation of HIV carriers in case of noncompliance. This administrative approach reflects the tradition of preventive medicine as a means of social control. (Pollak 1994, 13-14)

In 1985, the Finnish government set up the first AIDS Advisory Committee which consisted of experts from the medical field, the Finnish Red Cross, as well as members of sexual equality organizations, though the committee had a strongly medicalized perspective.

Grönfors and Stålström pointed out the limitations of this approach:

The powerful position of doctors in society meant that the interests of the medical profession were given priority over ethical considerations in information production and dissemination on AIDS. What would have happened had they taken into account right from the beginning the societal and emotional aspects of AIDS and had included in the working groups representatives of all concerned parties? Instead of limiting the issue to individual medical problems, the working group would have been forced to look at the situation of gays in the wider societal context as a discriminated and stigmatized minority, a subject which would have been rather more complicated and uncomfortable for the state and medical profession. (Grönfors and Stålström 1987, 60)

The earliest research in Finland on HIV/AIDS was based on medical science, rather than social science. This meant that many of the social categories created as risk groups were not initially analyzed from a social science perspective. The implicit faith in the wisdom of the medical profession and egalitarianism of the national health service in Finland represented a departure much of the controversy surrounding the plot of the politics of treatment which was prominent in the United States and other many other Western European countries. Indeed, the plot of the politics of science had little resonance in Finland where four-fifths of the Finnish public trusted the information given by the mass media about AIDS and three-fourths agreed with the AIDS prevention efforts by the authorities (Kunelius 1988, 106).

The founding of the Finnish AIDS Council on 13 October 1986 was one of the major milestones in the history of the AIDS pandemic in Finland. Established by SETA, the Finnish AIDS Council remained under its control for nearly a decade until its eventual independence through the founding of the HIV Foundation in 1997. SETA continues to play a significant role in the HIV Foundation as, according to the bylaws, SETA has the right to select four of the six members of the governing board of the HIV Foundation (HIV Foundation Bylaws § 5). Many of the same people active in early AIDS awareness through SETA continued on to work at the AIDS Council. Most significantly, it was the first non-governmental organization to begin working specifically with HIV/AIDS on a

professional level. In the decade after its founding, the Finnish AIDS Council gradually opened regional offices throughout Finland. A large amount of the work of the Finnish AIDS Council dealt with counseling the ‘worried well,’ who flooded phone lines. Nonetheless, the core client group of the Finnish AIDS Council throughout the 1980s was homosexual men. Throughout the decade, AIDS remained a highly stigmatized disease directly associated with the plot of gay cancer and homosexual lifestyle. Hence the Finnish AIDS Council played an important role as an advocate for the rights of its gay clients in employment, housing and other essential areas, though in a less ‘in your face’ manner than many AIDS activist groups in western countries with a more pluralist administrative culture.

One positive result of the struggle by SETA to have AIDS recognized as a pressing health concern, and eventually to contribute to the establishment of the Finnish AIDS Council, was that it began the process of raising issues of vital importance to the gay community to public awareness. The plot of AIDS as a gay lifestyle, as discussed in the previous chapter, associated AIDS with a specific set of social practices constructed as a stereotypical ‘gay lifestyle.’ Counternarratives to the plot of AIDS as a gay lifestyle thus tended to slowly validate or legitimize the diverse social practices of gay communities, which underlined the fundamentally common humanity of gay people, and expanded definitions of normality (Altman 1988). Among the changes brought about by the community activism engendered by these counternarratives were legal changes in the definition of next-of-kin as well as more culturally appropriate information and care targeted to the needs of gay patients, though it would take many years for these changes to take effect. Increased recognition of the impact of these counternarratives would eventually contribute to the implantation of the plot of AIDS exceptionalism on Finnish soil.

Controversy over the appropriate managerial response to AIDS initially focused on the issue of the ethics of testing. Initially, the largest daily newspaper in Finland, *Helsingin Sanomat*, supported the testing of designated risk groups (Kunelius 1988, 92). Fears of discrimination by those in the category of risk group, specifically gays, were dismissed

by mainstream media which trying to calm the public in the midst of moral panic, as the editorial argued:

Certainly, SETA's fear of discrimination may be justifiable. However, in this kind of a situation it is hardly possible to act on the basis of the bias of one group.<sup>58</sup> (*Helsingin Sanomat* 3.4.1985)

There was an ongoing debate in the Finnish Medical Journal for many years in the late 1980s and early 1990s over the merits of a hard or soft line in the application of public health law to AIDS cases (Hautamäki 2002, 44-46). Despite the initial salvo by the most vocal advocates of harsh measures towards potential 'AIDS carriers', these hysterical attitudes began to fade away after the moral panic in Finland eventually subsided and the WHO guidelines were broadly accepted.

Though HIV tests were routinely conducted in central hospitals in the early 1980s, after a provincial court ruled that this was not legal, and not in keeping with emerging WHO guidelines, Finnish policy changed. Mandatory HIV testing was considered a violation of constitutional rights and as Risto Kunelius terms it, a 'Finnish line'<sup>59</sup> was developed. This line emphasized the role of education and prevention methods:

The Finnish policy has been chosen: attempts are made to enlighten people to be more responsible for their sex lives; they are urged to take more tests and encouraged to use condoms more commonly.<sup>60</sup> (Kunelius 1988, 59)

There was widespread public faith in Finnish authorities to deal with the threat of AIDS and few political challenges to the guidelines drawn up by the government. The Finnish response to the AIDS epidemic can be characterized as a national consensus-oriented and public health-based strategy. The plot of AIDS exceptionalism as a basis for care was

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<sup>58</sup> Setan syrintäpelko saattaa tietenkin olla aiheellinen. Mutta tällaisessa tilanteessa tuskin voidaan toimia yhden ryhmän ennakkoluulojen perusteella.

<sup>59</sup> 'Suomalainen linja.'

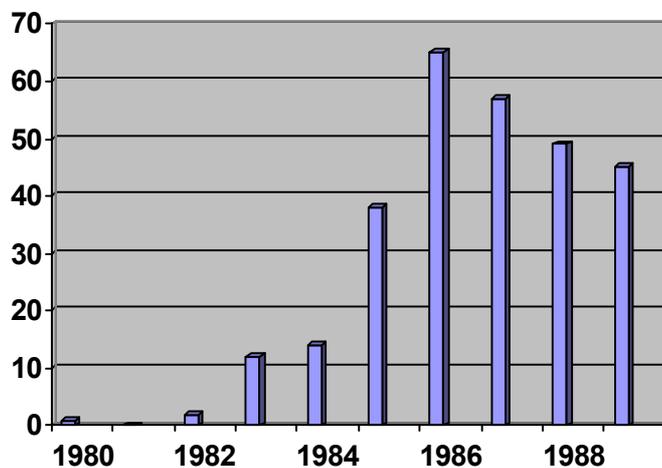
<sup>60</sup> Suomalainen linja on valittu: kansaa pyritään valistamaan vastuullisemmaksi sukupuolielämässään, testeissä kehoitetaan käymään enemmän, kondomin käyttöä pyritään yleistämään.

thus accepted with little resistance in Finland, despite the fact that public stigma against people living with HIV/AIDS has remained strong.

The Finnish epidemiological surveillance system designed and maintained by the Finnish Public Health Institute (KTL) is one of the most efficient in the world. In Finland, there are two categories of infectious diseases: reported and notified diseases. Reported diseases include those for which there is no compulsory testing or treatment while notified diseases are considered to be a danger to the general public. Syphilis, for example is a notifiable disease. The law permits mandatory treatment in certain circumstances. However, any disease that falls in the category of compulsory treatment requires that an effective treatment is available, which has not been the case with HIV/AIDS. Epidemiological data was collected anonymously from health care centers, hospitals and HIV testing centers. The clarification of Finnish public health guidelines regarding anonymity and epidemiological coding procedures ensured a high level of accuracy and ethical practice.

After a peak of diagnoses in the mid-1980s, HIV infections began to decline in Finland. The majority of infections in the 1980s were among gay men. Here we can see a table of epidemiological data of the progression of HIV in Finland in the 1980s:

### Notified HIV Infections in Finland (1980-1989)



Source: Finnish Public Health Institute, 2002

While a Finnish line was being constructed in public health in accordance with WHO guidelines and targeted at the general Finnish public, the lacunae of foreigners remained. Immigration was a new phenomenon in culturally homogeneous Finland and there was little experience with cultural diversity in the social and health care services. In addition to the moral panic over the emerging AIDS epidemic, in many ways a moral panic could also be detected in Finnish society over entry of the first foreign students at Finnish institutions of higher learning in the mid-1980s, particularly male African students. The dominance of the plot of African AIDS in popular perceptions of AIDS raised fears of a potentially xenophobic brew of contagion, sexuality and cultural hybridity erupting in Finnish society.

In 1987, a scandal erupted in the small town of Kotka when African students were accused of being 'AIDS carriers' by a local paper. Foreign students reacted against being stigmatized as 'AIDS carriers'. One tabloid interviewed the students and by giving them a voice in articles on the controversy attempted to calm the xenophobic tone of much of the public debate on the issue (Nikupaavo-Oksanen 1987, 89). Nonetheless, many foreign

students were required to take HIV tests when entering Finland. In 1987, one migrant made a complaint to the Ministry of the Interior:

According to [the complainant], forced testing of foreigners is an unfortunate example of how foreigners must become the scapegoats when the Finnish conscience must be cleansed. He asks whether there are not other Finnish risk groups that should be monitored, and whether it has been researched how many Finns have contracted AIDS from a foreign student living in Finland. From the writer's viewpoint, the fact that the demand for testing is targeted precisely at foreigners seems to be unjustified discrimination and a search for scapegoats.<sup>61</sup> (Nikupaavo-Oksanen 1987, 100-101)

There was a public discussion on whether foreign students should take compulsory HIV tests before being allowed to enter Finland (Huotari 1999, 25). Members of the Finnish AIDS Council demonstrated in front of the Old Student House in Helsinki in 1987 to protest the secret testing of African students.<sup>62</sup> The Finnish line that was being constructed at the time strongly mirrored the plot of AIDS exceptionalism and the notion of a policy of compulsory testing for foreign students would soon be dropped. However, the position of migrants within this policy would remain anomalous in many ways.

One major difference between the foreign students of the 1980s and migrants in the 1990s was the different socio-economic and educational background. There were very few foreign students in Finland in the 1980s. Most foreign students during that time were married to Finnish citizens or had scholarships at universities. There were very few private foreign students. Some foreign students were SWAPO or ANC members, sponsored by the Finnish government or non-governmental organizations. They remained closely involved with liberation struggles in their homelands, had experience with political resistance and viewed their stay in Finland as temporary. These students

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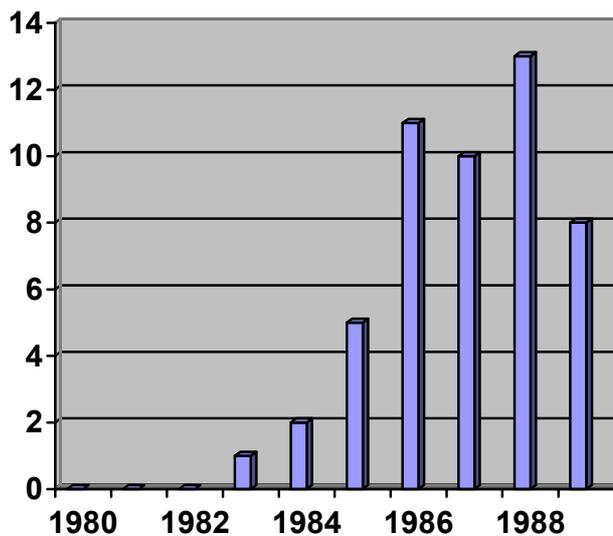
<sup>61</sup> Hänen mukaan pakkotestaus ulkomaalaisille on valitettava esimerkki siitä, että ulkomaalaiset saavat toimia syntipukkeina, kun suomalaisten omaatuntoa täytyy puhdistaa. Hän kysyy, eikö olisi löytynyt muita suomalaisia riskiryhmiä, joita pitäisi tarkkailla ja onko tutkittu, kuinka moni suomalainen on saanut aids-tartunnan Suomessa asuvalta ulkomaalaiselta opiskelijalta. Se, että testausvaade on kohdistunut nimenomaan ulkomaalaisiin, tuntuu kirjoittajasta perusteettomalta syrjinnältä ja syntipukkien haeskelulta.

<sup>62</sup> This information was given to me by Olli Stålström who participated in the protest.

therefore were articulate, educated and willing to speak out for their rights, though they were extremely few in number. Hence the threshold to challenging stigmatizing attitudes by the government and society was not as high as it would later be, though many foreign students did not feel they had a stake in Finnish society because their stay was intended to be temporary. The fact that their stay in Finland was often perceived as a stepping stone also meant that there was little continuity in the struggle for equal rights.

Immigration patterns in Finland radically shifted in the late 1980s with the arrival of more asylum seekers, refugees, and foreign students as well as the fall of the Soviet Union and consequent free movement of people across the border all contributed to the diversification of foreign residents. We can thus talk of the emergence of the migrant in Finland in the late-1980s and early 1990s. Many migrants intended to stay in Finland unlike many of the foreign students of the 1980s. Moreover, many migrants arrived in Finland after forced migration experiences which involved significantly greater health risks and difficulties in gaining access to the Finnish social and health care system. We can see that the number of migrants diagnosed with HIV increased with the spike in immigration in the late 1980s:

Notified HIV Infections of Migrants living in Finland (1980-1989)



Source: Finnish Public Health Institute, 2002

Arriving in a country with little cultural diversity and no large immigrant communities with organizational capacity meant that migrants largely remained unorganized in Finland. One significant outcome of SETA's involvement with the issue of AIDS from the very beginning was that the gay community had a voice and eventually became a stakeholder in policy discussions. This has been quite different with migrant communities who have been largely excluded from discussions for several reasons. Authorities have been slow to recognize the importance of involving migrant communities as key stakeholders in HIV policymaking. Furthermore, due to the enormous diversity of migrant communities, which have been in Finland for a relatively short period of time, there have not been community based organizations to represent migrants. Migrant communities therefore had few resources to resist xenophobia as embodied in the plot of African AIDS.

Despite the moral panic in Finnish society in the 1980s and the need for the staff to readjust cultural assumptions about gay people, according to Tommi, the care treatment in hospitals was very good from the beginning (Tommi interview 2002). For people living with HIV, many found it difficult to manage with strong managerial stigmatizing response when living with own fears. As Tapio Koskimaa reported in his master's thesis research on people living with HIV, the first reaction to testing positive was the fear of death and the fear of stigmatization. Thoughts of suicide often followed. The creation of the Finnish AIDS Council was thus necessary and provided strong psychosocial support for many people who had nowhere else to go. Nonetheless, there were few, if any, migrant clients coming to the Finnish AIDS Council in the 1980s. It is difficult to speculate in hindsight what the precise reasons might have been for the lack of migrant clients. However, the lack of culturally appropriate prevention, information, therapy and outreach efforts as well as involvement of migrant communities from the beginning as equal stake could be a possible reason why migrants did not seek out services.

Perhaps the biggest problem for PLWHA in Finland was job discrimination. As noted earlier, work has been intrinsically associated with the notion of *Finnishness*. Not being a member of the labor force thus had deep implications of social exclusion. Koskimaa

underlines that work had great significance in the lives of PLWHA. The majority of Koskimaa's interviewees did not inform their working places of their seropositive status despite the fact that job discrimination against HIV positive people was against the law due to fears that they would anyhow be fired and their relationship with other workers would be badly affected (Koskimaa 1993, 53-54). For migrants who face a myriad of hurdles entering the Finnish workforce (see Forsander 2002), HIV/AIDS was yet another discriminatory factor.

As Tommi, a man living with HIV, described in an interview, the main issues surrounding HIV in 1980s were the fear of disclosing one's seropositive status not only to wider community but also within gay community. There were fears of rejection, of being excluded, and of never having sex with anyone else again. Job discrimination was also a major concern. As Tommi stated:

There were some highly publicized cases of people being fired after having been found out to be HIV positive [...] and I think that when employers realized that they were likely to get into the headlines if they did something like that then adopted new methods. They just do sort of passive discrimination – the person doesn't get promoted because he's likely to pass away any day or his job description is changed so that he doesn't work in an operation theatre in a hospital or in a kitchen in a restaurant where there are sharp knives. But I think that the bigger problem was in people's minds. People were afraid of things like that happening more than cases actually happened. (Tommi interview 2002).

Fear thus remained a dominant theme of living with HIV in the 1980s. This was particularly attached to the fact that there was no known treatment for AIDS and it inevitably led to relatively rapid death. The trauma of the early sensationalist coverage of AIDS patients continues to resonate deeply in the psyche of many PLWHA.

To summarize, the plots of gay plague and the gay lifestyle resonated deeply within Finnish society in the early years of the AIDS pandemic. The plot of the politics of treatment, though, had little resonance in the Finnish context due to the universalistic structure of the welfare state. Finnish gay men and migrants nonetheless became

identified as the embodiment of risk to the nation. The gay community was better able to respond to the challenge of stigmatization due the action of its established organization, SETA, which became an important part of developing Finnish AIDS strategy. SETA continually challenged stigmatizing and controlling attitudes by the medical profession and worked together with the public health camp to develop the Finnish line of AIDS care and prevention which was based on human rights. By the end of the 1980s, Finnish AIDS strategy began to closely mirror the plot of AIDS exceptionalism in many aspects.

#### **11.4 AIDS in Finland in the 1990s**

The plots of Finnish stories of AIDS began to shift in the 1990s. With the emplacement of health prevention and promotion systems regarding HIV/AIDS, the establishment of the Finnish AIDS Council and Body Positive as well as the adoption of WHO guidelines, Finland had developed a well-functioning system of care for HIV/AIDS. After the hyperbolic impact of the plots of gay plague and the lifestyle hypothesis, the plot of AIDS exceptionalism became the most prominent aspect of Finnish AIDS policy, despite the fact that AIDS largely remained a faceless disease in Finland.

After an initial silence, AIDS in Finland was explored in several master's theses and doctoral dissertations. The topic of AIDS was analyzed in the fields of journalism (Hirvonen 1993; Kumpulainen 1992; Kunelius 1988; Nikupaavo-Oksanen 1987), law (Matikkala 1995; Rantanen 1999), social policy and sociology (Karhinen 1997; Stålström 1988a), public health and medicine (Kangasniemi 1996; Koskimaa 1993; Rantakari 1990) and education (Helle 1999). In the 1990s, there were at least three master's theses and a dissertation in Finland that used the methodology of deep theme interviews of PLWHA (Huotari 1999; Kangasniemi 1996; Koskimaa 1993).

According to Koskimaa's findings, HIV/AIDS remained an illness which was not generally accepted in Finnish society. This caused many PLWHA to hide their seropositive status from friends and family, though rarely from their partners, who were considered to be a major source of strength (Koskimaa 1993, 64). Many studies found

that Finnish PLWHAs listed work, friends, and the activities and network of the Finnish AIDS Council to be the most significant sources of support in coping with their illness. It is important to note, however, that the main three pillars of support (work, friends and the activities of the Finnish AIDS Council) were frequently unavailable to migrants far from home.

Kari Huotari's doctoral dissertation movingly explored the important connection between human and civil rights, social taboos and the everyday strategies for survival among people living with HIV through in-depth interviews (Huotari 1999). Huotari makes the point that the conflation of these complex factors makes the everyday situation of PLWHAs unique. Hence, as Huotari argues, hiding one's HIV status in a society that continues to stigmatize HIV as a disease of deviants becomes a survival strategy and not necessarily a statement of fear.

Perhaps one reason that stigmatizing attitudes remain embedded in mainstream Finnish society is the lack of information and personal narratives of HIV targeted at the general public. The two main books that were written for the general public were published in the 1980s (e.g. Saarinen 1992; Stålström 1987), however there has been little since then. One of the major differences between Finland and, for example, the United States is that discussion in Finland is largely confined to experts and there are few narratives written by people living with HIV whereas there have been many popular books written about living with HIV in the US (see, e.g., Doty 1997; Monette 1988)<sup>63</sup> which have served to humanize people living with HIV/AIDS.

Combination therapies (also known as highly antiretroviral therapy [HAART]) came into widespread use in Finland in 1996 (Tommi interview 2002). HAART treatments were aimed at reducing the amount of viral load through preventing HIV from replicating itself. One consequence of the introduction of HAART treatments was the common

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<sup>63</sup> Of course, it can be argued that these HIV/AIDS narratives represent only certain communities affected by the disease.

misunderstanding that they represented a ‘cure’ for AIDS. This could be seen in some areas of public opinion which tended to think that HAART treatments meant that “the problem has been solved” (Tommi interview 2002) and there was no need for greater investment in prevention efforts. In fact, the most significant impact of HAART treatment was that more people are alive and have to cope with HIV longer, which brought along its own set of difficulties and problems. This meant that counseling services provided by the Finnish AIDS Council had to be adjusted to the needs of people living with a chronic disease, rather than just preparing for impending death. Indeed, by 1998 it was no longer possible to receive an automatic pension from the Social Insurance Institution (KELA) on the basis of HIV infection alone.

The Finnish government emphasized linking HIV with general STD prevention (Pollak 1994, 25). However, with the combination of emerging HAART treatments and the steep economic recession of the early 1990s, funding for AIDS awareness projects tended to languish. As noted in a publication that surveyed HIV/AIDS work with young people in certain European Union nations:

HIV/AIDS prevention has not been a very high priority. There was an economic recession in Finland in the first half of the 1990s. This led to cuts in public health services which especially affected prevention work. There have been few specific HIV/AIDS prevention projects in Finland during the past decade due, to [among] other things, the lack of financing. Even though the economic situation has improved towards the end of the 1990s, there have as yet been no benefits to the public health care sector or prevention work. (Forrest and Reid 2001, 31)

HIV/AIDS prevention work was therefore not considered to be a priority in the midst of budget cuts. Nonetheless, many fears persisted amongst the public about AIDS with the Finnish AIDS Council and Finnish Red Cross reporting a high number of ‘worried well’ calling. A medical study of the fear of AIDS among suicides conducted in Finland in the first half of the 1990s indicated that there may be a correlation between suicide among

clinically depressed people and hyperbolic media coverage of AIDS.<sup>64</sup> Thus, the deathly specter of AIDS retained a strong presence in the Finnish imagination.

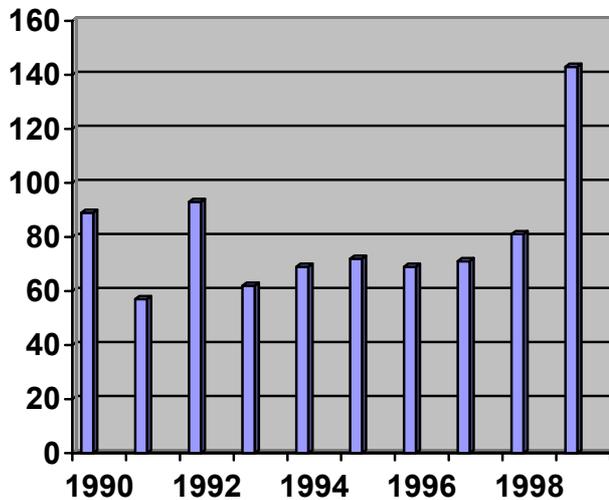
By 1995, real cooperation between the Finnish government and the Finnish AIDS Council began. At this time, the Finnish Ministry of Social Affairs and Health also began to embark on a more internationally-oriented policy. These cooperative ventures reflected the increasing understanding that global and regional collaboration was essential to mitigating the impact of the AIDS pandemic.

The HIV/AIDS situation in Finland began to change in the mid-1990s which can be seen in the development of several trends. Firstly, deaths from AIDS were down due to HAART treatments. Secondly, the rate of HIV infection remained stable until an explosive outbreak amongst drug users, primarily in the Helsinki metropolitan area, in the late 1990s.

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<sup>64</sup> “The fact that most of the suicide victims with fear of AIDS were clinically depressed and sought health care help during the last week of their lives, despite being somatically quite healthy, emphasizes the importance of identifying and understanding the phenomenon of fear of AIDS, but also of identifying and treating depression in the health care system...Newspapers wrote sensational pieces, including those about suicides committed due to fear of AIDS. All three Finnish studies reporting on AIDS fear-related suicides emphasized the role of the media and information campaigns in triggering the suicidal AIDS fear. Fear of illness in general, as well as fear of AIDS, seems to be exacerbated by sensational and topical media reporting.” (Aro et al. 1995, S196)

### Notified HIV Infections (1990-1999)



Source: Finnish Public Health Institute, 2002

Finnish epidemiological statistics indicated a shift in the types of population groups affected by HIV/AIDS. If HIV/AIDS was primarily considered a disease transmitted through unprotected homosexual contact in the early 1980s, by the mid-1990s it was increasingly associated with heterosexual contact and drug use. The changing epidemic found a rapid response in the corporatist professional administrative culture which quickly moved to implement harm reduction strategies.

One reason for this change was the social transition in neighboring countries from a socialist to a capitalist economy. The growing drug problem in Finland in the 1990s was certainly influenced by increasing social instability, poverty and vulnerability in the region. As Kyösti Urponen notes:

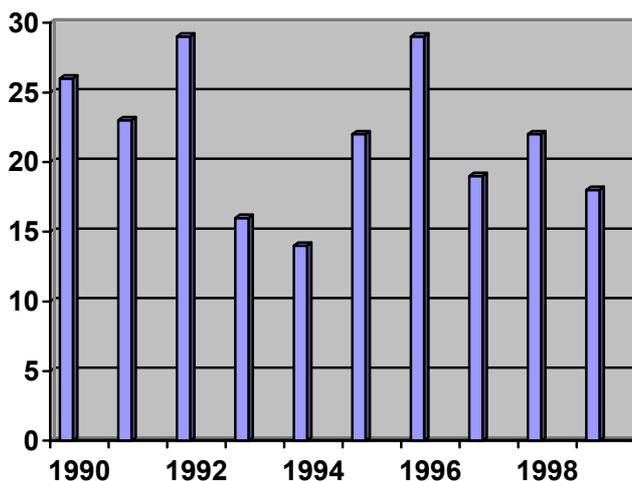
The link between HIV/AIDS and drugs means that the hidden structures and activities generated by the transition are a key factor underlying the problem. A good ground for the activity and market is provided by young people in difficulties who are fleeing the reality of their lives. (Urponen 2002, 101)

Urponen argues that the process of globalization often expedites the transfer of social problems from one area to another. Similar to Paul Farmer's point that social inclusion

and reduced social vulnerability is the best prevention policy, Urponen notes that the large-scale export of drug problems to Finland did not occur in the late 1990s, as was often expected, because ‘moral ramparts’ within the community remained strong (Urponen 2002, 103). In short, the social inclusion policies of the Finnish social welfare state can be seen as an important preventive measure for HIV/AIDS through its reduction of social vulnerability and poverty.

In Finland, one of the most vulnerable groups is migrants who do not necessarily have social welfare entitlements and are often in a precarious legal situation as asylum seekers or temporary residents. Many migrants lack a social network and have had traumatic migration experiences. Language and cultural differences also pose serious problems in care with migrants. Hence the significant sources of support cited by Finnish PLWHAs (work, friends and the Finnish AIDS Council) were often not accessible to socially isolated migrants. Despite the relatively large rise in the amount of migrants in Finland in the late 1990s, the number of migrants living with HIV did not rise appreciably. Here we can see in that the amount of migrants diagnosed with HIV remained relatively stable throughout the 1990s:

Notified HIV Infections of Migrants (1990-1999)



Source: Finnish Public Health Institute, 2002

There was some confusion among NGOs and governmental institutions over what would be the most appropriate way to approach the issue among migrants. Generally, this ambivalence resulted in few attempts to contact and inform migrants about HIV/AIDS (see Clarke 1999b, 2000, 2003a). Although vulnerability was recognized as a significant factor in HIV transmission, there was a tension between harm reduction policy of the Ministry of Social Affairs and Health and the criminalizing tendency of the Ministry of the Interior, particularly when it came to the increasing number of migrants in the 1990s.

A narrative plot that is very specific to Nordic stories of AIDS is the role of criminalization within corporatist welfare state systems of public health expertise. There have been several incidents in Nordic countries generally where individuals have been charged with attempted manslaughter by the intentional spread of HIV/AIDS. Many Nordic countries interpreted public health laws as criminalizing the ‘intentional’ spread of HIV. In Sweden, for example, it is illegal for people with HIV to donate blood, plasma or semen; in Denmark, it is illegal to have sexual relations repeatedly with a person who is unaware of the partner’s seropositive status (Europap 1999). Laws invoked to prosecute HIV transmission were thus based on intention to infect. This legal principle was fraught with difficulties because it focuses on the person living with HIV as having the sole responsibility for safe sex. Furthermore, evidence for knowledge of HIV seropositive status is difficult to establish in an intimate situation. Nonetheless, there have been several prosecutions which have resulted in fairly long sentences. How articulations of criminalization have been constructed as opposed to articulations of harm reduction are discussed further in Chapter 14.4.

The year 1997 was a turning point with the plot of African AIDS in a Finnish context as the case of African-American immigrant Steven Thomas hit the headlines. In the Steven Thomas case, the strong arm of the law came together with the plot of African AIDS. In 1997, a storm of publicity surrounded the Steven Thomas case. Steven Thomas, born in 1961, was an African-American man who had moved to Finland in 1991 from New York. He was married to a Finnish woman and had two children. Thomas was charged with attempted manslaughter on 13 December 1996 for having unprotected sexual relations

with women knowing that he was infected with the HIV virus. On 14 January 1997, the Finnish Criminal Police released an information sheet to the public that included Thomas' mug shot and called for Finnish women who may have had sexual relations with him to get tested for HIV.

This information sheet, reminiscent of an old western 'wanted dead or alive' poster, revealed the plot of African AIDS that resonated through mainstream Finnish attitudes towards migrants and HIV/AIDS in many respects. Firstly, the information is given only in Finnish, thus disregarding the possibility that people who are not fluent in Finnish might need such information. Secondly, the women who have had sexual relations with Thomas are described as 'victims' while Thomas is constructed as a 'carrier' – in other words, the women were constructed as innocent, while Thomas as a guilty predator. Thomas was portrayed as a dangerous DJ (aka 'Doggy Steve') who randomly picked up Finnish women partying at nightclubs in Helsinki. The growling mug shot of Thomas is also prominently displayed, a photo which was picked up by many of the tabloids and plastered on front pages throughout Finland, and even other Nordic countries. The plot of African AIDS emerged as a narrative of foreign threat towards Finland, through the embodiment of black men menacing the purity of Finnish womanhood. This narrative became a powerful image during a period in Finnish history marked by economic recession, high unemployment, and the shift from a country of emigration to immigration, increased female drinking and freedom.

In her social work master's thesis on the Thomas case, Katri Rintamäki utilized a textual analysis of news articles at the time and showed that tabloids regularly used terms such as 'HIV-carrier', 'HIV-Thomas', 'HIV-spreader' to refer to Steven Thomas while the Finnish women were referred to as 'women infected with the HIV virus' or 'HIV-positive victims'. The relationship of these women to Thomas, moreover, was generally termed as 'sex partners' or 'bed partners', with no deeper emotional ties mentioned (Rintamäki 1999, 72-76). Sari Karhinen, in a sociological master's thesis, read the Steven Thomas case as a series of 'us' versus 'them' constructions, both from the perspective of foreignness and sickness (Karhinen 1997).

Steven Thomas was eventually sentenced, after a closed courtroom trial, to 14 years for 17 counts of attempted manslaughter, the highest sentence ever given by a Finnish court.<sup>65</sup> The Thomas case became the defining event in the Finnish story of HIV/AIDS and migrants. It was the story of moral panic, xenophobia and irrational racist fears. The words used in many news articles about Thomas at the time (e.g. ‘carrier,’ ‘spreader’ and ‘killer’) reinforced the association with HIV/AIDS, death and the body of foreigners, particularly people of color (see Rintamäki, 1999, for an interesting discussion of the Thomas case in Finnish). The subtext of the Thomas story also closely correlated to African AIDS with the emphasis on the association of heterosexuality and promiscuity (see Patton, 2000). As Rintamäki showed in her analysis, the Finnish women involved in the Thomas case nonetheless remained innocent victims of the HIV-carrier Thomas. Indeed, the Thomas case was a cautionary tale for migrants – of the potent consequences of sexual contact with Finns as well as the level of blame and vengeance exacted by society when HIV/AIDS was involved. Furthermore, the Thomas case underlined the view that criminalization, rather than education, would increase safe sex practices.

Despite the fact that the Thomas case has received the greatest attention in public discussions of AIDS and foreigners in the Finnish context, there was a preceding case that has rarely been discussed. John Karara, a Rwandan refugee with Ugandan citizenship, was convicted of five counts of attempted manslaughter through the rape of five Finnish women while knowing that he was infected with HIV (van Krieken 2001, 381). Karara was sentenced to 11 years in prison and eventually deported on the grounds of his criminal conviction. The pattern of demonization and anxiety prominently displayed in the tabloid papers during Karara’s trial was a forerunner to what would occur some years later in the Thomas case.

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<sup>65</sup> A life sentence in Finland is generally calculated as 12 years. Therefore, Thomas’ sentence was two years over the maximum sentence. Thomas was also ordered to pay US \$63,000 to US \$73,000 to each of the five women he was charged with infecting with HIV. (reported by the Panos Institute, London, August 1997)

One of the important subtexts of African AIDS, especially when applied to black minorities in majority white nation-states, is the fear of sexual relations across racial and national lines. African AIDS, like most racist mythologies, relies on the pathologization of sexuality through constructs of essential difference (Bhattacharyya et al. 2002, 98-99). As Matthew Frye Jacobson notes in his study on the construction of whiteness in US society:

The policing of sexual boundaries – the defense against hybridity – is precisely what keeps a racial group a racial group...[T]hus sexuality is one site at which all the economic advantages, political privileges, and social benefits inhering in a cultural invention like *Caucasian* converge and reside. (Jacobson 1998, 3)

African AIDS in the cautionary tales of John Karara and Steven Thomas demonstrates the anxiety that Finnish society felt about migrants, particularly migrants of color, in the nation. These cases can also be seen as emblematic of the idea that AIDS is an external threat which can only be let in through sexual relations, similar to constructions of the gay plague that were conceived as threats to Finnish masculinity. As one interviewee noted, the commonsense belief in Finnish society was that a normal, decent person has nothing to worry about regarding AIDS (Tommi interview 2002). This ‘normal, decent person’ was thus constructed as a Finn who was not homosexual or having sexual relations with foreigners.

The Karara and Thomas cases were significant because they clearly showed that Finnish law enforcement officials were willing and able, and perhaps even under pressure, to impose penalties for the attempted spread of HIV. Indeed, there were several prosecutions of foreigners for the ‘spread of HIV.’ The Finnish idea of mutual responsibility in sexual relations was lost in these prosecutions. The idea of intent that framed the law insinuated that that the only purpose in having sexual relations was to infect the other person. Hence Steven Thomas was not only convicted of infecting others with HIV, but also of harbouring intent.

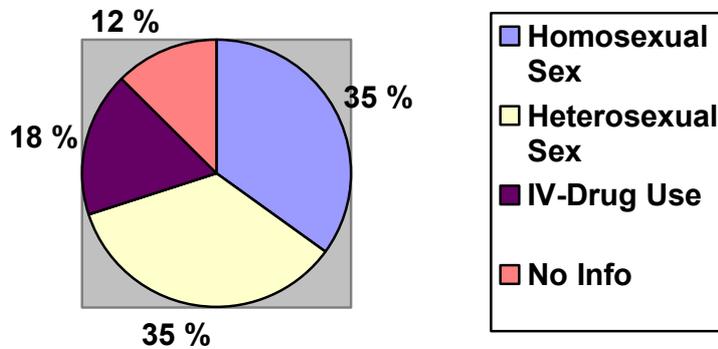
HIV remained relatively invisible in Finnish society throughout the 1990s because of low infection numbers (Tommi interview 2002). The vast majority of Finnish people are not personally affected by HIV/AIDS. According to Tommi, there have been changes in social attitudes amongst professionals in health care, particularly in Helsinki, due to AIDS pandemic (Tommi interview 2002).

There were two important trends in HIV/AIDS towards the mid-to-late 1990s. Firstly, women living with HIV began to emerge from the shadows, particularly through efforts by the Red Cross to develop support groups. Riitta Kangasniemi (1996) conducted an important study on women living with HIV. Secondly, a small explosive outbreak of HIV was seen in the intravenous drug using population of Helsinki. These trends indicated that the affected population groups in Finland had extended beyond homosexual men. Despite the fact that the plots of the gay plague and African AIDS remained strongly resonant in Finnish understandings of the pandemic, the epidemiological breakdown of people living with HIV/AIDS in Finland radically changed as more women, heterosexuals, migrants and drug users were diagnosed. Very few stories emerged to explicate the experiences of these new groups in the local AIDS epidemic which solidified their invisibility in Finnish society.

### **11.5 AIDS in 21<sup>st</sup> century Finland**

The epidemiological situation in Finland has indeed changed over the past two decades. Despite the strength of the plot of the gay plague in the public imagination, the epidemiological reality is quite different with a higher proportion of drug users, women and migrants represented amongst people living with HIV than gay men. According to the Finnish Public Health Institute, there were 1,406 notified cases of HIV infection in Finland as of 16 May 2002. In 2002, the breakdown of HIV incidence in Finland was the following:

### Means of HIV Infection



Source: Finnish Public Health Institute, 2002.

As Timo Sokura, the director of Body Positive, pointed out in an interview, from the very start of the pandemic, HIV/AIDS has been associated with all of the taboos of Finnish society and the western world, such as ‘deviant’ sexual behavior, drug use, prostitution and death (Sokura interview 2002). Hence it has been difficult to develop an open discussion in Finnish society about the disease, which demonstrates the limitations and contradictions of social constructions of a Finnish discourse on ‘healthy sexuality.’

The stigma that was connected with the plot of gay plague and African AIDS in the 1980s and early 1990s has been increasingly linked with drug users in the late 1990s (Sokura interview 2002). Lacking personal narratives, AIDS has consistently tended to be constructed as a disease of ‘otherness’ in the Finnish context. Nonetheless, it is important to point out that HIV is no longer viewed solely as a gay plague by the public, which represents an improvement over the early days of AIDS, though HIV does remain a stigmatized illness in Finland (Tommi interview 2002).

One of the important epidemiological changes in the Finnish AIDS epidemic has been the shift away from transmission by homosexuals towards transmission through drug use. Finnish government policy in the 21<sup>st</sup> century has emphasized harm reduction activities,

particularly through the opening of needle exchange clinics (see, e.g., Törmä et al. 2002). New systems were rapidly put into place in 1990s to combat the epidemic among drug users, unlike those infected in early days. This rapid reaction by authorities created significant harm reduction systems within the space of a few years. Despite efforts by the Finnish authorities, there continues to be a debate over harm reduction policies (which require contact with drug users) and repressive criminalization policies (which drive them underground). According to recent research, more young people under the age of 25 are infected through IV-drug use than sexual contact in Finland<sup>66</sup> (Forrest and Reid 2001, 25). Young drug users therefore represent a new challenge to Finnish HIV/AIDS support work as well as social and penal policies.

It is nonetheless important to recognize how far AIDS awareness has come in Finland, as Tommi said in an interview as he recalled when he tested positive in 1985:

Of course, that was a very different time from what we have now because there were no counseling services, no Finnish AIDS Council, nobody had a program for these people, so you just went home and suffered alone. And it was the same pretty much throughout the eighties. It was only the gay community affected and there were very few other people. (Tommi interview 2002)

The loneliness and isolation experienced by many in the early days of the AIDS epidemic has been alleviated to some extent through the development of the important activities of the Finnish AIDS Council. However, it should be pointed out – as Tommi himself notes - - that there was a strong connection between ‘the gay community’ that was singularly affected in the first days of the epidemic and the early grassroots organization of AIDS awareness and activism. The structure of organizations such as the HIV Foundation continues to be dominated by the main sexual minority association despite the fact that the populations increasingly affected by HIV/AIDS in Finland are not from the gay community. Indeed, four of the six members of the governing board of the HIV

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<sup>66</sup> As of 12 June 2000, 18% of new infections were among young people (under 25 years) while only 11% of sexual transmissions were reported among under 25 year-olds (Forrest and Reid 2001, 25).

Foundation are selected by SETA (HIV Foundation bylaws §5), though no other community organization is specifically named as having similar rights. This implies that much of AIDS awareness work in Finland is directed from the perspective of representatives of sexual minority groups with other groups, such as drug users, sex workers or migrants, largely excluded as significant stakeholders. Articulations of the needs of these special groups were often filtered through the corporatist tendencies of expertise in the Finnish welfare state. The dominance of certain groups as stakeholders and experts tends to reflect the constellation of power relations in Finnish society. These power relations and access to resources by particular groups is liable to have a significant impact on the recognition and quality of outreach and information services provided to other identity groups as well as has direct impact on these groups' access to culturally and linguistically appropriate services.

The plot of AIDS exceptionalism coupled with the Finnish welfare state ensured good social and health care for people living with HIV/AIDS. One main theme of Finnish care is that universal access to health care that was taken for granted as the right of every citizen and foreign resident registered within the social insurance system. This was considerably different than the plots in other countries and guaranteed a high level of medical care for PLWHAs. Narratives of striving to get into clinical trials had no resonance in Finland because all PLWHAs, who had social insurance cards, were eligible for the most appropriate treatment to their condition.

Perhaps most striking in the Finnish context has been the dearth of personal narratives in public about HIV. This fact has perhaps contributed to the view of AIDS as a disembodied medicalized or stigmatized issue. The experiences and lifeworlds of people affected by HIV/AIDS are largely relegated to the anonymous interview data of theses that are rarely read by the general public.

Of the 400 members of Body Positive, only three are willing to give interviews with names and faces (Sakari interview 2002). This reflects that fact that being out with one's

seropositive status is still not an easy matter. I asked Sakari about why people living with HIV were afraid of being public with their illness:

People are afraid of losing homes, jobs...their loved ones might turn their backs or something like that. But again, I think it's more in people's heads because I've been out with this disease for the last four years and nothing bad has happened. I have nothing to complain about. So, personally, I think that it is more about ourselves than we think. Of course, in earlier years I know that there are stories that people were thrown out of their jobs and apartments and so on. (Sakari interview 2002)

Tommi added:

It's still quite impossible to be openly HIV positive in Finland. Well, I don't think the situation is so different – I don't know so many openly HIV positive people in any country. And I wouldn't advise...people have asked me and I wouldn't advise anybody to go public as long as they are working. If they want to keep their job, if they want to get promoted...don't do that. (Tommi interview 2002)

As the interviewees underlined, discrimination against people living with HIV/AIDS is still prevalent in Finland. Silence and invisibility has thus become a survival strategy for many living with HIV/AIDS. Both Tommi and Sakari emphasized that it is easier to be public with HIV in Helsinki than in rural areas. This urban/rural divide can be seen in many western industrialized countries and reflects the ongoing stigma that being seropositive carries in smaller communities. Sakari reported that he was supposed to go speak at a rural school in Finland, but the trip was cancelled by the local mayor who told him to stay away because 'we don't have HIV.' Popular fears of HIV thus appear to remain deep in Finnish society at the same time that surveys of future professionals report more positive attitudes towards PLWHAs (Välimäki et al. 2000). These contradictions can perhaps be seen as part of the process of normalizing AIDS.

When I asked Sakari what it was like being public with HIV, he said:

In the beginning, it was only positive. But then this spring when three of my very close friends have got the disease and I was 'what?'...They've

been with me for so long, they should know better. It's like I'm too positive in public, if I were more sick they would take it like to be more aware and be afraid. So, these days I sometimes think that maybe we should come with some really sick people so they could see that this disease is really very scary. It's like people are not afraid any longer... It's been shocking this spring, three really very close friends. And then realizing that they don't understand that if everything goes well with me doesn't necessarily mean that it's ok for them. If medication works for me, it doesn't always mean it works for them. (Sakari interview 2002)

Visibility, particularly in the age of sound bites, can therefore be a double-edged sword in the sense that reducing fears about HIV can also increase the sense of normalcy and notion that HIV is not a serious disease. Detailed and complex narratives about living with HIV/AIDS (e.g. Monette 1988) would be an important counterweight to superficial descriptions or soundbites.

As a new generation comes to maturity in Finland, which does not necessarily have memories of the early days of the AIDS pandemic, the importance of creating appropriate health promotion and AIDS awareness information is crucial. Research has demonstrated that the success of prevention programs internationally can't be simply linked between national policies and type of welfare state. As AIDS researcher Monika Steffen points out:

This discrepancy needs explanation, as it results from the fact that the fight against the epidemic depends on policy responses from weakly established sectors situated *at the periphery of the welfare state*. Safer sex behavior depends mainly on community-based intervention and social control systems outside the state, notably peer groups and interpersonal networks. (Steffen 2000, 211) (author's italics)

Hence the involvement of the communities affected is essential to the development of successful and appropriate AIDS awareness interventions. The inclusion of underrepresented groups in AIDS awareness work is therefore one of the main challenges to Finnish AIDS work in the 21<sup>st</sup> century. This will require a more inclusive structure in many of the leading organizations and a more multicultural approach to information dissemination.

Many of the plots discussed in the previous chapter continue to have a deep resonance in Finnish society and the organization of services for people affected by HIV/AIDS. As noted earlier, many of the structures of AIDS services grew out of the plots of the gay plague and gay lifestyle. Articulations of appropriate measures to contain HIV/AIDS and promote health continue to be dominated by experts from the Finnish welfare state. There are few stories or counternarratives in the public domain by people from marginalized communities to challenge the dominance of global plots in societal understandings of HIV/AIDS.

Migrants and foreign nationals continue to be constructed in a stigmatizing manner in many studies of sexuality. A recent volume on sexual health in Finland contained no articles about culture and sexuality (Lottes and Kontula 2000). The few references to migrants tended to be stigmatizing. For example, the book claims that migrants are at greater risk of becoming drug users, though no evidence is offered for this conclusion (Lottes and Kontula 2000, 320). The authors also state: ‘Another area of concern is the high rate of STD transmission from foreigners to Finns’ (Lottes and Kontula 2000, 320); though a few paragraphs later they report ‘...the general agreement [of health professionals] was that the risk of getting a STD in Finland is greater from a regular partner than a sex worker.’ (Lottes and Kontula 2000, 320) These types of medicalized narratives sometimes tend to imply that foreigners bring diseases (STDs and HIV) and crime (as sex workers) to Finland which may add to stigmatizing attitudes against migrants.

A significant factor to consider in Finnish stories of AIDS is the continuing invisibility, and even denial, of difference which appears to permeate mainstream Finnish society. When analyzing essays written by Finnish high school students, a researcher on youth culture noted:

In writing about the theme of sexual minorities and school, essays typically related to the following subjects: the experiences of children of lesbian and gay parents in school, lesbians and gays in school, homophobic name calling and sex education. In considering these themes,

nearly all essays made reference to school teasing or the risk thereof and encouraged uniformity; thus these essays, for their part, generally involved pro-heterosexual pressures. It was surprising that so few of these essays related to personal experiences in school, even though the writers were all still in school themselves. On the basis of these writings it seems that the authors have not noticed non-heterosexual people in their schools. They write more from the perspective that *if there would be* lesbians or gays or their children in school, they would be very likely to be teased. (Lehtonen 1999, 29)

Here we can see that there was very little recognition of ‘outsiders’ within Finnish society, though certainly ‘they’ remain amongst ‘us.’ Indeed, many students suggested that sexual minorities should try to assimilate into the mainstream and not be noticeable. In this way, they thought, sexual minorities could avoid being bullied. It would be interesting to know what these students would recommend to ethnic or cultural minorities who might have greater difficulty in assimilating into the mainstream.

In another example, recent research has suggested that nursing students in Finland are informed about HIV and have a positive attitude towards people living with HIV. Students felt that sexual education was very important (Helle 1999). In imaginary cases, students stated that they would not have a problem treated people with HIV (Välimäki et al. 2000). Though, Kangasniemi’s 1996 study indicated that many women living with HIV experience negative or stigmatizing attitudes by non-specialized health care personnel (Kangasniemi 1996, 94), the increase in positive attitudes reported in the 2000 study may mark a turning point in attitudes towards the normalization of AIDS as an illness in Finnish society.

These examples point to a significant gap between the theoretical acceptance of diversity and difference and the reality of experience and behavior. In the cases discussed above, a certain cultural construction of equality appears to be posited as a subtext rather than dialogue or interaction as a point of departure. Assimilating to be part of the mainstream norm and treating everyone the same tends to be viewed as equality in practice. This issue will be taken up in more detail in Chapter 13, but I introduce it here to problematize how AIDS awareness has tended to be constructed in Finland. The international plots of

AIDS, discussed in the previous chapter, have empowered some formerly marginalized communities and ensured a high standard of social and health care for all PLWHAs through policy developments through the institutionalization of AIDS exceptionalism. Yet, the special needs of some migrants have remained excluded and invisible in Finnish society. One of the great challenges of Finnish AIDS awareness in the 21<sup>st</sup> century is to recognize and embrace the diversity of populations affected (from women to drug users to migrants) and empower members of these communities to become stakeholders in the development of information and services rather than promoting a bland uniformity of services which is ultimately exclusionary. This militates against the construction and articulation of AIDS services as part of the corporatist welfare state of experts. One of the first steps in meeting this challenge is to give space for underrepresented groups to speak and tell their own stories.

## **11.6 Summary**

The initial response to the Finnish HIV/AIDS epidemic was largely negotiated within a corporatist administrative culture amidst the tension between some representatives of the powerful medical establishment and the tiny Association for Sexual Equality (SETA), the national human rights organization for sexual minorities. Though both groups had the common aim of preventing the spread of HIV/AIDS in Finland, they articulated their methods in sharply diverged in many ways, which had contrasting implications for minority groups and human rights in Finland. As sociologist Aileen O’Gorman summarized:

Since HIV/AIDS was first identified in the 1980s it has developed a curiously demonic mythology quite unlike any other life threatening illness. Fears of contracting what was initially an untreatable disease, and the association of HIV with perceived ‘deviant behavior’ (such as homosexual sex and intravenous drug use) provided a ripe breeding ground for the multitude of moral panics and urban myths that developed around HIV/AIDS. (O’Gorman 1999, ix)

Thus, the initial managerial response in Finland to AIDS must be viewed within the context of the irrationality that the seeming randomness of the incurable disease provoked among the public. AIDS came on the scene at a time when there was great faith throughout the West that communicable diseases had been conquered. The quality of life and health outcomes in Finland had improved dramatically since the Second World War. Smallpox, tuberculosis and STDs had all been defeated through improved living conditions, vaccines and improved medical treatments. AIDS therefore created a great deal of anxiety regarding health and safety. Each society affected by AIDS struggled to articulate its own metaphors and stories to explain the apparently haphazard nature of the new disease. ‘Others’ or strangers often became a focus of blame, as was historically the case in many other epidemics. The impact of various international plots of AIDS (such as AIDS as a gay disease and African AIDS) on evolving understandings of the virus in Finland (as well as most other societies) was the tendency to conceptualize those deemed strange or deviant as a threat to the nation. Experts in medical science were constructed as the frontline between the healthy nation of Finland and the invidious influence of deviance. Unlike pluralist administrative cultures, which raise new social movements to struggle to be heard and affect policy, corporatist administrative cultures, such as that of Finland, encourages consensus and compromise in the policymaking process.

The three main groups that have been associated with AIDS in Finland are gay men, migrants and, more recently, intravenous drug users. All three groups have been constructed, represented, articulated, empowered (or disempowered) and othered in very dissimilar ways. Each group has been scrutinized at different points of the epidemic, in different contexts, and thus embodies different plots and understandings of the story of AIDS. Gay men, migrants and IV-drug users as AIDS constructions have had a very distinct levels of visibility and voice during the epidemic.

As I explore in later in Chapter 12, citizenship, poverty, race and ethnicity have a great deal of salience in explicating visibility and voice, particularly in the AIDS pandemic. Having the right to a residence permit, to make a home, to be accepted as part of the community – indeed, to feel at home – is a very significant factor in communicating

experience and perspective. Frameworks for policy and practice are constructed on perception of needs and experiences as well as power relations which privilege the narratives and stories of dominant groups. Hence silence, invisibility and the lack of recognition can have a very concrete impact in people's everyday lives through the definition of policies and practices. The global and the local are indeed inextricably linked.

The Finnish gay community has had the organization SETA, which has actively fought for human rights for sexual minorities over three decades and was at the forefront of the early skirmishes in defining the metaphors and stories of AIDS. SETA has fought to articulate positive images of sexual minorities in Finnish public discourse, to educate people on sexual minority issues and, most significantly, to lead the fight for human rights to overturn homophobic and discriminatory laws. The emergence of the AIDS epidemic in Finland can even be said to have hindered SETA's human rights efforts to promote equal rights for gays by diverting its energy towards public health issues. IV-drug users became prominent in Finnish AIDS discourse towards the end of the 1990s when an epidemic was widely predicted. IV-drug users have differed from gay men and migrants because their voice has largely been mediated and articulated by social and health care personnel through the corporatist administrative culture (see, e.g., Törmä et al. 2002). Despite being labeled as deviant, both groups, as Finnish nationals, are fully entitled to all social and health care services and have the possibility to advocate for their rights.

Migrants, however, have remained largely unorganized and silent in Finland, especially with regard to AIDS. There are many reasons for this silence, which are explored in greater depth in Chapter 15. However, two salient points should be made. Firstly, migrants constitute less than 2% of the total population of Finland and have very small communities indeed. As I have noted earlier, in contrast to countries with large well-established ethnic minority and migrant communities:

...the population of foreign-born residents in Finland...has not yet reached the stage of a critical mass in which the sheer numbers of groups who define themselves as different can make credible demands for inclusion. (Clarke 1999a, 7)

This means that many migrants tend to be rather socially isolated and often view themselves as individuals in Finland rather than members of a community, with all of the psychosocial support that could entail. Secondly, many migrants do not speak Finnish which excludes them to a rather large degree in the national debate as well as inclusion in articulating societal notions of *Finnishness*. Hence while language has been constructed as a litmus test for integration into Finnish society, it can also serve as an exclusionary device. These factors have coalesced to produce articulations of migrants that are largely produced by others and rendered migrants' own articulations of their circumstances silent.

Though this situation may be changing, for the most part the response among migrants to the HIV/AIDS pandemic has been decidedly muted, despite the fact that people of foreign origin account for 29% of HIV cases in Finland according to recent statistics (Finnish Public Health Institute 2002). Fears of revealing one's seropositive status and possible further legal and social consequences appear to be the main reason for this silence. As cultural studies researcher Barbara Browning has pointed out:

Words are dangerous. And this is painfully clear in the present epidemic. To articulate one's HIV status is a profoundly dangerous thing, which may result in loss of medical coverage, housing, employment, and acceptance in one's community. Articulating the prevalence of HIV infection in a given community can result in widespread social discrimination of that group. This is an obvious point to all members of so-called risk groups, regardless of their individual HIV status. (Browning 1998, 22)

AIDS remains a deeply stigmatized disease in Finland. When seropositive status is combined with foreign national status or ethnic origin different than what is commonly constructed as 'Finnish', the stigmatization tends to be doubled.

The arrival and trajectory of the AIDS pandemic in Finland, particularly with regard to the migrant population, mirrors the sharp increase (to Finnish standards) in immigration. Though the total number of migrants in Finland remains minuscule (slightly over 100,000 or approximately 2% of the population) in a European context, to Finnish standards the rise in migrants has been substantial. Finnish researchers have estimated that the amount

of migrants in Finland has quintupled since the late 1980s (Pitkänen and Kouki, 2002). Hence the increase in immigration to Finland occurred at the same time as the increase in HIV transmission. The plot of African AIDS thus becomes particularly relevant to the Finnish context when connected with the deep economic recession of the late 1980s and early 1990s and a growing atmosphere of xenophobia and insecurity within Finnish society as it began to receive a greater amount of new migrants.

AIDS is a social phenomenon that is redolent of metaphors. The use of metaphors, as Susan Sontag writes, is a 'mental operation' that gives birth to understanding (Sontag 1988, 93). It is therefore significant which metaphors are used to illustrate and explain understanding. As the Finnish social science researcher on AIDS Tiina Hautamäki has noted:

The metaphorical use of language is not neutral, because on their own part metaphors either reinforce or vacillate the value and moral systems of institutions. When using metaphorical language, the writer always allows something be revealed about herself. However, the bond between metaphors and values is not usually consciously thought about, because metaphors are part of conventional use of language and hence their significance is paid no special attention. (Hautamäki 2002, 112-113)<sup>67</sup>

The designation of AIDS by the media and many authorities throughout the West as an explicitly 'sexual epidemic', in Linda Singer's words, raises a whole range of issues surrounding questions of sexuality. In the framework of sexual epidemic, images of erotic access, freedom and choice give way to anxiety, unregulated contact and uncontrolled spread. Indeed, as Singer points out, communication becomes communicability, while access equals transmission and contagion (Singer 1993, 28). The inherent extremity of a situation termed epidemic makes it reasonable for authorities to exert disciplinary control over the management of bodies. These same metaphors of anxiety, unregulated contact, and uncontrolled spread can also be applied to the social construction of migration as a

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<sup>67</sup> Metaforinen kielenkäyttö ei ole neutraalia, koska metaforat omalta osaltaan tukevat tai horjuttavat instituutioiden arvo- ja moraali-järjestyksiä. Kirjoittaja tulee aina paljastaneeksi itsestään jotain käyttäessään metaforista kieltä. Metaforien arvosidonnaisuutta ei kuitenkaan yleensä ajatella tietoisesti, koska metaforat ovat osa konventionaalista kielenkäyttöä eikä niiden merkityksiin siten tulla kiinnittäneeksi sen kummempaa huomiota.

threat to a nation. Moreover, immigration regulations, which implicitly seek to control bodies, can be seen as the managerial response assembled by a nation to the perceived threat of outsiders.

Reactions to the AIDS epidemic in Finland, as well as throughout the world, have included increasingly intense homophobia and articulations of the need to strengthen the nuclear family as the only haven for 'safe sex,' calls for abstinence rather than condom use, the attempted control of mobility through immigration restriction, and the criminalization of 'spreading' the disease, as well as many conflicts over the parameters of antibody testing and counseling. However, it is difficult to discuss the issue of HIV/AIDS without considering the importance of marginalization and social exclusion, though this has only recently emerged as an important topic (in a European context see, e.g., Lert 2000). As discussed earlier, globalizing economic trends indicate an increasing international and domestic gap between rich and poor while neoliberal policies have promoted the rise of the exclusionary societies (see Young 1999). As marginalized and excluded people tend to have less access to social and health care services as well as culturally appropriate information and power over their lives, they are more vulnerable to be affected by HIV/AIDS.

Social memory articulates the boundaries of group belonging by providing a framework for understanding the group's past, present and aspirations for the future. Some scholars have made a distinction between history and memory. If history is viewed as an empirical documentation of events, social memory can be seen as the sense of the past in the present through the recollection of personal testimony (e.g. Misztal 2003, 99-125). In the foregoing discussion of AIDS narratives, I have argued that the making and remaking of social memory through narratives and plots has been a significant element in the developing AIDS pandemic. As Misztal has noted:

Assigning a new value to traumatic memory in a society that opens space and desire for a search for new identities and encourages people to stay in touch with their authentic culture enhances remembering. (Misztal 2003, 145)

Yet, the dominance of particular articulations of social memory reflects the constellation of power relations in society. Remembering AIDS narratives in a Finnish context, even the difficult and less visible ones, has the potential to open up new and more inclusive articulations of well-being in Finnish society.

In summary, there are four significant factors that should be taken into account when analyzing the Finnish social context regarding HIV/AIDS. Firstly, there is an intimate tie between social memory constructions of the Finnish nation and the Finnish language, perhaps to a stronger degree than many other nations. This is perhaps due to the fact that Finnish nationalism was shaped by the battle to have Finnish recognized as an equal official language, unlike other nations where the official language was a given from the start. As Finnish is only spoken by a few million people and part of the very small Finno-Ugric language group, it is not a widely spoken language throughout the world. This makes the linguistic challenge to migrants even more daunting in many respects, particularly when taking the social isolation of many migrants into account. However, it is through facility with the Finnish language that outsiders gain access to Finnish society. Hence articulations of the connection between social constructions of *Finnishness* as a genetic inheritance and fluency in the language tend to exclude many migrants from full participation in Finnish society.

Secondly, the fact that there was very little immigration to Finland in the 20th century, as well as the lack of colonial empire, has resulted in articulations of Finland as a homogenous nation. These articulations can take the form of ‘cultural racism’:

Cultural racism and the problematization of ethnic minorities in Denmark has been associated with the strengthening in the public imagination of the concept of a homogeneous Danish culture, perceived as a historically rooted set of traditions now under threat from globalization, the EU, and from ‘alien’ cultures. (Wren 2001, 148)

Here we can see that the dichotomy of ‘us’ and ‘them’ underlies the creation of a social memory of the nation as culturally homogenous and therefore exclusive of outsiders. The

end result of cultural racist tendencies is social isolation, discrimination and xenophobic attitudes towards foreigners.

Thirdly, AIDS has been largely constructed in the Finnish context as a disease brought by foreigners and those considered to be outsiders in Finland. AIDS has therefore been articulated as a disease of 'otherness' and difference, often used as a reason to stigmatize and marginalize migrants by many in Finnish society.

Finally, all of the factors listed above combined with the vulnerable socio-economic position of many migrants in Finnish society and the lack of large migrant communities has made the development of community based organizations difficult. The prevalence of a corporatist, rather than pluralist, administrative culture also discourages the development of diverse interest groups. Further, the paucity of organizational capacity in many migrant communities tends to further marginalize the promotion of migrants' issues in a circle of disempowerment. These factors contribute to an inability to place serious political pressure on decision-makers to improve the situation of migrants as well as to develop solidarity within communities.

#### **IV. Articulating migrants living with HIV/AIDS locally: migrants in the Finnish social and health care system**

This section examines how migrant identities and rights are articulated in the Finnish social and health care system for people living with HIV/AIDS. It examines what sense of cultural identity and belonging is constructed at the core of access to social and health care for people living with HIV/AIDS in Finland. This section considers how these constructions can render difference and needs invisible, thus making normatively-based services difficult to access. I start with a brief discussion of Finnish immigration policy and multiculturalism in Finnish society before turning to migrants' access to HIV/AIDS treatment and care in Finland, to provide a contextualized background to the legal and social circumstances of migrants in Finland. I then focus on how notions of equality are articulated in Finnish social and health care services. I explore issues of access to HIV/AIDS care in Finland through interviews of Finns and migrants as well as a textual analysis of available HIV information targeted at migrants. Finally, I discuss the interview data of migrants living with HIV as a commentary on the significance of identity, belonging and coping with life in Finland in relation to issues of access and power. This section therefore examines how the global processes in public health, migration and social welfare considered in the first section apply to a specific locale.

#### **12. Immigration, multiculturalism and migrant identity in Finland**

This subchapter briefly delineates some of the main features of Finnish immigration policy through a short historical survey of immigration to Finland. I consider how such policies have shaped visions of a multicultural Finland as well as migrant identities within articulations of *Finnishness*. The way that legal structures and governmental policies are constructed and articulated is key to understanding the ways of defining the civil, social and human rights of non-citizens. Articulations of social memory lay the borders for insiders and outsiders. These shifting cultural boundaries have a great impact

on the lives of migrants by molding native attitudes towards newcomers. Articulations of multiculturalism can therefore be seen as attempts to deconstruct or transform the modernist categories and hierarchies of race and the nation through the recognition of hybridity and cultural border-crossing, which has many political consequences. This chapter shortly outlines some of the key societal concepts evoked when discussing immigration, such as integration and multiculturalism, and attempts to contextualize the discussion in Chapter 7.4 on multiculturalism as a national phenomenon that is articulated in diverse ways. Further, this examination of notions of migrant identity in Finnish society makes a bridge with the next chapter which explores the construction of equality in Finnish HIV/AIDS services.

## **12.1 A brief outline of Finnish immigration policy**

This subchapter shortly sketches the recent historical context of Finnish immigration to place current policies and practices in perspective. Departing from the postmodern notion that cultural and ethnic identity is contextual, dynamic and continuously evolving (Hall and du Gay 1996), I briefly trace connections between Finnish migration history and the evolution of articulations of *Finnishness* in contemporary Finland. The aim of this chapter is less to provide a comprehensive overview of Finnish immigration policies and practices than to draw a broad portrait of migration in the Finnish context in order to better understand how notions of multicultural Finnish society are being articulated.

### 12.11 Migration and the construction of *Finnishness* as a racial and national attribute

Finland has never been a receiving country of mass immigration or large refugee flows. It has not been the destination of foreign guest workers, unlike many other European nations, nor has it been a colonial power. There has, nonetheless, always been a steady trickle of migration amongst the countries bordering the Finnish peninsula, though this has often received less attention (see, e.g., Harle and Moisio 2000). Indeed, until very recently most discussions of migration in Finland have focused on the phenomenon of emigration as a far greater number of Finns have left for other countries (such as

Australia, Canada, Sweden and the United States) in search of job opportunities than immigrants have come to Finland for similar reasons (see, e.g., Jaakkola 1976, 1984; Korkiasaari 1983, 1989, 1992). Only in recent years has the socio-cultural significance of increasing immigration to Finland become an area of growing scholarly interest (see, e.g., Huttunen 2002; Lepola 2000; Wahlbeck 1999) and public debate.

Despite the tendency in much contemporary Finnish discourse to focus on the novelty of transnational migration in 21<sup>st</sup> century Finnish society, it is important to point out that Finland has always been a multicultural nation. From the Sámi, the indigenous people of Finland, to the few, tiny ethnic minority communities, such as the Roma and Tatars, Finland has always embodied cultural diversity, albeit on a much smaller scale than many other nations. Furthermore, there is research on ethnic minority communities within Finland (see, e.g., Grönfors 1977, 1979, 1981; Liebkind 1974, 1994, 2000), though it is perhaps not been as extensive as the emerging body of research which is increasingly concentrating on growing transnational migration and its relation to multiculturalizing Finland (see, e.g., Hautaniemi 2004; Huttunen 2002). The historical dimension of discriminatory policies and ethnic minority groups has also been little analyzed in Finland.

The current focus on cultural difference in Finland as a transnational phenomenon reflects the influence of 20th century global political changes on social articulations of *Finnishness*. The construction of the nation as a culturally homogeneous entity exerts a form of exclusive social memory that ‘others’ (Wren 2001, 144-146). This impulse to exclude is a core feature of national imagination, but its articulation metamorphosizes in different situations and is shaped distinctly in specific historical circumstances.

Though ethnic minorities have always existed in Finland, as legal theorist Will Kymlicka points out, minority nationalism and immigrant multiculturalism are very different entities (Kymlicka 2001, 156-157). Minority nationalists see themselves as part of the nation, though they have their own distinctive traditions, languages and cultures. Their visibility, rights and inclusion in mainstream society is dependent on power relations

between the minority and majority groups. The sense of national belonging is implicit in this relationship, though it may be marked by skirmishes over how inclusion is negotiated and practiced. Representations of social memory of the nation tend to reinforce the binary division between ‘us’ and ‘them,’ and reinforce the uniqueness of the origin of the nation members. Immigrants, however, do not necessarily see themselves or want to be part of the nation. They may have hyphenated identities or identify themselves emotionally and culturally as completely separate from their current place of residence. The social memory nurtured in migrant communities may represent a place or events that are very distant from where they currently live.

It is important to underline that the earliest constructions of *Finnishness* emerged during Finland’s period in the 19th and early 20th centuries as a subject of Swedish and Russian rule. They were further shaped by the modernizing process of an industrializing nation (Alapuro 1988, 85-89). Though Europe has indeed been marked from early history by economic and refugee migration (Sassen 1999), strong loyalty to constructions of the nation-state emerged as a unique and central element of group identity in the modern era (Anderson 1991). The racial hierarchies and classifications characteristic to much of contemporary popular opinion, governmental policy and academic discourse on multiculturalism and immigration thus have their roots in the social science categories created during the modern period (see, e.g., Bhattacharyya et al. 2002; Gilroy 2000; Jacobson 1998; Stepan 1982). The conceptual link between articulations of ‘race’ and nationality – often taken as ‘common sense’ -- is one of the central outcomes of identity and nation building in the modern era (Goldberg 2002). The stability and solidity typical of the modern era, however, tended to mask the inherent malleability of constructed hybrid identity categories.

During the era of Swedish rule, for example, aliens in Finland were categorized in four groups:

- Aliens (foreign nationals)
- Jews
- Romanies

- Vagrants (Kuosma 1999, 243)

As legal researcher Tapio Kuosma points out, only the first two categories of people had rights to freely travel in Finnish territory as long as they had valid passports, while the latter two were confined to particular areas (Kuosma 1999, 243-244). Hence Finnish 'race' was not the definitive link to freedom of movement in Finland at that time, but rather it was tied to position in the social order.

The Russian Empire brought greater interchange amongst peoples of tsarist rule throughout its territories. The movement of ethnically diverse soldiers, tradesmen and officials produced a strongly multicultural influence within the multinational empire. When Finland transferred from Swedish to Russian rule, it became an autonomous grand duchy. This status ensured that Finland could maintain many of its cultural traditions, though periodically Russification projects were attempted. Russian, however, never became established as a strong second language, unlike Swedish which remained an administrative language in Finland.

Since its independence in 1917, small groups of refugees have periodically appeared in Finland during times of great turbulence in international affairs. In the aftermath of the Russian Revolution, for example, approximately 40,000 Russian refugees settled in Finland (Koivukangas 2003), though this historical legacy has largely been overlooked in discussions of immigration in the 1990s. The period between the trauma of the aftermath of the Second World War, where the existence of Finland as an independent nation was threatened, and the end of the Cold War, can be characterized as relatively closed (Koivukangas 2003, 4). The lack of migrants during this time combined with a strongly bipolar geopolitical environment which contributed to articulations of homogeneous *Finnishness* and historical amnesia about multicultural exchange.

If stories of early immigration to Finland remained few and far between, stories of the evacuation of Finnish Karelians from Soviet occupied parts of Finland before and during the war as well as the emigration of Finns to Sweden in search of work in the 1960s

remained strongly resonant in Finnish collective memory (e.g. Korkeamäki 2003; Nevalainen 2002). The trauma of migration has therefore closely been associated with Finnish stories but rarely linked with those of people coming to Finland. Hence rather little has been written in Finnish, for example, by the 180 Chilean refugees from the Pinochet regime or 500 Vietnamese refugees of the late 1970s (Reuter 2001, 8). In some ways, this has created an empathetic gap between tales of survival by Finns struggling to maintain the nation and perceptions of floods of immigrants coming to Finland as threats to the social order (on media images and immigration, see Horsti 2002a). As the postwar period of the Cold War found Finland in a relatively isolated international position with little immigration or cultural interaction, essentialist articulations of homogeneous *Finnishness* deepened in the public imagination, often broadening the gap between Finns and those deemed ‘outsiders.’

Throughout most of the 20th century, a far greater amount of Finns emigrated from the country than immigrants entered. In the 20th century, nearly one million Finns emigrated abroad, largely to Sweden, Canada and the United States (Korkiasaari 1992). The balance towards greater immigration to Finland only shifted towards the end of the 1980s. Finland continues to have one of the lowest proportions of immigrants in the European Union. The combination of low immigration with largely homogeneous cultural constructions of the Finnish nation has led to the pervasive and largely ahistorical belief in Finnish society that it is not a multicultural nation, or is just becoming one. Much of the structure of Finnish immigration and citizenship law, as well as dominant views of social integration, articulated Finland as an ethno-racial homogeneous society, though this notion is being increasingly challenged by social science research, public debate, residents and citizens (see, e.g., Gordon 2001; Suurpää 2002) .

There have been small groups of ethnic minorities in Finland for much of its history. Most prominent of these groups are the Swedish-speaking Finns, indigenous Sámi, Romanies, Jewish and Tatar communities as well as the old Russians. However, these communities have tended to be relatively small. According to a recent report by the Finnish League of Human Rights, fewer than 30,000 out of 5 million Finnish inhabitants

are members of ethnic minority groups, such as the Tatars and Roma (Streng 2002, 4). This figure does not include Swedish-speaking Finns or immigrants. Due to the minuscule proportion of ethnic minorities, they have not tended to exert a strong influence on articulations of *Finnishness*. More importantly, there has been little analysis of the role that discrimination, in all of its manifestations, plays in relation to certain ethnic minority groups in Finland.

Notions of *Finnishness* have been articulated through the cultural institutions, social order, regional differences, constellations of political power and representations of the social memory of people long resident in the Finnish peninsula. They have been further tempered by the casting die of Finnish nationalism which has been taught in mass educational institutions established in ideological constructions of the unique identity of the modern Finnish state (Alapuro 1988, 86-87). The constellation of power relations among groups also affected how ethnicity was perceived and categorized. The contemporary association of *Finnishness* with an ethnic, racial or national category is therefore a relatively new phenomenon, born of the 19<sup>th</sup> century Finnish National Awakening. National identity as a racial category can be seen as the forging of a national ethos as an essential attribute through representations of social memory. As David Theo Goldberg has noted:

Race may be thought of as the social or cultural significance assigned to or assumed in physical or biological markers of human beings, including the presumed physical or physiognomic markers of cultural attributes, habits or behaviors. Nation, by contrast, is the significance of cultural markers as assumed or assigned (imagined) indicators of common originary belonging, where race (or ethnicity, as cultural socialization) might be one of these (imagined) markers assigned significance or dominance in picking out members. Where this is so, race and nation overlap, more or less isomorphically. (Goldberg 2002, 118).

Articulations of *Finnishness* as a seamless racial and national attribute therefore represent a marriage of unique cultural and physical markers in the bodies of the Finnish nation. These constructions of *Finnishness* tend to reify an ethno-racialized identity which excludes those thought to embody racial difference. This reveals an ambivalence at the

core of inclusion and belonging in Finnish society, particularly towards citizens who do not fit into racialized or ethnicized definitions of *Finnishness*. The emergence of multiculturalism, with all of its attendant hybridity, has therefore sometimes been viewed as the birth of the articulation of a new Finnish nation.

Finnish immigration law, in the German legal tradition, is based on the citizenship principle of *jus sanguinis*. As noted earlier, this means that citizenship has generally been constructed as a cultural ethno-racial attribute that is acquired through blood or family ties to a Finn. The vast majority of migrants in Finland either fulfill the legal ethnic and cultural criteria of *Finnishness* or are married to Finns (Korkiasaari 1992, 2002). A new citizenship law that has just come into force (2003) allows for ethnic Finns who are citizens of other countries to have their Finnish citizenship restored. This new law reflects new trends towards hybrid forms of citizenship in a globalizing world. It also serves to maintain and reinforce Finnish identity among expatriates. Rationalized and bureaucratic definitions of Finnish citizenship thus tend to remain closely associated with ethno-racial conceptions of *Finnishness*.

To summarize, Finnish society has always included culturally diverse groups, though this diversity has been largely rendered invisible, or deployed strategically, in the articulations of *Finnishness* that emerged during the modern era. Nations are based on exclusions which serve to reify their cultural and ethnic uniqueness through social memory. In the Finnish national project, the invisibility of certain ethnic minority groups in mainstream Finnish society has served to articulate cultural and biological markers of identity. Furthermore, a specific ethno-racial definition of *Finnishness* has been enshrined in immigration law through the application of the principle of *jus sanguinius*. Though diverse ethnic minority groups have always been resident in Finland and there has been continuous migration throughout the Finnish peninsula, it has only been through rising immigration in the 1990s that the issue of multiculturalism became prominent in Finnish public discourse and research, though the voices included in these discussions are limited, as I will discuss in Chapter 15. Increasing cultural diversity in Finland is thus transforming articulations of *Finnishness*, though the legal construction of Finnish

citizenship continues to be tied to conceptions of ‘blood’ membership. The gap between new articulations, particularly from second generation migrants, and legal definitions of *Finnishness* may indeed increase and cause friction in the near future, particularly with regard to constructions of equal protection practices as citizens.

#### 12.12 Current trends in migration to Finland: Emerging legislation and policies

The amount of foreign-born residents in Finland increased from 39,153 in 1980 to 145,135 in 2001 (Korkiasaari 2002). When considering emigration out of Finland, the actual net migration into to Finland in 2002 was only 4,803 (Korkiasaari 2002). Unlike many other European countries, there have been no large migrations flows into Finland and there is thought to be extremely few undocumented aliens. At the same time, the amount of migrants quintupled in Finland between 1987 and 2002 (Pitkänen and Kouki 2002, 105). Hence the perception that floods of migrants are coming to Finland appears to be growing, particularly in metropolitan areas where most migrants settle, though the statistical reality shows quite a different picture.

Here we can see a comparison between Nordic countries on the amount of migrants in each country:

**Table 1. Immigrant Population in Nordic Countries**

<i>Immigrants in total population, %</i>	<i>1995</i>	<i>2000</i>
<i>Finland</i>	<i>1.2</i>	<i>1.7</i>
<i>Denmark</i>	<i>3.8</i>	<i>4.9</i>
<i>Norway</i>	<i>3.8</i>	<i>4.0</i>
<i>Sweden</i>	<i>6.1</i>	<i>5.5</i>

Directorate of Immigration (2002)

The amount of migrants is clearly far less in Finland than its Nordic neighbors. This can be attributed to historical and socio-economic reasons. While the Swedish economy

attracted many guest workers from many parts of the globe during the 1970s, Finns tended to emigrate far more than draw immigrants to their own country. Indeed, Finns are one of the largest ethnic groups in Sweden. However, many influential members of Finnish society and think tanks have begun to call for an increase foreign labor to Finland in order to face the demographic challenge of the graying of the Finnish population (Centre for Finnish Business and Policy Studies 1999). The core of the debate is centered on which foreigners are desirable and what impact this will have on shifting social memory and articulations of *Finnishness*. While much of the debate remains focused on the needs of Finnish society and integration measures, an interesting point that is rarely raised is what immigrants themselves would expect *from* Finland.

The vast majority of migrants to Finland are from the former Soviet Union. Many people of Ingrian ethnicity qualified to enter Finland as repatriates due to a policy initiated by President Mauno Koivisto in 1990. In an off-the-cuff remark at a press conference, Koivisto said that he believed Finland owed a ‘debt of honor’ to ethnic Finns resident in the former Soviet Union, which later emerged as a ‘returnee’ policy (Kuprijanko 2001; Lepola 2000, 96-107). This soon resulted in a wave of immigration by Ingrians to Finland, the basis of which has increasingly been challenged in the 21<sup>st</sup> century.<sup>68</sup> Ingrians were accepted in principle because they fulfilled the ethno-racial and cultural criteria of *Finnishness*, though on arrival in Finland many found that they faced many ambivalent attitudes both by Finns and towards being Finnish (Jasinskaja-Lahti 2000, 4-6, 12).

Since the late 1980s, there has also been a growing amount of refugees and asylum seekers from a great diversity of nations. Further, there has been a steady increase in the amount of marriages and cohabitations between foreigners and Finns (Korkiasaari 2002). As there has been no large-scale or chain migration (with the exception, perhaps, of Ingrians), migrant communities in Finland are enormously diverse, representing many different language groups, ethnicities and nationalities. Many migrants from ethnic

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<sup>68</sup> For an interesting discussion of the politics of the Ingrian policy, see Lepola (2000).

groups that are not recognized by mainstream Finnish society as embodying *Finnishness*, or another acceptable ethno-cultural identity, have faced sometimes significant stigmatization and discrimination in the labor market (Forsander 2002). According to Statistics Finland, unemployment is especially high in certain migrant communities (e.g., 74% among Iraqis and 58% among Somalis) and quite low in other communities (e.g. 9% among Germans and 8% among Chinese).<sup>69</sup> These statistics suggest that there are significant differences in social integration and discriminatory practices among migrant groups that do not necessarily correlate to ethno-racial or cultural status in Finnish society, but may be influenced by the existence of social networks, educational levels and other factors (see, e.g., Walhbeck 1999)

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<sup>69</sup> These statistics were based on an estimate provided by the Ministry of Labor (Statistics Finland 2003).

Here we can see the breakdown of statistics on migrant groups in Finland:

<b>Country of citizenship:</b>	<b>1990</b>	<b>1995</b>	<b>1996</b>	<b>1997</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>	<b>2001</b>	<b>2002</b>
Russia	.	9 720	11 810	14 316	16 861	18 575	20 552	22 724	24 336
Estonia	.	8 446	9 038	9 689	10 340	10 652	10 839	11 662	12 428
Sweden	6 051	7 014	7 291	7 507	7 756	7 809	7 887	7 999	8 037
Somalia	44	4 044	4 555	5 238	5 371	4 410	4 190	4 355	4 537
Yugoslavia <sup>1)</sup>	75	2 407	2 624	2 755	2 935	3 392	3 575	4 240	4 224
Iraq	107	1 341	1 855	2 435	2 670	2 960	3 102	3 222	3 420
United Kingdom	1 365	1 865	1 803	1 907	2 058	2 170	2 207	2 352	2 535
Germany	1 568	1 748	1 836	1 961	2 072	2 162	2 201	2 327	2 461
Iran	336	1 275	1 397	1 681	1 706	1 868	1 941	2 166	2 363
USA	1 475	1 844	1 833	1 905	2 001	2 063	2 010	2 110	2 146
Turkey	310	1 335	1 479	1 668	1 737	1 737	1 784	1 981	2 146
China	312	1 412	1 471	1 610	1 650	1 677	1 668	1 929	2 086
Former Soviet Union	4 181	6 163	5 187	4 675	3 628	2 966	2 447	2 249	2 011
Thailand	239	763	864	964	1 084	1 194	1 306	1 540	1 784
Vietnam	292	2 084	2 143	2 171	1 965	1 840	1 814	1 778	1 713
Bosnia and Herzegovina	.	928	1 342	1 420	1 496	1 581	1 627	1 668	1 701
Ukraine	.	366	536	654	766	849	961	1 133	1 248
Others	9 900	15 811	16 690	18 044	18 964	19 775	20 963	23 142	24 506
<b>Total</b>	<b>26 255</b>	<b>68 566</b>	<b>73 754</b>	<b>80 600</b>	<b>85 060</b>	<b>87 680</b>	<b>91 074</b>	<b>98 577</b>	<b>103 682</b>

1) Former Yugoslavia and Federal Republic of Yugoslavia.

Source: Statistics Finland, Demographic statistics, 2003

Previous to the 1980s, there was little need for legislation on the status of migrants in Finnish society. The first Aliens' Act of Parliament came into force in 1983 during the term of President Mauno Koivisto. This was the first time that the legal protection of aliens was clearly outlined (Kuosma 1999, 244). One of the most significant aspects of this law was the right to appeal a negative decision by the immigration authorities to the Supreme Administrative Court. A second Aliens' Act was passed by Parliament in 1991

(*Ulkomaalaislaki* 1991/378) further extended the legal protection of aliens resident in Finland. However, the process of applying for a residence permit remains long and complex which indicates a gap between policies of easier access and restrictive administrative practices.

Migrants are assigned a residence permit status based on their reasons for living in Finland. According to Finnish immigration law, a lettered status on an immigration document indicates the period of time granted for the residence permit, such as permanent or fixed-term, while numbers attached to the status indicate the purpose of stay. There are three basic categories in Finnish immigration law:

Status A: A stay of a permanent nature. After two years of continuous residence, a permanent residence permit may be granted.

Status B: A stay of a temporary nature. Persons receiving this status have a fixed-term residence permit which does not become permanent after a continuous two-year stay.

Status D: A stay of a temporary nature. Status D is issued to persons who temporarily cannot return to their own countries. Like status B, holders of a status D does not receive a permanent residence permit after a continuous two-year stay. (Finnish Aliens Decree, Annex 1)

The type of status that a migrant receives from the Directorate of Immigration determines his eligibility in the social insurance scheme. Migrants with a B status are not entitled to social welfare benefits or social insurance, except on a temporary basis usually in connection with employment. Migrants with status D are entitled to strictly defined and limited health care and social assistance, usually based on definitions of the need for urgent care.

The Alien's Act was under revision in the early 21<sup>st</sup> century, though at the time of writing it had not achieved a final form as a proposal to Parliament. The main areas targeted for modification concerned accelerated procedures to turn asylum seekers away from Finland as well as speeded up the processes of work and spousal residence permits. Finnish

legislation has continuously developed over the past decade in the attempt to create greater consistency and comprehensiveness in immigration laws. However, certain areas remain unclear, particularly with regard to defining the best interest of the child and children's rights in relation to naturalization and asylum procedures (Streng 2002, 12-13). Furthermore, there are many human rights and due process questions surrounding new proposals to accelerate procedures to reject asylum applications.

To summarize, Finnish immigration policy has traditionally been based on the principle of citizenship as equivalent to 'blood' heritage. The communitarian basis of social citizenship in the Nordic welfare state and corporatist administrative culture of Finland further formulated articulations of *Finnishness* that create significant barriers to newcomers. Skirmishes in public debates over the appropriate definitions and restrictions on social rights to newcomers reflect the emotional and political complexity of constructions of social memory as practiced by the Finnish welfare state.

Immigration law and policy has been informed and executed by the authorities within a corporatist administrative culture with little influence by non-governmental organizations (Seppälä 1997; Streng 2002, 12). There is little precedent in Finnish civil society for pluralist negotiations with migrant rights groups and few existing community based organizations. Indeed, immigration law has more often been viewed as an extension of foreign policy rather than a matter of human rights. The constellation of human rights issues that converge at the level of immigration policy will pose great challenges to Finnish society.

## **12.2 Multiculturalism and integration**

Homi Bhabha has conceptualized the cultural construction of 'nationness' as 'a form of social and textual affiliation' (Bhabha 1990, 292), which can also be seen as a form of social memory. Bhabha refers to the 'ambivalence' of the construction of the nation as a 'narrative strategy' and 'apparatus of power' which is essentially 'Janus-faced'. In this description, Bhabha recognizes the fundamental contradiction at the heart of notions of

the nation: it is constructed as eternal, unique and modern at the same time. As Benedict Anderson pointed out, the act of imagination which produces a nation is rooted in a sense of eternity and founding narrative myth (Anderson 1991). This type of national construction, which often celebrates a blood tie to the nation, is a mark of the chosen, promoted by narratives of social memory. Modernity, on the other hand, views the nation as constantly progressing and developing towards a greater future, which contradicts the notion of primeval, perennial and deified beginnings. If the former notion of the nation reflects the German-Romantic idea of the nation, then the latter mirrors the fraternity of the nation represented by the French Revolution. This ambivalence at the heart of constructions of the nation permeates societal discussions and debates on social integration and multiculturalism.

As immigration only began to increase in Finland towards the end of the 20th century, members of Finnish society have had very little practical or theoretical experience with migrants or outsiders as a postcolonial and globalized phenomenon. Previous to the late 1980s, 'foreigners' affairs' was largely a police matter and referred to the enforcement of legal regulations regarding passports and permits. Indeed, the themes of integration and multiculturalism are relatively new notions in Finnish society and there has been little agreement about what they imply for the future (Clarke 1999a, 82-97). This subsection briefly outlines some of the main themes that have emerged in discussions of integration and multiculturalism in Finland.

Multiculturalism was not a commonly used term in Finland until the 1990s when decision-makers and educators began to recognize the significance of a growing migrant population in Finland. I will not go into a detailed discussion of the historical development and contested meanings of the term, which has been dealt with elsewhere (see, e.g., Clarke 1999a, 97-113; Lepola 2000, 198-214); however, I can summarize these discussions as describing a bifurcation between members of the 'eternal' Finnish nation (with all of the communitarian ethno-racial implications) and outsiders who can never cross the divide into the nation. The social memory of *Finnishness* is therefore often

strategically articulated to reinforce the divide between newcomers and members of the eternal nation.

In the late 1980s and early 1990s, multiculturalism was thought to be something that imported or brought from abroad, not something that already exists in Finland. This, as we have seen earlier, represents a selective construction of social memory. Hence, in Will Kymlicka's (2001) terms, unlike discussions on ethnic minorities, who were invisible and perhaps marginalized yet somehow included in relation to notions of *Finnishness*, multiculturalism was associated with immigrants, people not necessarily accepted as members of the nation. As Leena Suurpää notes, to speak of foreigners, or non-Finns, is to implicitly construct comparative and mutually exclusive categories (Suurpää 2002, 109).

Some research indicates that the Finns with the most negative attitudes towards migrants tend to be those with the least interpersonal contact with foreigners (Jaakkola 1999). Other research has also suggested that generation and age tends to play an important role in assessments of outsiders (Helve 1999). Despite the dividing practices implicit in many articulations of multiculturalism in Finland, some studies of Finnish young people show that when asked to consider actual multiculturalism in everyday practices among real people, they demonstrated far more relativistic views of multiculturalism.

The attitudes and values of young people are in many cases contradictory and unanalytical. The same person can consider equality a good thing in a certain context, while expressing very racist opinions in another. My studies have shown that most young people's attitudes and values are not anchored in any political, religious or other ideology. They feel free to change their views according to the situation. (Helve 1999)

Theologist Helena Helve's research on Finnish young people's attitudes towards multiculturalism suggests that the postmodern global consumer society has an equally strong influence on youth as traditional, modernist articulations of national belonging. According to Helve, this accounts for weighing the significance of multiculturalism situationally rather than inflexibly.

In the mid-to-late 1990s, the rhetoric of multiculturalism became more prominent in Finnish public discourse and was increasingly connected with discussions of equal opportunities. This occurred at the same time that the Finnish government began to extend legal procedures to combat discrimination as the reality of racial and ethnic discrimination, which became a greater priority on the EU level. The office of Ombudsman for Foreigners was changed to the Ombudsman for Ethnic Minorities in 2001. The start of these discussions reflected a recognition of the growing cultural diversity of contemporary Finnish society, and perhaps even a deepening of the discussion of what this meant for the future of Finnish society. The Ministry of Labor set up a working group to consider how to implement anti-discrimination directives (Streng 2002, 7). Plans were put forward by the authorities via the Committee on Migration and Refugee Policies (1997) and the Ministerial Group against Racism (1996) (Vuori 1997). A study indicated that the Finnish police did not systematically collect data on racist violence thus making it difficult to assess its prevalence (Jaakkola 1999). There was concern at the high unemployment rates of migrants in Finland and its possible relation with discrimination in the labor market (Forsander 2002). Thus, ethnic, racial and cultural discrimination became increasingly recognized as a factor preventing migrants from gaining access to participation in Finnish society.

The positive tone of much of the Finnish discussion on multiculturalism can be contrasted to developments in Denmark in the 1980s, for example. As Karen Wren described, cultural racism strongly emerged in Danish public discourse with the rise of the political far-right and increasingly ethnocentric academic research on migration (Wren 2001, 152-153). Danish perspectives on multiculturalism have tended to articulate it as a threat to the nation. Finnish discourse on multiculturalism, on the contrary, tended to reflect a more cautious approach to emerging diversity (see, e.g. Horsti 2002b, on attempts for more inclusive media coverage).

According to many Finnish experts, however, there was a great need is for practical measures to fight discrimination at the level of everyday practices (Forsander 2002). The lack of systematic cultural awareness and anti-discrimination training was cited in a study

by the International Office of Migration as a significant barrier to combating discrimination in Finnish society (Vuori 1997). The prevalence of discriminatory practices in the labor market tends to further weaken the economic prospects of migrants resident in Finland (e.g. Joronen 1997).

With membership in the European Union and the recovery of the Finnish economy in the mid-1990s, a greater sense of pride began to mark societal constructions of Finnish identity (Center for Finnish Business and Policy Studies 1999) which was positively contrasted with other national identities. At the same time, the emergence of greater neoliberal challenges to the welfare state together with articulations of cultural racism has resulted in a hardening of attitudes towards the social rights of migrants. Research has pointed out that migrants are frequently considered to be a burden to Finnish society by Finns (Forsander 1999). These attitudes, which mirror many of the individualized stances prominent in discourses on globalization and the future of the welfare state, have given impetus to the development of a carrot-and-stick approach to integration through the instruments of the Act on Integration and the Reception of Asylum-Seekers (*Asetus maahanmuuttajien kotouttamisesta ja turvapaikanhakijoiden vastaanotosta* 1999/511).

The Integration Act has had the positive effect of requiring municipalities to clarify the responsibility for assisting migrants to integrate by providing language courses and other training. However, there have been many problems with its implementation. While greater demands have been placed on migrants to 'integrate' into Finnish society by learning the language and joining the workforce through the adoption of measures outlined in the Act on Integration or face a loss of social benefits, there are not concomitant requirements or sanctions of the authorities who may fail to meet the integration needs of migrants due to the lack of resources. In public discussion, integration has often been conceived as a one-way process whereby a migrant must take responsibility for herself by adhering to the program. What this type of discourse excludes, however, are the very real hurdles of discrimination, everyday racism, social isolation and vulnerability that many migrants experience in Finnish society.

Consequently, the emerging discussion of multiculturalism in 21<sup>st</sup> century Finnish society is characterized by a greater degree of esteem of Finnish identity as an articulated cultural category at the same time that stricter legal requirements and socio-cultural expectations towards migrants to adapt (or assimilate) into Finnish society have grown. Underlying many of the discussions of the significance and meaning of multiculturalism in Finnish society are racialized articulations of national belonging. This is embodied by everyday practices which continue to divide people by ‘blood’ heritage, for example when second generation migrants born and raised in Finland are asked where they are ‘from.’ Hence narratives of the nation have a very concrete meaning in articulating national belonging in practical, everyday interaction as well as defining the societal structures and institutions that recognize and accept cultural diversity as an intrinsic part of Finnish multicultural society.

### **12.3 Migrants forever?**

Historically, notions of *Finnishness* have traditionally been based on a sense of communal belonging that has often been defined by social memory articulated through the institutional practices of the Lutheran Church, the high social and moral value placed on work, and communitarian ideals of citizenship (Stenius 1997). Unlike societies defined by pluralist liberal traditions, Finnish society has been articulated through notions of the community and common responsibility for fellow citizens, rather than individualism. The social memory of *Finnishness* is often articulated as synonymous with ethno-racial cultural homogeneity. The combination of these factors as a signature of national identity serves to construct *Finnishness* as a rather exclusive category. This poses many challenges to an increasingly racially and culturally diverse Finland and raises the question of whether migrants can ever really belong in Finnish society.

Following Ruth Frankenberg’s discussion of the social construction of whiteness, we can see predominant constructions of *Finnishness* as a location of structural advantage and privilege. Further, *Finnishness* provides a standpoint from which Finnish people look at themselves and others. Finally, *Finnishness* refers to a set of cultural practices that are

often unmarked and unnamed (Frankenberg 1993). In short, *Finnishness* is constructed as equivalent to normalcy, but at the same time, it is often constructed as a quality that can only be obtained through membership in the ethnic ‘blood’ community of Finns. Hence migrants have been constructed in different ways in relation to *Finnishness*. For example, there are Ingrians and Canadians who are recognized by law and to some extent by the general public as ethnic Finns, even if they have never resided in Finland, while the children of Somali-born Finnish citizen parents who have grown up attending Finnish day care centers and schools, who are often never considered to be part of the nation, and have little possibility to become part of it.

At the core of questions of how to define a multicultural Finland is the notion of belonging. Issues of belonging and being a part of Finnish society are indeed concerns within migrant communities. This is because, as urban sociologists Kevin Fitzpatrick and Mark LaGory state: ‘place matters.’ (Fitzpatrick and LaGory 2000, 4-5) What Fitzpatrick and LaGory mean by this is that place and a sense of belonging to it is a very important part of our social identity, interaction with social structures and well-being. To exist in a state of non-belonging and alienation from place is to be an eternal stranger bereft of social ties and connection.

New narratives will need to be created to shape emerging articulations of multicultural Finnish social memory. The Finnish context is very different than many other culturally diverse Western European countries, particularly those with a history of colonialism and deep roots in inter-cultural migration. Articulations of multiculturalism and discussions of the meaning of cultural diversity have only emerged in the last decade. Due to the very recent increase in immigration, the difficulty of Finnish language acquisition, and the fact that few migrant graduates are hired by research institutions, there is a real lack of research by migrants in Finland. Therefore, representations and articulations of the migrant experience in Finland tend to be almost exclusively constructed and mediated by Finnish researchers.

The increased interest by Finnish researchers in the migrant experience is very significant, but it will perhaps be up to the next generation of migrants to provide the important voice of migrants that is missing at this stage in Finnish history. As Jennifer Langer has noted:

...second generation women often act as a voice for the first generation because the latter were not able to express themselves and felt alienated from society given that their priorities were their children and the desperate struggle for survival. (Langer 2002, 15)

The silence that surrounds many of the issues of importance to migrant communities in Finland may thus be broken by future generations that feel a stronger sense of rootedness and security in Finnish society and social memory. In the future, these new Finns may feel a greater need to communicate their experience to their fellow Finns and challenge the localized global power relations that maintain unequal racialized and ethnicized hierarchies.

### **13. Access to HIV/AIDS social and health care in Finland: Constructing the resident**

This chapter focuses on migrants' access to HIV/AIDS social and health care in Finland. Access has often been interpreted narrowly in social and health care as simply meaning the right to visit a social or health care practitioner. Access to care, however, involves a wide range of issues that do not start at the practitioner's door. Access includes the entire process of getting to the door: self-definitions of need, help-seeking behavior, personal empowerment, barriers, outreach services, appropriate information and communication, power relations in society, social and political rights, among other issues. Moreover, access is not merely an individual question, but also involves communities and their socio-economic and political status in society, as well as social attitudes and intercultural communication. Access is thus one element of the social matrix that translates power relations on an individual and community level (Farmer 2003, 30).

This chapter focuses on the different dimensions of access to HIV/AIDS care by briefly outlining Finnish social and health care policy and situating migrants living with HIV/AIDS in the national AIDS strategy as well as in the social and health care system. Building on the previous chapter which explored definitions and constructions of migrants in Finnish society, this chapter uses legal and policy texts in addition to information disseminated by non-governmental agencies to locate migrants and to explore absences, contradictions and invisibilities.

To contextualize this discussion, I start with a definition of the term access drawn from community health psychology (de la Canceleda et al. 1998) and explore its significance within the framework of Finland as a Nordic welfare state before moving on to the main lines of Finnish health care policy and how the system itself is structured. Certainly the system is far more complex than a short description like this can present. However, when considering the significance of the plots of international stories of AIDS in policy and

practice, it is important to render the model of the Nordic welfare state, and Finland in particular, appropriately distinct. The plot of African AIDS, for example, is articulated very differently in a Finnish context, with its recent history of immigration, cultural homogeneity and Nordic welfare state, than the UK with its history of colonialism or the United States with its legacy of slavery, adversarial movements for social justice and private health care systems. This sketch of the Finnish welfare state and health policy is therefore offered with the caveat that it is intended merely a compass to approach the main focus of this chapter: access to HIV care and treatment.

### **13.1 The notion of access and the Finnish welfare state**

The word ‘access’ literally means ‘coming to or towards; the habit or power of getting near or into contact with.’ (OED 1979, 54) Access means the capability to cross boundaries and to get in touch with others. It can also have frightening or negative connotations when associated with contagion or crime. Access as a social and health care term therefore encompasses the capacity to enter into the service system as a patient/client and to have one’s needs met. As the definition of the word indicates, however, access also has the deeper meaning of ‘the power of getting into contact with.’ This implies that in a social and health care context access has cultural, psychological, and socio-economic dimensions that are embedded in the social and health care encounter. In short, there are a myriad of complex factors that have an impact on the capacity to obtain help from the national social and health care system.

According to *The Right to the Highest Attainable Standard of Health* detailed in the 1996 International Covenant on Economic, Social, and Cultural Rights, four elements comprise access to health:

- Non-discriminatory services
- Physical accessibility
- Economic accessibility
- Information accessibility

Access is therefore not solely an individual issue but also involves the interaction between a professional culture and potentially diverse communities, groups or social classes, with all of the implications that power relations amongst and between these categories entail. As community health psychologists de la Cancela et al. have underlined:

We understand individuals to behave within family, community, societal, and political contexts, as well as with intrapsychic contexts, which shape human health [...] The community health perspective is intended to promote change via policy development, administration, and public health. The intended outcomes are the improved health of a community, empowerment for communities of color, and improved access and cultural competence in our systems of care. (de la Cancela et al. 1998, 2-3)

Access includes inclusion of needs in the financing of universal health care, public health policies that strengthen community action and the preconditions for healthy environments as well as orient services towards prevention (UNAIDS 2001, 23). Hence access to care in the modern welfare state is socially constructed through power relations in society because it is grounded on the notion of equality, a greatly contested and not necessarily self-evident concept. The special needs of underserved communities which have an impact on access, for example, might not be recognized in policymaking due to the fact that such communities are not represented as stakeholders in policy planning, professional training or on practice teams.

Articulations of of the appropriate means of access reflect cultural and social assumptions. Factors that enhance access to care for some (such as making appointments by telephone or internet) can be tremendous barriers to others who lack language skills, access to technology or find it difficult to express needs without face-to-face contact. Other, less tangible factors, such as the attitudes of the gatekeeper to services towards the person seeking help, can have a strong impact on the ability to gain access to services. Access to care is constructed through the visibility and recognition of the diversity of needs and ways to facilitate meeting them. Access opportunities are often based on normalized visions of equality that tend to construct a universal patient/client. These

types of constructions can render the special needs of diverse patients/clients invisible and thus act as a barrier to obtaining access to care.

Nordic welfare states have often been defined in contrast to continental and liberal traditions of the welfare state. Conceived as entities with a high level of governmental intervention in the economy, the Nordic model is based on the notion that all citizens should be included in a universal welfare state that ensures high quality, decommodified equal services within a liberal democracy:

Rather than tolerate a dualism between state and market, between working class and middle class, the social democrats pursued a welfare state that would promote an equality of the highest standards, not an equality of minimal needs as pursued elsewhere. This implied, first, that services and benefits be upgraded to levels commensurate with even the most discriminating tastes the new middle classes; and second, that equality be furnished by guaranteeing workers full participation in the quality of rights enjoyed by the better-off. (Esping-Anderson 1990, 27)

Esping-Andersen argues that universalism is the 'reigning principle' in Nordic welfare states which are among the most egalitarian countries in the world (Esping-Andersen 1990, 75). The Nordic welfare state model can also be seen as embodying a tension between control and integration, equality and conformity, the community and the individual, professional expertise and grassroots lay knowledge within the tradition of universal social citizenship. Nonetheless, to some degree, this notion of the Nordic welfare state is based on the assumption that there is a cultural consensus regarding universalism, equality and care. Nordic welfare state egalitarianism has always been marked by the shifting normative borders of national community inclusion.

### **13.2 The Finnish health care system and social insurance rights for migrants**

Finnish health care is divided into two basic areas of responsibility: primary health care and specialized health care. Primary health care is organized by municipal health care centers under the guidelines of the Ministry of Social Affairs and Health. Included in the

area of primary health care are health care clinics, maternal/child clinics, school and student health care, occupational health care, health screening, health care for the elderly, medical rehabilitation and environmental health care. According to recent statistics collected by the Ministry of Social Affairs and Health, there are 265 health care centers in Finland (Ministry of Social Affairs and Health, 1999d). Specialized medical care is also organized by municipalities through guidelines established by the Ministry of Social Affairs and Health. However, due to the geography and demography of Finland as well as in the interest of maximizing efficiency, specialized medical care is organized into 21 hospital districts throughout Finland. Each hospital district has a central hospital. There are five university teaching hospitals in Finland (Helsinki, Tampere, Turku, Kuopio and Oulu) which offer highly specialized medical care. Each hospital district which is organized by a federation of municipalities arranges specialized medical care for patients referred by a physician.

When making an appointment, patients first see a primary health physician at their local health care center. Patients are assigned to health care centers on the basis of their registered place of residence. Students and employees, however, attend student or occupational health care centers. Specialized care is available by referral of the primary care physician at the local health care center.

Access to social and health care services, excluding acute and emergency care, is based on the Act on Residence-Based Social Security (*Laki asumiseen perustuvan sosiaaliturvalainsäädännön soveltamisesta* 1573/1993). The Social Insurance Institution (KELA) defines eligibility for social insurance:

In order to be considered to be living in Finland, you must have a permanent dwelling and domicile in Finland and to be permanently resident here...In cases subject to interpretation, the determination of which country a person has the closest connections to is based on such factors as:

a. Persons moving to Finland can be considered to be living in Finland immediately if they enter Finland with the purpose of establishing

permanent residence here and have a residence permit for one year (if required);

b. Under special circumstances, even those with residence permits valid for less than one year can be considered to be living in Finland provided no grounds exist that would preclude renewal of the permit. Such special circumstances include family reunification or limits to the validity of the passport due, for example, to conditions in the bearer's home country;

c. Persons seeking asylum in Finland are not considered to be living in Finland while their case is pending. If, however, they have been issued a residence permit valid for at least one year, they are considered to be living in Finland from the date the permit was issued. 'Quota refugees' are considered to be living in Finland starting immediately from when they actually move to Finland. (Social Insurance Institution 1999, 2)

The key phrase in this definition is 'to be permanently residing here.' This means that any migrant on a fixed-term residence permit (B category), such as students and temporary workers, are not technically eligible to obtain a social insurance card in Finland even if they continually reside in the country for a decade. It is necessary to have a social insurance card to be registered in the national health system and have the right to attend the local health care center. However, as mentioned above, the health needs of students and workers are met through parallel health care systems, with certain limitations. Nonetheless, it is necessary to have a social insurance card to obtain subsidized medication. If an individual does not have a social insurance care, he must pay full price for prescribed medication. The only exception to this rule is medication prescribed for a disease designated as 'reportable', which are given free of charge (Act on Client Payments; *Laki sosiaali- ja terveydenhuollon asiakasmaksuista* 1992/734).

It is possible for patients to use private medical care in Finland. Depending on the procedure, the Social Insurance Institution offers partial compensation, calculated on the basis of the cost to attend public health services, to those patients seeking private medical services. There is no evidence that there are licensed private professional caregivers that specialize in working with migrants or ethnic minority communities, though there may be informal networks that provide alternative healing methods (see, e.g., Tiilikainen 1999, 2001).

### **13.3 Equality and rights to culturally competent services**

Finnish social and health care policy is based on the principle of equality. Equality is a highly contested and complex concept, the multiple meanings of which are beyond the scope of this study. This subchapter therefore focuses on central concept of equality solely in relation to migrants and their needs in the Finnish social and health care service.

#### 13.31 Finnish articulations of equality in the law

Without entering into the vast and complex debate on citizenship and inclusion in the welfare state, I raise a few points to become oriented towards a discussion of equality and migrants in the Finnish welfare state. In social policy, the notion of equality has traditionally been connected with ideas of citizenship, which is viewed as a status rather than a privilege (see, e.g., Marshall 1963). In this sense, modern articulations of equality in the welfare state have been embedded within the normative expectations and practices as well as the specific socio-economic, cultural and historical contexts of nations. Inclusion in the welfare state can therefore be seen as a marker of belonging in society. However, it is important to recognize that notions of equality, and their normative constructions in law, policy and practice, reflect the constellation of power relations in society. Equality, in short, is not singular or uniform concept that can be universally applied in all situations. Rather, equality is a relational concept that is articulated through decisions on the sharing of resources and is therefore subject to the prevailing socio-economic, cultural and political winds.

Equality in Finnish law is seen as parity before the law regardless of gender, ethnicity or socio-economic status. The system of social protection (preventive social and health policy, social and health care services and social insurance) is represented by the Finnish government as an essential element of the construction of equality in Finland (see, e.g., Ministry of Social Affairs and Health 1998, 1999d). It can be argued that the historic compromise between labor and capital can be most clearly seen in the universalization of social protection to all citizens. Furthermore, the Nordic tradition of the welfare state has

reinforced notions of gender equality through institutionalizing community solidarity, though this has often been considered a ‘mixed blessing’ (Nousiainen et al. 2001, 3-5).

Articulations of equality in the Finnish welfare state have faced new challenges in the postmodern era. With the deep recession of the 1990s and the rise of neoliberalism and market ideology through the impact of globalization, many of the traditional ties that have bound Finns together as equals in the national welfare state have loosened. New historical studies have raised questions about dominant constructions of social memory and their relation to constructions of *Finnishness* (e.g. Sana 2003 for a reevaluation of deportations during World War 2). Notions of fundamental social rights and inclusion have been debated in an era of scarce public resources. The growing rural/urban income divide, strength of individualist-consumerist neoliberal political philosophy, and the increase in the number of migrants with special needs have put pressure on the Finnish care system and decision-makers who allocate resources, as well as the on articulations of the borders of inclusion in the Finnish welfare state.

In her research, legal scholar Anu Pylkkänen has suggested that liberal values of individual rights in law have traditionally been relatively weak in the Finland (Pylkkänen 2003). When combined with the discussion of the construction of *Finnishness* as communal membership in the culture of Lutheranism as suggested by Anttonen (1998) and Stenius (1997), we can see a stronger emphasis on articulations of community in Finland rather than individuality as in many other, particularly Anglo-American, nation-states. Hence the challenges of neoliberalism in many ways represent a fundamental reassessment of the social memory of *Finnishness* as a communal blood tie that have emerged through making meaning of the historical experiences such as the Civil War, Second World War and postwar reconstruction efforts.

Certain population groups in Finland have so-called ‘subjective rights’. This means that individuals who fulfill certain preconditions have the guaranteed right to special services. The disabled, for example, have the subjective right to certain special services which cannot be abrogated due to deficits in resources. Subjective rights cannot be negotiated

on the basis of lack of municipal resources and must be provided. Subjective rights in Finland are powerful tools to ensure the client's equal position in the social and health care system. Subjective rights differ from discretionary rights. Discretionary rights are framed in the law as strong recommendations but do not mandate authorities to ensure their fulfillment. Many of the rights of migrants, such as the right to interpretation in services initiated by the client, are discretionary rights.

Finland is officially a bilingual country (Swedish and Finnish). Section 17 of the Finnish Constitution concerns linguistic and cultural rights. It explicitly states that the linguistic, cultural and societal needs of Finnish and Swedish-speaking Finns must be met. The cultural and linguistic needs of the Roma and Sámi people, as well as the hearing impaired, are also recognized, though they do not have the same status as the Finnish and Swedish languages. The notion of *Finnishness* as a cultural-legal concept thus encompasses two linguistic communities as well as the ethnic minority communities of the indigenous Sámi and Roma, though there is an implicit difference in the legal position of the communities in terms of linguistic rights.

The Language Act (*Kielilaki* 1922/148; revised 2003/423) outlines the rights of the Swedish and Finnish linguistic communities to receive information and services in their own mother tongue. Indeed, the vast majority of complaints regarding discrimination made to the Parliamentary Ombudsman concerned the lack of services available in Swedish rather than racial or ethnic discrimination (Streng 2002, 20). Currently, a new version of the Language Act has been drawn up by the Ministry of Justice. The main aim of the Language Act reform is to reformulate linguistic rights in a postmodern society facing the challenges of globalization (Ministry of Justice 2001). One of the main thrusts of the reform of the Language Act is that public authorities should be responsible to guarantee linguistic rights on their own initiative rather than having a law that refers to specific linguistic rights (Ministry of Justice 2001, 5). This represents a dangerous trend, common to much of the laws on migrants, that relies on the goodwill of local authorities to ensure equal linguistic and cultural rights rather than compulsory measures which would ensure resources to realize anti-discriminatory measures. Voluntary compliance

rather rights-based legislation leaves the door open for neglect of compulsory measures to promote equality.

The postwar emergence of human rights as a prominent feature in international law has had an impact on the development of Finnish law. Legal frameworks were further developed to further guarantee individual rights as well as ethnic minority rights. Gender equality, for example, was formalized in the Act on Equality between Men and Women (*Laki naisten ja miesten välisestä tasa-arvosta* 1986/609). However, though there are laws against incitement to racial hatred and criminal racial discrimination, there is no general law on ethnic or racial equality yet in Finnish legislation (Sirva and Stenman 2002, 9). Few cases of racial discrimination have been tried in court.

Discrimination can be defined as

...unfair treatment or denial of normal privileges to persons because of their race, age, sex, nationality or religion. A failure to treat all persons equally where no reasonable distinction can be found between those favored and those not favored. (Black's Law Dictionary 1993, 323)

Discrimination consists of both direct and indirect actions that result in unequal treatment. Indirect discrimination can result when policies and practices have a discriminatory impact on people from certain groups.

Since the 1990s there has been a trend towards specifying individual's rights in law. The Act on the Status and Rights of the Patient (*Laki potilaan asemasta ja oikeuksista* 785/1992) ensures that patients are entitled to informed consent, information about reasons for and estimated time on a waiting list, access to medical records, among other rights. As such, it is one of the most progressive pieces of legislation found in the industrialized world.

Migrants and their needs, however, remain largely invisible in Finnish equality law. One of the primary reasons for this is the implicit ambivalence in Finnish law on cultural

diversity within the nation. Traditionally, social entitlements have been based on nationality in the Finnish welfare state (Kainulainen et al. 2000, 2). As many migrants are not Finnish citizens, they are therefore not explicitly included in national law. As noted above, the Finnish Constitution takes into account traditional minority groups which have resided in Finland for centuries, such as the Roma and Sámi, but it does not make mention of new migrants. Though Finland has laws against racial discrimination (Finnish Penal Code §11.8 and §11.9), they focus on the criminalization of intentional discrimination. In other words, this conceptualization does not take into account the practices of everyday and hidden discrimination which may be very difficult to prove in the absence of explicit legislation. These ambiguities make a narrow construction of discrimination that takes into account only a limited amount of practices. When ideas of norms and rights are tied to a culturally defined notion of equality and specific cultural ideas of clienthood/patienthood exist, then the cultural and linguistic needs of diverse populations can be constructed as special and extra and not a fundamental human right. In such a situation, everyday discriminatory practices are often not recognized as the basis of inequality in society.

### 13.32 Equality in social and health policy guidelines

The four cornerstones of Finnish social and health care policy, according to public health researcher Raija Taavela, are the respect of self-determination, anti-discrimination, equality, and respect for the needs of culturally diverse patients and clients (Taavela 1999, 64). The main legislative guidelines that guarantee migrants' human rights in the Finnish social and health care system include the basic laws for all people resident in Finland that prohibit discrimination in public services, such as the Act on the Status and Rights of Social Welfare Clients (*Laki sosiaalihuollon asiakkaiden asemasta ja oikeuksista* 2000/812), the Integration Act (*Asetus maahanmuuttajien kotouttamisesta ja turvapaikanhakijoiden vastaanotosta* 1999/511), the Act on the Status and Rights of Patients (*Laki potilaan asemasta ja oikeuksista* 1992/785) as well as laws on administration procedure and public health which guarantee equality (Taavela 1999, 63).

As we have seen earlier, explicit legislation against cultural, ethnic or racial discriminatory practices does not exist in Finnish law.

The Integration Act states the obligations and rights that migrants have in Finnish society, but it does not explicitly mention migrants' right to culturally or linguistically competent services or care. Furthermore, the Integration Act does not designate migrants' rights to interpretation services as subjective rights, unless the action is initiated by the authorities. Here we can see how articulations of the social memory of the Finnish community functions as a set of cultural practices that can mask everyday discrimination, marginalize or produce exclusions.

For the purposes of this study, the most significant piece of legislation is the Act on Patient's Rights which states:

The mother tongue, individual needs and culture of the patient have to be taken into account as far as possible in his/her medical treatment and other care. (Act on the Status and Rights of the Patient, 1992/785)<sup>70</sup>

This is an important legal instrument for multicultural patient advocacy, though the basic right is hedged by the words 'as far as possible.' Indeed, at the time of writing, there is little research to indicate how migrants' rights as patients with diverse cultural needs are met in practice in different municipalities.<sup>71</sup>

Further, the rights of culturally diverse clients are noted in the Act on the Status and Rights of Social Welfare Clients (*Laki sosiaalihuollon asiakkaan asemasta ja oikeuksista* 2000/812) which explicitly states:

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<sup>70</sup> Potilaan äidinkieli, hänen yksilölliset tarpeensa ja kulttuurinsa on mahdollisuuksien mukaan otettava hänen hoidossaan ja kohtelussaan huomioon.

<sup>71</sup> Among the exceptions are the dissertation Maahanmuuttajien palvelujen laatu Suomen perusterveydenhuollossa by Raija Taavela (1999) and the qualitative studies, Welfare research into marginal communities in Finland: insider perspectives on health and social care (Clarke 2003b) and The problematics of well-being: experiences and expectations of New Finns in the Finnish welfare state (Clarke forthcoming), which feature reports by migrants on experiences with the Finnish social and health care system. Research in this field can be expected to grow.

When social care is realized, the client's wishes, opinions, interests and individual needs, as well as the client's native language and cultural background must be taken into account<sup>72</sup> (2000/812 §4)

If the personnel of social care can not speak or understand the language that the client uses, or if the client can not be understood due to sensory impairment, a speech impairment or other reason, interpretation and the use of services of an interpreter should be acquired when possible. If the question is of an issue that can be initiated by an official, interpretation and the services of an interpreter must be arranged as is regulated (2000/812 §5) in the §22 of the Administrative Procedure Act (1982/598)<sup>73</sup>

The Law on Administrative Procedure (*Hallintomenettelylaki* 1982/598) also states:

- 1) The authority shall arrange for interpretation and translation in cases where a concerned party in a matter that may be initiated by the authority does not know the language to be used before the public authority pursuant to the Language Act (Act 1922/148) or where he cannot make himself understood due to a sensory handicap or speech disorder.
- 2) For a special reason, the public authority may also arrange for interpretation and translation in cases other than those referred to in Paragraph 1.
- 3) The public authority shall ensure that citizens of the Nordic countries receive the necessary interpretation and translation assistance in matters considered by the said public authority.<sup>74</sup>

In these laws we can see that there is some recognition of the specific needs of culturally diverse patients and clients. However, the language of the law does not mandate the use

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<sup>72</sup> Sosiaalihuoltoa toteutettaessa on otettava huomioon asiakkaan toivomukset, mielipide, etu ja yksilölliset tarpeet sekä hänen äidinkielsensä ja kulttuuritaustansa. (2000/812 §4)

<sup>73</sup> Jos sosiaalihuollon henkilöstö ei hallitse asiakkaan käyttämää kieltä taikka asiakas ei aisti- tai puhevian tai muun syyn vuoksi voi tulla ymmärretyksi, on mahdollisuuksien mukaan huolehdittava tulkitsemisesta ja tulkin hankkimisesta. Jos on kysymys asiasta, joka voi tulla vireille viranomaisen aloitteesta, on tulkitsemisesta ja kääntämisestä huolehdittava siten kuin hallintomenettelylain (598/1982) 22 §:ssä säädetään. (2000/812 §5)

<sup>74</sup> Viranomaisen on huolehdittava tulkitsemisesta ja kääntämisestä, jos asianosainen asiassa, joka voi tulla vireille viranomaisen aloitteesta, ei osaa viranomaisessa kielilain (148/22) mukaan käytettävää kieltä taikka aisti- tai puhevian vuoksi ei voi tulla ymmärretyksi.

Erityisestä syystä viranomaisen voi huolehtia tulkitsemisesta ja kääntämisestä muussakin kuin 1 momentissa tarkoitettussa asiassa.

Viranomaisen on huolehdittava siitä, että muiden pohjoismaiden kansalaiset saavat sen käsiteltävissä asioissa tarvittavan tulkitsemis- ja käännösavun.

of culturally and linguistically appropriate services, but states that they should be provided 'when possible' and 'should be taken into account.' They are therefore framed as discretionary rights, which mean that there are few instruments to require the development of culturally appropriate practice which can result in indirect discrimination.

According to Finnish law, equal opportunities in terms of language, for example, are provided only to migrants with a permanent residence permit. Permanent residents of Finland have a subjective right to interpretation and translation services in a specific procedure if the action is initiated by the state or municipality. These types of situations usually involve contact with the police, law courts or infectious disease control. If the matter is initiated by the migrant, such as an appointment at the labor office, health care centre visit or social welfare office visit, then the authorities are not required to provide interpretation or translation assistance. Interpretation in this situation would be defined as a discretionary right. This suggests that equality in service provision continues to be articulated through culturally normative frameworks.

The Finnish government has regularly drawn up national health policies (e.g. *Health for All* [1986]) that highlight the most important priorities of Finnish health care. The most recent national public health policy is *Health 2015* (Ministry of Social Affairs and Health, 2001). In this policy document, the government sets out its main priorities for developing public health. Interestingly, despite the rapid increase of immigration in Finland, there is only one mention of ethnic diversity as a challenge to Finnish health care (Ministry of Social Affairs and Health 2001, 13). Here ethnic diversity is connected with the ageing population as a challenge to Finnish health care without further elaboration. There are two mentions of the need to prevent cultural exclusion (Ministry of Social Affairs and Health 2001, 13-14), placed in association with ageing and social exclusion, but no discussion of the significance of culturally competent care. The reality and significance of cultural diversity in the caring situation is thus effectively undermined through the hollow use of generalizations and the lack of emphasis on cultural competence as a core principle of good practice.

There is a strong basis in Finnish law for human rights in health care. Finnish health policy, however, has not developed a viable strategy to cope with the special challenges that migrants bring to health care because articulations of equality in the welfare state remain tied to the exclusions of Finnish social memory. Due to the privileging of Finnish cultural assumptions which underlie concepts of health, care and equality, culturally competent practices have not yet been developed in a systematic manner.

### 13.33 Culturally competent care

Cultural competence as a caregiving skill can be defined as

The service provider who is culturally competent can deliver professional services in a way that is congruent with behavior and expectations normative for a given community that are adapted to suit the specific needs of individuals and families from that community. (Green 1999, 87)

As Green emphasizes, cultural competence does not mean that the caregiver must act ‘as though’ he were part of the client community, but rather that he has systematically

...learned and tested awareness of the prescribed and proscribed values and behavior of a specific community, and an ability to carry out professional activities consistent with that awareness. (Green 1999, 87)

Hence cultural competence means methodically developing awareness of the implications and practices of cultural diversity in caregiving work. Underlying notions of cultural competence is the recognition that all caring work is inherently cultural. In other words, there is no such thing as culture-free or culture-blind caring work (Pinderhughes 1989, 13).

Cultural competence is particularly important in the caring professions which often personify societal power relations. As Elaine Pinderhughes, an expert on cultural competence training, has pointed out:

Power is an often unspoken but central dynamic in cross-cultural encounters. We have observed its presence in the associations of dominance, superiority, and denigration, with ethnic identity, and group status; in the common perception of difference from others as ‘better than’ or ‘less than’; and in the dynamics of race (racism), which is itself a power system. In the cross-cultural clinical encounter where power is embodied in both cultural dynamics and clinical role, its existence has been virtually ignored. But the power and lack of power, inherent in the roles of clinician and client and in their cultural group status, can affect clinical process and outcome. (Pinderhughes 1989, 109)

Hence cultural competence requires continuous reflection on how culture, ethnicity, race, gender and sexuality, among other identities, have an impact on the power relationship between caregiver and client or patient. It demands unremitting professional and personal reflection on ethics and values. Most importantly, it challenges traditional power relations by empowering and including the patient and client as an integral part of the caregiving encounter.

The Finnish social and health care system has not adopted cultural competence as a core priority in the strategy to improve equality and services. Some Finnish policymakers have been hesitant to encourage the development of culturally and linguistically appropriate services because they fear that it will ‘parallelize’ existing services and thus reduce equality (e.g. Mattila interview, 2002; Hormia 1999). In this framework, social and health care services can be seen as a means of integrating migrants into Finnish society through culturally-defined articulations of needs rather than as a multi-dimensional resource to empower healthy diverse communities and individuals. Cultural competence in this view may be seen as an unequal practice rather than an important preventive measure to ensure better health outcomes

Education for caregivers in Finland, such as physicians, nurses and social workers, tends to underline their role as culturally neutral experts. Equality is often constructed in Finnish social and health care curricula as uniformity and providing the same for all. This view of equality can result in indirect discriminatory practices in which the special needs of clients are not recognized and real equality is not promoted. Exploring the complexity

of articulations of equality in social and health care education, moreover, could offer the opportunity to address unresolved issues from the past, such as the legacy of eugenics, to challenge the exclusions of social memory and initiate a dialogue on the role of professionalism in promoting equality (Thompson 1998, 142-145).

Within the culturally normative articulations of needs and service provision in the Finnish welfare state, migrant clients are often constructed in terms of their deficits in the Finnish social and health care system. They can be defined as not speaking Finnish, not having the same family patterns as Finns, and not having the same cultural or personal beliefs as Finns. Focusing on deficits rather than building on the strengths and resources of migrants, can promote indirect discrimination in the social and health care encounter.

Migrants in Finland tend to inhabit an ambivalent position in the social and health care system. They do not have subjective rights to culturally or linguistically competent social and health care services. Though the universalist premise that services should be accessible to all is a fundamental human right, it is important to underline the significance of culture, ethnicity and residence status in provision of services. The provision of linguistically and culturally appropriate care could enhance the quality of care, broaden access and contribute to better social and health care outcomes. These are important issues that need to be addressed and go to the heart of the practice of equality in Finnish society.

## **14. Social and health care for migrants living with HIV/AIDS in Finland**

This chapter explores the care and treatment offered to migrants living with HIV/AIDS in Finland. I start by giving a broad outline of the treatment of HIV/AIDS and various social support issues specific to the disease. I then continue by delineating the relevant laws, strategies and organizations to fight HIV/AIDS before focusing on the interview data of Finns and migrants on cultural differences in HIV/AIDS care. Finally, I conclude with a textual analysis of information available to migrants in English on HIV/AIDS. The aim of this chapter is to provide perspective on how Finnish HIV/AIDS social and health care for migrants is constructed.

### **14.1 HIV/AIDS treatment**

The name, acquired immune deficiency syndrome (AIDS) was accepted by the National Library of Medicine in 1983. This reflected the new understanding of the illness. AIDS was expressly conceived as a *syndrome*, not a disease per se. A syndrome is "...a constellation of symptoms constituting a clinical entity but not an etiological unity." (Grmek 1990, 33) Hence infection with HIV could manifest itself in a variety of ways, from a totally asymptomatic state to symptomatic conditions of various diseases. Among the illnesses produced by the weakening of the immune system by HIV, and considered to be part of the syndrome, were opportunistic infections such as PCP, toxoplasmosis, MAC (*Mycobacterium avium*), Kaposi's syndrome and tuberculosis. The threshold for the transition from infection with the human immunodeficiency virus to AIDS has been measured by counting the number of lymphocytes (also known as T-cells). As HIV becomes a part of the body's lymphocytes, which are cells that fight infection, a decrease in the number of lymphocytes indicates that the body is less able to fight infection. However, there are still many unanswered questions regarding HIV/AIDS. For instance, it was not and still is not known why people who have contracted the human immunodeficiency virus are predisposed to certain types of cancers and opportunistic

infections, but not others. It is also not known what routes HIV takes after entering the body to destroy the immune system or how it actually does so (Altman 2001). HIV disease can thus be characterized as a continuing struggle between a replicating virus and the immune system.

After diagnosis, people living with HIV/AIDS in Finland are referred to specialized care. Specialized care for HIV takes place in one of the 21 central hospitals in Finland. Some central hospitals have less than five HIV patients. In 15 of the central hospitals, HIV/AIDS patients are treated by an infectious disease specialist, which, in the Finnish medical system, is a subspecialty of internal medicine. In the remaining central hospitals, treatment is performed by an internist when a specialist in infectious disease is not available. In cases where a greater level of specialized expertise in infectious disease care is required, such as multiresistant HIV strains, women living with HIV who are giving birth or whose labor is being induced, patients are referred to university hospitals. Highly specialized services for people living with HIV, such as family planning for HIV-discordant couples, are centralized at the Helsinki University Hospital.

In the early stages, the physician takes numerous tests to determine the viral load of the patient and begins to consider whether a course of medication would be necessary.

Clinicians consider three criteria when considering the need for medication:

- Clinical presentation of disease compatible with AIDS
- Viral load
- Level of CD4+ cells (T-cells)

HAART (highly active antiretroviral treatment) treatment, which is considered the standard for care, is a combination of potent antiretroviral drugs (protease inhibitors and nucleoside-analogue reverse transcriptase inhibitors and non-nucleoside-analogue reverse transcriptase inhibitors) that acts to suppress the HIV virus. A drug regimen is planned and adjusted by the physician to suit the needs of the individual patient. Physicians must consider the individual tolerance to medication as well as possible interactions with other medications that the patient may be taking for other reasons. Perhaps most importantly,

physicians must take into account the patient's living conditions and daily routines when prescribing a course of treatment. An important determinant of compliance is the patient's ability to follow the treatment regimen. Therefore, doctors must consider how easy it is for the individual patient to take one pill daily as opposed to three. Some patients have adverse reactions to HAART medications and thus are not able to participate in the new treatments. Non-adherence to a HAART regimen can also create intolerance to medication in a patient. Patients who are able to take the new medications nonetheless can experience a wide range of side effects, such as fatigue, lipodystrophy, mitochondrial toxicity, neuropathy and even cardiac problems.

In Finland, antiretroviral medication is provided free of charge to all patients diagnosed with HIV disease, who are included in the Finnish social insurance system. Access to treatment was never tied to clinical trials in Finland as it was in the United States (Tommi interview 2002). In many ways, HIV/AIDS care presents many challenges to specialist physicians because they must be more intimate with HIV patients than many others. In order to tailor medication and care, it is necessary that the physician ask many personal questions regarding work, lifestyle, diet, sexual practices and family life. Hence cultural sensitivity is a critical clinical skill and poor communication can be a significant barrier to attaining a high level of care.

#### **14.2 Social support issues for people living with HIV/AIDS**

HIV/AIDS presents many mental health challenges both to seropositive people and loved ones affected by the disease. People living with HIV/AIDS tend to be fairly young, and sometimes have small children. The disease therefore has a strong impact on family relations, the ability to earn income, participation in family life and planning for the future. Feelings of guilt and anxiety may prevail within the affected family. People living with HIV/AIDS may face a high level of stigma, which can result in job and housing discrimination as well as social exclusion from the larger community. The general development of the disease is marked by a high level of uncertainty, due to the very individual responses to the new anti-viral medications. The medications may have

complicated instructions for use and strong side effects that cause illness, fatigue, depression and chronic disability. On the other hand, combination therapies have brought a new lease on life to many patients. People living with HIV/AIDS who have reacted well to treatment regimens have been able to pursue careers, start families and live healthier lives for longer periods than ever thought possible in the early days of the pandemic.

The depression and social isolation that many migrants experience in a new and unfamiliar society can heighten the threshold to seeking help. Susan Simola, a social worker at Aurora Hospital, noted that many African patients had seen relatives die of AIDS at home due to the lack of medication and treatment options. Sometimes these patients may experience 'survivor guilt' because they are able to be treated, while their relatives are not (Simola 2004). Mental health and social work professionals working in this field need to have client-centered, culturally competent counseling skills. Workers need to be aware of the role of culture in health seeking behavior, beliefs and knowledge, as well as the needs of special populations.

Many western biomedical models are disease-oriented. They promote the separation between body and mind and focus on the individual. The individualized approaches of many HIV counseling programs sometimes overlook the important role of collective structures, such as the family and community, in the lives of people from other cultures. Therefore interventions must be carefully planned in cooperation with the communities in question to be culturally appropriate.

All Finnish hospitals have medical social workers whose task is to organize necessary social support for patients who may need assistance. Housing, income support, information, counseling, interpretation and employment issues are among the many matters that medical social workers must help patients sort out. Patients may come into contact with the municipal social welfare system as a client of the income support system or family services, hence municipal social work does not deal with HIV-related issues per se. Non-governmental agencies, such as the Finnish AIDS Council, provide professional counseling in issues related to HIV/AIDS.

The hospital which has the broadest experience with HIV-related illness in Finland is Aurora Hospital in Helsinki. It has two full-time social workers. These social workers are often able to develop a long-term client relationship and frequently work with crisis situations. As Susan Simola has described:

Aurora Hospital follows a strong needs-led principle in its assessments. The focus of work with service users is to try to engage with them, to build their trust in social workers by meeting the needs that they themselves perceive, and so to try to ensure that contact with social services and health is maintained. (Simola 2002)

Aurora Hospital social workers provide multi-agency coordination to meet the diverse needs of their clients. Teamwork between the hospital staff and social workers is a fundamental element of Aurora's good practice. Medical social work thus offers an important source of support to people living with HIV/AIDS in Finland.

### **14.3 Finnish Laws on HIV/AIDS treatment and care**

The framework for human rights in health has a strong basis in Finnish legislation. Legislation passed in the 1980s and 1990s strengthened the legal position of patients in the health care system. A triad of legislation: the Act on the Status and Rights of the Patient (*Laki potilaan asemasta ja oikeuksista* 785/1992), mentioned earlier, explicitly outlines the human rights of each patient in the Finnish health care system; the Decree and Act on Communicable Diseases (*Tartuntatautiasetus* 1986/786; amended 1997); the Decree on Client Payments for Social and Health Care (*Laki sosiaali- ja terveydenhuollon asiakasmaksuista* 1996/734); discussed below, provide a firm foundation for the right to health care regardless of income, national origin, ethnicity, gender or race.

The Decree and Act on Communicable Diseases permit the collection of detailed information concerning communicable diseases for the purposes for surveillance. This is primarily needed for public health reasons. Tracking cases, outbreaks, epidemics along

with detailed demographic information generates information on trends and thus provides the basis for the creation of preventive policies and practices as well as the proper use of resources. This law presents guidelines for the management of diseases considered to be of great public health importance through disease notification, contact tracing, and partner notification.

The Decree on Client Payments for Social and Health Care stipulates that the examination and treatment of people with reportable diseases (which includes people living with HIV/AIDS) are to be free of charge. Medical treatment for HIV/AIDS is therefore provided free of charge by the Finnish national health care system. However, to be entitled to free treatment, migrants must fulfill eligibility requirements within the social insurance system of Finland.

Asylum-seekers and migrants with temporary residence permits present special challenges to formulating a drug regimen because their future in Finland is not ensured. Asylum-seekers are entitled only to necessary medical treatment and must pay for any elective care out of their own pockets (Ministry of Labor 2003, 5). If a physician documents that an asylum-seeker urgently requires antiretroviral medication, this is generally accepted as part of the emergency medical treatment guaranteed to asylum-seekers by the Finnish state. However, there is little information about the long-term situation regarding access to treatment by migrants with temporary residence permits. Asylum-seekers in Finland often receive a minimal level of social benefits while they await their decisions, unless they are employed. Necessary medical expenses, such as prescription medicine for secondary health conditions, are also taken into account when determining the level of monthly social benefits by social workers at reception centers. Deciding whether to start a treatment regimen with asylum-seekers or migrants who do not have permanent residence permit requires the physician to take many factors into consideration.

#### 14.4 Criminalizing HIV

Despite the strong human rights framework in laws concerning patient care, Finnish criminal laws have been invoked to prosecute people living with HIV. In this issue, we can see the contrasting tendencies of harm reduction by the Ministry of Social Affairs and Health and the criminalization efforts by the Ministry of the Interior. Many Nordic countries have criminalized the ‘deliberate’ spread of HIV through unprotected sex with uninformed partners.

Articulations of criminalization focus on the individual. They tend to construct all PLWHAs as potential criminals that threaten the innocent non-infected. In this framework, criminal regulations are considered necessary to punish those who ‘unknowingly’ transmit HIV. Some legal scholars have pointed out that criminal laws on HIV are exceptional in the sense that it is enough to prove that the accused has engaged in the forbidden behavior (e.g. Dalton 1993). In articulations of criminalization, the state of mind or degree of knowledge of the accused is less important than the behavioral act which must be punished. Articulations of criminalization are not informed by a public health perspective and are aimed at punishment and deterrence rather than prevention.

Articulations of harm reduction take a broader collective view of the effect of HIV on society as a whole. Harm reduction is defined in these articulations as a bundle of strategies that aim to limit or reduce the negative consequences of certain behaviors, such as IV-drug use and unprotected sexual contact. Articulations of harm reduction are thus strongly tied to public health and social policy perspectives (see, e.g., Riley and O’Hare 2000).

A policy options paper by UNAIDS (2002a, 20-21) has argued that there are four objectives of the criminalization of HIV:

- Incapacitation: putting offenders away in prison where they are unlikely to spread HIV.

- Rehabilitation: offenders can be coerced into rehabilitation.
- Retribution: offenders are punished for having harmed others.
- Deterrence: reduces HIV transmission by deterring others from similar behavior.

However, UNAIDS disputes the argument that criminalization is a useful instrument of HIV prevention or containment. It points out that prisons are one of the main vectors of infection and notes that coercion rarely instills motivation for human behavioral change. Furthermore, it states:

A principle justification for criminalizing certain conduct is that it deserves punishment because it is morally blameworthy; society appropriately imposes penal sanctions on those who engage in such conduct. This is punishment for punishment's sake, after an offence is committed. This justification for criminal sanctions is not concerned with deterring the offender or others from the prohibited conduct. Retribution has nothing to do with protecting the public health by preventing HIV transmission or risky behavior; it is about punishing past conduct deemed blameworthy. (UNAIDS 2002a, 20)

Hence the use of criminalization as an instrument of retribution or deterrence often has very little public health value because it tends to discourage people from being tested or seeking help. To be convicted of the 'deliberate' spread of HIV, the perpetrator must have knowledge of his or her seropositive status and means of transmission. There is also the question of intent which raises complex legal issues. Moreover, criminal laws can be applied selectively to marginalized groups, such as commercial sex workers, migrants, drug users and others who have little access to legal counsel or services.

In the Finnish context, the code against the 'deliberate' spread of HIV has only been invoked in a handful of cases.<sup>75</sup> Nonetheless, fears of being charged with the 'deliberate' spread of HIV appear to be a concern amongst people living with HIV (Huotari 1999). Though specific circumstances and actual charges differed, the three cases concerning HIV that have received the most publicity in Finland involved migrants: an African-American, a Ugandan refugee, and a woman from Thailand. These types of cases provide

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<sup>75</sup> For an interesting discussion of the basis of individual rights and AIDS in Finland see Rantanen (1999)

a forum for fears and anxieties about miscegenation, sexuality, and disease may serve to reinforce the plot of African AIDS amongst the general public.

#### **14.5 Locating migrants in the Finnish national AIDS strategy**

In 2002, the Ministry of Social Affairs and Health coordinated an expert group which formulated a national AIDS strategy for 2002-2006. The expert group was made up of various representatives of health, social, patient and advocacy groups. The purpose was to draw up an AIDS policy which could facilitate the prioritization and allocation of resources directed at HIV treatment and prevention targets. The national strategy has eight basic proposals:

- The prevention of infections is the cornerstone of preventive measures
- The effectiveness of treatment and support measures is an integral part of prevention
- It is essential to support the full empowerment of persons who have been infected and to reduce their vulnerability
- HIV tests and epidemiological follow-up systems generate information to be used in the planning of future measures
- International cooperation is a prerequisite for conquering the HIV epidemic
- The education of professional staff must be expanded and the level of competence must be maintained
- Legislative reform might become necessary as the HIV situation changes
- Management of the situation calls for improved coordination and a multidisciplinary approach (Finnish National AIDS Strategy 2002)

The 2002 national AIDS strategy is very significant because it is the first official strategy drawn up over a three year process of cooperation between experts and representatives of civil society (Tommi interview 2002). In many ways, the new strategy largely confirmed the good practice already in use in HIV/AIDS care and prevention in Finland. The purpose of the strategy was to provide non-binding guidelines for municipalities.

As one of my interviewees argued, AIDS never dropped off the agenda in Finland in the late 1990s, unlike many other European countries, due to the rising HIV epidemic amongst IV-drug users in the Helsinki metropolitan region in the late 1990s (Aaltonen et

al. 2002). Indeed, funding for the Finnish AIDS Council and Body Positive slightly increased during this period (Tommi interview 2002). As noted earlier, one of the most important areas emphasized in the national AIDS strategy is the need to establish harm reduction measures regarding drug use, such as free needle exchange centers. These approaches tended to predominate over leanings towards increased criminalization.

It is interesting to note that migrants remain invisible in the strategy, despite the relatively high proportion of MLWHAs compared to Finns. The strong emphasis on prevention, the reduction of vulnerability, and empowerment is articulated within a cultural vacuum. The key to effective health promotion and disease prevention is to provide accurate information in a culturally and linguistically appropriate manner to both identity and ethnic groups (Patton 1996, 112). Recognition of the cultural nature of all information and embarking on a dialogue with the variety of affected individuals is the first step towards engaging diverse communities. The invisibility of migrant communities and their specific needs in the Finnish national AIDS strategy can thus be seen as a form of indirect discrimination.

#### **14.6 Non-governmental agencies and services for people living with HIV/AIDS**

There are five non-governmental agencies that provide services for people living with HIV/AIDS:

- Finnish AIDS Council (non-governmental organization) – the main organization that does professional client work
- Body Positive (peer organization)
- Finnish Red Cross (non-governmental organization)
- Folkhälsan (non-governmental organization for Swedish-speaking Finns)
- Finnish Family Federation (non-governmental organization)

The Finnish AIDS Council, which is run by the Finnish HIV Foundation and funded by the Finnish Slot Machine Association, Ministry of Social Affairs and Health and project

grants, is the primary non-governmental organization in Finland that offers professional counseling, anonymous testing and information services on HIV. Adaptation courses and outings are also organized by the AIDS Council. With six regional centers, the Finnish AIDS Council has the most extensive and highly trained specialized staff in HIV work. According to the executive director of the Finnish AIDS Council, in 1999 there were approximately 180 people living with HIV who used their services. This figure included clients from 20 different cultural backgrounds, mostly from the African continent, who usually had Finnish partners (Lindblom 1999). The Finnish AIDS Council is also one of the most significant voices in public discussions on HIV/AIDS related issues and advocates for the human rights of people affected by HIV.

Founded in 1989, Body Positive is a registered organization of people affected by HIV. It is a peer organization that supports and advocates for people living with HIV. The fundamental idea of Body Positive is 'by people with HIV, for people with HIV.' Body Positive has a drop-in center in Helsinki which offers free meals, talks and lectures. The Body Positive office also has internet access and a washing machine which are very important services for many people living with HIV, especially those on a fixed income. Body Positive is not a professional organization like the Finnish AIDS Council. Its purpose is therefore to provide mutual support rather than professional counseling.

The Finnish Red Cross has 'plus points' in Seinäjoki, Joensuu, Jyväskylä and Kuopio where it is possible to anonymously take an HIV or hepatitis test, be counseled or have a support person. The Red Cross also runs a helpline where people can call anonymously for advice four nights a week. In the past, it has held a support group for women living with HIV (Korte 1999). The Finnish Red Cross also runs an annual summer condom campaign targeted at young people.

Folkhälsan is a non-governmental organization that serves the needs of Swedish-speaking Finns. It has a helpline in the Swedish language and provides extensive information on living with HIV. Folkhälsan also arranges training for professionals in HIV.

The Finnish Family Federation is a large non-governmental organization that was founded in 1941. It develops research on family, housing and population policy. It specializes in services for infertility and other family matters. Most importantly in this context, it offers counseling in sexual health and family matters through several regional counseling clinics. The Finnish Family Federation also has several development cooperation projects in lesser developed countries on HIV/AIDS prevention.

As of the time of writing, none of these agencies have projects or programs targeted specifically at migrants living with HIV in Finland. Policymakers and planners apparently believe that there is a lack of interest in such issues.<sup>76</sup> It is unclear, nonetheless, who is uninterested: Is it the migrants and their communities or the policymakers and practitioners?

#### **14.7 Finns, migrants and HIV/AIDS care**

The greatest concentration of migrants in Finland is in the Helsinki metropolitan area. Furthermore, most of people living with HIV in Finland are registered as Helsinki residents. Hence most migrants living with HIV are resident in the Helsinki metropolitan area which has the most extensive network of services for people living with HIV/AIDS. Though most migrants in Finland live in urban centers, they share many of the same problems that Finns living with HIV in rural areas face, namely social isolation and the lack of a social network to support them with issues related to seropositive status. However, migrants living with HIV/AIDS also face special challenges due to their cultural, racial, and linguistic differences from mainstream society. Therefore, for many migrants the most pressing issue in their lives is not only HIV/AIDS but also the emotional and practical difficulties of living in Finnish society as a foreigner.

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<sup>76</sup> This information was given by Bengt Lindblom, executive director of the Finnish AIDS Council, in a personal email message.

#### 14.71 Shifting needs in social care for people living with HIV/AIDS

The two Finnish interviewees living with HIV/AIDS stressed the difference between the ‘early days’ of AIDS and now. Both discussed the historical context of the HIV epidemic in Finland at some length. According to one informant, in the 1980s most people went to Finnish AIDS Council to pass time waiting for death. There were many ceremonies, such as lighting candles, to remember those who had died. For the most part, counseling was designed to help people adjust to the situation of having HIV and to enable them to admit they were ill and face the reality of death. As we have seen in the previous section, the intrusive and often lurid attention of the media in the 1980s traumatized many people diagnosed during that decade. One informant claimed that there was a clear difference between the old and new generations of people living with HIV/AIDS which he largely attributed to the terror of the early years.

A radical shift in HIV counseling came with the development of HAART in the mid-1990s. Suddenly, the death that many people living with HIV had prepared themselves for so many years was taken away. This produced an enormous psychological crisis in many people who asked: for 15 years I have been preparing to die, how do I now go on living? HIV counseling and programs also had to shift their focus from coping with certain death to ways of living with the virus.

Tommi, a Finn living with HIV who has been involved with AIDS advocacy on a European level, briefly outlined stages of living with HIV and their relation to counseling. He noted that not everyone seeks counseling. Indeed, he stressed that people with a strong social network often don’t come to HIV/AIDS support services. Tommi spoke of three primary phrases of HIV counseling:

- Diagnosis: feelings of guilt, shame of sexuality or drug use. Desire to find information.
- Start of medical treatment: during the asymptomatic stage there is still a sense of health. Treatment begins when symptoms appear. In order to tailor drug therapy it is necessary to experiment with various medications and test the tolerance of side

effects. At this point, one must acknowledge that the disease is progressing. The recognition of illness often leads to a desire for therapy.

- End of working life: at the point one can no longer work due to the progression of the illness. This can create many social and personal problems similar to others who have been pensioned early. Questions arise about the meaning of life and what to do with one's remaining time become prominent. Almost all people living with HIV/AIDS come to counseling at this stage

These stages described by Tommi closely mirror previous studies of people living with HIV and survival strategies (see, e.g. Huotari 1999; Kangasniemi 1996; Kylmä 2000). These stages are, however, based on certain assumptions, most fundamentally, that HIV is the preeminent crisis in the individual's life. For many migrants facing significant difficulties regarding residency status, employment, traumatizing migration experiences, and everyday problems living in Finnish society, HIV may not be considered to be the main crisis in life.

#### 14.72 Finns' perceptions of migrant needs

Few of my Finnish informants had had much personal contact with migrants living with HIV/AIDS. They were aware that migrants did indeed utilize HIV services, though much of the information they gave was contradictory. Similar to Helena Helve's findings, my informants seemed to view migrants and their needs situationally.

In my interviews, I asked two of the Finnish informants living with HIV how they perceived migrants living with HIV/AIDS and their needs. Tommi started his reply by emphasizing the 'intrinsic' nature of *Finnishness*:

Finns are old-fashioned [more stoic] in this sense – 'there's a problem, let's fix it and move on.

Here we can see the construction of two essentialist cultural categories (us and them) with implicit opposing attributes. In this articulation, Finns are posed as pragmatic, while it is implied that foreigners are not. When speaking on a general level, cultural difference

thus appears to be viewed as a significant factor that can preclude solidarity among people living with HIV/AIDS regardless of national origin.

In my interviews of Finns living with HIV or working at AIDS counseling centers when informants generalized about migrants they were often constructed as a mass, not individuals, who were thought to know little about their illness and were fearful of other migrants. The Finnish interviewees thought that the main reason that migrants did not use services was that "...they are afraid if they meet people from their country here that they will tell the others."

Migrants' ignorance was a theme that was underscored in many of the interviews and strongly contrasted to the business-like approach of Finns living with HIV. One of these interviewees described migrants as living in 'closed societies' and having little interest in information. Throughout the interviews, migrants were continually characterized as a mass, lacking individual characteristics, and as diametrically opposite to notions of *Finnishness*. The ignorance of migrants was a theme that was consistently underscored in interviews. Two informants claimed that migrants knew very little about means of HIV transmission. During the interviews, I often had the sense that this lack of information amongst migrants was implicitly attributed to cultural difference and a personal failing, rather than the paucity of informative material or counseling available in Finland.

When speaking specifically about a particular counseling center, Tommi, who had been actively involved with AIDS services through the years, said that migrants did indeed use the services. He felt that the counseling staff coped very well with migrants and welcomed everyone. He was able to speak at length on the provision of services from a good practice perspective. Tommi made four main observations on migrants and HIV social services:

- English is the main foreign language spoken by workers, which is a problem for French speakers, for example. Though clients can use an interpreter, it is unclear how this is organized in smaller municipalities.
- Migrants use services much less, probably because of language.

- Migrants who do come only use individual services and don't join groups.
- Migrants do come to meals at the Finnish AIDS Council. They sometimes come with their families and usually come during period of crisis.

Here we can see that when speaking specifically about a location, Tommi tends to contradict his earlier statement that Finns focus more on problem solving because he clearly says that migrants do indeed locate services when they feel a need for them. Tommi attributed the problems in the provision of services less to essentialist cultural difference than communication problems despite his initial words.

In short, the interview data with Finns living with HIV seemed to suggest that they thought language and ignorance were the primary problems for migrants and HIV, though one informant did acknowledge that "...migrants are facing so many everyday problems" it was difficult to focus solely on HIV-related issues. Further, neither Finnish informant spoke from the perspective of friendship with a migrant, thus compounding the otherness and strangeness of foreigners in the system. Migrants were indeed always 'them'. Cultural difference appeared to act as a barrier to HIV solidarity across national origins, paralleling many exclusionary views in articulations of *Finnishness* as an ethno-racial attribute.

The Finnish informants' assumptions regarding migrants' lack of knowledge of HIV issues were based on a certain degree of speculation as neither one had very much experience in dealing with migrants. The word 'ignorance' repeatedly arose in the interviews of the Finns living with HIV who thought that migrants were not educated and had little knowledge of biology. Interestingly, much of the research emerging from migrant communities seems to refute the construction of migrants as ignorant. Josephine Adjekughele noted in her study of African mothers in Finland that she expected her respondents to include illiterate women, yet found that all of her respondents were in fact educated (Adjekughele 2003, 43). Rajkumar Sabanadesan's study on asylum-seekers in Finland noted that most of his respondents were aware of how HIV is spread and understood the importance of antibody testing (Sabanadesan 2001, 79). This raises the

question of how 'ignorance' is perceived and defined as well as how this term can parallel negative attitudes towards cultural and ethno-racial difference.

#### 14.73 Migrants' views of care

Migrant informants had a very different point of departure than Finnish interviewees as they described their experiences. When asked about coping with HIV, migrant informants first discussed medical services rather than social or counseling services. Both in discussions with Justin and Kidane, as well as according to the responses to the questionnaire distributed at the university hospital, migrants appeared to be highly satisfied with the treatment received by specialized medical professionals. Nurses were particularly singled out as very important sources of information and psychological support, while the role of social workers was less emphasized. However, I should note that social workers in Aurora Hospital, for example, wear white coats. This might lead to the mistaken impression that they are medical staff.

Kidane claimed that most migrants don't know about the Finnish AIDS Council, though social workers at Aurora Hospital in Helsinki said that all migrants in their care were informed about all counseling services in the metropolitan area. He said that he had found out about the Finnish AIDS Council because he had 'tagged along' with his Finnish wife. He spoke about the many 'good things' that the AIDS Council did, listing outings, seminars and particularly meals as important events for him. Yet, he also underlined the fact that he felt the Finnish AIDS Council was too oriented towards gays and that, although he was not homophobic – as he continually stressed – he did not always feel comfortable there. The Finnish AIDS Council has recognized this difficulty as the executive director said in a speech:

When people from very different cultures are visiting the same centers there can be difficulties, which often are based on the vast differences in ways of living, thinking and communicating things. One HIV positive African man said that he feels very uncomfortable when he finds himself together with so many gay men. (Lindblom 1999)

Kidane emphasized the need for a private, exclusive meeting place of their migrants' own where people could talk freely amongst themselves. He said that he did not feel shy about talking about HIV with people in his own community, many of whom knew about his seropositive status. This was an interesting contradiction to the Finnish informants who claimed that migrants were not be interested in having their own groups.

Justin also emphasized the great problem of knowing where to go for help as a migrant living with HIV. He said that the Finnish AIDS Council had been very helpful but did not seem to have any special expertise in migrants' issues. Justin had found it very difficult to get any proper advice on how to cope with the many legal problems that he had faced during his residence of under 5 years in Finland. During this time, Justin had always worked and paid taxes, though he had a temporary residence and work permit (B). These legal problems were directly related to his health situation, such as obtaining a social insurance card so that he could get antibiotics when prescribed to improve his general health, for example, at the subsidized rate. Indeed, I was very surprised when interviewing him to find that he had not been informed of many of his basic rights as a migrant by any of the agencies he had visited. He said that he had gotten the best advice about how to organize his work permit from a person he had met in a bar.

The sense of belonging (or not belonging) emerges as a central theme in Justin's description of the social care available at the Finnish AIDS Council:

I think that in terms of HIV medical support - once a person knows how to get it - a person definitely knows that they are being looked after and have a place to go to. I refer particularly to Aurora in this regard. However, then it comes to general social support, I think there is a lot to be done. I know that my attitude towards the AIDS Council is not very positive at the moment, but I have never felt a sense of belonging there (with the exception of two friends who are always willing to listen and help if they can) - the attitude there is very inclusive and one constantly has to deal with questions like 'When are you going to learn Finnish?' and 'Glad to see you have coped with the Finnish winter'. This does not make a person feel at home. An individual never gets simple, supporting questions such as 'How are things going?', or 'How's the treatment?' or 'Let's get together sometime?' Often if I have a meal there (at the AIDS Council), I am asked

why I am sitting on my own - and the reason(s) are simple - there is nothing in common and also the people don't really have a zest for life. If I try to discuss something positive, then they moan about how terrible it is to be self-retired, etc... (Justin email 2003)

Justin told a story that he had once heard about an event being planned for migrants at the Finnish AIDS Council but had been told that it was not for him, perhaps (he thought) because he was gay. At any rate, Justin reported that only one migrant turned up for the meeting. This story together with Kidane's indicates that there is a certain ambiguity regarding the best way to approach developing culturally appropriate approaches to meet the needs of migrants at the Finnish AIDS Council. Furthermore, the fact that migrants were not involved as equal partners in arranging the meetings perhaps reflects the lack of connection with migrant communities.

In the questionnaire distributed at the hospital (see Appendix 4), we asked specifically about the use of services and wishes. Neither respondent indicated that they received any counseling, social care services or visited the Finnish AIDS Council.

When asked about needs, one respondent replied:

I need a place to live (house), social support because I cannot work – not that I really cannot work -- but because [they] are not accepting to give us, the asylum-seekers, a job.

Here we can see that the expectations of many migrants living with HIV/AIDS extends beyond the usual tasks of AIDS service agencies. The profound difficulties that migrants face living in Finnish society were thus a greater issue than specific issues related to HIV.

As the questionnaire respondent continued:

I don't [want] to change anything but what I just want is that the society should make an effort [to] offer us a job because we are really suffering from that.

Migrants living with HIV/AIDS were most concerned with finding ways to live and integrate into Finnish society. Issues of belonging and difficulties in everyday life as a foreigner in Finland dominated migrants' discussions of living with HIV.

#### 14.74 A social worker's view of migrants in the caring encounter

My interview with Susan Simola, a social worker at Aurora Hospital in Helsinki, gave a different perspective on migrants living with HIV/AIDS in Finland. As noted earlier, Aurora Hospital has the broadest professional experience with HIV disease in Finland and is located in Helsinki as well, which has the highest amount of migrants. Therefore, the social work staff at Aurora Hospital probably represents the most extensive professional experience with MLWHAs.

Simola pointed out that when HIV patients were referred to social workers at Aurora, they entered into a long-term relationship. This is due to the efficacy of the new combination treatments which has extended the life expectation of people with HIV disease. Simola has been working with some of her clients for over 10 years. The caring encounter is therefore a process which takes place over time and may involve dealing with a variety of crises and issues that occur in different stages of living with HIV.

Simola emphasized that building trust is the initial challenge in her work with migrants. According to Simola, migrants come to the social work encounter with multiple issues. Many migrants do not have an understanding of the professional ethical responsibility to maintain the client's confidentiality and are afraid that their seropositive status will be revealed to others. They also do not know what services they are entitled to in the Finnish welfare state. Sorting out these issues requires teamwork and coordination with municipal social services.

Simola pointed out the migrant clients often require much more time with social workers because they are dealing with many complex issues. Migrants may be afraid of laboratory tests and treatment, which they do not understand, and need reassurance. They may also

have more extensive needs for information on living with HIV. Simola has a great deal of material in different languages on living with HIV/AIDS, which she uses to explain questions to clients. Social workers at Aurora tailor their work to the individual needs of the client.

Some migrants are grieving for relatives who have died of AIDS at home and feel survivor guilt. These strong emotions, combined with the everyday difficulties of living as a migrant in Finnish society, require different counselling skills from social workers than those used with Finnish people living with HIV. Furthermore, intercultural communication and language skills are very important in working with migrants because ways of expressing questions, comprehension and politeness may vary among cultures. Finally, MLWHAs sometimes prefer to have a family member as an interpreter in counselling situations, but Simola stated that this was not best situation because professionals could not be sure that information was correctly relayed to the client. According to Simola, good practice at Aurora meant that an interpreter was always called when necessary.

In terms of access, Simola stated that all migrants included in the social insurance system are entitled to treatment, just as Finns are. She noted, however, that students seeking treatment at Aurora can present complex questions of entitlement. Students are generally not eligible for social insurance in Finland. Many are not covered for treatment by private insurance either. However, many criteria are considered when considering an application for treatment and each person is treated individually. In acute cases, the individual is treated. As students tend to be young, they sometimes have difficulties in planning their long-term prospects. Many migrant students are very worried that someone will find out about their seropositive status and inform the authorities who will send them back. All in all, Simola emphasized, there are rather few cases of uninsured people.

#### 14.75 Summary: perspectives on migrants living with HIV/AIDS

The interviews of Finnish people living with HIV, migrants living with HIV, and Finnish professionals working with people living with HIV/AIDS provided a kaleidoscopic view of the situation for migrants. The main theme that emerged from the interviews was a general consensus that the medical and social care for MLWHAs in Finland was considered to be excellent. None of the migrants I interviewed or who responded to the questionnaire listed any complaints about the quality of care.

The needs of migrants were viewed differently from the diverse perspectives of the informants. The two MLWHA interviewees expressed frustration at their sense of disempowerment as active clients in AIDS advocacy agencies. They also called for more spaces for MLWHAs and migrant communities to discuss issues specific to their situations. In my interviews, professionals and Finnish people living with HIV tended to emphasize the fear that many migrants felt about the possibility that their seropositive status would be revealed. The apparent contradiction of these two perspectives on migrants' feelings about living with HIV might be explained by different senses of empowerment of living with HIV. In other words, it may be that social workers may have a higher prevalence of clients that require support and are fearful, while the two interviewees, who were willing to be interviewed, might feel more empowered in living with HIV. Certainly, migrants living with HIV/AIDS represent a plurality of experiences and views on living with the illness. Hence it is possible that both of these perspectives can be true at the same time.

Migrants living with HIV continually emphasized that issues of belonging and everyday life in Finnish society were considered to be the most stressful. While the statutory social work at Aurora Hospital reflected an individually-tailored approach to migrants' needs, the good practices used there need to be systematically disseminated to all agencies working with MLWHAs. The great challenge for non-governmental AIDS agencies in Finland is to find a way to address these matters as a core element of their work. The issues and complexities facing migrants living with HIV in Finland extends beyond

traditional AIDS work and goes to the human impact of racism, social exclusion and marginalization. For many migrants, life in Finland only begins after receiving a permanent residence permit. This, however, can be a very prolonged period. Particularly for migrants with temporary permits on the margins of society, HIV may seem to be the least of their worries.

In my interviews, I had the impression that there was little real human connection between Finns and migrants living with HIV/AIDS. I attribute this less to malice or racism than to the lack of structures in non-governmental AIDS agencies that could help empower migrants as active participants in Finnish society and create bridges between Finns living with HIV/AIDS and migrants living with HIV/AIDS. Perhaps hiring migrant workers would be one way to bring a migrant perspective to HIV work. Outreach work could be targeted at Finns as well as migrants to help sensitize Finns living with HIV to the needs of their migrant counterparts. The strangeness of Finns and migrants living with HIV/AIDS to one another indeed appeared to mirror the larger relations between citizens and foreigners in Finnish society.

#### **14.8 Examining HIV/AIDS information in English**

I have collected all of the information available in English on HIV/AIDS by systematically seeking out information as a migrant in Finland. After inquiries to the Finnish Red Cross and Finnish AIDS Council, I came up with one pamphlet in English and one photocopy in Russian. The Finnish AIDS Council has also expanded its information in English, Russian and Swedish on its website. The Red Cross redirects visitors to an international site of information International Federation of Red Cross and Red Crescent Societies. Body Positive has a great deal of information in different languages at their office in Helsinki which they have obtained from various international agencies. They have translated information produced by a Dutch foundation on living with HIV from English into Finnish, but have not produced the material themselves.

This textual analysis solely focuses on information available in English produced here in Finland because it is one of the primary languages used in working with migrants which spoken by social and health care personnel as well as many migrants, at least as a second language. Russian, Somali or French would also be important languages to investigate, particularly as Russian is the major foreign language spoken by migrants in Finland. The website information is examined in detail as an example of the information available to migrants.

In the course of writing this section, I stumbled on several English language brochures available from Folkhälsan, the agency for the Swedish-speaking population in Finland. It had not occurred to me that the agency specialized in working with Finland's linguistic minority would have information in English. I had never heard mention of them before by either HIV workers or people living with HIV and found this information by navigating through a Swedish language website. Though I do not understand Swedish, I managed to order some brochures via the Folkhälsan website. To my surprise, several brochures arrived in the post within days. Hence the texts used in this analysis are from the Finnish AIDS Council, Body Positive and Folkhälsan with the main focus on the texts actually produced in Finland.

#### 14.81 The Finnish AIDS Council

There is one printed brochure available in English and Swedish translations produced by the Finnish AIDS Council. A Russian language photocopy of the brochure has also been created. The text of this brochure is the same as that of the English website. The English information on the website of the Finnish AIDS Council aims to give a brief but comprehensive outline of information on HIV and the services provided by the AIDS Council. After explaining its source of funding and the fact that its services are free, it then organizes information around the following themes:

- Virus
- What is HIV?

- What is AIDS
- How is HIV Transmitted?
- In an [sic] Unprotected Intercourse
- Through Blood
- From an HIV Positive Mother to a Child
- How is HIV Not Being Transmitted [sic]?
- How Safe is Oral Sex?
- HIV Positive Persons
- The Finnish AIDS Council: Support and Advice
- Anonymous and Safe Testing

Here we can see the construction of information in four basic categories: definition, means of transmission, help and testing.

The information starts with a description of viruses:

There are all sorts of viruses on this planet. They are a natural part of the ecosystem and life itself. Some of these viruses are more dangerous to human beings than others. Many of these dangerous viruses are known and can be treated with medicine, *but in certain places, particularly in the rainforests and other remote places, there still live unknown viruses* [sic]. (Finnish AIDS Council 2002) [my italics]

This is an interesting description of viruses because it does not actually define what a virus is. It connects danger with particular geographical features (rain forests) and reinforces a certain center/periphery view of the geography of the world by positing certain places as ‘remote’. However, the significance of the alleged connection between remote places and viruses remains unclear.

The second section of the website that describes what HIV actually is notes in the first paragraph that “...it is believed that it [HIV] was originated somewhere in Central Africa, from where it started to spread all over the world during the 70’s.” (Finnish AIDS Council 2002) Here we can see that labeling HIV as a disease of ‘remote’ places and Central Africa is considered to be of key importance. The plot of African AIDS thus emerges strongly through so-called objective scientific information. Indeed, the geography of AIDS is considered to be of such importance that it is stressed in the first

two paragraphs. Assigning a geographical location is thus constructed as fundamentally essential to the definition of HIV, though at no point does the material actually tell what a virus is or why place is so significant.

The information given in the explanatory sections on HIV and AIDS requires a great deal of tacit scientific knowledge. Terms such as ‘host cell’, ‘white cells’, ‘immune system’ and ‘retro virus’ are used with minimal explication. The difficulty of being infected with HIV is compared to another infectious disease: ‘it is at least hundred times (sic) easier to catch hepatitis B than an HIV infection’. Yet to comprehend the possibility of being infected by HIV in this framework of explanation, a high level of scientific knowledge of other infectious diseases is necessary to understand the comparison.

The information of the Finnish AIDS Council then focuses on describing the means of transmission through sexual activity. The description of the risks of unprotected intercourse in the Finnish AIDS Council brochure uses very formal language, such as ‘vaginal penetration’ and ‘water-based lubricant’. Any mention of gender, sexuality or social context is consistently avoided in the text.

Finally, the brochure explicitly lists many of the ways that HIV cannot be contracted, such as hugging, touching or mosquito bites. It also emphasizes that anyone could be seropositive regardless of social status or nationality. The focus on everyday behaviors and practices is in stark contrast to the earlier text on viruses and means of transmission. Nonetheless, this is very important information and goes far in challenging prejudiced understandings of HIV/AIDS as well as people affected by the virus.

#### 14.82 Body Positive

Body Positive has a guidebook *Living with HIV*, produced in English by the Foundation September in The Netherlands. This guide has been translated into Finnish and modified to reflect information needs of the local context. This book is available free of charge to

anyone living with HIV, others pay a small fee. It is the most comprehensive guide available in Finland.

*Living with HIV* gives extensive advice to people living with HIV on issues ranging from basic needs and medicine to patient rights in the Finnish social and health care system and contact information about helping agencies. It is important to note, however, that no attention is paid in the text to the special needs of migrants living with HIV. There are no sections or information on migrant issues or ethno-racial, linguistic or cultural difference from mainstream society and HIV. There are no Finnish agencies or projects listed to support the needs of migrants affected by HIV. The special informational needs of migrants in a Finnish context may fall in the gap between the languages: the English language material is produced in The Netherlands and therefore lacks the specific information relevant to the Finnish context while the Finnish language translation is solely targeted towards Finns who do not necessarily require information on migrant issues. At any rate, there is a paucity of information for migrants affected by HIV in Finland in the *Living with HIV* handbook.

Body Positive has a website in English. It also has material in many languages available in its office, largely produced abroad, as well as videos. Body Positive's bimonthly newsletter comes with an English summary and an offer to translate any article in detail to anyone who comes by the office.

#### 14.83 Folkhälsan

I received three English language brochures from Folkhälsan:

- Protecting oneself and others against HIV
- Testing for HIV – Why, how and afterwards
- Understanding HIV infection

All three were produced by the Swedish Institute of Public Health and therefore were not produced in Finland. For this reason I will not analyze them at length, but simply

highlight some significant issues in contrast to the one brochure available from the Finnish AIDS Council.

The most important difference with Folkhälsan brochures is that they discuss HIV/AIDS in great detail. Each brochure is over 20 pages long and utilizes English which is far more fluent and explicit than the Finnish AIDS Council information. Each brochure dealt with social issues related to HIV information, with subchapters such as ‘is there such a thing as ‘shared responsibility?’’, ‘psychological consequences’ and ‘safer sex – for whom?’ Though none of the brochures had a subsection specifically devoted to migrant issues, the material addressed a diversity of sexualities and cultural understandings of HIV issues as part and parcel of its informational content.

In the brochure *Get Smart: Understanding HIV Infection*, by contrast to the Finnish AIDS Council material, the international story of AIDS is told from its beginning as GRID to the contemporary pandemic. Though HIV is mentioned in connection with Africa<sup>77</sup>, the international nature of the pandemic is underlined:

No matter where or how the HIV epidemic started, the virus will be with us for decades to come, regardless of whether or not scientists manage to produce a cure for those who are infected and a vaccine that will prevent infection. Consequently, preventing the spread of HIV is of the utmost importance and this calls for individual as well as collective efforts by all of us.

The information focuses on the significance of prevention rather than seeking to assign a locale or blame for the origin of the virus. The material available from Folkhälsan can be contrasted to the Finnish AIDS Council information in its length, comprehensiveness, cultural sensitivity as well as focus on prevention rather than the geography of AIDS.

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<sup>77</sup> ”During 1983 and 1984, we learnt a great deal about AIDS in certain parts of Africa. It became increasingly clear that AIDS was a sexually transmitted disease and that it was passed on from men to women and from women to men as well as from men to men.”

#### 14.84 Summary: HIV prevention texts available in Finland

The primary aim of health promotion and disease prevention material is to inform the public about risks to their health and to encourage healthy living. Writing a text implicitly involves a relationship between the writer and the presumed audience of readers.

Particularly when writing informative material, authors must have a clear notion of the informational needs and cultural understandings of their target group. As health and risk involve behaviors that exist within a social and cultural context, health information material must address how to change potentially unhealthy behaviors within a network of human, socio-economic and cultural relationships. Linguistic and cultural appropriateness is therefore essential in health promotion and disease prevention texts.

Creating material that deals with sexually transmitted diseases has always been problematic (see, e.g., Brandt 1987). Sexuality is a cultural artifact whose meaning resides with the social matrix of culture, not in a vacuum. Medicalized versions of sexual health information are often articulated through culturally normalized points of departure that construct sexual knowledge as objective. One of the challenges of the HIV pandemic, which the gay community in many western countries rose to meet, has been to redefine normalized forms of sexual expression in culturally and socially appropriate information brochures. It is therefore important to recognize that there are multiple ways of talking about sexuality, and there is no such thing as a transparent language about sexual issues (Wallman 1997, 37). The development of culturally appropriate material thus requires firsthand knowledge of how these issues are approached from a community or cultural viewpoint. Therefore, the development of appropriate information that can approach HIV prevention from a diversity of cultural and sexual perspectives is essential.

There is very little printed information available to migrants in Finland about health issues in general, but in the specific case of HIV/AIDS there is virtually no information that is widely available and easily accessible by migrants. According to qualitative research carried out for the European Project AIDS & Mobility by Rajkumar Sabanadesan, which was based on interviews of asylum seekers in Finland and their

attitudes towards HIV/AIDS issues, any information his informants had about the disease came from knowledge obtained before coming to Finland:

None of the respondents received any kind of information regarding HIV/AIDS or STDs from Finnish health care professionals. One respondent stated that he was told about prevention methods only after he was diagnosed with a certain type of STD. All nine respondents had known something about HIV/AIDS and STDs when they were in their country of origin. (Sabanadesan 2001, 79)

Thus, it appears that brochures about HIV/AIDS are not widely disseminated to migrants. Contradictions can be seen between the findings of Sabanadesan's research, namely that migrants are informed about the cause and prevention methods of HIV, the apparently widespread perception by Finnish informants that migrants are ill-informed about HIV, and the paucity of material formulated about the prevention and care for people affected by the virus in a Finnish context accessible to non-Finnish speakers.

The internet has been cited as an important source of information about HIV/AIDS (Sabanadesan 2001, 79; Kidane interview 2002). However, there appears to be differences between migrants with regard to computer literacy. Despite the fact that internet use is high in Finland, many migrants do not own a computer or have access to one. The internet access provided by the Finnish AIDS Council and Body Positive are therefore very important to migrants. Nonetheless, Kidane pointed out that his working hours often prevented him from using public sources of access to the internet and he could not afford a computer at home. As the three primary aims of HIV information are prevention, to let people know how to find help, and how to live with HIV, it would seem that there could be many possibilities to utilize the internet as a means for disseminating culturally appropriate information. The internet, while not a panacea for HIV prevention, could serve a significant role in disseminating further information and developing virtual communities to promote discussions.

Justin spoke at length about the lack of information available at various HIV/AIDS counseling centers during our discussion. However, Justin appeared well informed about

HIV health issues. Justin seemed more concerned about obtaining information to help him cope with living with HIV as a migrant in Finland. He said that he often felt very frustrated because there was very little available information that clearly stated migrants' rights and contact information for various agencies and projects. Justin continually stressed the impact of being a migrant and cultural difference on living with HIV. He said that Finnish people may not recognize this lack because they themselves do not need such information. Questionnaire respondents and interviewees felt that they badly needed information on managing in everyday life in Finland. Issues surrounding residence permits, work, and housing were therefore considered to be more pressing than HIV. Living in Finland as a migrant was continually stressed as being more significant than living with HIV.

There is a dearth of HIV prevention material targeted at migrants in Finland. The one brochure published by the Finnish AIDS Council in English (on both paper and their website) reflects an ambivalence about the purpose and target group of the information. While the brochure clearly outlines a geography of AIDS, it does not effectively convey prevention information in a clear manner. By choosing to attempt to present information devoid of any social context, perhaps in the attempt not to offend anybody, the Finnish AIDS Council's material winds up addressing nobody. In this respect, the material available from Folkhälsan and Body Positive is more detailed and culturally appropriate because it takes note of behaviors within social contexts. Yet, the area that my migrant interviewees and respondents repeatedly stated that they wanted information about was how to manage living in Finland as a migrant. This was the one issue that none of the material on HIV prevention and management dealt with whatsoever. The invisibility of the information needs of migrants living with HIV/AIDS reflects the fact that Finnish AIDS agencies have made little attempt to break through the silence of migrants to find out what kind of information they would need and address the special needs of MLWHAs.

## **14.9 Cultural competence and the construction of Finnish HIV/AIDS social care policy**

Finnish social and health care policy and practice has tended to be articulated along culturally normative notions of what constitutes care, what types of information are important, and what equality means. The ‘taken-for-granted’ nature of much of social and health care tends to remain largely unchallenged as evidenced in the lack of cultural competence training offered to practitioners and students as well as a certain amount of resistance to the development of cultural competence in policy and practice. Much of this resistance stems from a lack of awareness of the significant role that culture, race and ethnicity can play in the caring encounter.

Care is ultimately a cultural process because it involves choices, decisions and services offered within a communal framework. Being treated or cared for is both a personal and shared experience that is composed of beliefs, feelings, emotions, physicality, hopes and expectations (Green 1999, 50-51). On an individual level, cultural competence can be conceptualized as an awareness of the one’s limitations as a caregiver and openness to cultural differences. On an institutional level, cultural competence can be characterized as a willingness to utilize appropriate cultural resources and share power to promote client-centered care.

In Finland, there has been a tendency not to provide culturally competent specialized health care services specifically targeted at migrants for many reasons. Equality has tended to be articulated as ‘sameness’ and migrants as a client group are a relatively new development. This raises possibilities that policies can be exclusive through practices of indirect discrimination. As one analyst of HIV/AIDS services has noted:

Due to a lack of resources, efforts should be made not to put too much emphasis on special groups. Still, there is the unsettled question of treatment for immigrants and asylum seekers. (Hormia 1999, 17)

Hormia's point apparently is that limited resources should be used in an equal manner. In this framework, the provision of culturally competent services appear to be constructed as an 'extra' that cannot be justified in the interests of client equality. It is important to note that equality is not a neutral or objective term, but rather an inherently political term:

Equality is a word that means different things to different people. This is due, in no small part, to the fact it is a *political* term. Like 'democracy' and 'freedom', equality is a term used by different political groups or affiliations to promote their own particular values or interests. In this sense, equality is an *ideological* concept. (Thompson 1998, 7)

As Thompson argues, the concept of equality is used to justify existing power relations which are linked to the development of citizenship (Turner 1986). Some comparative studies of inclusive health care policies in Europe have suggested that the level of inclusivity in health practices is dependent on the relationship between political representation in the decisionmaking process and the recognition of the needs of migrant communities (see, e.g., Bollini 1993). Articulations of *Finnishness* as a set of cultural practices and social memory of the community privileges certain people and practices, which resonates in the textual information provided to migrants.

Not addressing the socio-cultural implications of increasing cultural diversity in Finland means that the social and health care issues runs the risk of laying the foundation of a dual and unequal care system through practices of indirect discrimination (Byrd and Clayton 2000, 415-416). Research on Finnish health services has suggested that there are significant cultural obstacles to delivering quality health care services. These obstacles range from self-reported racist and xenophobic attitudes by health care personnel, lack of knowledge of different cultural mores and norms, inflexible working practices and the lack of a common language (Taavela 1999). Reevaluating articulations of culturally normative definitions of equality means addressing the increasing cultural diversity of Finland. This does not necessarily imply a reification of essentialist cultural categories but rather reflects the enhancement of quality social and health care services to all population groups in a society.

As we have seen, nonetheless, there are agencies such as the social care unit at Aurora Hospital in Helsinki, which use cultural competence as an integral part of their work with clients. The methods used in such centers of excellence could be studied and systematized to benefit practices throughout the entirety of the system.

The great variety of migration patterns, family structures, help seeking behavior, views of the body, social and physical well-being, language fluency, and ways of interacting are all part and parcel of intrinsically multicultural nature of caretaking in the postmodern global world. Awareness of the significance of these issues in the caregiving encounter is one of the primary motivations for placing cultural competence at the center of policymaking and practice which ensures higher quality care and more effective prevention methods. In this regard, the recognition of cultural competence as a core element of caretaking policy and practice is a cost-effective measure (de la Cancela et al. 1998, 32). Yet, multicultural policies and practices are often articulated as a political challenge to the social memory of the community, which can provoke a popular backlash against those perceived as others.

## **15. Silence and living with HIV/AIDS**

The purpose of this chapter is to bring together some of the themes of this study through a reflection on the interview data collected from Justin and Kidane. In this chapter I focus on the significance of difference and living with HIV/AIDS in Finland. I problematize the mainstream descriptions of living with HIV by presenting the thoughts of migrants living with HIV in Finland. As I have noted earlier, my research on care for migrants living with HIV/AIDS has shown that there is a general consensus that the quality of care in Finland is very high. Greater concerns were expressed about the everyday realities of living in Finnish society as a migrant. Due to the narrow focus of many definitions of care issues for people living with HIV/AIDS in societies constructed as homogenous, problems of cultural marginality are often not addressed. The powerlessness of people in such marginal positions can be seen in the silence surrounding these issues. In this chapter, I therefore explore why telling one's own story is an important element of empowerment through the examples of the stories Justin and Kidane told me about living with HIV in Finland. Finally, I consider the silence of migrants and migrant communities in general and regarding HIV/AIDS particularly.

### **15.1 Postmodern illness and telling stories**

Illness has become a subject of increasing interest in postmodern theory (Frank 1995; Kleinman 1988; Morris 2000). Postmodern theorists tend to distinguish between 'disease' as an etiological category and 'illness' as a personal and subjective experience (Morris 2000, 37). Postmodern studies of illness are concerned that 'bodies need a voice' about the experience they are undergoing (Frank 1995, 4). Frank argues that 'wounded storytellers' indeed have a duty to tell their stories of the subjective experience of illness to guide the bodies that will come after them:

Telling stories of illness is the attempt, instigated by the body's disease, to give a voice to an experience that medicine cannot describe. This voice is

embodied in a specific person, but it is equally social, taking its speech from the postmodern times we live in. The voice of the ill person is made possible by modernist medicine, but it cannot be contained within modernist assumptions, particularly those about medical professional dominance and the narrative surrender this dominance requires. A divide has been crossed into new territory, the postmodern, and we know this crossing by the new voices that are heard. (Frank 1995, 18)

In the concept of postmodern illness, telling one's story reflects a reversal of the modernist biomedical model, which constructs patients as passive receivers of care, towards patient empowerment. Telling stories is thought to preserve experiences through creating shared memories. This serves to dissolve the mind/body divide created in the modernist biomedical model of the body. Furthermore, it create a community of patients, and people affected by illness, with a language to speak of their realities and concerns and gives space for the inclusion of culturally diverse understandings of health.

Health has increasingly become a measure of socio-economic status in global society as health disparities appear to be growing within nations as well as between nations. Health outcomes can therefore be seen as a fairly accurate gauge of socio-economic inequality in society. Stories told by patients can challenge medicalized discourses of disease which tend to remove the patient from the experience of illness and social matrix of power relations in their everyday lives. As we have seen earlier in this work, AIDS as the first disease of globalization has been richly storied in a way perhaps unprecedented in history. Stories and narratives of AIDS have been closely related to the empowerment of some communities affected by the disease, while other communities have remained invisible. The silence surrounding the lived experience of AIDS in Africa, for example, in international narratives of AIDS can be seen as indicative of global power relations that disembodiment and render invisible the humanity of some of the poorest people in the world.

The postmodern focus on stories and voice has been summarized by Arthur Frank: "Postmodern times are when the capacity for telling one's own story is reclaimed." (Frank 1995, 7) Yet, reclaiming one's story requires empowerment. Indeed, the capacity to tell one's story does not ensure that one is listened to nor does it guarantee that the

story won't be appropriated. Many feminists of color have stressed the central role of storytelling as an important strategy of constructing alternative views that challenge dominant narratives that marginalize and deny. Through a diversity of voices, the complexity of different realities, stories and histories can emerge which has the potential to challenge dominant discourses that construct reality (Bhattacharyya et al. 2002, 94).

Coming to voice, as Patricia Hill Collins notes, implies a process of empowerment in which a storyteller resists silencing and erasure. By telling a story, the teller can give a name to suffering or oppression. As Collins states: "Naming oneself and defining ideas that count as truth are empowering acts." (Collins 1998, 237) Through counternarratives, tellers can challenge prevalent views of reality by presenting alternative perspectives that may dispute dominant belief systems and preconceptions (Delgado and Stefancic 2001, 42). By naming and articulating the truth of suffering, individuals can start the process of overcoming the damage of silencing (Collins 1998, 237).

Yet, telling a story implies having a listener. If silencing is an act of denial and repression, then listening is an act of recognition, though not necessarily acceptance. Listening is an ethical act which shares power and allows for the possibility of dialogue:

One of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore, because these voices are often faltering in tone and mixed in message, particularly in their spoken form before some editor has rendered them fit for reading by the healthy. These voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to. Listening is hard, but it is also a fundamentally moral act; to realize the best potential in postmodern times requires an ethic of listening. (Frank 1995, 25)

Ethical listening is not therefore passive, but an actively shared experience which demands mutual participation. It is fundamentally an act of trust and recognition. The ethical listener does not necessarily know how the teller is going to tell the story, but is open to hearing what the teller wants to say, but the story doesn't end here.

Ethical listening may be the first step towards recognizing and attempting to connect with the reality of disempowered and invisible communities and individuals, but it still does not take the place of action. As Patricia Hill Collins has pointed out, sometimes oppositional knowledge (or fighting words) is not enough, critical social theory has to not only ethically listen but also begin to engage with challenging the power relations that constitute the act of research (Collins 1998, 193). In other words, as ethical listeners we are bound to examine how we act to exclude others and maintain dominant power relations, as well as how we can contribute to transforming unjust power relations.

During the course of this research, a Finnish researcher commented to me that she had migrant friends that she suspected were living with HIV. She said that she felt hurt that they did not trust her enough to tell her their stories. I had often heard a similar complaint by volunteers and workers at AIDS counseling centers who sincerely wanted to help migrants living with HIV/AIDS. This made me ponder what these people expected to hear in the stories of migrants living with HIV/AIDS. I wondered whether these expectations interfered with the possibility to really listen to what migrants wanted to say. The migrants I interviewed for this work did indeed have stories to tell about living with HIV in Finland, but they just did not focus on illness as much as on the personal consequences of the sense of dislocation in Finnish society. Migrants' unwillingness to discuss HIV illness as the central problem of their lives was often attributed to 'denial' or 'ignorance' by my Finnish interviewees, but in fact tended to give me the sense that they not really listening to what migrants were trying to say. This indicates to me that HIV illness may be experienced differently in Finnish society. The bigger questions in the lives of migrants living with HIV/AIDS appeared to be the greater existential questions of belonging and living in Finnish society.

### **15.2 Eternal dislocation: on living with HIV/AIDS as a migrant in Finland**

As I approached the final stages of writing this work, I came to know Justin and Kidane, two migrants living with HIV, informally and naturally because we happened to meet at an event. When I explained that I was writing a dissertation on the subject of migrants

living with HIV/AIDS we struck up an email correspondence which eventually led to actual interview sessions. The interview sessions were very informal. Although I had some themes I followed, I basically listened to what Kidane and Justin found important to say and discussed the ideas of this work with them.

Neither Kidane nor Justin found it particularly important to talk about HIV per se. They said that they considered the doctors and nurses at their HIV clinic to be the most significant support they received. Both stated numerous times that the medical care given was 'superb' and 'excellent'. They reported receiving information from the nurses and seemed extremely positive about the health care personnel. Further, they did not speak of themselves as being sick nor did they appear to be forthcoming in discussing their health. Instead, Kidane and Justin wanted to talk about belonging in Finnish society and their experiences as migrants here.

When starting the interviews as Justin and Kidane both explained to me in detail why they felt insecure about having their names associated with the interviews and didn't want to be tape recorded. Both felt that the consequences of revealing one's seropositive status could be devastating, particularly as migrants who did not necessarily have strong social networks and faced discrimination in the labor market. When writing about the reaction that some Finnish acquaintances had on discovering his HIV status, of Finnish society Justin summed up his view on being public with HIV in an email message: "I do believe (in Finland) the less said the better...." (Justin email 2003). Justin felt that the ignorance of the Finnish general public about HIV and the new medications coupled with the tendency to pity people living with illness was reason enough to use discretion in disclosing his seropositive status. Hence the prevalence of stigmatizing attitudes towards people living with HIV/AIDS appeared to be taken for granted by both Justin and Kidane, and not considered worthy of further comment. HIV was thus constructed on two levels in their talk: as an illness well-managed by the Finnish welfare state and as a stigmatized status that had to be carefully negotiated in personal encounters.

The importance of work was a recurrent theme in the interviews. Both Justin and Kidane appeared to experience a degree of insecurity in the workplaces. Neither informant had openly disclosed their health status to their co-workers or employers. Justin and Kidane spoke of work insecurity as more related to their status as migrants than their seropositive status, though they also emphasized fears that discovery that they were HIV positive could threaten their jobs. It was interesting that work figured so significantly in the stories told by Kidane and Justin and perhaps reflected the recognition of work as symbolic of being a 'good' person in the Finnish value system to some degree. Work thus represented entrance to Finnish society however tenuous. On a more practical level, job insecurity represented very real socio-economic stress and worry that must have had a negative impact on their health.

Susan Simola, the social worker at Aurora Hospital, reported that migrants that had jobs were often very reluctant to accept sick notes. Having a job represented a degree of inclusion in Finnish society as well as a vital source of income. Taking sick leave appeared to mean risking the shaky foothold that migrant workers had obtained in Finnish society. Simola contrasted migrants' attitudes towards sick leave to that of Finnish patients, who she said were more willing to accept, and even requested, time off for health reasons. I would interpret these different attitudes towards sick leave less as reflecting qualities of diligence or laziness than the contrasting sense of security in Finnish society. For Finnish patient, health appeared to be the central concern, but for migrants inclusion (in this case, through employment) remained the preeminent issue.

Only Kidane reported HIV-related discrimination at the workplace which he related in the following story. He said that he had worked many years as a skilled manual laborer. One day there was an accident at work and he ended up with a large gash on his arm. He was taken to the occupational health center where he felt compelled to tell the doctor who was dressing his wound that he had HIV. The doctor made a note on his chart and took the appropriate precautions. Years later, Kidane applied for another job with better pay at a large company. It is routine in Finland that many companies require health certificates to be accepted as an employee. Kidane was asked by the new company to consent to

having his old medical records forwarded from his former employer's occupational health center. Without giving it a second thought, Kidane approved. When Kidane went to the check-up to get his health certificate, the physician read that he was HIV positive from his medical record and told him that there was no chance that he could have the job. Kidane, who had great hopes of getting the job, said that he cried and asked the doctor: 'Can you forget this part of the story? What would you lose?' But the physician told him that he had an obligation to protect the company's financial interests because there was the possibility that Kidane would require more days of sick leave than other workers or even early retirement.

This story exemplifies the fact that there may be laws against discrimination towards people who are sick, but the reality of working life is quite different. Justin emphasized to me: "You need to be careful who you tell you have HIV." He noted that many Finns living with HIV also faced job discrimination. When I asked Tommi if I could use his name in this study, he laughed and said yes, but I never advise anyone else to do it if they want to keep their job. One Finnish acquaintance at the Finnish AIDS Council had told Justin that he too had faced discrimination when his old employer had informally informed his new employer that he had HIV which resulted in the loss of the job. Justin claimed that many Finns living with HIV were on early retirement because of job discrimination. However, for migrants the stakes were a little higher: in a position with a temporary contract and with no permanent residence in the country, the loss of the job could be devastating and lead to the non-renewal of a residence permit or even deportation which could have severe consequences for the continuity of medical treatment.

The notion of early retirement did not appear to be a realistic option to Justin and Kidane not only because they had not lived here for decades but also because they appeared to feel an ambivalence about their future in Finland. Both Justin and Kidane emphasized that the root of their problems was not HIV but everyday living in Finnish society. Justin said that he had met many people in Finland, but felt that even when you get to know them "it is like this dead space." The sense of social isolation and difficulty to

make good friends with Finns militated against the creation of a supportive social network. The temporary nature of work contracts and lack of close friends thus served to reinforce the sense of living a contingent life in Finland. Neither Justin nor Kidane ever spoke of a future in Finland. Both had vague plans of moving away to another country.

Through the interviews, the main difference that I could perceive between Finns and migrants living with HIV related to the sense of belonging. Both Justin and Kidane repeated their sense of being outsiders in Finnish society and reported struggling with major depression and anxiety in trying to cope with their situations. Kidane spoke of being in the 'darkness.' He continued by saying that 'I don't forgive myself for being stupid.' These feelings of guilt, shame and struggle must be difficult and hard to avoid in a society in which HIV continues to be a stigmatized disease. Neither Kidane nor Justin reported receiving regular counseling and indeed their struggle with their illness seemed in many ways to be a private one. As Kidane said: "There is a big price to pay for being a foreigner in Finland." With this statement, I understood Kidane to refer to the personal distress experienced as a result of social isolation and everyday difficulties of existence as a migrant in Finland.

Kidane told of his encounters with social workers as his time in Finland has also been marked by periods of homelessness and poverty. He said: "Social workers can't see the foreigner in their eyes, but they can see the Finn." By this, Kidane explained that he meant that Finnish social workers could understand the motives, weaknesses and need for help from Finnish alcoholics, for example, but foreigners as a whole remained strange and inscrutable. A clear division between Finns and foreigners – that often verged on an essentialist discourse -- continually underscored the talk of both Justin and Kidane.

The ambivalence and private pain that these men expressed seemed to me strongly attached to a sense of rootlessness and living many years as a stranger in Finnish society. Both related many stories of attempts to be a part of Finnish society but at the same time continually referred to examples of rejection that appeared to be a source of suffering. What was perhaps most striking in the interviews was the lack of a vision of a future in

Finland, the strong sense of dislocation, and the sense that no one wanted to listen to them.

### **15.3 Silence as a strategy and tactic**

Silence has multiple meanings and tends to mirror the constellation of power relations, as Foucault noted:

Silence itself – the things one declines to say, or is forbidden to name, the discretion that is required between different speakers – is less the absolute limit of discourse, the other side from which it is separated by a strict boundary, than an element that functions alongside the things said, with them and in relation to them within overall strategies. (Foucault 1977, 27)

Silence is not solely imposed by the powers that be but can also be a strategic choice by marginalized or disempowered groups. Selective mutism, deafness and amnesia can all play important roles in resisting representation and withholding knowledge (Seltzer and Loona 1995, 26). Migrants often choose to be silent. The silence that resonates from migrant communities, I believe, is not simply a reflection of passivity but comes from a tacit resistance to the intrusion of ‘experts’ in their communities as well as a sense of powerlessness, invisibility, and being silenced in Finnish society. As visibility often brings increased scrutiny, silence can obscure surveillance (Collins 1998, 51). Silence can be a strategy of avoidance, accommodation or resistance to prevailing discourses or representations of migrants in society (see Walter 2001, 169-171 on Irish women in Britain). Silence can be a critique of dominant representations of migrant groups in the mass media, academic research or popular discourse, because a forum for voiced criticism is often denied to migrants. Finally, silence can reflect suffering that resists voice and meaning (see Morris 1997).

Patricia Hill Collins writes about ‘breaking silence’ as a process of empowerment in which individuals begin to ‘come to voice’ to speak out for the needs of a collective group that are often oppressed or marginalized (Collins 1998, 47-56). I would suggest

that because migrants represent relatively new and complex communities which have not yet attained a critical mass, silence has been one of the most viable strategies of survival and resistance to pressure to conform to Finnish cultural standards as well as attempts to categorize and thereby control migrants. Silence is a logical response to the suffering that these pressures bring to migrant individuals, families and communities. 'Breaking silence' can only be done by members of the community and cannot be done by outsiders, hence the importance of research and storytelling by migrants on their own communities.

Silence, however, can also reflect the inarticulateness of suffering and of the inability to give a name to a source of pain. As David Morris has noted:

...the silence of suffering also points to very practical breakdowns of speech. Its silence, that is, reflects something not ultimately ungraspable but merely resistant to description. Suffering tends to make people inarticulate, and in this sense the voicelessness of suffering often resembles the quiet retreat of people who live with chronic pain...Such patients withdraw into uncommunicative isolation, constructed in response to an environment where effective help and concern have all but vanished. (Morris 1997, 28)

Social isolation, a sense of rootlessness and dislocation, the lack of having a language to communicate with, exclusion from the labor market and marginalization from mainstream society are all factors that can contribute to a sense of social suffering and personal distress, the dimensions of which may be difficult, if not impossible, to articulate.

Despite the fact that they took stigmatizing attitudes towards people with HIV/AIDS for granted as prevalent in Finnish society, Justin and Kidane continually insisted in interviews that they felt their status as migrants, rather than people living with HIV, was their greatest challenge in Finnish society, though they felt that this was not often recognized. Certainly, this perspective would be important in developing services for migrants affected by HIV/AIDS. It is therefore imperative to ensure that the stories of

people outside of the mainstream could be listened to despite the dominance of certain plots of HIV in public perceptions and policymaking. By including counternarratives and new stories, policies and practices can be changed and developed to be more inclusive. However, empowering marginalized people to come to voice challenges power relations and is therefore not always welcomed by governments or agencies that may have social or political reasons for organizing care in a particular way. Indeed, coming to voice by the marginalized implicitly challenges privileged standpoints and cultural practices by raising divergent perspectives that may not be favored by decision-makers.

The danger that the pain, dislocation and loneliness experienced by many migrants in Finnish society is culturally appropriated by experts from the mainstream media and research can be a serious threat to the development of migrants' own critical paradigms and voice. The absence of migrants' own voices in research and information about their own experiences in Finnish society means that the stories of migrants' experiences and visions of Finnish reality tend to be filtered and edited by Finnish experts and researchers. This can be a perilous trend because it can serve to produce a double exclusion whereby migrants are not only unable to gain access to Finnish society but are unable to gain access to the discourse on themselves.

Silence and non-participation can also be a strategy of resistance, of boycotting in a sense. While both Justin and Kidane were quite willing to meet me and talk under the condition of anonymity, neither was particularly active in either Body Positive (the peer organization of PLWHA) or the Finnish AIDS Council. They were not aware of or active in any migrant community organizations either, though they both expressed an interest in being active in these issues. At times, the reasons that Kidane and Justin gave for not being involved largely regarded the cynical sense that nothing could be changed and therefore it was better to be silent. However, on other occasions, they said that their attempts to be active had not been recognized or encouraged by workers at AIDS agencies, which appeared to lack an ethic of listening. Both Justin and Kidane felt that migrants were always considered to be volunteers rather than people equally worthy of paid community project work in AIDS organizations. Justin, for example, had been asked

to correct the language in texts by an AIDS agency but never often any compensation despite the fact that the agency was well-funded. The inaccessibility and unwillingness to share resources with potential migrant community workers was therefore sore point for both Justin and Kidane and reinforced their view that migrants were largely powerless to have an impact on HIV prevention and support efforts for their own communities.

Breaking silence is always dangerous because it reflects an insubordination to the dominant social order and discourse. Coming to voice can therefore involve enormous personal risks. Increased visibility can lead to greater vulnerability but it can also bring freedom from fear (Collins 1998, 50-51). Breaking silence ultimately benefits those who have been beaten down by the experience of racism, xenophobia, homophobia, sexism and exclusion. Discrimination and prejudice harms people by objectifying by individuals and communities and therefore denying their basic humanity. Coming to voice thus provides the opportunity to seize back one's own humanity, engage in a dialogue on needs, hopes and expectations, as well as to fight for social justice.

Often it seemed in the interviews that there were many missed opportunities for communication, on both migrant and Finnish sides, which led to bitter and confused feelings. To bridge the gap between the two groups, an open dialogue would be needed which is prepared to challenge the constellation of power relations in AIDS awareness that have come into place since the early days of the epidemic. The plots of AIDS which have guided and developed structures to cope with the epidemic are no longer necessarily relevant to the current needs of people living with HIV/AIDS. The inclusion of members of diverse socio-cultural groups in the position of stakeholders on policymaking, as well as paid employees, would be very important, particularly as the epidemiological breakdown of groups affected by HIV has so drastically shifted in Finland in recent years. In short, it would be necessary to have a greater degree of mutual support to give those who are silent the courage 'to come to voice' and thereby contribute to increased AIDS awareness for all members of Finnish society.

## 16. Conclusions

The aim of this work has been to examine four dimensions of HIV/AIDS on two interconnected levels: the global arena and Finnish welfare state. Firstly, I have explored the development of AIDS as an exceptional health issue and its relation to globalizing socio-economic trends as well as the transforming traditions of public health and social welfare. Secondly, I have examined how stories of AIDS emerged and affected policy development on both global and local levels. Thirdly, I focused on how migrants living with HIV/AIDS are constructed in the Finnish welfare state; and finally, I investigate how cultural identity is constructed at the core of access to services in Finland. These four dimensions of HIV/AIDS have been considered within the theoretical frameworks of human rights, social memory and postmodern illness.

According to the most current statistical estimates by UNAIDS available at the time of writing, approximately 38 million people are thought to be living with HIV/AIDS worldwide, with over 20 millions deaths due to AIDS in the past two decades. According to the report, 15 million children (under age 18) have lost one or both parents due to the pandemic, 12 million of these children are in sub-Saharan Africa. Nearly half of people currently living with HIV are women. The African continent has 10% of the world's population, but has 70% of people living with HIV/AIDS. UNAIDS estimates that if current infection, funding and access trends continue, only 60% of African youngsters now aged 15 will not reach their 60<sup>th</sup> birthday. Growing epidemics are also documented in the former Soviet Union and Asia. Finally, UNAIDS report points out that only 7% of people living with HIV/AIDS in low and middle income countries have access to treatment (See UNAIDS 2004).

These statistics document the seriousness of the global pandemic. The number of people affected by HIV/AIDS globally rivals earlier pandemics, such as the Black Plague and the 1918 Influenza epidemic. Despite being twenty years into the pandemic, the global

fund for AIDS remains desperately short of money and the only medications available to slow the progress of the virus are unattainably expensive for the majority of people throughout the world. Millions around the world continue to lack information about HIV that is appropriate socially, culturally and linguistically. Access to condoms and testing remains very limited in many parts of the world and among many social groups. The socio-economic structures that produce growing global inequality and poverty also contribute to increasing social dislocation through shifting employment patterns, urbanizing processes and forced migration, among other issues. Social dislocation can have a devastating impact on stable and nurturing communities. The unraveling of communities tends to multiply risky and self-destructive behaviors, such as IV-drug use, unprotected sexual encounters, and sex work, because individuals living outside of cohesive and supportive communities often lack a social network or must find new (and sometimes illegal) and contingent ways to earn a living.

The social significance of these facts about the AIDS pandemic is open to interpretation. Although the specifics of how the epidemiological data has been collected and analyzed can also be debated, these statistics remain an important point of departure for discussion about the AIDS pandemic because they frame the enormity of the problem facing humanity.

### **16.1 Globalization and HIV/AIDS: the challenge of human rights**

The most fundamental of human rights is the right to live, yet defining this basic right becomes complicated in the arena of health. Throughout history, infectious disease has shaped history and embodied the social relations amongst groups of people (see, e.g., McNeill 1976). The etiology of disease is complex and includes individual and collective, biological as well as socio-economic and cultural factors. Hence articulations of the human right to health unify both positive (e.g. minimal standard of living, a sanitary environment) and negative (freedom from interpersonal and institutional abuse and oppression) aspects of human rights talk. Health outcomes are intimately connected with social circumstances because health is supported through societal structures, such as

public health, environmental and sanitary measures, as well as social welfare institutions and interventions.

The responsibility for ensuring the human right to health tends to fall on the national -- not global -- level. Despite popular aspirations to achieve a universal standard of human rights, there are no international organs yet that have the power to compel (or support) nation-states to comply with minimal standards of social and health care infrastructure and interventions.

The health and social welfare policies and practices of nation-states articulate and embody the social memory, cultures, socio-economic and racial hierarchies, ruptures, social orders and political debates of each specific nation-state context. Similar to the Janus-face of national identity, state health and social policies and practices reflect both inclusive and exclusive impulses as they construct definitions of needs and ways to meet them. The paradoxes and restrictions of modern welfare states often affect the marginalized of society and migrants most because they tend to lack social networks to compensate for exclusions and are frequently stigmatized by mainstream society as outsiders.

Health and social problems are nonetheless extraordinarily mobile. Indeed, social problems and disease are rarely stopped by borders. The rise of the globalization at the end of the 20<sup>th</sup> century put into play a new set of socio-economic, political and technological factors that affected inter-state and local contexts of health and social support and interventions. Accelerated international migration, multiplying information technology, the steep growth of income disparity among and within societies, shifts in the global political landscape, the diminishing public sphere for health and welfare structures and interventions, as well as the social dislocation of many communities, all coalesced in the early 1980s to produce a set of circumstances that set the preconditions for the emergence of the AIDS pandemic.

Public health is an important cornerstone of the modern western welfare state as well as development efforts in less developed countries. The practices developed by the science of public health since the industrial revolution have greatly improved the quality and quantity of life in industrialized societies as well as guaranteed the preconditions for health and well-being for all members of society. In addition to infrastructural requirements such as sanitation systems and hygiene rules in the workplace, public health measures nonetheless can involve a degree of personal compulsion through quarantine, mandatory testing and contact tracing. Public health measures have always raised conflicts about the correct balance between the definition of community interests and the human rights of often stigmatized individuals. Though public health measures have helped to shape the interventionist social agenda characteristic of the modern social welfare state, they have also been occasionally used to abuse human rights.

As public health utilizes the tools of epidemiology and social intervention to prevent disease and promote health and well-being, it starts its analysis by creating social categories of populations. Despite its empirical basis, epidemiology incorporates a strong element of social constructionism. The creation of a multifactoral model in analyzing and preventing disease, for example, requires knowledge of social relations and communities. Epidemiological models often emerge from the predominant conceptual frameworks of how societies and social groups are composed and therefore reflect how social knowledge about groups of people is produced. Social groups that are underrepresented or disempowered in mainstream society may face ignorance, invisibility or even prejudice when their health needs come to the fore, particularly in time of epidemic. This means that relevant socio-economic or cultural factors or behaviors may be overlooked or stigmatized, which can affect the efficacy of public health measures.

State intervention in managing public health issues directly affects the bodies of the population and has important social and cultural implications. The urgent nature of an epidemic requires states to act quickly and manage situations before they spiral out of control. Deep societal, cultural and personal fears of diverse sexualities, foreigners, blood, and substance use have had a strong impact on attitudes towards the disease and

illness, the organization of services, funding as well as prevention and information efforts. In short, there are complex layers of cultural significance in the social construction of HIV/AIDS, as well as articulations of measures needed to prevent and manage it.

The emergence of the AIDS pandemic in the early 1980s posed great challenges to traditional public health and social welfare systems. As the initial groups affected by the virus tended to come from the more stigmatized, disempowered and invisible sectors of global society, national responses to the epidemic were often slow and inadequate. The struggle to put AIDS on the agenda forged an alliance among diverse community activist groups across national borders that created a critical mass of protest which redefined AIDS as an exceptional public health concern. As a result, many of the compulsory measures used by public health to contain epidemics are not used in the case of HIV/AIDS. Moreover, steady community pressure helped to build the recognition amongst policymakers and practitioners that harm reduction methods can be more effective in getting people to testing and counseling than compulsion. The important work of empowered community groups, HIV patient organizations and other AIDS agencies has served to demythologize AIDS and struggle against stigmatizing views of the disease. Yet, many of these community activist groups reinforced dominant global socio-economic, gendered and racialized constellations of power in their own structures.

The international epidemiology of HIV/AIDS nonetheless reflects the prismatic nature of globalization. Many of the socio-economic globalizing processes of late capitalism have further concentrated financial power, particularly in the hands of transnational corporations. These shifts have resulted in growing income gaps between social classes within and between countries. The role of the public has diminished as private corporations have increasingly taken over tasks that have traditionally been part and parcel of the public sphere, such as health care provision and public utilities, through contracted services. Citizens have therefore increasingly become consumers in the postmodern world. This shift has important implications regarding social rights, which are based on membership in the community. These cultural, economic and societal

changes have had a direct and concrete impact on the spread and prevalence of the HIV/AIDS pandemic. Though the HI-virus transcends social class, nationality, ethnic group, it clearly affects those with fewer resources and on the margins of society (Farmer 1999). According to a 2000 report by UNESCO/UNAIDS, over 95% of HIV infections are in developing countries (UNESCO/UNAIDS 2000, 1). HIV/AIDS has thus increasingly become a disease of social vulnerability and poverty in the process of globalization, rather than linked with identification with a specific social or identity group.

As infectious disease increasingly becomes a marker of exclusion and inequality in global society, the challenge of realizing universal human rights becomes ever more pressing. Discussions of human rights issues tend to focus on 'negative' rights, such as the freedom from torture while 'positive' rights, such as health and social well-being, have been increasingly constructed as consumer issues. The increasingly prevalent neoliberal discourse on individualism is often evoked to justify and characterize the exclusion of the vulnerable individuals as a personal failing rather than the failure of society to sustain and support community life. Indeed, it can be argued that there is a link between the lack of investment in public infrastructure, growing inequality, and the expansion of the AIDS pandemic. The concept of human rights therefore remains an important framework for understanding AIDS in both a global and local context.

## **16.2 AIDS narratives and the employment of public policy: postmodern illness**

From its outbreak, AIDS has been a deeply storied disease resonant with meanings. Emerging at a time of transition from the modernist to globalized/postmodernist era, AIDS embodied a distinct mythology or metaphor from earlier diseases, such as tuberculosis and cholera. If modernist illness can be characterized as the conceptualization of disease as a purely biomedical phenomenon divorced from the lifeworld of the patient, then postmodernist illness can be considered as the marriage of the lived experience of illness and the biophysical reality of disease. In this sense, AIDS can be seen as the preeminent postmodern illness.

From the earliest days of the pandemic, epidemiologists and public health officials focused on white, western gay communities because male homosexuals were the first group associated with the emerging disease. HIV/AIDS was thus quickly associated with negative popular attitudes towards homosexuality. However, gay rights groups in western industrialized countries successfully challenged the stigmatizing plots of the gay plague and gay lifestyle of the early days of the AIDS pandemic by creating pending narratives and counternarratives that confronted homophobic and shaming attitudes towards gays. These counternarratives humanized gays living with HIV/AIDS and raised their concerns to the public. Drawing on the experience of gay liberation movements, AIDS community activist groups took the initiative in challenging dominant discourses on AIDS in the early 1980s, which eventually served to construct AIDS exceptionalism as a unique illness requiring special public health measures. Well-organized activism made gay community groups a significant actor in many western countries in the developing field of AIDS work and served to help articulate the meaning of AIDS as a postmodern illness as well as the measures needed to cope with it. The strength of gay community activism therefore had a strong impact on articulations of AIDS policies in many western countries.

The response to racialized and gendered narratives, such as African AIDS, however, has been much more muted, which perhaps reflects the inequities of global racialized relations. The invisibility and disempowerment of marginalized socio-cultural groups such as migrants, women, people of color and other minorities, can be seen in the paucity of counternarratives to dominant AIDS plots as well as lack of articulations of marginalized experiences of HIV/AIDS. This absence has had an impact on AIDS policy by reinforcing the invisibility of marginalized groups in HIV/AIDS health and social work practices and interventions.

In the Finnish context, the government line on AIDS faced a crossroads between a punitive policy of quarantine or expanding AIDS exceptionalism in the early 1980s. Despite the progressiveness of Finnish society in terms of gender equality, sexuality and children's rights, social attitudes remained rather conservative towards homosexuality.

Hence few narratives of AIDS emerged in Finnish. The corporatist nature of Finnish public administration emphasized the role of medical professionals and other experts in defining AIDS policy. Furthermore, in keeping with Finnish political culture, much of the activism of community organizing took place behind the scenes rather than in the streets. The activist efforts of SETA (The Finnish National Organization for Sexual Equality) and harm reduction perspectives of some physicians and public health officials eventually triumphed over the regressive and stigmatizing views of more vocal medical professionals that sought to use traditional public health measures of quarantine. The Finnish public policy line on AIDS thus took the route of AIDS exceptionalism and a strong network of services was created.

The international plots and counternarratives of AIDS played a significant role in defining Finnish public policy. Nonetheless, few first person narratives of AIDS were published in Finnish; rather public policy, developed by a multi-professional team which included community activists, gradually influenced public opinion to accept the premise of AIDS exceptionalism. The Finnish version of AIDS exceptionalism was constructed within the social memory of a homogenous society. Hence the plot of African AIDS became strongly resonant in a society facing new identity challenges due to increased immigration. The plot of African AIDS, for example, linked fears of outsiders to disease. The underrepresentation of migrants living with HIV/AIDS in AIDS work contributed to their invisibility in public policy initiatives.

In the notion of postmodern illness, suffering is no longer viewed as a private matter but is also a public issue. Articulations of private suffering thus have public resonance and meaning. Though public narratives of AIDS in Finland remain few, Finnish society has incorporated the special needs of people living with HIV/AIDS in its policies and services through the lines of AIDS exceptionalism and harm reduction, which has succeeded in keeping HIV infection levels low, though stigmatizing attitudes are still common. Migrants, however, occupy an ambivalent position in the Finnish story of AIDS. Migrants with the requisite residence permits are guaranteed the same social and health care rights as their Finnish counterparts. However, the special needs of migrants as

outsiders in Finnish society tend to remain largely invisible due to the lack of articulations of their lived experiences of HIV/AIDS in the policymaking process. The silence emerging from the migrant community on the issue of HIV/AIDS can be seen as both as a form of resistance and disempowerment. Therefore, AIDS can be seen as being articulated as a postmodern illness selectively because certain patient groups have had their lived experiences and stories incorporated into national policies while others have been rendered invisible. These power relations and inequalities are mirrored globally.

### **16.3 Cultural competence and access to care: social memory in practice**

Articulations of national social memory assign meanings to social realities and shape societal institutions through constructions of embodied practices. Social memory is a continuously contested territory and subject to the prevailing political winds. Social memory articulates how a group of people understand their past and present experiences as well as their aspirations for the future. Though states may have official histories, there is no one national social memory but rather a complex weave of stories and recollections that are articulated in diverse ways at different times. As the prominent historian Howard Zinn wrote:

...we must not accept the memory of states as our own. Nations are not communities and never have been. The history of any country, presented as the history of a family, conceals fierce conflicts of interest [...] (Zinn 2003, 10)

Finland has never been a country of large-scale immigration, though there have always been small ethnic minority communities. Since the late 1980s, immigration to Finland has grown rapidly but numbers remains small, though nationalities are highly diversified. Ethnic minority communities have been largely absent in predominant articulations of *Finnishness*. Increasing cultural diversity through immigration, though, has raised a public debate on the significance of multiculturalism in Finnish society. This debate, in turn, has evoked different articulations of national social memory that construct Finland as a culturally homogenous nation as well as emergent social memory of cultural

diversity within the Finnish nation. These articulations of social memory have a strong impact on the development of social and health policies of the Finnish social welfare state by defining the basis of inclusionary practices and access to services.

*Finnishness* as a subtext of the welfare state has been marked by articulations of cultural consensus and the construction of Finnish society as an ethno-racial monocultural society. The welfare state has also been an important means of articulating notions of Finnishness by defining rights, responsibilities, social needs and the normative means to meet these needs.

In a social and health care context, access refers to all of the elements that facilitate or bar a person or community to obtain services and care. Access is not solely a set of rules, but involves articulations of policies and practices that affect structural and interpersonal interaction between diverse individuals and groups. Restrictions and limitations on services offered to migrants, both in terms of the lack of culturally and linguistically appropriate policies and care as well as cultural competence training of professionals, can create unequal opportunities in social and health care services by limiting access.

The Finnish social and health care system is based on the fundamentally equal right of all residents to obtain high quality services. Basic social and health care and support is guaranteed to all eligible residents by the Finnish welfare state. The preservation of these fundamental social rights for all residents is a great accomplishment, particularly in the light of growing neoliberal globalizing political agendas which militate against public responsibility for issues increasingly constructed as consumer concerns. Notions of equality in the Finnish social welfare state have nonetheless often been linked to articulations of *Finnishness* and inclusion in Finnish society. This means that the social and health needs of residents that do not fit into the parameters of mainstream definitions may be rendered invisible and therefore not taken into account in policymaking and the delivery of services. In this sense, promoting greater equality in services requires a recognition that a normative definition of service provision does not necessarily mean that all residents are treated equally. Expanding normative definitions of residents and

their needs further requires a reevaluation of articulations of social memory of the nation and inclusion. Cultural competence, for example, has not become a systematic element of caregiving on the policy, practice and training levels precisely due to the ambivalence about emerging multiculturalism in the Finnish welfare state.

In the context of HIV/AIDS care, the ambivalence about emerging multiculturalism in Finnish society can be seen in the paucity of culturally and linguistically appropriate health information material and social services targeted specifically at the needs of migrants. While the Finnish social and health care system provides excellent medical care for people living with HIV/AIDS, and there are many centers of excellence in the social services, there is no specific AIDS policy directed at systematically developing culturally competent services to an increasingly culturally diverse population. This implies that articulations of *Finnishness* as a monocultural quality continue to dominate the definition of AIDS work. Cultural competence cannot be developed unless growing cultural diversity is articulated as an intrinsic part of transforming *Finnishness*. Articulations of social memory must therefore be challenged to render meaning for the new social realities in Finland.

Currently, there are few mechanisms for migrants to participate as stakeholders in the process of developing HIV/AIDS services for their own communities. Often migrants are doubly excluded because they are not invited to participate in the policymaking process and have no voice in the discourse on their own needs. These structural barriers make it difficult to for migrants to challenge existing normative definitions of people living with HIV/AIDS and to become empowered as people living with HIV/AIDS in Finnish society.

The practice of human rights begins when the fundamental humanity of all people is recognized and all are democratically included as participants in the endless task of articulating and constructing a socially just society. The recognition and respect for cultural diversity is the first step on the road to addressing deeper and complex issues of unequal global power relations and their impact on communities and individuals. The

challenge of the AIDS pandemic globally, and the concomitant formations of community mobilization in diverse local contexts, has been to overcome class, citizenship, national, sexual orientation, cultural, gender and race differences into a unified movement that would place human rights at its center. Unfortunately, the promise of a unified human rights movement aimed at eradicating and alleviating the preconditions for AIDS remains unfulfilled.

## Appendix 1

### Acronyms and Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral treatment
CBO	Community based organization
CDC	Centers for Disease Control
HAART	Highly active antiretroviral treatment
HIV	Human Immunodeficiency Virus
IVDU	Intravenous drug user
MAI	Multilateral Agreement on Investments
MLWHA	Migrants living with HIV/AIDS
MSM	Men who have sex with men
NSM	New social movements
PLWHA	People living with HIV/AIDS
SETA	The Finnish National Organization for Sexual Equality
TNC	Transnational corporation
WTO	World Trade Organization

## Appendix 2

### Finnish HIV/AIDS Timeline<sup>78</sup> in an International Context

This timeline presents the events of the Finnish AIDS epidemic. Selected milestones in the international pandemic are listed to provide a framework for comparison.

#### 1981

The CDC reports in *MMWR* of 5 unusual cases of pneumonia in Los Angeles. (4 June)

The CDC reports in *MMWR* of an outbreak of Kaposi's sarcoma. (3 July)

#### 1982

Centers for Disease Control link new virus to blood

- First article on AIDS appears in SETA Magazine.
- SETA approaches Helsinki STD clinic to cooperate in prevention efforts.

#### 1983

Virus that causes AIDS isolated by the French Pasteur Institute

*The New England Journal of Medicine* reports that virus may be transmitted from men to women

Manifesto of people with AIDS as a self-empowerment movement published as the Denver Principles

- SETA distributes anonymous survey to gay men starts cooperation with study funded by the Academy of Finland.

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<sup>78</sup> These events are grouped by year and do not necessarily reflect an accurate chronological listing of each event within each year.

- First AIDS case confirmed by doctors.
- First AIDS case in Finland hits the newspapers. Over 2000 calls logged by SETA during July.
- SETA starts information sheet on HIV/AIDS.
- Expert group on AIDS convened by Ministry of Social Affairs and Health.

## 1984

### AIDS identified as being caused a retrovirus and different modes of transmission recognized

- Dispute over ethical issues, particularly concerning confidentiality issues, renders cooperation between Academy of Finland research team and gays impossible.
- Dr. Sirkka-Liisa Valle, head of research team, blames the gay liberation movement for creating conditions for spread of AIDS in *Tiede 2000*.
- First Finnish AIDS death publicized.
- Expert group formed. The Finnish National Public Health Institute agrees to cooperate with SETA.

## 1985

### Blood test for HIV approved in US

### Body Positive, first HIV self-help group, set up in the UK

- Virologist Antti Vaheri says that Moses may have had good medical reasons to prohibit disease-spreading behavior, such as the 'unnatural acts' homosexuality, in the national newspaper, *Helsingin Sanomat*.
- National Board of Health (*lääkintöhallitus*) forms advisory committee on AIDS.

## 1986

### Soviet Union reports first AIDS case

### Scientists discover second type of HIV

- New communicable diseases act (*Tartuntatautilaki 583/1986*) comes into force. HIV/AIDS not defined as a danger to the general public.
- National Board of Health funds million mark AIDS education project.
- Finnish AIDS Council founded by SETA. Offices opened in Helsinki and Turku.
- Question of compulsory care introduced by Swedish Dr. Michael Koch in interview with *Helsingin Sanomat* entitled "Fear is the Best Weapon." Public discussion on whether compulsory testing should be carried out.
- WHO guidelines on voluntary HIV-testing accepted as policy in Finland.

## 1987

### US develop regulations against the entrance of HIV+ immigrants and travelers

- AIDS Support Centers founded in Tampere, Oulu and Lahti.
- Finnish state begins financially supporting AIDS Support Centers.
- A national reference laboratory was established to facilitate the development of testing techniques as well as principles (guidelines for anonymous testing, and other ethical issues, etc)
- 500 decision-makers invited by National Board of Health to discuss AIDS strategy.
- National Board of Social Welfare (*sosiaalihalitus*) starts taking an active role in AIDS.
- New communicable diseases act (*Tartuntatautilaki 583/1987*) provides guidelines for quarantine measures.
- National Board of Health bases program on WHO guidelines.

- *Sextiin* magazine mailed to teenagers by the Ministry of Social Affairs and Health. Its objective is to give information about sexuality, HIV/AIDS and STDs in a youth-friendly way.

## 1989

- Body Positive (*Positiiviset ry*), a patients' peer organization of PLWHA, founded.

## 1991

10 million people estimated to be infected with HIV worldwide

Red ribbon campaign becomes symbol of AIDS

- Responsibility for collecting HIV/AIDS statistics given to the Public Health Institute. Prevention work is the responsibility of the Ministry of Social Affairs and Health.

## 1992

The eighth International AIDS Conference is held in Amsterdam "A World United Against AIDS."

- Law on Patients' Rights (785/1992) ensures the right to treatment, confidentiality in care and informed consent in treatment.

## 1993

- Ministry of Social Affairs and Health appoints a standing expert committee on HIV/AIDS to monitor and evaluate the HIV situation in Finland.
- Intensified home care project for PLWHA initiated by Aurora Hospital and Finnish AIDS Council.

## 1995

New York Times reports that AIDS is the leading killer of Americans between the ages of 25 and 44. (31 January)

US admits that the Pasteur Institute was responsible for the discovery of the HI-virus

WHO program on AIDS closed due to widespread criticism

- Cooperation between Finnish government and Finnish AIDS Council becomes more systematic.
- Constitution of Finland (1995/969) amended to include section that prohibits discrimination on the basis on race, gender, age, ethnic origin, among other things. Most importantly for PLWHAs, this amendment prohibits discrimination on the basis of health or disability. However, critics feel that the amendment does not go far enough to ensure equality.
- Finnish penal code on health crimes (RL 578/1995) is modified. People convicted of endangering the health of others are to be charged with aggravated assault instead of manslaughter.

## 1996

UNAIDS replaces the WHO program on AIDS

Viral load test developed to provide information on disease progression. Triple combination therapy suggested to be more effected than dual therapy.

- The first low-threshold service site for injecting drug users established. This was a very important step regarding the subsequent development of prevention strategies and providing the means for prevention to one of the most vulnerable groups.

## 1997

- Finnish AIDS Council starts a project, financed by the European Union and Ministry of Social Affairs and Health, that includes a comprehensive survey on men's relationships, sexual relationships, information related to HIV, condom use and safe sex education that includes structured interviews and detailed data.

- The first local outbreak of HIV among IVDUs started. Renewed emphasis on arranging credible treatment options for drug dependence, and later, to antiretroviral treatment among the largest group of young IVDUs living with HIV.

## 1998

- All expectant mothers tested for HIV at maternal care clinics as part of general health screening.
- The HIV Foundation is established as an independent entity. The HIV Foundation directs the activities of the Finnish AIDS Council and its six regional offices throughout the country.

## 2002

UNAIDS reports that women comprise 50% of HIV infections in the world.

- New AIDS strategy is published by AIDS expert committee.
- Finnish Aids Council starts a pilot project in the back rooms of sex clubs in Helsinki together with SETA and *Protukipiste* (Prostitution Counseling Center) in order to prevent new infections among MSMs. Moreover a poster and a postcard with the theme 'Men to men safely' is distributed throughout Finland.
- Finnish AIDS Council makes an application to the Finnish Slot Machine Association for a three year project targeting MSMs. The background is an increase (although still small) in HIV among this group. This application is has the support of the Finnish Public Health Institute.

## Appendix 3

### Questionnaire text

The following questionnaire was formulated by a small group that included workers from an AIDS Support Center, a Finnish nurse, a migrant nurse and myself during a meeting on migrant issues. It was then distributed to 8 migrant outpatients at a hospital in Finland, 2 were returned. The questionnaires were available in Finnish, English, French, Russian, and Estonian. The 2 that were returned were in English. Originally, it was intended to do a study with a migrants' community based organization, but the idea was soon dropped by the organization due to lack of interest. I was responsible for sending them to the hospital where they were distributed by physicians. The responses were sent to me. For reasons of privacy, specific organization names which could identify the town have been left out.

### QUESTIONNAIRE

We would like to ask you to take a few minutes to fill out this questionnaire. This questionnaire has been written by the migrants' organization that is made up of Finns and migrants, which seeks to improve social and health care services for migrants in Finland. The AIDS Support Center has also taken part in formulating the questions. **You do not need to put your name on the questionnaire. All replies are completely anonymous and confidential.** The purpose of this questionnaire is to ask migrants living with HIV in Finland about what services they need and to hear how existing services could be improved. We also hope to better understand the situation of migrants living with HIV in order to support migrants and their families in Finnish society. If you have questions regarding this questionnaire, please do not hesitate to contact (my name and a person at the AIDS Support Center, with telephone numbers). Thank you for participating!

1. What is your gender?

Male                  Female

2. What is your marital status?

Married              Partnership (living together)    Single

3. Do you have children?

Yes                    No

4. Age

18-25	26-30	31-35	36-40	41-45	46-50
51-55	over 56				

5. How long have you been HIV+?

6. What social and health care services have you used?  
(please tick any that you have used in the last year)

- Local health care center
- Family support center
- Mental health center
- Income support services
- Home nursing
- Home help
- AIDS support center
- Other (please list)

1. What type of social and health care services would you need/like to have?
2. What would you like to change/improve about the social and health care services offered to you?
3. Do you feel that you receive adequate support for yourself as an individual/family/migrant?
4. Is there anyone (such as a partner, family member, professional helper) that you can share your concerns and worries with? Would you like to tell about this person(s)?  
(no names or details needed)
5. Do you feel that you have received adequate information about your situation and available services?
6. If not, what kind of information would you need?
14. Are there any other issues that you would like to raise to our attention?

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Finnish Penal Code

Language Act (2003/423)

Law on Administrative Procedure (*Hallintomenettelylaki* 6.8.1982/598) Official English translation available <http://www.finlex.fi/pdf/saadkaan/E9820598.PDF>

## **Interviews**

(all interviews took place in English)

Katarina Huuska (worker, AIDS Council Tampere) 12 June 2002

Justin (pseudonym) 2 October 2002

Kidane (pseudonym) 1 October 2002

Tommi (pseudonym) 20 September 2002

Dr. Jukka Mattila (senior physician, Ministry of Social Affairs and Health) 1 October 2002

Outi Pesonen (district office manager, AIDS Council Tampere) 12 June 2002

Susan Simola (social worker, Aurora Hospital, Helsinki) 10 March 2004

Timo Sokura (worker, Body Positive Helsinki) 11 June 2002

Sakari (pseudonym) 11 June 2002

## **Questionnaires**

2 English language replies to the questionnaire duplicated in Appendix 4.