Facing the Mirror : The European Union as a postmodern actor in the fight against HIV/AIDS in Central and Eastern Europe

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ABSTRACT

HIV/AIDS is taking catastrophic proportions on the Eastern border of the European Union (EU). Because the number of people infected with the virus is increasing drastically among the countries that joined the Union in 2004 and 2007, there is an imperative to act. But the EU has minimal competencies in health. The present thesis aims at understanding how deeply the EU has been able to imprint its postmodern strategy on the new Member states of Central and Eastern Europe. The study concludes that the EU, which built up a postmodernist approach based on its tradition, is successfully diffusing its approach within the new member states. The EU strategy is based on the elimination of the repressive model of epidemiological control, the end of the state monopoly over health system, the imposition of a horizontal structure over actors, the defence of human rights, and the diminution of vulnerability through policies that fight marginalization rather than encourage it. This evaluation will be made in light of two-case studies, Estonia and Poland, and the qualitative analysis of 18 different interviews among HIV/AIDS actors.

When cholera is over, we will still have to face mirrors
Jean Giono, The Horseman on the Roof

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LIST OF ACRONYMS

ACT-UP : AIDS Coalition to Unleash Power
AIDES: Association d'aide aux maladies, d'aide à la recherche et d'information du public sur le Sida
AIDS: Acquired Immuno-Deficiency Syndrome
ART : Antiretroviral therapy
CEE: Central and Eastern Europe
CEU : Council of the European Union
EC: European Commission
ECHR: European Convention on Human Rights
ECtHR: European Court of Human Rights
ECJ: European Court of Justice
EP : European Parliament
EU: European Union
Global Fund : The Global Fund to fight AIDS, Tuberculosis and Malaria
HAART : Highly Active Anti-Retroviral Therapy
HIV : Human immunodeficiency virus (HIV)
IDU: Injection drug user
INGO : International non-governmental organization
LGBQTT: Lesbian, Gay, Bisexual, Queer, Transsexual and Transgender
MTCT (sometimes referred as MCT by some authors): Mother-to-child transmission
MS: Member states of European Union
MSM : Men having sex with men
NGO : Non-governmental organization
PLWHA: People living with HIV/AIDS
WHO: World Health Organization

Prevalence: All the cases / population
Incidence : New cases per unit of time / population

INTRODUCTION

July 1981, the headline of the New York Times published a revelation that would change the end of the century: forty-one homosexual men showed symptoms of a very rare form of cancer. What was first a puzzle became a major health crisis. When cases discovered around the world were amalgamated into an epidemic, an already complicated enigma became even gloomier.

The origins of Acquired Immuno-Deficiency Syndrome (AIDS) are still debated. We now know that a strain of the retrovirus that causes AIDS, the Human Immunodeficiency Virus (HIV), was present in Central and West Africa before the 1980s. But we lack precision because AIDS was often being confused with malaria or other tropical diseases at that time, and scientists did not pay sufficient attention to the phenomenon as they most had yet to realize its existence. In a world where epidemics had become stories from the past, the scientific and medical communities were taken by surprise. The last mortal epidemic that humanity had faced was the Spanish Flu, leaving more than 70 years of relative peace in the field of epidemiology. Before AIDS reached San Francisco in 1981, the whole world was convinced that the age of infectious diseases had long come to an end in wealthy industrialized countries (Rosenbrock et al., 2000, p.1609).

The nature of HIV itself was something completely new. In the early 1980s, retroviruses were merely an intrigue for a couple of obscure specialists. The particularly slow evolution of HIV, which was contracted long before the first case of AIDS, made it possible to have huge waves of AIDS cases in a relatively short time during the early 1980s. When the *surveillance network* noticed the new pandemic on their radar screen, it was already too late to avoid a catastrophe. HIV/AIDS is a long-wave disease, unlike tuberculosis (TB) or the plague (Barnett, 2006a, p.393). This means that it takes years to develop the symptoms of the virus, which makes

it difficult to clearly understand when and how one gets infected with HIV. For public authorities, the long incubation period of HIV requires a long-term strategy, and actors are difficult to mobilize early on since the ravages come later on when it is often too late for action. Most importantly, there is a high likelihood that initiatives taken for the best short-term results will make the long-term situation worse. This is common in countries that wait too long before taking action, and act too swiftly when AIDS cases boom in hospitals (Barnett, 2006b, p.361).

The shock created by this new epidemic and its particularities revealed the unpreparedness of the modern health-care system and policy makers. HIV/AIDS called for a revolution. It reversed the established patterns that emphasized primary health care over prevention. It created the feeling that "clinical medicine was powerless" in the face of an illness on which we had "hardly any facts or certainties" (Rosenbrock et al., 2000, p.1609).

Beyond what was happening in the labs, HIV/AIDS forced us to reconsider the philosophical concepts behind health. Countries with similar income levels, cultures and health capabilities face different outcomes in their fight against the retrovirus: we can look at Uganda, which successfully tackled the pandemic, in contrast with Kenya. We could also look at Ukraine and Poland, the latter being more able to keep the infection rate low even if it did nothing more than the former. These cases illustrate well how outdated the concepts and understandings of health policy-making had become. They also explain why we stopped to consider the spread of AIDS as an epidemic, and started talking about a pandemic, referring to an illness contained by borders, as virtual and unclear they may be.

Fighting HIV/AIDS necessitated dealing with sensitive issues that were not previously submitted to policy-makers' scrutiny, and it became human history's most analyzed illness (Clarke, 2004, p.157). No epidemic has ever been this political, and politicized. The states, multinational corporations, international actors, private initiatives, and civil society all became

important actors and defenders of particular visions, representing a wide spectrum of values and norms, some more constructive than others.

In this framework, the European Union (EU) is just an actor among several others. It came up with a different answer and offered an alternative to the national ones that appeared to be limited in their efficiency to fight HIV/AIDS. Thus, the EU diffused a postmodern way of dealing with health in the member states of the last two waves of enlargementsThe present thesis aims at understanding how deeply the EU has been able to imprint its postmodern strategy on the new member states of Central Europe and Eastern Europe, although with different levels of success. In other words, it wants to look how a postmodern EU has been able to change the relations among the different actors involved in HIV/AIDS, including the EU itself, states, non-governmental organizations (NGOs), or individuals.

The first chapter will provide the theoretical background and address the issue of postmodernism and HIV/AIDS. It will define what postmodernism means in this context, and why is it necessary to fight the pandemic efficiently.

The second chapter will provide the historical and institutional framework of the EU strategy against HIV/AIDS. It will present the context within which the strategy arose, and will analyze the EU's institutional capabilities in health matters. It will also analyze the strategy at the European level, and explain why it is postmodern.

The third chapter aims at studying the extent of the crisis among the new member states. It will describe the history of the illness, and explain the state of health system in the wake of the EU accession and the epidemiological facts, all while keeping a close eye on our case studies.

The last chapter will be devoted to our two case studies: Estonia and Poland. It will present findings on the postmodernization of health policy-making in those countries, and will discuss how the EU has been able to influence their health systems in the light of four criteria: the

end of the panopticon, the diffusion of new narratives and power relations, the implementation of a human rights approach, and a capacity to eliminate marginalization.

I have reached the conclusion through the analysis of interviews made on a person-to-person basis or through email question-answers, involving 18 different HIV activists involved in Poland and Estonia, in August and September 2007. Many documents produced by national governments, national agencies and non-governmental actors have also been analyzed to complement findings in the field. A more detailed review of the methodology will be provided in the beginning of Chapter IV.

A review of existing literature justifies the pertinence of this thesis. There is a considerable body of literature devoted to European Union capabilities that can be qualified as postmodern. Robert Cooper and Peter Van Ham, through various works, developed institutional analyses of the EU as a postmodern actor, focussing on security, citizenship and political participation, the relevance of which is limited for this thesis since they concern areas dissimilar to health (Cooper, 2000; Van Ham, 2001). This literature is still relevant because it is part of a considerable body of literature presenting the EU as a postmodern actor. This literature remains very theoretical and does not attempt to look at how, in practical terms, the EU's purported postmodern character unfolds into concrete actions.

Some authors offer stronger conceptualization with clear criteria of what it means to call the EU a postmodern actor. Paulette Kurzer and Ian Manners provide a good study of the EU's "normative power", an important feature of what postmodern governance means. For them, the EU is postmodern because it diffuses norms and values rather than implementing ideas through the threat of force, a concept that can easily be applied to social welfare (Kurzer, 1999; Manners, 2002).

Others also focus on the role of the EU in supporting the development of new narratives, an important element of what it means to be a postmodern actor. Melissa Anne Parker represents a good analysis with her paper studying how EU institutions shape a new European Muslim identity, showing the importance of the European institutions as an arena to frame new narratives (Parker, 2005). Douglas Holmes uses postmodern theory to emphasize the role of the EU in the emergence of what he calls "integralism", explaining another side of how the EU institutions are part of the process of shaping narratives and identities (Holmes, 2000).

Some scholars have studied more particularly postmodern EU and social issues, such as Sandro Cattacin and Barbara Lucas. Their focus remains on the West European experience and they fail to clearly circumscribe the role of the EU (Cattacin & Lucas, 1999). They highlight the importance of the Union in creating a *rapprochement* among different actors in social issues, offering an opportunity to modify power relations (Cattacin & Lucas, 1999, p.397). The EU institutions, according Cattacin and Lucas, also based their answer on horizontality. The structure of the Council and the Open Method of Coordination (OMC) are an important trademark of this horizontality, which is another concept that makes the EU a postmodern actor.

The "inviolability of human rights" in social welfare is also an important feature of the EU as a postmodern actor, as highlighted by Delanty and Rumford (Delanty & Rumford, 2005, p.111). More importantly for the purpose of our study, the two scientists do a good job of presenting the conflict between modernity and postmodernism within the European Union, particularly relating to the European social model (Delanty & Rumford, 2005). Nevertheless, they focuses on defining the European social model at large, including health among many other fields, but fail to explain how it works. Their research still offers useful direction to our study.

In sum, the idea of postmodern mechanisms within the EU, even if not clearly labelled as such, is not particularly new, and is more than simply a theoretical framework. Many authors

have already set the cornerstone to our study. The innovation of the current thesis is to expose how this vision can also be found in health, more precisely the fight against HIV/AIDS, and to refocus the criteria on issues that are important for health systems.

The available literature focusing on health and the EU is very limited, even if we leave aside postmodernism. Monika Steffen developed some of the most exhaustive studies of the European health system in her different works. With Wolfgang Lamping, she presents a useful framework to understand how the European institutions can influence health, and which are the mechanisms that can be used. Their work describes the EU's role in Western Europe, but presents no analysis on the relation between the EU and the newest member states in terms of health (Lamping, 2005; Steffen, 2005; Steffen, 2004). Diane Dawson and her colleagues propose a comparison between the European and American health care systems (Dawson et al., 2006). Again, this study provides an ontological and static look, but does not offer a picture of the dynamics of health actors within an enlarged EU. Similarly, Richard Freeman and Michael Moran provide an analysis of different European health care systems, but their analyses focus on state capabilities within Western European nations (Freeman & Moran, 2000). The role of the EU remains marginal to their analysis. Richard J. Coker focuses his study on communicable disease control in an enlarged EU with a clear focus on state as the main actor (Atun, 2004). His realist stance seems to reject any role for the EU whatsoever. Oliver and Mossialos are among the sole authors who provide an analysis of the EU health capabilities with a postmodern influence (Mossialos, 2005). That said, their approach remains very broad, and focuses mainly on the EU's capacity to diffuse knowledge. They attempt to describe different philosophies of European health systems rather than providing a thorough analysis of postmodernism in the European health response, or explaining the dynamics of a EU health system. Therefore, all literature remains descriptive, and is not concerned with the structural dynamic of the entire EU system.

Literature focusing on HIV/AIDS and the EU is even more limited. Monika Steffen remains the sole scholar who has studied HIV/AIDS at the EU-level from an institutional perspective. The shortage of authors who studied the pandemic explains why the upcoming thesis highly relies on Steffen's work. Her work provides a good understanding of EU capabilities, but relies on the Western European perspective. It remains descriptive, and focuses more on the sum of European national answers than the EU's role. Christiane Panchaud also provides a typology of Western European national responses, but alludes to a EU role (Panchaud, 1995). Peter Aggleton and Richard Parker offer what will be the closest to a postmodern analysis of the EU as an HIV/AIDS actor (Aggleton & Parker, 2003). They offer a vision of how a postmodern European response to the pandemic should look, without clearly labelling it as such. They list different priorities that the member states should adopt. Nevertheless, they focus on Western European states to implement these strategies. The authors do not credit any role to the EU, do not offer a theoretical background, and are not concerned with implementation. There is an exhaustive body of literature that deals with the legal aspect of HIV/AIDS in Europe. Jean-Yves Carlier, Stanislaw Frankowski and John A. Harrington provide an overview of the different legal frameworks affecting HIV/AIDS, both at the national and the European level (Carlier, 1999; Frankowski, 1998; Harrington, 2002). They provide an exhaustive description on how law infringes on HIV/AIDS in Europe. No material has been produced on the effect EU policies have on the fight against HIV/AIDS in the new member states, except official assessment documents produced by the European Commission.

On the other hand, there are an many authors who offer a postmodern framework on health in general. Michel Foucault and Jean-François Lyotard, two important thinkers of the postmodern movement, provide both important keys to understand what it means (Foucault; Lyotard, 1979). Our theoretical background will draw straight from those important philosophers.

In terms of the role of postmodernism in the fight against HIV/AIDS, a considerable amount has been written. Kris Clarke and Susan Sontag have significantly contributed by presenting original frameworks that apply a postmodern theory to well-developed and precise case-studies (Clarke, 2004; Sontag, 2001). Others provide useful tools inspired by a postmodern vision, without identifying themselves as such. Rhodes offers a new way to understand vulnerability under a postmodern eye (Rhodes et al., 2005), while many others provide a good analytical framework of the effect of stigmatization on HIV/AIDS (Brouwer 2007, Delor, 2000, Goldin, 1994; Gilmore, 1994). More precisely, authors like Gyarmathy, Atlani and Kalichman offer strong analyses of the concept of marginalization and HIV/AIDS in former Communist countries (Atlani, 2000; Kalichman, 1999; Gyarmathy, 2005).

It might be unclear to the reader what is the conceptual link between the EU postmodern capabilities and these different postmodern analyses. The importance of these analyses is that they unveil important features of the HIV/AIDS pandemic, such as the importance of social theory as an effective means to fight the pandemic and the importance of stigmatization and marginalization in HIV transmission. Those postmodern analyses are necessary to clearly understand which challenge the pandemic represents, in comparison to other illnesses that could be handled with more traditionalist approaches. In other words, before assessing whether the EU is efficiently fighting HIV/AIDS, we need to understand who is the enemy and what are the necessary conditions for an effective fight. And much more important, postmodern analyses are necessary to establish the criteria that will allow us to assess efficiency. A postmodern analysis of the illness helps us by offering the concepts necessary to develop our own study.

The reader must remember that the present thesis does not attempt to build a postmodern analysis of the EU's approach to HIV/AIDS. Rather, it acknowledges that the EU has developed capabilities inspired by postmodernism and attempts to analyze the extent to which these

capabilities have affected developments in the new member states in Central and Eastern Europe. The current work will first explain what those postmodern capabilities are in the particular area of health. Then, it will see if this strategy seems to work in the field.

In contrast to the approach taken by Kris Clarke and Susan Sontag, I do not focus on narrative at the individual level. For example, I do not explore the diversity of individual narratives about HIV/AIDS that are present or emerging in Central and Eastern Europe under the influence of the EU's policies. While Clarke and Sontag studied HIV/AIDS as a phenomenon at large, beginning and ending at the individual level, this work takes a different path by focussing on political institutions and power relations, rather than individual narratives or the individual psyche. This study is based on the understanding that political institutions can provide tools to allow multiple personal narratives to emerge, even if those institutions do not themselves frame the personal voices that express those narratives. Institutions can become a channel and support for the initiation of those individual voices.

This evaluation wishes to understand if the EU has successfully changed the power balance among the different actors through its postmodern strategy, thus allowing those diverse narratives to be voiced. In other words, this work does not itself undertake a postmodern analysis, and does not pretend to be postmodern. Rather, it posits that a postmodern philosophical vision serves as an important foundation for the European HIV/AIDS strategy, and that, as a tool available like many others, its efficiency can be assessed through an outcome-oriented positivist perspective. This will be the main goal of the present study, something that has never been done in the literature. In particular, our research evaluates how successfully the EU's postmodern policies have been able to influence Estonian and Polish national responses, in part by affecting power relations in those countries.

CHAPTER ONE. THEORETICAL BACKGROUND: POSTMODERNISM IN HEALTH POLICY, WHAT DOES IT MEAN FOR HIV/AIDS?

On June 25th 1984, Michel Foucault, a pillar of postmodern thought, died of AIDS. He learned he was HIV-positive only a couple of hours before his death. This might be a powerful image to illustrate how postmodernism got involved in the insulated world of health policy-making: through a backdoor. Of course, the philosophical current was growing at a time where people tried to make sense of the illness, shocked by this pandemic that took the Western world by surprise. Any available tool to explain this tragedy was allegedly useful at the time, postmodernism being one among others.

But the relationship between HIV/AIDS and postmodernism is also subtle since the former was asking very difficult questions about individual human behaviour, revealing this part of darkness that some may refuse to see, such as sexuality and drug addiction. It forced society to look at itself straight in the eyes, offering a vibrant stage for the ideas developed in Foucault's work.

The present chapter aims at setting the theoretical foundations for explaining why postmodernism is more than a framework to understand HIV/AIDS; it is also an efficient tool to fight it. First, we will look at the modernist mechanisms underlying health policy-making in the wake of the HIV/AIDS crisis. Then, we will define postmodernism by looking at how main authors originally explained it. Finally, we will focus on the relevant concepts of the philosophical current that can be applied to epidemiological control and health systems, focusing on how it can provide a useful foundation to fight HIV/AIDS.

1.1. HEALTH SYSTEM?

The recent concept of "health system" increasingly replaces the one of "public health". Health system was introduced and diffused by the World Health Organization. It consists of "all

the people and actions whose primary purpose is to improve health", including policies and institutions (WHO, 2000, p.1). A health system is a combination of healthcare and health promotion, or "the sickness branch of social security and prevention" (WHO, 2000). It is much more than healthcare. It includes a wide spectrum of actors and responsibilities, from toxic analysis of children's toys to national flu shot campaigns. The choice of using health systems rather than "public health" or "health policy-making community" is based on the assumption that health is also a social, cultural, scientific, economic and political phenomenon. It fits more with the idea developed in this thesis that defines health politics as a dynamic relationship between different political actors, including the patient. In other words, this concept attempts to recognize that patients are part of the policy-process rather than being simply the object, an important idea for a postmodern thinker. Finally, the choice of "health system" fits more with the EU's role. The EU, as we will see in chapter two, does not have much health policy-making capabilities, even if it influences European health systems, and can be considered as one.

Health systems can play three distinct roles when attempting to prevent the spread of HIV/AIDS. Primary prevention is about stopping people from getting infected in the first place. Secondary prevention is about containing the pandemic. It implies damage control and an attempt to stop the progression of the disease once it is introduced in the system. Finally, tertiary prevention attempts to contain the disease within the body, or delay the patient's death. The latter step is more scientific, accomplished through the use of antiretrovirals (ARV).

1.2. FOUCAULT'S ANALYSIS OF MODERNISM

In the wake of the HIV/AIDS outbreak, health systems were relying on the modernist tradition. To circumscribe a strict definition of modernism could be a daunting enterprise that would need to go back to the Enlightenment. We will not go as far.

The word "contain" is important in understanding what modernism means in relation to health care. A postmodern would see modernism as the incarnation of the repressive model as presented by Foucault in different works, including *Surveiller et Punir*, and *Naissance de la Clinique*. In *Surveiller et Punir*, Foucault elaborates an entire analysis of the penal system, and then extends his reflection to other realms, such as the hospital. His analysis focuses on the concept of discipline, i.e. trying to restrain the body to a given societal norm (Foucault, 1975, p. 251). Central to discipline is the metaphor of the panopticon: "panopticon is the general principal of a new political anatomy where the object and the goal is not sovereignty relations, but disciplinary relations"[1] (Foucault, 1975, p.243). The panopticon refers to the physical structure of jails, where a warden is surrounded by a hemicycle of prisoner cells. The warden's position allows him to see what is happening in every cell, while the inmates can neither see their neighbours nor the warden. Foucault believed that this concept could be extended to many realms of human life, including health systems. The hospital duplicates the panopticon. Its disciplinary power also exercises its force by making itself invisible. At the same time, it imposes a mandatory visibility on the people that it subjects (Foucault, 1975, p.220).

Beyond the panopticon is a gigantic system that isolates the patient. Through the "divisions of the bodies" and an intricate system of classification, medical surveillance is based on solitude. The body that gets incorporated in the machine must submit to it. Solitude and individualisation prevent the body from relating to others. The entire system takes advantage of this patient's isolation by becoming stronger than the sum of its units (Foucault, 1975, p.192): divide and rule, in other words. This is how hospitals became "buildings to watch from the inside" (Foucault, 1975, p.203).

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[1] Original quote : « *Le panoptisme, c'est le principe général d'une nouvelle 'anatomie politique' dont l'objet et la fin ne sont pas le rapport de souveraineté mais la relation de discipline* », translation from the author.

The medical panopticon is tied to bureaucratic procedures. The medical process is supported by a well-developed system of examination following strict rules and supported by an intense system of recording and of archives (Foucault, 1975, p.222), what Foucault calls disciplinary writing. In this fashion, individual statistics are integrated at the general level. This makes the individual a "case", placing him in a category that gets rid of personality (Foucault, 1975, p.224). In sum, Foucault argues that "disciplinary procedures changed the relation, simplified individuality to a lesser level and made of this description a mean of control and a method of domination" (Foucault, 1975, p.224). The repressive modernist model is thus about imposing norms of societal discipline on the body, a discipline that will ensure that everything previously able to harm society will be managed or destroyed.

In *Naissance de la Clinique*, Foucault goes even further by posing the question: what differentiates the ill patient from the illness itself? Since an illness needs a body to be revealed, Foucault is arguing that the hospital is a place where bodies become strict vehicles of an illness, which takes away the patient's individual characteristics. The illness thus becomes "an individual in itself" (Foucault, 1963, p.13). It has a well-circumscribed physiognomy and a well-analyzed set of symptoms. Epidemics also gain "a certain historical individuality[2]" (Foucault, 1963, p.24). The individual who becomes ill must give up his individuality to become "a case". The body of the ill is reduced to being the visible and hard casing of the illness (Foucault, 1961, p. 154). The science behind medicine takes away all the individual rights and responsibilities of the ill. Therefore, the ill must give up any control over his illness, which owns him and annihilates his individuality. In the process, the patient must also give up control and responsibility over his body.

[2] All translation from French sources are the author's.

Another important image that Foucault brings forth in *Naissance de la Clinique* is "*le regard calculateur* » (the planning look) (Foucault, 1963, p.89). This *regard* coincides with the rise of "positive medicine", based on the new values of positivism and enlightenment (Foucault, 1963, p.35). Since the XVIIth century, observations led medical scientists to believe that certain behaviours were healthier than others, which in turn led to increased hygienic standards and to an awareness of public behaviour. This is how medical scientists started to make proper value judgements on behaviour. The violence of this is the clear division between what is "normal" and "abnormal" (Foucault, 1975,p.232). Modernity institutionalized these moral standards. This is why Foucault came to this conclusion: "medicine in the XIXth century is more about normality than health" (Foucault, 1963, p.35).

If there is such a thing as normal behaviour, therefore, it is the role of the "system" to ensure that the population fits within this established scheme. And, while the role of the doctor was initially to heal the sick, it changed to encompass more imposing standards, which eventually invaded the entire realm of the patient's life. The "*regard calculateur*" (the planning look) is thus fusing the social and the medical space into one, where the "doctor's eyes become a framework by imposing a constant surveillance" (Foucault, 1963, p.41). It is in this context that the concept of the "all-powerful doctor" is born. Today, medical institutions must "protect healthy people against illness", and "protect the ill against the practices of ignorant ones". They must "preserve people from their own errors" (Foucault, 1963, p.41). A modernist policy thus assumes condescension of authorities over the general population.

With its bureaucratic structures based on secret writing, the medical doctor is also able to keep "the illness and the sick separated" (Foucault, 1963, p.54). This knowledge is now the privilege of a group. The entire system relies on medical doctors who are treated as god-like figures, "the apotheosis of the medical character" (Foucault, 1961, p.281). Knowledge becomes

the possession of this little group, which creates an "esoteric form of the knowledge" by not allowing the ill to have a grip on his condition (Foucault, 1963, p.54). Over the last century, the medical doctor has seen his power increased, according Foucault. And the ill person will "accept giving up control over his body to the benefits of the medical doctor, who is both divine and satanic, but, in any circumstance, far above the human realm" (Foucault, 1961, p.288). The main problematic of the repressive model is that the ill person loses all control over his illness. The illness belongs to the realm of the all-knowing, which implies that the patient must give up his rights and responsibilities towards his own body.

In sum, Foucault's vision has two implications for this study. First, Foucault provided a strong critique of the modernist approach that favours a strong centralization of the health response within the state institutions. His work brought forward the idea of "a revived communitarianism coupled with an emphasis on individual responsibility" and with a "critique of the all-powerful State" (Barry, 1996, p.1). The claim is clear: we need to re-empower the individual before a gigantic machine aiming at disciplining him. Foucault's theory is thus a "tool to understand some of the contingencies of the power system we inhabit and which inhabits us today" (Barry, 1996, p.4). Therefore, he provides a strong questioning of why the system is confiscating the rights and responsibilities of the sick.

Second, Foucault came to the conclusion that scientific knowledge is a tool of domination among others. In sum, reason should be an activity rather than an institution (Barry, 1996, p.21). The scientist, in this context, acquires "powerful capacities, not only in linking deliberations in one place with actions in another, but also in promising to align the self-governing capacities of subjects with the objectives of political authorities" (Burschell, 1996, p.32). The medical body is part of the discipline mechanism, respecting the motto "social control

exercised not through physical force, but through the production of confined subjects and docile bodies" (Aggleton, 2003, p.17).

Foucault's work calls for a "new relation between expertise and politics" (Rose, 1996, p.54). For the French philosopher, the "new powers that the technologies of welfare accorded to experts enabled them to establish enclosures within which their authority could not be challenged, effectively insulating experts from external political attempts to govern them and their decisions and actions" (Rose, 1996, p.54). The postmodern era must find "new ways of responsibilizing [sic] experts in relation to claims upon them other than those of their own criteria of truth an competence, and assemble them into new relations of power" (Rose, 1996, p.55), or a "pluralization of social technologies" (Rose, 1996, p.56). Foucault questions the central role of science. He concluded that "fields such as psychiatry and biomedicine are best understood as cultural systems that offer different claims to truth" (Aggleton & Parker, 2003, p.17).

1.3. POSTMODERNISM : LYOTARD'S VISION

Foucault set the grounds for postmodernism, but we owe to Lyotard one of the first conceptualizations of the movement. Lyotard's work starts with the question of scientific knowledge, focussing on the issue of legitimation. Straight at the beginning of "*La condition postmoderne*", a report ordered by the Quebec government, Lyotard clearly states the claim of postmodernism: "an incredulity towards any narratives" (Lyotard, 1979, p.7).

The point that needs to be highlighted in Lyotard's work is definitively the relationship between power and knowledge. Early in his work, the French thinker presents one of his basic ideas: "knowledge and power are two faces of the same problem" (Lyotard, 1979, p.20). Lyotard explains that scientific knowledge is in fact only one of the many architectures that enable us to acquire knowledge. Moderns just assume that scientific knowledge is stronger than any other kind of knowledge: "scientific knowledge is not all-encompassing. It has always been in

competition, or in conflict with another kind of knowledge that we could call narrative, to simplify our quest" (Lyotard, 1979, p.18).

The source of the problem lies in legitimation, according him. Legitimation, for the French author, is the "process by which a legislator is authorized to promulgate a law into a norm" (Lyotard, 1979, p.19). Basing himself on Ludwig Wittgenstein's work, Lyotard locates the issue of legitimation at the language-game level. Language-game refers to a process within communication where, "in the practice of the use of language, one party calls out the words, the other acts on them" (Wittgenstein, 1953, p.4). Wittgenstein came to the conclusion that "human behaviour can only be understood by studying the symbolic and social context" within which human beings behave and use language-games (Gillett, 1994, p.1126). The role of the institutions, in the realm of language-games, is to "limit those games", and to restrict the inventiveness of the partners (Lyotard, 1979, p.34).

Scientific knowledge necessitates the isolation of "language-games", for Lyotard. It is based on exclusion of alternative meanings for the sake of the denotation (Lyotard, 1979, p.46). Scientific knowledge is faithful to positivism and needs institutions to be legitimized, since, contrarily to narrative knowledge, it does not gain any benefit from being outspoken by someone else (Lyotard, 1979, p.46). Institutions must acknowledge the legitimacy of scientific knowledge for this latter to become a truth. The institutions must acknowledge it to be considered. Institutions and scientific knowledge are interdependent. As Lyotard said, "the game of science implies a diachronic temporality" (Lyotard, 1979, p.47). Scientific knowledge needs a memory and a project to be legitimized. The institutions need an epic aiming at bringing legitimacy. This is necessary for the institutions maintaining power and acquiring credibility in the face of the public (Lyotard, 1979, p.49).

Lyotard goes even further in his critique of scientific knowledge by undermining its premises. According to him, modern science is based on a platonic discourse, which is not itself scientific, reiterating the importance of the Ideal in the scientific discourse (Lyotard, 1979, p.51, 56). In this context, knowledge is not the subject of the discourse, but is submitted to it. Its sole remaining legitimacy is to allow morality to become reality (Lyotard, 1979, p.60). In other words, scientific knowledge is about keeping order and maintaining itself, to transmit well-agreed facts. Science is not driven by a quest for truth, but for power (Lyotard, 1979, p.76). This is how scientific knowledge becomes a representation of violence and a tool of social control.

Thus, the postmodern condition first expresses its suspicion towards "meta-narratives", or transcendent and universal truth that cannot be contested. This is the end of knowledge being ordered by a centralized will, and the acceptance that other forms of knowledge can have a role and a certain claim to "truthfulness". Furthermore, it is the conclusion that scientific knowledge is a narrative knowledge like others.

Concretely, for the field of science, Lyotard's critiques had four repercussions. First, the great project of the enlightenment launched in the 17th century came to an end. There is no longer "a single coherent rationality", but "rather a field of conflicting and competing notions of the rational" (Turner, 1990, p.16). Thus, we live in a "fragmented, diversified and decentralised discursive framework" (Turner, 1990, p.16). Second, we can "no longer appeal to the court of a single rationality" and a single morality. The "grand narratives" of previous epochs (science, reason, enlightenment, humanity) have collapsed into "a pile of conflicting myths and stories" (Turner, 1990, p.16). Third, "hierarchies within science, morality and aesthetics have simultaneously broken down, thereby obscuring the relationship between elite culture and mass culture" (Turner, 1990, p.16). Finally, the lines between pop culture and university intellectuals are becoming blurred (Turner, 1990, p.16). Welcome to Lipovetsky's "*Ére du vide*".

1.4. POSTMODERNISM VS HIV/AIDS : THE ISSUES

So far, we have studied postmodernism at a broad level. The following section aims at focussing on the implications of this philosophical trend for the emerging HIV/AIDS crisis, and trying to understand why the modernist model needed to be placed aside.

Epidemics, before the AIDS era, were easily managed and controlled through the traditional repressive model based on quarantine, mandatory testing and exclusion as described by Foucault (Favereau, 2006, p.213). This system was authoritarian in many ways, forcing the ones who did not want to be cured into the system, an idea based on territorial control. Fighting epidemics was about tracking viruses and other biological agents on a territory, and eliminating them by keeping them out of a delimited area. The episode of the city of Oran being closed to the outside world, depicted in Albert Camus' *La Peste,* remains a vivid example of what the logic of epidemic control was like before the emergence of HIV/AIDS. In this context, a postmodern will see that respecting patients is not a chief preoccupation of modernist actors. Protecting the nation-state would be a foremost priority of the modernist. As we have seen, the system denied the ill both their responsibilities and their rights. And it was highly relying on geography and state boundaries.

To summarize Lyotard's theory, scientific knowledge was sovereign in the field of governance and it was excused as the only legitimate narrative in the medical field. For a postmodern, the existing epidemiological model fit with a perception of the body as a machine, where any public health issue could be solved with this easy equation: scientific technology + good economy = less illness (Clarke, 2004, p.90-91). And, on top of the hierarchical ladder was an all-powerful medical body that had exclusive knowledge of the secret potions necessary to cure illnesses. It was a system based on centralization, and industrialization of health. With the

reign of curative medicine, health protection began to be "perceived essentially as a question of free access to health care and medical innovation" (Steffen, 2001, p.28).

The particularities of HIV/AIDS transmission challenged this existing model. Everything started with this Steffen's idea: "HIV/AIDS was the first XXth century pandemic that went beyond the medical" and challenged its fundamental assumptions (Steffen, 2001, p.30). Is HIV/AIDS solely responsible for the arrival of postmodernism in the medical realm? The answer is obviously no. There is no point in providing an exhaustive study of how much the spread of HIV/AIDS is responsible for this "postmodernization". What we want to focus on is why a postmodern framework is necessary to efficiently fight HIV/AIDS.

1.4.1. The end of the panopticon

Postmodernism undermines the powerful position of medical specialists and challenges the discipline that is traditionally imposed on the body. "Divide and rule" is no longer a valid and efficient strategy. From a postmodern viewpoint, the system is striving to reach a certain horizontality in its inner structures, giving more power to individuals, and giving back the rights that were initially taken from the sick.

Since the end of World War II, European national health strategies had been centralized in the hands of the *État-providence* and its specialists (Steffen, 2001, p.27). This highly centralized system, which seemed efficient until the 1980s, was conceived strictly in terms of scientific answers and control, leaving no room for other approaches. From the 1950s to the 1980s, prevention was not "part of public health of the *État-providence*" and "evolved outside" the realm of epidemiological strategies (Steffen, 2001, p.29). In the HIV/AIDS era, prevention became central/crucial, because no purely scientific answers, such as vaccines, could be effectively used. From then on, managing HIV/AIDS was not the responsibility of a single centralized structure legitimizing the distribution of pills, but of many structures coming together

in rather more horizontal shapes. Different organs developed different point of views, transforming a widely-acknowledged truth into a low-consensus, and breaking the power among the different heads of the same hydra (Steffen, 2001, p.31). Steffen would summarize the entire phenomenon this way:

> Fighting the epidemic required comprehensive strategies of public-health management, beyond the limited medical model, at the periphery of the welfare state. Responding to the ill-structured problem contributed to organizing the previously weak public health sector. A lasting political consensus was elaborated for public-health strategies, and new public resources were made available for the health sector. Large-scale health education constituted the main policy tool (Steffen, 2001, p.17).

This is also how social science got involved in epidemiology. This is nothing new. Anybody who has read the work of Zola would agree with this. In the XIXth century, public health included social medicine (Osborne, 1996, p.106). But somewhere in the early XXth century the field of "social medicine" and prevention has been marginalized in the public health realm. The modernist experience, therefore, just ignored this tradition to refocus public health management on preventing the spread of diseases and promoting health (Clarke, 2004, p.94). During the XXth century, it started to conceive "defence against illness as personal hygiene matter" (Clarke, 2004, p.96). HIV/AIDS brought back the issue of poverty and social exclusion into healthcare management (Clarke, 2004, p.101). Osborne would frame it in this fashion: "the social is not some kind of transcendental domain colonized by that of the medical; rather, in some part medical knowledge and technology have been constitutive of what we have come to mean by the "social" (Osborne, 1996, p.99). Concretely, moving away from the panopticon means to embrace new approach based on prevention and on a social science perspective: promoting condom use, developing harm reduction, promoting substitution therapy. Their efficiency relies on making one responsible for his body. It is about increasing human potential and skills, and not simply imposing a medical act on their body.

Health policies, in the HIV/AIDS era, started to be increasingly concerned with "risk environment", which included "all risk factors exogenous to the individual" (Rhodes et al., 2005, p.1027). The risk environment is "the product of the interplay" of the many facets of human life (Rhodes et al., p.1028). This how that health system actors came to understand that growing inequalities, when not addressed, also influence the spread of HIV/AIDS through economical migration, sex and human trade, or poverty (Clarke, 2004, p.42). This is how the concept of Triple Threat, linking the HIV/AIDS epidemic, food security, and weakened institutional capacity, was framed as being a very threatening and explosive cocktail (PlusNews, 2007, http://www.plusnews.org).

More precisely, a postmodern framework tells policy-makers that any efficient health policies must take into account the need to "change physical, social, economical, legal and environmental settings" (Rhodes et al., 2005, p.1027). There was more attention given to the need for structural HIV prevention and fighting of inequalities (Rhodes et al., 2005, p.1036). Policy makers began to realize the significant "role of culture as a translator of risk management in diverse transnational settings" (Clarke, 2004, p.84).

The end of the panopticon also meant the end of closed walls to imprison the ill body. There is no longer a need for geographical delimitation and containment. Travel restrictions for HIV/AIDS patients "are unlikely to achieve the objective" of containment (Gostin & Lazzarini, 1997, p.85). Such measures may "actually hinder efforts to control the spread of HIV/AIDS and to mitigate its impacts" (Gostin & Lazzarini, 1997, p.85). Indeed, efforts "to enforce travel or immigration barriers may consume valuable resources while minimally reducing HIV transmission. The process of testing is expensive and time-consuming" (Gostin & Lazzarini, 1997, p.86). In other words, HIV/AIDS made the whole concept of "regard calculateur" (the planning look) irrelevant. It is the end of enforcement and repression in the way health system

works, and the beginning of normative influence and collaboration. It is proposing a political role to the ill. He is not anymore a "patient" or a "case", he can become an actor involved in the health system.

1.4.2. New narratives, new power relations

Postmodernism refers to Lyotard's notion of deconstructing meta-narratives that emerged from the Enlightenment' scientific model and positivism. It also applies to the field of medicine. Dr Nick Raithata, a general practitioner, sees postmodernism as going against "universal beliefs" and a direct attack on dogma. In other words, postmodernism forces the medical body to revise their own perspective and assume that other narratives could hold parts of the truth. It is a pledge for relativity, or like Raithata said: "to the postmodern eye truth is not out there waiting to be revealed but is something which is constructed by people.[...] We have to be postmodern if we are going to treat our patients appropriately rather than simply impose our dubious value system on them" (Raithatha, 1997, p.1044).

The scientific community, under the influence of postmodernism, came to the conclusion that scientific narrative is limited. Gillett explains this accurately: "we came to see that any scientific description is in fact a partial representation of the world which conveys certain truths and conceals others and thus that every theory [...] has weaknesses" (Gillett, 1994, p.1126). Therefore, medical science, framed under modernist structures, is reductive (Gillett, 1994, p.1126). It works well where there is "a biochemical and/or structural defect that provides a simple key to understanding the disease studied." (Gillett, 1994, p.1126), but is strongly limited for more complicated cases, such as HIV/AIDS. Postmodernism is not a total rejection of the scientific legacy, but it is the relativitization of the scientific knowledge that monopolized the medical debate over the last century. It is the end of Lyotard's scientific meta-narrative that organises the entire medical community in a vertical structure.

The narrative of medical doctors, who are the central figures within the hierarchy of the modernist health system, has been overthrown. Postmodernism leads to the end of the technocratic monopoly over the practice of medicine. Clarke would refer to the phenomenon as the "deconstruction of grand narrative of universalism in social welfare provision" (Clarke, 2004, p.146). Following this deconstruction, there are no possible one-size-fits-all solutions.

We can divide the responses to the HIV/AIDS crisis into three periods, postmodernism becoming more influential at every step. The first was impregnated by the modernist approach. At this point, "specific groups were named and singled out for exclusion or conversion against a backdrop of stigmatization" (Delor, 2000, p.1558). The second stage could be perceived as a transitional stage, where HIV was identified as the cause of AIDS. HIV transmission was now understood in terms of behaviour, but not identity. There emerged the possibility that HIV/AIDS belonged to "a particular category of individuals to which one did not belong and who were likely to carry the 'risk'" (Duclos, 1987, p.249). Finally, the third stage was definitively influenced with postmodernism. It "stressed the importance of taking into account the characteristics of the relationships and interactions" (Delor, 2000, p.1558), leaving aside the punishment of the body, or moral judgement, as described by Foucault. At this level, who you are or what you do is irrelevant, but how you do it and where is crucial. This step allows us to understand why two people, being part of the same group and having the same behaviour, will face different risks. This process will be studied more deeply when we will address the issue of marginalization

A postmodern management approach implies that governments are trading moral judgement for efficiency, that different practices can create better outcomes, and that the sick need to be involved in their own healing process. There is no such thing as normal and abnormal, because no universal or absolute truth holds. And if there is no moral judgement, there are no

"deviants". It is the rise of a narrative based on pragmatism: a "desire to identify and promote what works best regardless of theoretical niceties" (Aggleton & Parker, 2003, p.404). The notion of right or wrong does not apply anymore. One of the effects was to change national public policies about contraception in a way where a contraceptive, the condom, would now be publicized and actively promoted. Similarly, many countries stopped perceiving drug addiction as a crime. They began to perceive it as a physiological illness, and responded by creating syringe exchange programs, something now available all around Europe. (Favereau, 2006, p.109).

Different narratives cohabit in a postmodern framework. AIDS is not simply an illness anymore; it became a multi-faceted phenomenon. Therefore, any new angle to look at the phenomenon enriches its comprehension since postmodernism relies on the "basic assumption that illness is socially constructed, involving biological processes and cultural processes" (Goldin, 1994, p.1361). Clarke, once again, provides the best explanation of how narrative knowledge got involved in the matter: "the concept of postmodern illness reflects the notion that disease can also be read. It sees an intimate relation between knowledge, power, voice and the body" (Clarke, 2004, p.158). Many would consider this argument esoteric, but not a postmodern. If postmodernism argues that "many truths coexist at the same time" (Clarke, 2004, p.159), it is everyone's responsibility to construct a truth that fits reality.

Many authors studied the semantics of HIV/AIDS. Among them, Susan Sontag provides one of the most thorough analysis in *AIDS and its metaphors.* Sontag compares the AIDS crisis with the black plague, which used to be the highest standard of "collective calamity, evil, and scourge" (Sontag, 2001, p.44). From this, she concludes that AIDS is understood "in a pre-modern way", as a disease incurred by people both as individuals and as members of a risk group that "revives the archaic idea of a tainted community that illness has judged" (Sontag, 2001, p.48).

Surrounding the physiological condition, a complicated set of symbols and metaphors has emerged. Depending where one positions oneself towards those symbols and metaphors, a person would gain a different understanding. For example, no one would deny that the spread of HIV/AIDS changed our perspective on gay identity. The Lesbian, Gay, Bisexual, Queer, Transsexual and Transgender (LGBQTT) community, which was traditionally marginalized and evolved behind mainstream circles, came into the spotlight with AIDS. HIV/AIDS revealed a part of themselves that had yet to be made public. First, HIV/AIDS forced the LGBQTT to get out in the streets and gain a public face. Second, the community shared a common grief, giving people a symbol to gather around. The LGBQTT community created "a body of representations of life experiences of persons with AIDS" (Goldin, 1994, p.1362). This community gained power through the affirmation of its narrative. This is far from being the narrative developed at first by the ones who considered themselves as being the "normals", and who viewed the "abnormals" as ultimate Others. HIV/AIDS unfolded around a semantic of fear, in a similar way that xenophobic propaganda has always depicted immigrants as bearers of disease (Sontag, 2001, p.62), HIV/AIDS became another tool to embody those irrational fears, the way Putin's camp distributed flyers saying that its opponents had AIDS during December 2nd 2007 electoral campaign. Therefore, an illness is not simply an illness; it also plays a social role, the embodiment of a collective psyche. In this transition, patients became a "phenomenon" that refused to be confined to a strict medical concern. Postmodernism will take this into account, and will even transform this into a strength. This is the birth of linkage politics, where one can talk about securitization of health, for example. Postmodernism, in other ways, attempts to distribute power equally, and to give back power to the ill, even on the narrative of one's own illness.

1.4.3. Human rights approach

A postmodern epidemiological framework is about respecting the rights of individuals and groups, rather than confiscating them as in the traditional repressive model (Gostin & Lazzarini, 1997, p.45). This leads to the conclusion that health system managers have an impact on human rights, that human rights have an impact on health, and that both are tightly interlinked (Clarke, 2004, p.109). HIV/AIDS is an obvious proof of this statement. Human rights violations led to further stigmatization, which in turn led to more contamination (Gostin & Lazzarini, 1997, p.43). The strategy is simple: respect of human rights aims at empowering individuals and helps communities achieve voluntary changes (Gostin & Lazzarini, 1997, p.51). AIDS policies should be formulated in cooperation with vulnerable populations and implemented with respect for individual autonomy (Gostin & Lazzarini, 1997, p.51).

The concept of human rights primacy made its way in epidemiological surveillance and disease control. It is now common belief to consider mandatory screening as a human right violation (Gostin & Lazzarini, 1997, p.77). Under a human rights-based approach, testing is voluntary and confidential (the state should require informed consent and provide pre and post-test counselling) (Gostin & Lazzarini, 1997, p .82). This approach also implies that policy makers must have the objective of fighting discrimination and exclusion, and ensure that all have access to needed benefits, privileges, and services (Gostin & Lazzarini, 1997, p.82).

At the same time, a human rights-based approach ensures respect of the right to be informed. This is why governmental censorship of educational messages "does not merely interfere with the positive rights to education, health and life", but "it also violates the negative rights to free expression and information" (Gostin & Lazzarini, 1997, p.73). It also means finding a proper way to address the difficult issue of partner notification.

In the postmodern view, a human rights-based perspective, in other words, is a necessary step to simultaneously address the issues of marginalization, power diffusion, and a destruction of the panopticon.

1.4.4. Marginalization, stigmatization and vulnerability

HIV/AIDS led to a new way to conceive the meaning of the sick body and the Other. It might be important at this point to define three words that are crucial to understand a postmodern approach on health: vulnerability, stigmatization and marginalization. Vulnerability is the potential for a particular person to be infected. It was, at first, defined in strict medical terms. It concerns one's risk of exposure to an illness. As an example, someone living in Africa is more vulnerable to malaria than someone living in Canada, since the virus does not support cold temperatures very well. Each illness has its own vulnerability, depending on the nature of the illness. Although the definition of vulnerability has a neutral consonance at first, it can easily turn into a negative connotation when moral judgement gets involved , such as in the case of HIV/AIDS.

Stigmatization happens after contamination. It is the process of being labelled as the carrier of the disease. A stigma is "an attribute that is significantly discrediting, which in the eyes of society, serves to reduce the person who possesses it" (Aggleton & Parker, 2003, p.14). Stigmatization in this context becomes "the identification of a bad or negative characteristic, in a person or a group of person and it involves treating them as not deserving of respect or less worthy than others on this basis" (Gilmore & Sommerville, 1994, p.1341). It is, in other words, the politicization and socialization of vulnerability.

Stigmatization is about power, and maintaining an institution that itself maintains power. Like the French sociologist Pierre Bourdieu said, "stigma is deployed by concrete and identifiable social actors seeking to legitimize their own dominant status within existing

structures of social inequality" (Aggleton & Parker, 2003, p.18). Stigma is a symbolic system that tends to "define the bearer, rather than the sign carried by the bearer, and the bearer becomes known by the disease carried" (Goldin, 1994, p.1360). This led Aggleton to explain that stigmatization and discrimination can only be understand in relation to power and domination (Aggleton & Parker, 2003, p.16). Stigma, in this, plays a "key role in producing and reproducing relations of power and control" (Aggleton & Parker, 2003, p.16). They concludes that:

> Stigma and stigmatization function, quite literally, at the point of intersection between the relationships between culture, power and difference – and it is only by exploring the relationships between these different categories that it becomes possible to understand stigma and stigmatization not merely as an isolated phenomenon, or expressions of individual attitudes or of cultural values, but as central to the constitution of social order" (Aggleton & Parker, 2003, p.17).

Stigma was necessary in the world of modernist epidemics because stigmatization aimed at isolating the bearer of an illness. The Black Plague was contained by the process of isolation of infected bodies. Therefore, sick patients were stigmatized, and were prevented from leaving their house. In the case of AIDS, the harm done to the stigmatized patient "far outweighs any beneficial outcome" (Gilmore & Sommerville, 1994, p.1341). It increases the risk of HIV transmission because "fears of the consequences of open discourse and self-identification have created a silence that threatens all of us" (Goldin, 1994, p.1359). It could be easily linked to the ACT-UP slogan "SILENCE = DEATH". In sum, "effective prevention and treatment strategies require an understanding of cultural frameworks, including an appreciation of stigmatization" (Goldin, 1994, p.1361).

Marginalization appears before and in spite of stigmatization. The term "marginalized" refers to a patient that has become an outcast of society. Marginalization increases vulnerability. It is being the "Other", but not necessarily having to publicly bear the stigma. Marginalization can be invisible to the public eye and it happens before stigmatization. Tim Rhodes, specialist on

issues of social vulnerability and HIV/AIDS, has described the phenomenon of marginalization in those words:

> At the macro-level, the vulnerability of persons to HIV is influenced by broad social structural characteristics. These 'core' or distal causes may be far removed from individuals' control, but impact their lives through economic inequalities, racism, sexism, discrimination and stigmatization directed towards groups at high risk. (Rhodes et al., 2005, p.1027)

The marginalized are people who evolve outside the system, and who do not correspond to what the majority will consider "normal", whether because they are gay, because they are injection drug users (IDUs), sex workers, or in certain societies, simply because they are females. It happens before stigmatization. People may become vulnerable to HIV because they are marginalized.

Vulnerability, marginalization and stigmatization are interconnected. A modernist epidemiological strategy would argue that we have to isolate those vulnerable entities to better protect the main body of society. But the more a person is stigmatized, the more that person is marginalized. And the more he or she is marginalized, the more the person becomes vulnerable. Marginalization is a vicious circle which has a negative impact on the containment of the AIDS virus.

Stigmatization, which was the first reflex of all OECD countries health systems when AIDS appeared, did not stop the pandemic. When AIDS first emerged, Men having sex with men (MSM), sex workers and migrants automatically became stigmatized. If this model has been efficient, we could have avoided contamination of the "normal" population. Indeed, statistically, the so-called "normals" began getting infected. What went wrong?

The answer to this riddle is called the "bridge population". Simply, the bridge population can be defined as those "men and women who have sex with both high-risk and low-risk partners" (Atlani, 2000, p.1552). This transmission involves "possible transmission of HIV across

different physical modes of transmission of HIV and across different risk behaviour subpopulations" (Atlani, 2000, p.1552). If defining it seems quite easy, the whole story gets more complicated when it is time to put a real face on this bridge population. In Thailand, it can be those men who go to the brothels and then go to their wives. In Ukraine, it could be an IDU that infects his drug-abstinent partner. Situations vary around the world depending on which group is marginalized, and what needs to be kept "secret" according cultural norms and values.

For the Ebola virus, the bridge population is everybody that will move from an infected village to a healthy village. Close a village off from the outside world and the disease will stop spreading. Unfortunately, for HIV transmission, it is impossible to identify a person in the bridge population. The bridge population for HIV/AIDS is invisible and cannot be delineated. Therefore, the frontiers between the "normal" citizen and the "Other" are invisible. In this case, the modernist policy of building a stigmatized Other is not useful at all (Clarke, 2004, p.101). Postmodernism revisits the notion of vulnerability. The word "vulnerable" suffers itself from "a semantic overflow since it refers to dependency or fragility as well as insecurity, centrality, complexity, the absence of effective regulation, gigantism, and low resiliency" (Delor, 2000, p.1558). In a postmodern theory, vulnerability is not "stable", it is not a fixed characteristic of an individual. It evolves in a time frame (Delor, 2000, p.1564), and "the diversity of individual interpretations is organized and refers to symbolic trends that themselves are subtended by cultural systems" (Delor, 2000, p.1560). It is about a "social context" that influences the moments, stakes and forms of encounters between different trajectories" (Delor, 2000, p1560). The postmodern approach acknowledges that "HIV infection requires at least two individuals and thus two trajectories to meet" (Delor, 2000, p.1560). So, Delor proposes a postmodern way to understand vulnerability that is more relevant to HIV/AIDS. He sees vulnerability as:

> Superimposing spaces on each other reinforces the person's vulnerability, since several, possibly competing, processes will criss-cross (general complexification) fewer and fewer resources will be mobilizable (internal situations) and the probability of potentially threatening events will increase (external situations) [...]Vulnerability is first an analysis of difference" (Delor, 2000, p.1567)

Dismantling vulnerability leads to dismantling stigma and marginalization. Acknowledging different narratives is the end of the single meta-narrative, which ends political control of the institutions over alternative narratives. In a postmodern health strategy, the concept of "the actively responsible self arises, individuals are to fulfill their national obligation to one another but through seeking to fulfil themselves within a variety of micro-moral domains or communities" (Rose, 1996, p.57). It also serves "to dismantle the archipelago of institution within which welfare government had isolated and managed social problems", and within which the ill had gained a "learned helplessness" (Rose, 1996, p.59). Therefore, we need to eliminate the problem at its base, and this starts with attacking marginalization mechanisms.

Postmodernism is also about framing a voice for the marginalized. In the case of HIV/AIDS, the LGBQTT organizations made the difference. In all industrialized countries, the first actions against the traditional "order" came from those associations (Steffen, 2001, p.82). This was not the case for injection drug users (IDUs) whom, in spite of many breakthroughs, still have a low level of organization (Steffen, 2001, p.82). The LGBQTT movement was not well organized in the beginning of the 1980s, but it quickly reached a "high degree of organization" when the ghost of stigmatization appeared (Steffen, 2001, p.83). Thus, HIV/AIDS allowed the reinforcement of an LGBQTT identity and empowered the victims (Clarke, 2004, p.159). Through the fight for recognition, "individuals are to become experts of themselves" (Rose, 1996, p.59). It becomes a strategy of empowerment and personal responsibility over one's own illness (Rose, 1996, p.59). Therefore, it is giving back power to individuals, power which used to

be confiscated under a modernist system (Aggleton & Parker, 2003, p.22). Postmodernism also appeared from a bottom-up approach where states were faced with an ultimatum and had to start listening to these powerful pressure groups.

1.5. CRITIQUE OF A POSTMODERN APPROACH

Postmodernism also has its limitations, and we need to be aware of them before fully understanding the role of the European Union in diffusing postmodern ideas. The point that needs to be stressed is that postmodernism is neither a miracle nor a revolution. It is a valuable tool and an ontological perspective, which happens to be extremely useful in fighting HIV/AIDS. But it is not enough to triumph in the battle against the pandemic. Strategies of different philosophical currents need to be used conjointly. The biggest achievement of postmodern thought in the medical field is that there are no longer absolute truths, and that different narratives can now coexist. In fact, it justifies social theory as a weapon to fight HIV/AIDS, and highlights the need to involve many political institutions left aside by modernist strategies. The inclusion of social science to help reduce the transmission of the AIDS virus does not imply an exclusion of medical science. On the contrary, it means that we need to rethink their relationship and explore new linkages.

Postmodernism could be analyzed in many other directions, but what needs to be kept in mind is that it allows a better diffusion of power in the fight against HIV/AIDS, and that the modernist structure of legitimation, as presented by Lyotard, is undermined by this novel perspective. Nevertheless, Altman is quite right when he highlights that "the irony is that in practice the global response is largely at a rhetorical level" (Altman, 1999, p.575). Postmodernism brings a lot of people in rooms to talk, but it cannot be sold easily because it takes years to become fruitful. It consumes time, and necessitates important changes. It makes it difficult to incorporate a strategy with clear objectives and means of evaluation, unless a

majority does legitimize it. In other words, it needs compromise from the entire society. Is it realistic to change a majority to improve the position of a minority that suffers of HIV/AIDS?

In a postmodern world, two logics live side by side: one that fosters autonomy, and one that increases dependency (Lipovetsky, 2004, p.21). This implies that every gain of autonomy creates a new dependency; some citizens remain careful and responsible with this increasing power, others adopt destructive and irresponsible behaviour not knowing all to deal with such power (Lipovetsky, 2004, p.21). In other words, this new empowerment works for some, but not for all. The postmodern framework was supposed to liberate, but it led to indifference. But the indifference of the post-68 movement has now left place for existential insecurity and fear (Lipovetsky, 2004, p.63). Some face a strong institutional dependency : some people are more likely to turn to big bureaucracies in times of crisis (Curtis, 2004, p.55). Therefore, a strong HIV/AIDS policy should not rely exclusively on state capacities. Similarly, the legal world is still framed through a state-based approach. There are no international regulations to force a country to accept within its borders an HIV-positive non-citizen. Like Gostin said, "human rights start and finish with borders" (Gostin & Lazzarini, 1997, p.87). Indeed, defence of human rights is still primarily handled by national state laws, and not on the global legal framework (Clarke, 2004, p.346). The state is, for this aspect, the sole guarantor of postmodernism. In other word, HIV/AIDS needs both a strong civil society and a strong state. The solution is not the eradication of the state, something that could almost be justified by postmodernism, but a redefinition of its role and method.

Postmodernism is also about diffusing power. One of the issues with such a framework is that increasing the number of actors also means a diminution of power in the hands of any actor. To put it in images, it means that if everybody is in charge, nobody will be responsible. A horizontal approach is wonderful when there is plenty of time to reach consensus, but it is not the

most efficient method in times of crisis or when decisions need to be taken quickly. Discipline and hierarchy are useful at times, especially times of emergency, when irrationality, panic and fear are invading society.

And finally, postmodernism might reveal itself as a useful strategy to limit the repercussions of the HIV/AIDS crisis, but we should worry if it begins taking too much space in the health system. Postmodern thought cannot do anything about a Bird Flu pandemic for example, which would still be most effectively contained with a strict traditional repressive model, since transmission is much less related to taboo issues. In other words, the issue is one of fine balance, and of using proper strategies to deal with different types of crises.

CHAPTER TWO. HISTORICAL BACKGROUND : THE HIV EUROPEAN ANSWER.

There is no such thing as a common HIV/AIDS crisis in Europe. Each country faced a different challenge. Beyond those divergences there are lines of similarity that appeared over time. The European Union approach has built on these common reference points. The present chapter aims at delineating what could be called a common European approach to HIV/AIDS, in order to understand how the EU became an agent of diffusion of postmodern thought and policy.

First, we will look at the context of the European strategy for HIV/AIDS. This will be done by looking at different countries to understand what have been the different national answers that influence how we understand HIV/AIDS and the health system. Second, we will look at the European Union itself and at the different structures which can be involved in health policy-making. We will provide an institutional analysis of the EU's health capabilities. Third, we will look more closely at what the EU did and does to reduce the spread of HIV/AIDS, focussing on its role in imposing a postmodern framework, and its ability to break previous norms.

2.1. THE STORY OF THEM ALL: NATIONAL DIVERGENCE IN CONFRONTING THE HIV/AIDS PANDEMIC

An "*état des lieux*" is necessary to understand the motives of an EU response. But before it was debated at the European level, the crisis was framed through a national lexicon. It is not possible to exhaustively review the HIV policies of the 15 countries that were EU members before the last two waves of enlargement; they all faced a different crisis and lived it differently. This is why we chose to briefly present four meaningful cases that were highly influential and representative of the European fight against the spread of HIV/AIDS. According to Monika Steffen, a leading scholar in terms of both European health and HIV/AIDS, the four most representative cases are the United Kingdom (UK), Italy, France, and Germany.

2.1.1. The United Kingdom (UK)

The UK had since the beginning of the pandemic one of the lowest HIV rates among IDUs in Europe. It is among men having sex with men (MSM) that it was the highest until 2003. Then, it was heterosexual contacts that became the main source of infection, pushing the UK to the status of second most affected country in the EU-15. The British health system was characterized by a tradition of private-public partnership, leaving a lot of room for civic organizations, and adopting one of the most liberal approach that leaves a lot of room for private actors (Steffen, 2002, p.235). But it also suffered from being one of the most conservative societies with a high level of marginalization for IDUs and MSMs, putting huge barriers in the political system for these groups (Steffen, 2001, p.40). Indeed, the 1980s were also Margaret Thatcher's years. The Department of Health had, during the 1980s, a very "conservative conception" of public health, particularly on drug addiction and criminalization of substance abuse, following the guidelines of the Iron Lady (Steffen, 2001, p.45). Civil society organizations in this context were simply relaying the official governmental policies. If things changed slowly, it was due to the militancy of certain groups, spearheaded by the Terrence Higgins Trust, a gay recreation association. Policies were implemented strictly using a top-down approach, and change came from the base, before reaching the highest levels. The British case demonstrates the importance of strong private initiatives to counteract outdated and rigid national state policies.

2.1.2 Italy

Italy, at the beginning, was typical of the Southern EU-15 countries since most people got infected through drug injection - almost 50% in 1985, and MSM was not much of concern (Eurostat, 2004, p.4). The Catholic Church, contrary to what one might expect, was very discrete and focused on using an approach based on humanitarian compassion rather than Manichean judgement. In spite of pressures from the US for more repressive laws on drugs in the 1980s,

Italy had, at the beginning of the crisis, some of the most liberal drug laws and one of the most active civil society (Steffen, 2001, p.124). Substitution therapy and other social approaches to help IDUs fight their addiction were already in place before the crisis began to materialise as HIV/AIDS. The pandemic just accelerated their implementation, strengthened the Italian public structures and highlighted the importance of harm reduction (Steffen, 2001, p.139). It was a clear case where both public and private actors were highly involved, open-minded and where there was little controversy about the means (Steffen, 2001, p. 119). Italy remains one of the most vivid European cases of a civil society and a government that combined their efforts to quickly limit the expansion of the disease by adopting imaginative and progressive policies, mostly in terms of including harm-reduction, drug-substitution and moving away from criminalization (Steffen, 2001, p.139).

2.1.3. France

At the beginning of the crisis, France used outdated prevention methods and one of Europe's most repressive models against IDUs, a model similar to the German one (Steffen, 2001, p.128). During the 1980s, the simple possession of a syringe was "a presumption of consuming acts" leading straight to jail. The French Republic was the last country to develop policies in support of IDUs. Legislation and practices against IDUs changed only from 1996 (Steffen, 2001, p.139). At that time, France was also the only EU-15 country where personal consumption was punished (Steffen, 2001, p.137). Nevertheless, the pandemic started first among MSMs, and retained a significant infection rate among migrants.

The story of France in the HIV/AIDS era is one of total rupture and "intensive learning" at all levels (Steffen, 2001, p.215). From a very "centralized, autonomous and categorizing system", France developed one of the most progressive approaches (Steffen, 2001, p.130). Many reasons explain this rapid learning process, one being that it was the country where medical

doctors had the least power at the policy-making level. Another reason might have been that France was under Mitterand's presidency, who was a socialist supported by gays and liberal-mind groups. Yet another factor that explains this quick transition is the privileged position of civil society. If organizations were very powerful in French society, they were often in conflict with the state structure, and they were "set aside from political decision circles and stuck in a role of service provider" (Steffen, 2001, p.213). In other words, they were well organised, but not powerful enough to be listened to at the policy-making level. Nevertheless, they played a huge role in bringing a psychoanalytic perspective to the problem and putting social science in the French answer to the pandemic, which also influenced the entire world's response (Steffen, 2001, p.134). Among them, AIDES, founded by Foucault's long-term partner, Daniel Defert, brought forward the "*déshomosexualisation du Sida*"[3], making it everybody's concern (Steffen, 2001, p.39). In Defert's opinion, for HIV/AIDS to be efficiently fought, society needed to properly fight stigmatization. Policy-makers needed to address the pandemic in universal terms rather than from a communitarian perspective, where some groups fight exclusively for the rights of their members. Very early in the debate, AIDES and the official public agencies, placed stigmatization and the protection of individual rights at the forefront the debate (Steffen, 2001, p.226). Therefore, France was the leader of the postmodern revolution in fighting HIV/AIDS. France is also one of the only countries where HIV/AIDS became an electoral issue, when the Socialist Party was voted out of government after the "contaminated blood scandal". Because of this, France represents the most blatant case of a very active and powerful civil society that was able to change society's perspective on the HIV/AIDS crisis, and taking a position at the forefront of non-governmental organization (NGO) networking at the European level. France also saw one of the most radical evolutions of policy-making. It is also a good example to demonstrate

[3] Could be translated in English by "ungayifying" AIDS

how political the debate about the pandemic could get. French civil society will be quite important in the development of a European answer, especially in creating networks.

2.1.4. Germany

Germany's health policy-making in the wake of the pandemic was similar to France's. The epidemiological structure of the crisis was also similar. But what differentiates Germany is how effectively its institutions were able to block what could have been one of the most effective strategies. Even if it was one of the first countries to try to address the crisis, all the national initiatives were blocked at the regional level by lack of consensus. In spite of a certain associational life that could have made a difference, the issue of HIV was constrained by the *Länder*, which are responsible for health policy making in the German federation. This led to many disruptive and discriminatory measures, Bavaria being a particular case, imposing in the early 1980s mandatory testing on vulnerable populations. At the same time, medical doctors were very powerful in the regional health policy-making structures, imposing traditional epidemiological control measures, in opposition to more social-science oriented specialists at the national level (Steffen, 2001, p.114). It is only in the 1990s, after a national commission studied the problem of dissemination, that Germany opened its doors to social medicine, and took drastic measures to deal with the problem (Steffen, 2001, p.117). Germany thus remains a reference point in how institutions can block a potentially efficient answer to HIV/AIDS, and it highlights the needs for a strong consensus to solve this complex issue.

2.1.5. A Common European Approach?

From these four cases, it is at first difficult to find a common trend. Nevertheless, they all highlight the impacts of good and bad public policies and reiterate the crucial role of the state to fight HIV/AIDS in the EU-15.

Several authors have concluded that a broad European model exists. They defined it as the "commitment to an inclusive social security system, public health and education systems funded from progressive taxation of incomes in all European states" (Delanty, 2005, p.110). All European states had a more or less effective public health care system. When HIV/AIDS appeared, Europe was coming out of the "*Trente glorieuse*". The term refers to the period between 1950 and 1980 where health care coverage was constantly expanding (Steffen, 2001, p.28). The 1980s brought two threats to this expansion: neoliberalism and recession. These factors pressured the system to cut social spending, while HIV/AIDS asked for more resources. In spite of varying political contexts and institutional specificities, the state was central in fighting of HIV/AIDS in all European countries (Steffen, 2001, p.245). States, in the wake of the pandemic, increased their epidemiological surveillance capabilities. These had been neglected during the *Trente Glorieuse* (Steffen, 2001, p.235). They also quickly moved on prevention, crucial to limit the spread of HIV/AIDS. The capacity of each country to fight HIV was dependent on government capabilities to build a consensus over prevention. To stop a long-wave disease like this, they needed to quickly attack the causes of the problem. European countries had a better start at this than other countries, having well-developed governmental capabilities that quickly came to focus on the role of prevention (Steffen, 2001, p.31).

An important similarity between European national responses is the use of social science approach to help reduce transmission rates. One author even suggested that the "hallmark of the European response" would be the use of a theory according to its usefulness. They were "not scared to dig into sociology, anthropology, psychology or any sort of explanation, if they thought they could help reduce the spread of the pandemic" (Aggleton & Parker, p.404). In fact, European social scientist had been participating in shaping health policy for many years, and they had been much more involved than in the other OECD countries (Steffen, 2001, p.29).

Nevertheless, their role was still limited at the beginning of the crisis. Limited, but organised enough to be able to assume a proactive role when asked to get involved. In Western Europe, decisions "against the old public health was easier to make because, in contrast to past epidemics, elements of an alternative strategy were available" (Rosenbrock et al., 2000, p.1609).

Fighting stigmatization and promoting a preventive approach became important in all European countries. Most countries have adopted the custom of separating condoms (associated with pleasure) from AIDS (linked to solidarity) in public advertisement, a clear move to avoid stigmatization of HIV-positive citizens (Steffen, 2001, p.72). All countries also quickly moved to change their policies on IDUs, developing syringe exchange programs and adopting progressive laws, abandoning criminalization (Cattacin & Lucas, 1999, p.383). Politics on MSMs also changed. The States moved from a voluntary blindness to a conscious acknowledgement of their existence. The European answer quickly left moralistic judgements aside and start to develop policies on and with the help of MSM and IDUs, rather than against them. This was a radically different path from the one in the USA under Reagan, or many Canadian provincial governments.

European countries were forced to conclude that neither civil society nor the government had all the answers. They have been quick in searching for a new balance of power between civil society groups and the state. This is why most European countries developed national agencies in charge of the HIV/AIDS crisis. Their goal was to provide an overall vision, and balance the power of all actors involved. Civil society groups tend to implement community-based responses that can be unsustainable (Rau, 2006, p.288). The national agencies therefore must assess those local approaches, taking in consideration "wider factors" (Rau, 2006, p.288). They must also ensure that a consensus emerges, it is an engine of change and it guarantees an efficient imposition of decisions through the identification of actors (Cattacin & Lucas, 1999, p.387). In other words, European national policy-makers have been quick to open up to private actors, but

have also attempted to balance the power of different actors, without abandoning them to the associational sector, the way many African countries did. They also avoided keeping all decision-making entities within Health Ministries, like Canada did.

European national responses emphasized governmental responsibilities in respect to civil society in three important ways. First, states provided reliable and accurate information to the population, allowing society to take enlightened decisions. Second, government offered resources that could be sustained to help the infected deal with their condition or take proper decisions through counselling and peer-support. Finally, institutional rules, even in health policy-making, were subjected to effective social control, increasing the participation of social scientist into health departments (Curtis, 2004, p.55).

The EU member states had already made considerable steps towards postmodernism, especially when compared to other OECD countries. A European Union approach thus started with the sum of these national conclusions. Before presenting the EU's role in shaping a global European response, the reader must understand that national responses to HIV/AIDS were not homogenous. Christine Panchaud provides a substantive comparative study of national differences on HIV policy (Panchaud, 1995). She classifies the countries in a typology of three welfare mix-approaches based on common features. The first group includes Italy, Portugal and Belgium. The second group includes the Nordic countries, and the third group is composed of the Netherlands, Switzerland and Germany. Finally, she considered that France, Austria, and the United Kingdom, were distinct cases. She based this categorization on many criteria such as prevention, care, level of moralization, and policy coordination. A similar research project, the

Gosta Esping-Andersen typology of European welfare system[4], came to a similar classification, even if it was based on different criteria and goals. In sum, we can conclude that there has no common European response to HIV/AIDS. We could only emphasize that there are certain broad similarities and common parameters, one of them being that the state will be part of the answer.

2.1.6. International organizations active in the EU

At this point, before focussing on the EU's role, we need to clarify the role of three important international organizations active in Europe : the World Health Organisation (WHO), the Joint United Nations Programme on AIDS (UNAIDS), and the Global Fund to fight AIDS, Tuberculosis and Malaria (Global Fund).

The World Health Organisation (WHO) is an important element of the European response to HIV/AIDS. The role of the institution in HIV/AIDS is to provide "evidence-based, technical support to WHO Member States to help them scale up treatment, care and prevention services as well as drugs and diagnostics supply to ensure a comprehensive and sustainable response to HIV/AIDS" (WHO, 2007). Its approach is mostly scientific, identifying best-practices and offering technical support.

UNAIDS is an umbrella organization made up of ten UN system organizations, including WHO. Its role is to help the world "new HIV infections, care for people living with HIV, and mitigate the impact of the epidemic" (UNAIDS, 2007). It helps mount and support an expanded response to AIDS.

For Europe, the impact of those two organizations is limited. Their main contribution is through the creation of EuroHIV, an entity responsible for epidemiological surveillance. The EU still does not have its own surveillance system (Hamers, 2004, p.84).

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[4] Refers to the model developed by Gosta Esping-Andersen to explain the different variations in European Welfare state, developed in different articles and books, including "New Risks, New Welfare: The Transformation of the European Welfare State".

An important player in Europe is the Global Fund. This international initiative is a partnership between governments, civil society, the private sector and affected communities. It is a international financial institution : it operates as a financial instrument, not an implementing entity (Global Fund, 2007). Its goal is to back national answers, providing project-based grants to countries. The Global Fund attempts to make the international system work more efficiently, but its major role is in "pushing, cajoling and advising governments around their response to HIV" (Altman, 2006, p.579). It funds short/middle term projects that are not necessarily compatible with a long wave pandemic (Barnett, 2006). It also "has been supporting primary and secondary prevention, this has been somewhat piecemeal and the penetration of the campaigns directed at those most at risk often inadequate" (Atun, 2004, p.1391). In other words, it failed to "develop appropriate mechanism of coordination and unified action" (Altman, 2006, p.579), and is far from being a global governance tool. The Global Fund lacks the vision needed to efficiently fight a long-wave disease like HIV/AIDS. Funding short and middle-term project can be very useful, but like Barnett said, there is a "high chance that actions taken for the best in the short term will make the situation worse in the long term" (Barnett, 2006b, p.361). HIV/AIDS needs long-term planning, especially to fight marginalization, and The Global Fund is not helping with this.

EU countries are both recipient and donors. The European Commission contributed with 638 millions US$ so far. We have to add to this the amount given by national countries. Three EU countries received grants from the Global Fund : Romania, Bulgaria and Estonia.

In sum, the three organizations play an important in the response, but remain outside of the realm of policy-making in Europe.

2.2. THE EUROPEAN UNION AND HEALTH

Public health has never been a priority in the EU integration process. In fact, it is not a repetition to state that public health does "not even feature prominently" in the process of EU

enlargement (Atun, 2004, p.1391). Steffen justified the minimal concern for health in the following way:

> The first and most traditional perspective is to conceptualise *Europeanisation* as *institution building* at supra-national level and to focus on EU-level policy-making, via formal institutions, established networks, and guiding norms, and on its direct output in terms of collectively binding European policies. Compared to many other policy fields, health policy seems to be little or less concerned by this perspective. (Steffen, 2004, p. 4).

That does not mean that health was completely left aside from the European integration process. In fact, we could easily say that in the European model, "social policy is economical [sic] policy" (Delanty, 2005, p.110). The topic of health was implicitly invoked when the issues of safety in consumers goods and the question of worker's mobility were negotiated. The notion of competition in health care also brought considerable attention to the definition of European competencies on the health issue. As the European Court of Justice (ECJ) has made "clear that Treaty provisions on free movement apply to health services, regardless of how they are organised or financed at national level", the EU did get involved significantly in health care (Commission, 2006a, p.3). So far, it has attempted to ensure that the principle of free movement does apply to medical services and that a certain quality is maintained over the EU's national system. In spite of some directives in this sense from the EU, the Open Method of Coordination (OMC) remains the main tool of harmonization of European national healthcare, as it will be explained more exhaustively later on (Commission, 2006a, p.7). Like Commission textually said it : "much more remains to be done to realise the potential for European cooperation" (Commission, 2006a, p.7).

Nonetheless, the European Union never made a clear attempt to become an actor in health care. The role of the EU in health grew inadvertently as related issues were bundled into a web of decisions that ended up by creating some sort of a health system. The following section aims at

addressing how this build-up happened, and at identifying the tools that have been developed over the years.

2.2.1. Legal and institutional framework of an EU health system

At first, not much power had been attributed to the EU in treaties on health. Conceding that healthcare is the responsibility of member states, the Treaty on the European Community (TEC), in its third article, states that the EU is committed "to the attainment of a high level of health protection", including improving health, preventing human illness and disease, eliminating sources of danger to health, and ensuring that all European policies protect health (Maastricht Treaty, Art. 129-10). In addition, the TEC concedes that "European Union action in the field of public health shall fully respect the responsibilities of the Member States for the organisation and delivery of health services and medical care" (TEC Art. 152-5; Convention Art. 174-3). Article 42 of the TEC explains that the EU cannot interfere in national institutions, except on the basis of cross-border social security rules. European health laws are unclear and vague, which means they leave a lot of opportunity for interpretation and flexibility. The story to unfold will be based on these institutional developments.

Any health policy made at the EU-level is limited by the Subsidiarity principle. This principle stipulates that "the European Union can only justifiably legislate and pursue policies in areas that fall exclusively within its competence, if the Member States are incapable of acting adequately on their own, or if the scale and effects are such that the Union can achieve the objectives more effectively" (Treaty on European Union, Article 3B; Treaty of Amsterdam, Article 5). Subsidiarity is more than a principle, it is a "political institution" that "constrains and enables actors" (Van Kersbergen, 2004, p.159). This is an important element of an EU multi-level governance based on the idea of shifting and overlapping zones of power (Van Kersbergen, 2004, p. 144). Under the Subsidiarity principle, "national governments in the EU are

permanently involved in balancing and re-balancing the precise allocation of delegated – or in the words of the draft Constitution 'conferred' – competences across decision-making levels" (Van Kersbergen, 2004, p.145). Health falling under the Subsidiarity principle, it is a difficult topic to address at the European level. Atun explains the limitation of the Subsidiarity principle in those words:

> Unfortunately this provision has long been used by member states to constrain the ability of the EU to act in the area of public health, shown by how the German government, with the tobacco industry, has challenged the EU directive on tobacco advertising (Atun, 2004, p.1392).

Policy-making at the EU works like tectonic plates. It is through the shock of the different institutions that the landscape is made. The subsidiarity principle is just a guarantee that the whole process will be smooth, and that it will not be destroyed by an earthquake. But it also means that it delays the process, setting clear obstacles to integration.

The EU still has some capabilities to override the Subsidiarity principle. Lamping identifies at least four different ways in which European integration can impinge on domestic welfare states.

First, it can impact national policy through direct positive pressure, which results from a political decision at the European level. This happens when any of the European institutions takes a decision that must be respected by the lower political layers. It is a clear vertical approach. In terms of Health, the Commission proposed different directives on blood-safety, including them in the *Acquis Communautaire*.

Indirect pressure is the second tool in the hands of the EU. This is the spill-over originating from market-building and intergovernmental self-binding decisions, and the responses of national actors to these challenges (Lamping, 2005, p.22). The Council works through this approach. For HIV/AIDS, the common declaration following the Bremen Conference represents

a good example. The EU did not pressure directly the member states to accept the principles of the declaration, but they face a certain peer-pressure to comply.

The third one is negative integration policies through the four freedoms guaranteed by the EU treaty (freedom of movement of persons, goods, services, and capital). A member state may have to modify its policies to conform to those liberties, often after European Court of Justice (ECJ) intervention. A famous case of such an action is the German attempt to annul the Directive 2003/33/EC on limitations over tobacco advertisement, which ECJ dismissed. In many cases, there is no need for a Court intervention, the EU law is enough to enforce a policy. As an example, the EU competition law may restrict government intervention in private health care insurance market (Mossialos & Olliver, 2005, p.12).

Finally, the Open Method of Coordination (OMC) is the "institutionalization of self-reflection and self-control". The mechanism allows member state to "become part of complex, multiple and dense networks of interaction and cooperation embedded in the grey area of European supranationality" (Lamping, 2005, p.26). All four pressure strategies have been used to influence national health policies of member states. The OMC also became a valuable tool of EU integration by helping to solve the national anti-commission bias created by the subsidiarity principle, and thus found a solution when every other means of integration failed (Van Kersbergen, 2004, p.153). "Social inclusion" is an important area targeted by the OMC. This revealed to be an area where member states have no intention to cede powers to the EU level, and that European institutions do not have any legitimacy on. Nevertheless, the OMC allows to bypass this, and attempts to do something on the issue.

Subsidiarity, in spite of those four mechanisms, is also counterbalanced by a second principle that affects the way EU deals with health : solidarity. It is a clear case of direct positive pressure. Enshrined in the basic laws and traditions of the EU and many Western Europeans,

solidarity means in this context "that all members of society must have access to health care, regardless of their ability to pay", and that "health care is organized and managed on the basis of universal access, without risk selection, based on income-related premiums or tax finance, and with no significant differences in the benefit package" (Dawson et al., 2006, p.688). The expression of this principle guarantees free health care for all members of the union. The European Court of Justice (ECJ) has played an important role in its verdicts in operationalizing "the solidarity principle in the field of social security" and forcing countries to comply to the principle (Dawson et al., 2006, p.696). Solidarity is the new justification to expanding European institutions' influence on health.

In spite of its circumscribed jurisdiction on health as defined by the treaties, the EU's institutions are still an important arena to create opportunities for voluntary collaboration or for networks to emerge (Atun, 2004, p.1392). These networks are called "epistemic communities" (Haas, 1992). The term refers to the establishment of stabilized networks of issue-interested groups and the direct institutionalization of problem-solving capacities, mainly "through the creation of European agencies and observatories, comprehensive databases and comparative information systems, diffusion of best practises and incremental extension of regulatory competencies" (Steffen, 2005, p.6-7). In those networks, we can find individual health policy experts, representatives of European and national research units, selected officials from Member States and, most importantly in this sector, specific interest groups and non-governmental organizations (NGOs), such as patients' organisations (Steffen, 2005, p.6-7).

AIDS stimulated the emergence of important networks within the EU. Although Article 129 of the Maastricht treaty provides a certain basis for action, the only real European effort in communicable disease was focused on HIV/AIDS surveillance and prevention, under the "Europe against AIDS" programme (MacLehose, 2004, p.187). This programme was based on

short-term project-funding to support "a range of networks assembled largely by groups of enthusiasts in national surveillance centres and academic departments who had identified a need for coordinated action that seemed to have been overlooked by governments of the Member State" (MacLehose, 2004, p.187). The networks enabled databases of cases "to be pooled, allowing detection of outbreaks involving more than one country that might previously have been missed and providing countries with information about outbreaks" (MacLehose, 2004, p.188).

The EU has also acquired some formal institutions in response to the HIV/AIDS crisis. It built up a surveillance network based on decision 2119/98/EC of European Parliament and Council. This gave birth, in 2005, to the European Centre for Disease Prevention and Control (ECDC), an EU agency which aims to strengthen Europe's defence against infectious diseases. One of its goals is to improve surveillance of communicable disease (Commission, 2004, p.13).

The ECDC has several publications relating to health, among them, *Eurosurveillance*, a scientific journal devoted to the epidemiology, surveillance, prevention, and control of communicable diseases (Eurosurveillance, 2007). It is a whistle-blower publication, but its editors have no political authority. It provides early warnings and suggests response systems for many communicable diseases. Its has gained credibility in the wake of a potential Bird Flu epidemic and with the growing threat of a new non-curable tuberculosis outbreak.

2.2.2. Increasing actions from the European Commission

The European Commission has made a clear attempt to get more involved in health policy-making. The treaties might have restrained the Commission's role, but there is still a commissioner and a directorate attached to the position; the DG of Health and Consumer Products, or DG SANCO.

Steffen defines the role of the Commission in this context as the "master craftsman in initiating and fostering EU-level policy discourses between experts, professionals, public

administrations and governments from all Member States: it establishes health-policy networks, helps build supporting coalitions, exchanges knowledge and institutionalises expertise" (Steffen, 2005, p. 18). Of course, it has no explicit competence in this field, but the Maastricht Treaty (Art. 129-10) still considers that the Community shall encourage "cooperation between the Member States and, if necessary, lending support to their action" (Freeman & Moran, 2000, p.51).

It is under the legitimacy provided by this article that the EU started to build specific programs. It is important to keep in mind that the EU's regulations complement, but do not replace national provisions. As an example, EU regulations have been crucial to begin regulating the pharmaceutical industry, a domain that could easily be connected to the Single Market, particularly in terms of the sensitive issue of access to antiretroviral drugs (ARV) and drug patents (Freeman & Moran, 2000, p.52).

Since the mid-1990s the Commission has promoted a Union-wide dialogue on health issues. If there is no point in making an exhaustive history of the development, one thing that needs to be kept in mind is the role of the Commission in building new institutions, mostly new agencies that complement national agencies. As Steffen said:

> These EU agencies are not only functionally and politically important institutions, responding to the need of market regulation by professionals (market integration and market functioning via standardisation and harmonisation), they also have a high inherent potential for vertically and horizontally integrating the EU as a political and administrative entity. (Steffen, 2005, p.10).

This, combined with the increasing mobility in the health sector, will have major repercussions on the permeable national systems. In the European context, health care is becoming an important issue in terms of people's mobility. Therefore, solidarity and new agencies created a new phenomenon: European citizens have carefully started to compare health-care systems, to demand equal or higher quality treatments, and to use mobility to get better care when their state does not want to improve the quality of its services (Steffen, 2005, p.15). Thus,

even if there are no structures to impose change in national health care systems, the European Union created structures that opened a dialogue with formerly closed institutions. As Lamping explained: "social Europe is on its way, but, rather than driving on the main highway, it is taking detours" (Lamping, 2004, p.20)

Finally, we have to acknowledge that the EU influenced health policy-making through the Helsinki Enlargement strategy before the 2004 and 2007 waves of expansion. Candidate countries faced a serious challenge with upward pressure on health care expenditure and the need to improve population health as a means of reducing demand on EU health services (MacLehose, 2004, p.17). The candidate countries slowly began to participate in Community health programs touching AIDS, cancer, drugs and health promotion. Several other measures were taken, and conferences called, putting an emphasis on health from the European level, and thus attracting a very active participation (MacLehose, 2004,p.20).

PHARE, a program under the responsibility of the Commission, also participated in building a European health answer by providing grants for civil society, and targeting HIV/AIDS more specifically (AIDS Action Europe, p.16).

2.3. EU AS AN ACTOR IN HIV/AIDS

HIV/AIDS has been central to developments in EU health capabilities. Once again, Steffen is quite right when she states that :

> The process is most obvious in the wake of public health catastrophes like AIDS: the epidemic was a catalyst for both an intensification of cross-national health management and co-operation, and the organization of public health capacities at EU level. The EU regulation of medical devices and drug abuse or blood safety policies exemplify these reciprocal processes of policy development, norm diffusion and policy adoption and reform. (Steffen, 2005, p.6)

We could also talk about what Lamping calls "Europeanization by crises", which can be understood as "a discontinuous and accidental but extremely powerful process eluding to

competence accumulation at Community level under the pressure of emergency" (Lamping, 2004 p.191). HIV/AIDS was definitively one of these cases, but we might first attempt to look at why the pandemic is still important for the EU in the XXIst century.

2.3.1 Why should the EU bother with HIV/AIDS?

As we have seen in the previous chapter, epidemiological control was traditionally based on containing a disease within a geographical unit, borders being crucial to the process. With the implementation of the Schengen agreements, epidemiological models automatically became updated since this geographical conception could not hold anymore.

The concept of an EU citizenship gained increasing relevancy over the last years, changing the meaning of national citizenship. A similar passport, a common frontier, a freedom to move without crossing customs, the creation of common symbols, a tentative to frame a constitution : these all have effects on what national citizenship means. But health and citizenship are intrinsically linked. One needs to be citizen of a country to be eligible to its health care benefits, which still mainly depend on state capacity. European national health systems have been founded on the principle of universality. But this universality is still based on having the national passport of a member state. With increasing population mobility, exclusion based on citizenship leaves many people out of health strategies (Clarke, 2004, p.145). In the Schengen area within which populations can move freely, such a mindset just does not work since the pandemic does not discriminate passport colour. If citizenship goes beyond national barriers, epidemiological control must also transcend those borders.

Another important issue is definitively one of foreigners coming to an EU country, and that do not hold a passport from a member state. So far, in spite of an attempt to achieve harmonized restrictions, every EU country has a different rule on HIV/AIDS and migration. This will be a source of debate, sooner or later, especially now that national legal dispositions are void

under the Schengen mobility zone, and controversy is expected to increase with the inclusion of new members into the Schengen zone (Carlier, 1999).

Enlargement of the EU will have "important consequences for the surveillance and control of communicable disease within all of Europe, because of the greater volume of travel not only within the expanded Union but also across its new frontiers" (Atun, 2004, p.1392). Even if the scale of the impact is still unpredictable, it will become a major issue. Since borders and major trade routes are "physical structural determinants of heightened HIV vulnerability given that they facilitate population movement and mixing", any HIV/AIDS strategy will need to be assessed in the light of these developments (Rhodes et al., 2005 ,p 1028).

HIV prevention programs are even more important with the new Eastern frontier. The European Union is now neighbouring the region where the HIV prevalence rate increases the fastest. Surveillance systems in Ukraine, Belarus and Russia are "struggling because of under-funding, reliance on obsolete systems and infrastructure, and a lack of epidemiological capabilities" (Atun, 2004, p.1390). Furthermore, the suspension/reinstallation of the Global Fund support to Ukraine illustrates the challenges of health governance in former Soviet Union countries (Atun, 2004, p.1390). If the EU needs a robust and coherent communicable disease control system within the larger EU, it also needs to support public health system beyond the EU's new border (Atun, 2004, p.1390).

The EU did not remain unresponsive to these issues. Europe has given "perhaps the most systematic and co-ordinated attention" to the HIV problem within migrant populations (Dubois-Aber, 1999, p.1358). In spite of this effort, many scholars came to the conclusion that "migrant health is still not adequately addressed" (Dubois-Arber, 1999, p.1369; Atun, 2004).

But an HIV/AIDS European policy is not justified only on the basis of the issue of mobility. Health is increasingly perceived as an obstruction to the European single-market,

especially with the Directive on services in the internal market (Directive 2006/123/EC, also known as the Bolkestein directive), which aims at the liberalization of services in the Union. The EU extended its web to new fields on the basis that it needed to ensure a functioning single market. On the other side, the new countries are still "fragile transitional societies and institutions" which could endanger the entire single-market if they came to face instability (Atun, 2004, p.1392). HIV/AIDS is on the verge of becoming a serious health, security and economic crisis that could threaten this single market in many of those countries. In Estonia and Latvia, it is already a serious threat. This is why scholars like Atun conclude that the institutions of the EU "must be part of the solution", and fight at the roots problems that could potentially affect the good functioning of the common market (Atun, 2004, p.1392).

2.3.2. The EU's answer

There is a long history of direct and indirect involvement of EU institutions in HIV/AIDS. The cornerstone of the EU' strategy can be traced to February 2004's Dublin declaration, when the Irish presidency clearly presented AIDS as a European concern. Still more a declaration of intent than a real action plan, it foresaw what would the basis of upcoming work on the issue be: ensuring multilateralism and fighting marginalization, especially women's exclusion. If the declaration was still very general, it clearly states, for the first time, that attention should be sustained on the Central Eastern and Central Asian front, the first explicit mention of the upcoming Eastern crisis.

In April 2004 the Health and Consumer Protection Directorate General established an HIV/AIDS Task Force within the Directorate for Public Health and Risk Assessment. This Task Force draws resources from different units in the Directorate, thus bringing diverse expertise to the group. There are currently ten staff members in the Directorate that are attached to the Task Force and two of them work only on HIV/AIDS issues. (Commission, 2007). The Task Force has

also been responsible for gathering and disseminating best practices and undertaking preliminary assessments of multinational scenarios (Jager, 1995, p.48). It has also been responsible for stimulating the integration of knowledge and skills from relevant disciplines (epidemiology, social sciences, health services research and economics), and to strengthen the link between data collection, mathematical modelling and impact assessment (Jager, 1995, p.48). It is thus responsible for developing and applying a common methodology for AIDS scenario analysis at the EU level (Jager, 1995, p.48). In 2004, the EU built a certain institutional capability to gather information and knowledge, and prepared everything that was needed for policy-making, but it failed to frame those policies.

A few months later, the Vilnius declaration, drawn in September 2004, was the first document that constituted a declaration on HIV/AIDS within an enlarged EU, stating clearly what were the incentives and goals of a European approach. The document has a clear focus on the marginalized, mentioning women and migrant populations among others. There is also a clear commitment to fight stigma. The declaration also highlights the importance of including civil society, and of "partnership and collaboration" to "minimise duplication of efforts and maximize synergies" (Commission, 2004). It also addresses the need for coherent, comprehensive and multi-sectorial national HIV/AIDS coordination structures. This led to the 2004 "Coordinated and integrated approach to combat HIV/AIDS within the European Union and in its neighbourhood", which is a more precise tool to define future Commission's actions. This paper targets the areas where the EU should get involved: prevention, harm reduction, diminishing the impact of the epidemic, and coordination and leadership of the effort. It also enunciates the basis of a financial plan and sets some goals. It clearly reaffirms the EU's role as "supporter" of health care coordination and policy.

The EU's HIV/AIDS answer became a real and concrete strategy with the "Communication from the Commission to the Council and the European Parliament on combating HIV/AIDS within the European Union and in the neighbouring countries, 2006-2009", adopted in 2005. For the first time, the EU framed a clear plan with clear targets and set a timeframe to achieve those objectives. The document does not contain only intents; it has clear benchmarks for evaluating progress and a strong notion of reality.

The important thing in this declaration is the affirmation that strategies are "closely linked to strengthening the general European values on human security and the protection of human rights, including sexual and reproductive rights, the rights of minorities and the fundamental rights of migrants, refugees and displaced persons" (Commission, 2005, p.2). It also expresses the concern of the Commission about the "diminished focus on prevention" (Commission, 2005, p.3), making a move towards health policy-making. It reiterates and emphasizes many other aspects: human rights must be respected, surveillance must be improved and harmonized, and harm of minorities must be reduced through knowledge which will lead to healthy behavioural changes (Commission, 2005, p.3). It also states that the fight against stigma must also pass through voluntary testing, treatment, care and support (Commission, 2005, p.8).

This Commission's strategy puts an emphasis on "capacity building" rather than concrete medical projects. It also acknowledges the important role of education by promoting "the development of tailor-made training curricula for health care personnel and other professionals involved in services dealing with people living with HIV/AIDS and with populations that are particularly vulnerable to HIV/AIDS", including intravenous drug users (IDU) and migrants (Commission, 2005). The approach also includes promotion of "effective behaviour change among youth in schools and other appropriate settings through the exchange of information and

best practices and development of training modules", that break-up with former national initiatives which focussed strictly on the medical aspect of AIDS (Commission, 2005).

Since this document was published, many different multilateral meetings and activities demonstrated that there was a significant effort to meet the targets. Different actions have been done. As an example, the President and the Council have prepared a protocol setting that describes best practices to diminish HIV cases among European IDUs (Council, 2007). Among other things, this report stresses the importance of needle-exchange programs, substitution treatment and screening to report infections. These three recommendations are a clear attempt to impose a certain methodology. This is especially relevant because it comes at a time when many countries tend to choose the path of criminalization rather than harm reduction, such as Canada and the USA. Also in 2005, the Commission proposed recommendations to encourage the adoption of a harm reduction strategy in every member state, highlighting the need for distribution of condoms, outreach work, and training for street outreach workers (Commission, 2007a, p.4). The innovation is that it infringes on national health care in proposing criteria of quality, monitoring and evaluation. It also emphasises the need to "develop research-based, fact-driven policies and to implement evidence-based activities" (Commission, 2007a, p.9).

The 2007 Bremen Conference was an important declaration even if it did not bring anything new. It was the first declaration that directly included the 12 new members. It was drafted in the name of the Council, meaning that it was representative of all EU-27 members. Thus, it is the first document that clearly engages the Central European and Baltic countries in the postmodern framework.

Finally, the EU also understood the limitations of its policies if neighbours, that do share borders with certain member states do not participate in the process, Estonia neighbouring Russia being a strong example. This is why Russian Federal Service for Narcotics Traffic Control and

the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) adopted a common agreement in the EU-Russia meeting in 2007, proposing to exchange information as much among authorities than the scientific community that works on drug issues.

2.4. EU AS A POSTMODERN ACTOR?

The EU is not just a postmodern actor in HIV/AIDS. Its actions are diverse, and some follow other conceptual frameworks. It would be unfair to see the EU strictly as being postmodern. For example, the creation of ECDC is a clear attempt to build modernist strategies, even if those efforts are limited. The upcoming section aims at defining what in the EU strategy can be defined as a postmodern strategy, which does not exclude that the EU is also developing capabilities that are not postmodern.

The European strategy has been focussing on overcoming "differences, based on comparative promotion evaluation of national policies, particularly surveillance, prevention strategies and the care of the most vulnerables" (Steffen, 2001, p.245). It is a strategy that is based on sharing and accumulating knowledge with restricted policy-making capabilities. We can divide its postmodern influence in four different effects.

2.4.1. Breaking in the panopticon

So far, the European Court of Justice (ECJ), through its different rulings, has been the most active organ in influencing national health care management. It needs to be kept in mind that the EU is not there to provide services; it makes regulations. It rules through norms and influence. Its essence, its role and its available means to achieve its goals prevent it from being a modernist actor defending the repressive model of epidemiology.

European integration did not confiscate powers from national levels. Slowly, through networking and discussion, it built up capacities that were complementary to the Member State's role. This is the first step to a postmodern answer. The EU is not trying to impose a vision, it

diffuses its vision. In other words, it reinforces horizontality, while putting its nose in a field jealously defended by member states. The former is now obliged to talk and listen, and national authorities have, at least at the European level, had to stop building secluded health system. The EU-level is also collecting information on best practices and on knowledge of health. Through this accumulation of perspectives, a comparative assessment is made, forcing countries to look at each other, and opening windows where there used to be walls (Lamping, 2004, p.192). Policy-makers are not invisible anymore, offering at the same time more possibilities to the ill body than to submit to the "*regard calculateur*" (the planning look). This is definitively breaking the panopticon pattern. Instead of valorizing a pattern based on discipline, it searches to put all the different actors in the same room to reach an informal consensus.

For health-care officials, being forced to talk to their European counterparts is the beginning of a postmodern shift. It is, by the very process, an opening, a capacity to admit that there are other actors that have the right to get involved, and therefore a complete change from modernist health system where health strategist were at the top, and no other actors were involved. Now, European networks of NGOs have a direct entry in Brussels, and they just can't be ignored by national governments. This is an important feature, especially for the newest members, which still have difficulty engaging their civil society in the HIV/AIDS debate.

2.4.2. New narratives, new power relations

The Commission, as it is stated in many working papers, actively involves civil society at the policy level, and tries to involve civil society actors in policy development, implementation and monitoring. Through this, the power lines are swiftly changing, empowering communities in the process. Empowering communities is very important in the postmodern framework because it is in direct opposition to a modernist one focussing on destroying the enemy, the illness. Empowerment implies giving communities and groups the tools to defend themselves against the

pandemic, and ending the modernist repressive model. The EU strategy aims at this in two different ways.

The first goal is to give people power over their own lives and allow them to make voluntary changes (Gostin & Lazzarini, 1997, p.57). It is about framing an effective strategy that will take out marginalization of MSMs, IDUs, sex workers, migrants, and other targeted groups. The EU' strategy papers clearly targets women when it states that "equality between men and women" and the respect of the "right to reproductive and sexual health" are important goals (Commission, 2004,). In the face of the exponentially growing number of women that are exposed to the virus, it is important to give them the tools to protect themselves. In ECE countries, women are more "likely to become clients of the social welfare system due to their roles as caregivers, their greater vulnerability to unemployment, and their lower wages" (Brunell, 2002, p.467), creating a gender marginalization. Many studies have revealed the vital link between HIV/AIDS and marginalization of women (Kalichman, 1999 p.279 ; Turmen, 2003, p.413), and it cannot be dismissed, especially in light of the latest statistics which indicate an important increase in HIV prevalence rate among women all over Europe. Therefore, partially due to this framework, people can now gain access to power and diminish their marginalization more easily.

Secondly, empowerment and community support also means that "AIDS policies should be formulated in cooperation with the affected populations and implemented with respect of individual autonomy" (Gostin & Lazzarini, 1997, p.57). The way to do this is to attempt to build on social capital in order to solve societal issues and to design policies that are focused on active listening (Rhodes et al., 2005, p.1032). HIV-positive citizens can be responsible for their health, but, even better, they can ensure that policies really respond to their needs through this

involvement. Including civil society in the process of health system management is crucial for community empowerment.

The European Commission supports and funds many civil society initiatives, which play different roles. In many cases, civil society organizations at the European level are umbrellas of smaller national groups. For example, AIDS Action Europe and the Integration Projects are networks of NGOs dealing with HIV/AIDS. Although they are different, both aim at improving national NGO skills and weight. Some other networks of NGOs, like The European Region of the International Lesbian and Gay Association (ILGA-Europe), defend particular groups. Other initiative are simply about increasing communication among actors, creating new spaces for sharing experiences. One example is the Northern Dimension Partnership in Public Health and Social-Being, an umbrella organization with its own secretariat and capabilities which gathers civil society groups, international institution, and national governments around the same table in an attempt to improve all actor's health. The EU, by directly funding those different initiatives, becomes a strong supporter of a new balance of power.

Furthermore, local NGOs from the new member states are receiving support and tools from well-established and powerful organization like AIDES or Act-Up, through networking. This allows them to share best practices and resources to strengthen their efficiency in fighting the pandemic. The creation of a European civil society also becomes crucial in sharing the "you are not alone" message, offering a stronger voice to groups that are badly organized, like sex workers. Civil society groups are thus more able to challenge the modernist state monopoly on health policy-making, forcing new narratives and power-sharing within national health systems.

Civil society is not only pressuring national states, but the EU too. There are purely European NGOs that aim at directly pressuring the EU. The European AIDS treatment group (EATG) would be a good example. It is a second generation organization that played a "key role"

in homogenizing "access conditions to ARV around the EU countries" (Steffen, 2001, p.228). It is a lobby group that stands by itself, without any smaller national entities. It has played an important role when many HIV-positive persons migrated to new countries in order to gain access to better treatments, like the many Italians who crossed the Swiss borders in the early 1990s (Steffen, 2001, p.229). EATG is thus responsible for a more Europeanized strategy on ARV. European groups are clearly lobbying to increase the role of the EU and to shape policies, making the EU a stronger actor.

The EU is not simply fostering a reconfiguration of powers and narratives: by doing so, it also becomes a strong actor itself. The EU, by developing many capabilities such as surveillance, is now able to diffuse information, allowing all the players to be on a same level, but mostly to ensure that the debate is shaped by several different narratives. In other words, "the EU frames the information base of policy-making, in the health sector and influences policy agendas and power balances between policy actors at European as well as national level" (Lamping, 2004, p.189).

In sum, the EU has considerably complicated the lines of power, framing a new pluralism where there formerly was a state monopoly. In this new emerging pluralism, "national governments are in no way forced into the role of spectator" (Lamping, 2004, p.37). Within such interactions, health policy is characterized by no clear dividing line between the national state and the European arena (Lamping, 2004, p.37). It is a policy domain where "policy responsibilities are not neatly divided between country and European arena", but they rather "waver between the two" (Wallace, 2000, p.43). The frontiers among the different actors are becoming fluid, creating a political structure where power is constantly challenged, and where no one can have ultimate control of the system. This is postmodernism.

2.4.3. Human rights approach

The EU is imposing a legal framework in a field where respect of patients' rights was traditionally not an important concern. The EU clearly emphasizes the role of human rights and the rule of law in health management. Human rights are commonly included in all EU declarations on HIV/AIDS. Working strategies highlight what has been established through the European Court of justice and the European Court on Human Rights (ECtHR) decisions. The ECtHR justified its decisions through articles 5 and 8 of the European Convention of Human Rights.

The question of "human rights" and HIV/AIDS is important because an HIV policy can be seriously undermined if it is not strictly surrounded by a strong legal framework. Public health and human rights have a long "historically contentious relationship" (Harrington, 2002, p.1425). Outdated laws on contagious disease and discriminatory regulations remain in force in many countries, where the use of mandatory screening limits the rights of those considered to be in the "risk group" (Atlani, 2000, p.1554; Gostin, 1997, p.77). In addition, travel bans and limitations on certain professions have proven to be counter-productive as well as being human right violations (Gostin & Lazzarini, 1997, p.77). Therefore, consent given by the patient have become "the only legitimate ground for interference in their lives or any intrusion upon their person" (Harrington, 2002, p.1426).

In the early 1980s, when HIV/AIDS was identified as an infectious disease, it led to "considerable panic and heated discussions" (Harrington, 2002, p.1427). Coercive methods have been applied by some countries, Bavaria and Sweden being two blatant European cases. Those traditional epidemiological patterns can easily lead to invasion of one's privacy, leading to further stigmatization, and thus increasing someone's HIV vulnerability (Gostin & Lazzarini,

p.43). The EU strategy emphasizes the importance of voluntary testing and confidentiality, based on informed consent both before and after the test (Gostin & Lazzarini, 1997, p.82).

In this context, the European Court of Justice (ECJ), the European Court of Human Rights (ECtHR) and other legal actors have promoted "pro-autonomy interpretations and applications of the relevant legal doctrines and statutes" (Harrington, 2002, p.1428). When states have attempted to infringe on their population's rights, the Courts have given their full support to the different associations that were resisting coercion, gay lobby groups being the most prominent (Harrington, 2002, p.1428). The different courts have been central to acknowledging the "proportionality principle", which in this case means that the appropriate means to fight HIV/AIDS are not repressive ones (Harrington, 2002, p.1429).

European courts were also an important arena to fight marginalization. In one significant move, the ECtHR brought at the forefront the issue of HIV-positive migrants by stating that "it would be inhuman and degrading treatment, and therefore impermissible, to deport an illegal immigrant with full-blown AIDS" (Harrington, 2002, p.1429). This case had a considerable impact on EU regulations and methods, forcing a review of national laws. The courts have also been important in the issue of harm reduction, and in framing national legal frameworks in a way to ensure that syringe-exchange programs are not being hampered. The Courts did not change the laws of the EU in terms of human rights and rule of law, but definitively interpreted legislation to give them a stronger voice. Indeed, even if the ECtHR is not an EU institution, it plays an important role in the EU's strategy.

2.4.4. Fighting marginalization

Fighting marginalization is a complicated process that is addressed indirectly by the three first parts of this section. But the EU is also acting directly by imposing itself as an actor in the scene of social inclusion. Imposing its presence means that the EU is forcing some unwanted

actors out of the debate in a way to ensure that nobody is promoting norms and values that do not fit with the European ones, and that are increasing marginalization. The Commission's strategy paper clearly states its intent to work "with partners in eliminating unproductive competition" (Commission, 2004). This very polite phrasing alludes to program duplication with international partners on HIV/AIDS. It targets any two programs which share the same goals, but also applies to two different programs, initiated by two different actors, dealing with the same issue, but with different outcomes.

The EU stands against strategies that are either fostering marginalization or are destructive in other ways, and that oppose basic European norms and values. The Vatican's anti-contraception and anti-homosexual stance, which is quite influential in Poland, is one of the most obviously destructive policies. But the "Bush moral guidelines" (often referred as the Global gag rule) which can be found in the USAID strategies can also be considered detrimental, especially for Eastern Europe (Altman, 2006, p.266). Funding, in this case, is strictly reserved to management plans that focus on abstinence and faithfulness as prevention methods (Glasier, 2006, p.1550). Like Horton said, we should be concerned when US officials and scientists make moral judgments and use works like "morally distasteful" (Horton, 2006, p.1549).

This kind of restriction does not take into consideration that abstinence is often not an option for poor women and girls who have no choice but to marry at an early age, and for whom being faithful will not guarantee their partner's faithfulness, to use Bill Gates' words (Glasier, 2006, p.1551). Thus, abstinence increases marginalization, rather than fighting it, and denies one's responsibility over its body, would defend a postmodern thinker. The EU has been a strong entity to keep those unwanted restrictions out of the debate by imposing certain values through its different institutions. The 2007 judgement of the ECtHR on abortion, Tysiąc vs Poland, represents an important decision in defending women's reproductive rights (European Court of

Human Rights, 2007). Similarly the Bremen convention, reiterating the importance of condom and harm reduction, is another clear attempt that, in the EU, HIV/AIDS will be fought by making people responsible for their behaviour, rather than making them ashamed of what they do.

International institutions do not necessarily fare better. If the EU found some strong allies, such as the WHO and UNAIDS, others demonstrated less effective strategies. As we have seen in section 2.1.5, the Global Fund is an important player, that offers an innovative and interesting response to HIV/AIDS, but its vision remains short-term once again.

Other international financial institutions (IFI) put considerable pressures on the transitional countries for them to adopt neo-liberal policies, in opposition to the "solidarity principle" included in European norms and values. EU accession has protected the new members from IFI's pressure in some degree, Romania and Bulgaria being two countries that faced strong pressure to implement neoliberal reforms. Those neo-liberal strategies increase marginalization, thereby diminishing the efficiency of the strategy against HIV/AIDS. A blatant case of the negative effects of the IFIs is Ukraine, especially about the marginalization of women, as documented by Kolisnichenko (Kolisnichenko, 2006, p.25). As we have seen earlier, the policies to regulate the HIV/AIDS crisis have been most effective in the regions with strong public healthcare systems. The IFIs, by pressuring states to dismember their social welfare structure in order to diminish the weight of the state, are contributing to increasing marginalization.

However, what is even more important about the international organizations and the EU's strategy is that many foreign agencies forget that their strategies will be perceived as "alien".(Williams, 1995, p.12). This is where the European strategy is impregnated with postmodernism : it realizes top-down strategies do not work. Therefore, the EU strategy sees that what is transferable is more "the philosophy of prevention work, including the standards of programme development and management, which then need to be implemented in the specific

contexts of individual countries" (Mayer, 1995, p.185). In other words, prevention work may "draw on the experience of others, but it must also respect the political structure, cultural background and social development of the country at hand" (Mayer, 1995, p.185). No strategy can work if it is not framed according the particularities of the people at which it is aimed.

The role of the EU in fighting marginalization is not strictly in muting unwanted voices: it must also provide a voice to the voiceless. There are no statistics on HIV/AIDS within Roma and Sinti communities, and no programs targeting them. So far, the European Union is the only governance entity that has raised the question. No national policies take them into account. Migrants, be they illegal or legal, are also excluded from national strategies. If nobody can ignore them today, it is because their story as been told repeatedly through its inclusion in all European protocols.

2.5 CRITIQUE TO AN EU APPROACH ON HIV/AIDS

The EU strategy is far from being perfect. It is easy to blame the Global Fund for lacking a long-term vision, but the EU did not show much in this field either. It has the capacities to frame long-term policies, and expresses its will through its protocol, but has applied little long-term vision in its deeds. Most of the initiatives funded by the Commission remain project-based. In other words, even if marginalization is a very difficult issue to tackle, the EU needs to reach even further.

Nevertheless, one must remember that postmodernism came into the European Union from its incapability to develop other health capabilities. On one side, there is a need for the EU to act, and the other side, it must respect the member states who still resent an opening in health policy-making at the European level. Therefore, this postmodern framework is a compromise, and has been developed because there were no other obvious options. If the EU has shown how regional integration could lead to imaginative and progressive solutions on the verge of a crisis,

the European approach remains limited, especially since the EU relies on the will of member states to implement its policies. European postmodern governance is possible because there are strong national states to enforce European decisions. Therefore, the EU is not an independent actor. It can influence, but this influence is justified by the weight of its member states.

Another important limitation, especially when we talk about postmodernism, is the issue of legitimation. The EU is still perceived as a "foreign entity" for many citizens, and is often being referred to as an institution that lacks democratic legitimacy. This leaves considerable limitations on any European strategy, especially when dealing with sensitive and controversial issues like marginalization. In Poland, Euro-rejection and homophobia were joined when the European institutions condemned homophobic attacks. A campaign of vilification of the EU followed the European Parliament resolution on the increase of racist and homophobic violence in Europe, adopted on 15th June 2006. Many Polish actors attempted to stigmatize the EU as an Other that promotes immoral behaviours. *Mlodziez Wszechpolska,* an influent youth extreme-right group, which is affiliated to former minor coalition party *Liga Polskich Rodzin*, adopted expressions such as "*Pedofile, pederaści to są euroentuzjaści*"[5] (pedophiles and faggots are euro-enthusiasts) and "*Precz z UE*" (Europe, get out). More subtly, the Sejm, the lower house of the Polish Parliament, adopted a resolution to answer the European parliament. It stated: "the Sejm, identifying itself with the Judeo-Christian moral heritage of Europe will not approve of the introduction of such a term as 'homophobia' into the documents of the European Union".

Poland shows the limitation of national strategies based on the motto "if we do this, we will be blamed by the EU", something that can be too easily exploited by opposition movements. Therefore, if the EU does not have a strong legitimacy in a country, it will not be able to impose its values. Diffusion of norms, as defended by a postmodern, relies also on legitimacy. Fighting

[5] All translation from Polish sources are the author's.

HIV/AIDS through a postmodern strategy may thus be impeded if a member state does not accept the EU as part of itself.

The next chapter will provide a closer look to the reality in Central and Eastern Europe.

CHAPTER THREE: CENTRAL AND EASTERN EUROPEAN HIV/AIDS PANDEMIC: FROM 1980 TO ACCESSION

HIV/AIDS appeared in times of transition for the former Communist countries of Central and Eastern Europe. Facing pressure for economical, social and political reform, the states had to deeply transform their nature to conform to the new reality, while facing the pandemic.

This chapter aims at providing an understanding of the pandemic since its appearance in the 1990s till the 2000, before the EU accession process seriously had an impact on the region's policy making. To do so, we will first present a general historical perspective of HIV/AIDS in Central and Eastern Europe from the beginning of the pandemic until accession. Then, we will look at the epidemiology of the region, focussing on our two case-studies. Third, we will observe the communist legacy in terms of health management, and subsequent developments in Poland and Estonia. We will also provide a short picture of marginalization in those countries.

3.1 THE BIRTH OF THE PANDEMIC AND EPIDEMIOLOGICAL TRENDS

The picture of HIV/AIDS on the other side of the Berlin wall before it fell down remains very obscure. Communist authorities were not reliable in providing numbers or publicizing health issues, and we can easily imagine that many AIDS cases disappeared from public scrutiny in the bureaucratic maze. Soviet secrecy was justified due to their fight against the West (Sontag, 2001). Therefore, Communist populations had to be healthier and had to live longer than their western counterparts, at least on paper (Kalnins, 1995, p.180). Statisticians provided the political weapons for the regime.

The first cases of HIV/AIDS in the Soviet bloc are suspected to have been among workers that lived with Cubans in Angola. It is also assumed that an important outbreak occurred in the eighties among MSMs, but there is little evidence (UNDP, 2004, p.10). In reality, there is no way to accurately assess the pandemic until the mid-1990s, but the strong travel restrictions in the

region probably help keeping the numbers low. Even until the year 2000, discrepancies in data and arguable epidemiological methodologies left gaps in information for many countries of the region.

In spite of the concealment of information throughout the 1980s, the percentage of infected citizens in Eastern European countries was low. The former Communist bloc was "relatively untouched" by the pandemic that outburst everywhere else in the world (MacLehose, 2004, p.193). What happened next was best described by UNAIDS director Peter Piot: "in Eastern Europe, the underestimation had been very strong" (Favereau, 2006, p.193). For most countries of the region, the 1990s saw an "exploding outbreak" among IDUs. In the next decade a second wave occurred when HIV/AIDS leaked out of the IDU population via heterosexual intercourse, fuelled by commercial sex work and exacerbated by high rates of other sexually transmitted diseases (MacLehose, 2004, p.193; Hamers, 2003). In other words, HIV infected the population through the bridge population, a situation that soon became a catastrophe in former USSR countries.

The Baltic States followed the Eastern European pattern of dissemination. The initial spread of HIV among IDUs in the late 1990s was similar to epidemics among IDUs in neighbouring countries, in particular the Russian Federation (ECDC, 2007, p.7). It was also different in that the epidemiological trends showed that the pandemic started much later in the three Baltic countries than in Russia or Ukraine. Nevertheless, after a long period of low figures of infection rates, the Baltic States are now facing the highest incidence rates[6] on the entire European continent (UNAIDS, 2006). The year 2001 has been crucial for Baltic countries. That year, 1,474 new HIV cases were diagnosed in Estonia. In comparison, for 2000, only 390 new

[6] Incidence rate is the number of new cases within a certain period of time divided by the population. Not to be confused with AIDS incidence rate, which evaluates the number of new people developing AIDS (having a CD-4 count below 200).

cases were diagnosed, and for 1996, eight (EUROHIV, 2007, pp.12-13) . In 2005, the number of new cases went down to 621 and seems to have "stabilized" since then (Lohmus & Ruutel, 2006, p.1). Still, HIV in Estonia still spreads ten times faster than anywhere else in Europe (Integration Projects, 2007, p.8).

In 2007, in Estonia, the HIV new infection rate was 504 cases per million inhabitants (UNAIDS, 2007a, p.34). The Estonian HIV prevalence rate for 2006 was 1.3%[7]. Latvia and Lithuania had respective prevalence rates of 0,8%, and 0,2% (UNAIDS, 2006). Before the 2001 explosion, the majority of the Estonian cases were among MSMs. But from 2000 until now, the main victims to be diagnosed were IDUs. Simultaneously, these countries faced a major hepatitis B and C epidemic, which went totally unnoticed, a sign which could have foretold the upcoming HIV/AIDS crisis (UNDP, 2004, p.19). Many observers believe that heterosexual intercourse might now be the number one means of transmission of the virus, but new surveillance numbers are needed to confirm this.

In terms of geographical representation, most HIV-positive people are in Tallinn or in the East, in the Narva region or along the Russian border. If there are no statistics on language and HIV prevalence available, geographical location provides a good in-sight. Other statistics confirm this harsh truth: 90 to 98% of IDUs are Russian-speaking (Downes, 2003, p.1). Another important issue is that people living with HIV/AIDS in the Baltic countries tend to be younger than anywhere else. The 15-24 year olds account for 55% of the HIV cases in Estonia (ECDC, 2007, p.1). For the whole Baltic region, 80% of the cases are diagnosed in people under 30 years old (UNDP, 2004).

[7] HIV prevalence rate is the number of all HIV-infected persons divided by population. Remark in footnotes no.4 on AIDS also applies.

Evidences suggest that in Latvia and Estonia, there is no more hope to halt the crisis. The focus now needs to be on secondary prevention, which means in this case that health policy-makers need "to think in terms of minimising its social costs, by preventing the further spread of HIV/AIDS and by developing effective treatment programmes for people living with HIV and AIDS" (UNDP, 2003, p.24). This is called damage control, not prevention.

The only similarity between the new members from Central and South-Eastern Europe is that their figures remain low for now. Specialists suspect that this low rate of HIV among IDUs in Central Europe is probably caused by their non-exposure to the virus (Integration Project, 2007, p.6). The main argument for this is that there has been for the last years an important increase of hepatitis B and C among IDUs in Central Europe, two blood-transmitted diseases. In other words, the conditions are set for a rapid increase of HIV/AIDS transmission in these countries, which are similar to Estonia's figures in 2000 (Integration Project, 2007, p.6). There is dynamite there, but it still needs the spark.

Poland had a prevalence rate of 0.1% for the year 2006, and the incidence rate for 2005 was of 16.9 per million inhabitants. The first eleven cases were reported in 1985, five of them being among haemophiliacs and/or MSMs. Even if Polish figures remain low, the country still faces the highest prevalence rate of the Visegrad countries. What is most preoccupying is that, like Romania, Poland is facing a "concentrated epidemic" within its IDU population (UNAIDS, 2006). IDUs represented 78.6% of infections detected in 2005, or 47.9% of all cases (Rosinska, 2006, p.1). But even more worrisome is the important rate of unknown infections. In November 2007, on 44 new reported HIV cases 37 cases had unidentifiable sources of transmission (84% of the cases). This means that those invisible people are not tested at public agencies or NGOs, but they go to commercial private clinics for testing. Nobody really knows the cause of their infection, but it is legitimate to believe that they got infected through sexual contacts, and that

they are less marginalized, foretelling that HIV crossed the bridge population. Geographical location supports this theory. The most infected Polish regions are Warsaw, the region surrounding Kaliningrad, and the region of Zeliony Gory, which is located close to the German border, the last three being well-known areas for prostitution and trafficking (Rosinska, 2006, p.4). The rate of unknown transmission route in the registered cases in those two regions is also much higher than in Warsaw.

There are three main issues with the figures from the new members of Central and Eastern Europe. First, the issue of MSMs is a common one. Numbers appear to remain low among MSMs, but reality might be different. MSMs still face considerable prejudice in most countries of the region. Homosexual men are thus "driven to secrecy and discouraged from disclosing their sexual orientation even to obtain help and information they need, including counselling and testing (Hamers, 2003, p.6). If countries like the Czech Republic and Hungary move quickly in providing a legal framework that allows them to fight marginalization, others like Poland and Estonia are lagging behind. The reality is probably worse than what the figures show.

Second, an important issue with all the Central and Eastern European countries is the percentage of people ignoring their status. In Central Europe, this percentage is estimated at around 30% (ECDC, 2007, p.11; Barcal, 2005). In Poland, this number is evaluated at 50%, meaning that half of HIV-positive Poles ignore their status (ECDC, 2007, p.11). No figures are circulating on Estonia, but many activists interviewed for this study suggested that they are high.

Third, in all countries, strategies are hitting a wall. The population is taking increasing risks, especially MSMs and the youth (ECDC, 2007, p.8). People under 25 years of age are facing an explosion of human papillomavirus (HPV) and chlamydia, and a significant increase in sexually-transmitted hepatitis B and C (ECDC, 2007, p.10). Numbers for reported HIV/AIDS cases should follow this trend and go up, not down. Especially now that we know that real

numbers only become accurate many years after infection, once HIV develops in full-blown AIDS. And experience shows that it can happen very quickly. Some countries might face a crisis right now, but will truly be able to understand it in few years. For the moment, UNAIDS judges that the pandemic is stable in the region in its latest epidemical update (UNAIDS, 2007, p.34).

3.2. POST-COMMUNIST HEALTH-CARE: AN OUTDATED APPROACH?

Although communism in itself did not provide an effective preventive method against HIV/AIDS, it spread later in the East because "the political restraints of the Iron Curtain placed on the population by their totalitarian regimes considerably delayed the penetration and slowed the spread" of HIV in Central and Eastern Europe (Mayer, 1995, p.180). It was neither a question of better social behaviour, nor of better social policies.

Therefore, the first answers to the pandemic were modernist, and relied on the traditional repressive model of epidemiological control. Officials thus implemented a strategy against HIV/AIDS based on building the "Other", which ensured the preservation of the "Us" from the "Them". Susan Sontag analyses the Communist vocabulary on AIDS as "a non-familiar diatribe against the 'soft' West, with its hedonism, its vulgar sexy music, its indulgence on drugs, its disabled family life, which have sapped the will to stand up to Communism" (Sontag, 2001, p.63). AIDS is the "favourite concern of those who translate their political agenda into questions of group psychology, of national self-esteem and self-confidence", she reminded us (Sontag, 2001, p.63). Therefore, the language that built over the years partook to a semantics of decadence and, ultimate evil, the West. From the beginning, the message was clear: you were HIV-positive because you were an enemy of the healthy and morally-inclined Communist people (Sontag, 2001, p.63). The stigma would persist and make the lives of HIV-positive people very difficult, even after physical walls had fallen down. The West might not have been the ultimate evil, the ultimate cause of disease transmission, but the necessity to blame an invisible "Other" remained

(Sontag, 2001, p.63). To this day, many government officials still encourage this kind of seclusion and marginalization.

In all Communist countries, decisions relating to health were made at the highest level through very vertical structures (Williams, 1995, p.64). Power was highly centralized and followed a structure which shared many of the "characteristics of a totalitarian regime of state authority", based on a "highly developed administrative and bureaucratic nature" (Kolisnichenko, 2006, p.17). Health policies were nevertheless free and universal, at least on paper. Of course, reality proved that, even if access was universal, resources were restricted by scarcity and corruption.

In the West, public health, in spite of the important role of the medical body, drew increasingly on other health disciplines including epidemiology, bio-statistics, health administration, occupational and environmental health, medical sociology, health psychology, behavioural science, and health promotion (Kalnins, 1995, p.180). This was not the case in former Communist countries where the health system was "the exclusive responsibility of physicians who have received traditional illness-oriented training in faculties or institute of medicine" (Kalnins, 1995, p.180). Lack of open-mindedness to other disciplines in health system management implied a lack of statistics, which maintained a gap between available information and reality (Kalnins, 1995, p.180; Andersson, 1998, p.1594). These structural bases, which relied purely on medical answers, remained untouched during the 1990s, while the end of Communism left behind a crumbling health system. Those emerging democracies were thus "unequipped to deal with the challenge of HIV/AIDS" that would come simultaneously (Mayer, 1995, p.180).

The problems plaguing post-communist public health systems were numerous. A "prolonged economic downturn, high levels of unemployment, sharply reduced social security, widening income and wealth differences, falling health standards [...], have all contributed to

frustration, disillusion and mounting political tensions" (Makara, 1998 p.177). All these factors created pressures on the health system. While more and more people needed health care, the access was "increasingly limited because of insufficient public financing [...] and the transition to a system of paid medicine (Kolisnichenko, 2006 p.21). Lack of resources became an important issue and huge budget deficits throughout the region have "left little room for manoeuvre on AIDS policy" (Williams, 1995 p.18; Mayer, p.185). The collapse of this welfare state has meant that these states were no longer able to maintain, finance, and provide social welfare on the scale and extent to which the population was hitherto accustomed.

It is not simply a question of lack of money, but also of efficiency. The system was plagued with serious problems of cost-containment and of inefficient management (Kolisnichenko, 2006 p.22). This manifested itself through "dysfunctional organizational frameworks", "inadequate and unfit personnel", and "outdated methods" (Makara, 1998, p. 179). These factors reduced the network of medical institutions available to citizens and led to a shortage of free medicines for the sick, as well, as a constant fear of illness, inadequate treatment, and even total impoverishment (Kolisnichenko, 2006 p.21).

The transition also led to increased pressures from the international financial institutions (IFI) for reforms, a process that further diminished the importance of social policy (Ksiezopolski, 1993, p.182). Countries had to find a new and difficult balance between the public and private funding in terms of social issues (Ksiezopolski, 1993, p.181). In fact, as an example, the "introduction of the market economy in Poland has been accompanied by deliberate efforts to marginalize social issues in the overall reform strategy" (Ksiezopolski, 1993, p.183). In other words, the lack of macro-economical stability and political leadership in all post-Communist countries led them to blindly follow the rules of the IFIs (Makara, 1998 p.181). In this context, all the attention was focused on reducing public financial participation, not on increasing quality.

They did not reform the philosophy or the essence of health-care, they simply focussed on reducing the complexity of structures in a way to reduce costs. Old modernist theories prevailed, but in this case, no one was present to accept responsibility for health care failure, not even medical doctors. It was thus an outdated approach limited by lack of resources.

Another important issue in the analysis of post-communist health-care is responsibility. Communist authorities expressed a "lack of concern or of appropriate education towards teaching individuals to be responsible for their own health problems" (Mayer, 1995, p.182). In other words, under Communism, it was the state's responsibility to ensure their citizens would receive basic health care services. This is a very modernist approach based on taking rights and responsibilities out of citizen's hands. This national strategy led to "an insufficient degree of preventive behaviour and low awareness of factors that might damage health" (Mayer, 1995, p.182). The issue has been formulated quite clearly by Makara: "all this has induced deep distrust and suspicion towards any real initiative in the field of prevention; traditional public health was not capable of responding to the challenges of the new epidemiological era" (Makara, 1998 p.179). Prevention, which is a central element in the fight to contain the AIDS virus, was thus "pushed into the background in the hierarchy of power in the health sector, in medical education and research" (Makara, 1998, p.179). People depended "on the omnipotent central state in vain to solve their problems so the practice of health promotion based on the community and self-empowerment did not develop" (Makara, 1998 p.179). This legacy still underlies many AIDS strategies in the region.

This explains why NGOs, voluntary organizations, organized self-help programs, or other civil society initiatives are often outsiders to national strategies in post-communist societies. Under communism, such civic initiatives were simply banned (Mayer, 1995, p.183). This has had two important consequences. First, governments developed a deep suspicion of NGOs and are

still unable to work efficiently with them. Second, civil society is extremely fragile and private initiators often need consultancy and managerial help in order to increase their ability to set appropriate targets and goals (Mayer, 1995, p.183). This is why, unfortunately, NGOs, association, and/or communities were "not in a position to assume joint responsibility for AIDS policy" before the EU accession process (Williams, 1995 p.19).

The issue of responsibility and prevention is also the incapacity to frame health under another framework than a scientific one. The first programs in the region clearly demonstrated this lack of awareness that health is also a social problem, by neglecting the psychosocial problems associated with HIV (Mayer, 1995, p.183). For example, one important issue would be the issue of contraception and family planning. Inadequate family planning programmes are clearly connected to the persistently high abortion rates, reflecting the pattern of unsafe sex (Mayer, 1995, p.182). Many years later, the promotion and use of condoms remain an important source of political debate, especially in Poland.

These countries also established their inability to address the issues of marginalization and stigmatization, often amplifying those rather than fighting them (Hammers, 2003). The mass media, during the 1990s emphasized that AIDS was a problem of deviants such as IDUs, sex workers and gays (Williams, 1995 p.13). It would be unfair to say that the mentalities have not evolve since then. Indeed, all anti-sodomy laws have been repealed during the 90s in the region. But growing political rights for LGQBTT-identified people failed to destroy the misrepresentation of MSMs, sex workers, and IDUs in the head of the medical body and the general population alike (Williams, 1995 p.154). The lack of political representation of vulnerable groups, such as what was achieved by gays and sex workers in the West, has not brought any pressure to empower these minorities. A lack of information persist, and this is reflected in health legislation as well as social behaviour (UNDP, 2004, p.28).

As for harm reduction, in spite of early implementation in some countries like the Czech Republic and Slovenia, it took many years for these policies to be adopted in the region (WHO, 2006). Post-Communist countries still treat drug users as criminals. Personal consumption is penalized harshly both in Poland and Estonia. In spite of controversy, all countries adopted harm reduction in the 1990s (AIDS Action Europe, 2003, p.6). It is not that governments suddenly became more open-minded; it is just that they faced a serious problem and could not deal with it by using traditional tools anymore. Even if the first cases in the region were observed among MSMs, the first meaningful outbursts were, almost everywhere, among IDUs. And the problem got even more serious with the dramatic increase in drug consumption after 1989.

There are many reasons for this: economic hardship and insecurity, the erosion or relaxation of rigid social controls, and the armed conflicts that accompanied and followed the collapse of the Soviet Union and socialist Yugoslavia. All are good reasons to explain the increase in drug use during this sensitive period (UNDP, 2004, p.25). But the main reason is simply availability. The international political events of the last 20 years changed the opiates trade route, which now passes through Central and Eastern Europe. The new routes follow the Silk Road or pass through the Balkans. But, still more importantly, the quantity of drugs produced and shipped abroad exploded. For example, it is estimated that during the 1990s, the world production of heroin quadrupled (Atlani, 2000, p.1550). It got even worst with the war in Afghanistan which further boosted the world's production of opiates. This important increase in supply made opiates cheaper and more accessible (UNDP, 2004, p.26; Atlani, p.1550).

Nevertheless, it would be incorrect to understand the booming numbers strictly in terms of increasing drug supplies. The fundamental problem is marginalization, not drug addiction. In his studies, Gyarmathy concluded that "discrepancies in HIV rates in Central and Eastern Europe suggest that in addition to risk behaviours, social contact patterns that influence the risk of

exposure and epidemic spread also play an important role" (Gyarmathy, 2005, p.102). In sum, there are two different kinds of drug users: the marginalized and the socially-integrated. If there is a similar "risk behaviour" among the two groups, the marginalized, by their "environment" and through their relations, will be more vulnerable to infection. In other words, the postmodern framework of circle of vulnerability is necessary to understand vulnerability to AIDS in the region (Gyarmathy, 2005, p.104-105). All marginalized face similar problems. An educated gay person with a stable partner will be much less at risk than a married man with kids who sporadically visits rest areas to have sex with other men. Similarly, an internet escort faces much less risk than a street prostitute. Therefore, circles of marginalization are interacting with each other: gender, drug addiction, sexual orientation, sex workers, poverty, urban vs rural, jailed, Romas, etc. (Estebanez, 2000; Rhodes et al., 2005). High or low HIV prevalence rate depends more on "risk environment" within a society where growing social inequalities bring drastic divergence in ways of life (Rhodes et al., 2005; Atlani). This process will show that, even if two groups have the same behaviour, some might not be contaminated simply because their group did not encounter HIV (AIDS Action Europe, 2003, p.4). Strategies need not to focus on risk factors at the individual level, but rather on social and contextual dynamics, something that was constantly changing in post-communist countries' transitional times (Wright, 1998). But, the more circles of vulnerability someone is attached to, the less he is represented in political institutions (Gyarmathy, 2005). This explains why migrants and Romas are not part of any strategy in the region. They do not exist politically. We have no idea of their current serological situation, and therefore cannot address sufficiently their needs.

3.3 . SELECTION OF CASE-STUDIES

For the current work, we opted for two case-studies : Poland and Estonia. The two countries face an important disparity in terms of prevalence rate: Estonia being the highest HIV

prevalence rate in the EU, while Poland has one of the lowest in the whole EU but the highest among the Visegràd countries. This offers a good opportunity to use Mill's method of agreement.

Even more, the main justification lies in the fact that both Estonia and Poland have injection drugs as main HIV transmission route. This differs from the Czech Republic, Slovakia and Hungary, where the main route is sexual contact, especially among MSM. Romania has a very unique situation, the main route being among orphans and youth hospitalized during the nineties, which would have complicated any comparative study.

Another reason to justify the choice of Poland and Estonia as case-studies is the availability of statistics. Romania and Bulgaria, the latest members of the EU, have important gaps in their national statistics that would undermine any conclusions. Even more, their later accession suggests that diffusion of the EU strategy would also be delayed, thus complicating any comparison with other new member states.

Finally, Lithuania and Latvia would also be interesting cases to look at due to their their statistical similarities with Poland and Estonia. The infection route pattern is similar, and the general HIV prevalence rate is between the two. Nevertheless, they were rejected on the basis that it appears that Poland would offer a better contrast to Estonia.

3.4. POST-COMMUNIST POLAND: HIV POLICY FROM 1989 TO 2000

In light of the recent decade, we tend to perceive Poland as a nest of conservatism. Nonetheless, Poland has been one of the most innovative in the region on certain aspects of its HIV/AIDS policy. Unfortunately though, those pre-EU HIV/AIDS policies were often blocked by a lack of political will or resources. Needless to say, in those times of scarcity, HIV/AIDS did not become a priority for this emerging democracy. Votes were won on issues which seemed more pressing at the time, and there were no strong groups created to exploit the potential political cleavage of the AIDS debate.

Poland was particular because, even under its communist regime, private health care was available for independent farmers (McMenamin & Timonen, 2002, p.104). Of course, the post-communist transition forced an important opening of this private sector's role, but the tradition did help to face the change (McMenamin & Timonen, 2002, p.104). Poland, in the transition years, passed from a universal health-care system funded by the government to a regime that was funded by employers. This reform aimed at rescuing a "system nominally based on equal access to healthcare guaranteed by the state" by means of "efficiency enhancing market-type mechanisms and a greater involvement of, and clearer relationship with, the private sector" (McMenamin & Timonen, 2002, p.116), This new insurance scheme came in competition with other health service providers, such as hospitals, which now felt obliged to "create moral hazards within their institution" in order to secure higher levels of funding (McMenamin & Timonen, 2002, p.112). The chaos emerging from this policy led some hospitals to cut down on "unpopular" health services for patients who couldn't afford to pay for them (McMenamin & Timonen, 2002, p.113). Services for IDUs and sex workers were of course among the "unpopular" services which were first eliminated. In addition, the following game of defining new responsibilities on health left a lot of room for ambiguities, especially in terms of infectious diseases and prevention. HIV/AIDS patients definitively suffered from this policy transition.

In 1993, Poland created the national coordinating bureau for AIDS prevention under its health ministry, which created a diagnostic and therapy centre in Warsaw. Only in 1995 did Poland create a national program for HIV prevention, a program which has been judged inefficient by many specialists. Through this initiative, the government was able to offer free and anonymous testing for citizens everywhere in Poland. However, testing has been difficult to access in public facilities in remote regions. Furthermore, surveillance systems which were supposed to be increased through this initiative were "struggling because of under-funding,

reliance on obsolete systems and infrastructure, and a lack of epidemiological capabilities" (Atun, 2004, p.1390). When ARV and other treatments became available in the end of the 90s, they were strictly available in Warsaw (Integration Project, 2007, p.7). Even today, treatment centres are still concentrated in the biggest cities. In the wake of Poland's accession to the EU, its health system was weak and the country will need many more resources to effectively deal with the HIV/AIDS health crisis.

Legal institutions have played an important role in updating the country's practices. The national answer on HIV/AIDS was based on the 1963 Law on Infectious Disease, a law widely recognized as "inadequate" (Frankowski, 1998, p.346). On the basis of this law, patients suffering from other STDs had much more legal protection than those infected with HIV, which was classified as infectious. Poland also updated the legal protection surrounding medical confidentiality in 1996, defining sanctions for the one who will not respect the basic principles of article 40(2) of the Law on Medical Professions, the first important reform of the 1963 law.

Legal institutions were also very important in fighting prejudices and getting rid of the traditional repressive model. In 1989, the Polish parliament enacted a law forbidding the refusal of medical services to HIV-positive people. Medical workers, if they refused to provide those services, could face criminal sanctions (Frankowski, 1998, p.356). No such cases have ever been brought to courts. But this does not mean that, in practice, discrimination is not present among the medical staff. A poll held in 1990 revealed that 60% of medical staff wanted a mandatory HIV tests on all patients, a demand following the traditional repressive model of epidemiological control (Frankowski, 1998, p.359). There were strong defenders of prejudice and stigmatization in the Polish medical field. In 1998, 42% of health specialists said that HIV-positive patients were responsible for their infections (Frankowski, 1998, p.349). According to Frankowski, the 1990s have been marked by this fear and ignorance stemming from the health system

(Frankowski, 1998, p.349). The medical body thus "contributed to widespread hysteria about AIDS and to stigmatization and discrimination against AIDS patients" (Frankowski, 1998, p.346). But while numbers were still growing, they should have "acknowledged that attempts to normalize AIDS through applying the methods used to combat other infectious diseases have failed" (Frankowski, 1998, p.346). And, we have to highlight it: health departments were mostly staffed with medically-trained specialists. These prejudices are thus the ones of the entire health system. And those civil servants, without any sort of training other than purely medical, will block initiatives that are not theirs.

It is the legal institutions that insisted on prevention and fighting marginalization. Polish legal scholars emphasized "that repressive measures designed to prevent the spread of AIDS must be accompanied by a variety of preventive measures in many areas of social life" (Frankowski, 1998, p.376). The Polish national program has been influenced by such a way of thinking. As Frankowski explained:

> National programs for AIDS prevention is one of the examples of this way of thinking. It is based on the assumption that unwarranted violation of human rights of HIV carriers or AIDS sufferers (accompanied by stigma and discrimination) increase the probability of spreading HIV infection and, subsequently, AIDS (Frankowski, 1998, p.376).

But no cases of discrimination have been brought to courts, and the national program, in the wake of the enlargement, was strictly a paper with no measurable impact on society.

Preventive policies were lacking in the pre-accession Polish health system, even if, in theory, prevention should have been a focus. Coker politely framed the problem by saying that, even if there were prevention campaigns, "they had been somewhat piecemeal and the penetration of campaigns directed at those most at risk often inadequate" (Atun, 2004, p.1391).

Civil society was able to provide a certain alternative, as toothless it might seem at first glance. Poland was the first country to develop a strong civil society that actively participated in

HIV/AIDS issues. In 2000, some 80 percent of government activities and funds in the area of prevention were sub-contracted to NGOs (UNDP, 2004, p.59). But in spite of this, policies would flow top-down, creating inefficient structures that lacked coordination, a clear vision, and once again resources. NGOs were simply given money for what government judged useful, without having their say.

In theory, the country had progressive and interesting tools. It had a strong legal framework and an active civil society. But in practice, those progressive means were made inefficient by political and medical institutions fostering marginalization and refusing to change their approach. Good intentions were blocked by powerful actors, and remained on paper.

Finally, we cannot address the particularities of the Polish pre-accession AIDS strategy without referring to the Catholic Church. The country of the former Pope Jan Pawel II is the Central European state with "the most conservative representation of risk groups and the carrying of condoms" (Goodwin et al., 2003, p.1381). The influence of the Catholic Church in the media has been "pivotal in the restriction of safer-sex messages, making sexual health promotion a puzzle" (Goodwin et al., 2003, p.1381). In Poland, in a poll asking respondents to make free word associations with HIV/AIDS, a majority of the population did not hesitate to link "sins" and "gays"; the Polish people also freely associated AIDS with "misfortune" and "intolerance", something common in other Southern European catholic states, and Georgia (Goodwin et al., p.1380).

3.4.1. Marginalization in Poland

For Poland, the most at-risk were so marginalized that they did not even appear in the pre-accession strategies. The pandemic in Poland, like anywhere else in the region, started among MSM, bringing a strong stigma on this population. A 2004 poll concluded that 57% of Poles saw homosexuals unfavourably (Pogodzinska, 2006, p.59). Behaviours would prove that those

numbers would be even worse in the 1990s. The opening of centres for HIV/AIDS initiated many popular protests asking to put all MSMs in jail (MONAR, 2007, p.11). This led to massive waves of arrests in gay hang-outs for the sake of "protecting the public's health". This explains why governments chose a clear repressive path to epidemiological control, a strategy that failed as the number of infected cases rose drastically (MONAR, 2007, p.8). In 2000, the few cases of MSM transmission in the official statistics both address vulnerability and prejudice (AIDS Action Europe, 2003, p.3).

Poland, in spite of Monar, a powerful NGO that quickly established itself as a reference in drug addiction, was not able to contain the stigmatization and marginalization of HIV-positive drug users. In a poll asking the population "whom would you the least rather your daughter marry" respondents placed drug addicts in first position, before murderers or rapists. Those deeply entrenched prejudices are shared among many state officials and justified the refusal to offer HIV-related care on the basis that IDUs have no adherence[8] to ARV. This stereotyping stigmatized the IDUs even more, and contributed to unequal treatment for them, even if many studies demonstrated that lack of adherence is not necessarily true (Ware, 2005). However, since 2000, the real issue is not drug addiction anymore (MONAR, 2007, p.10). In 2006, 60% of new known infection would have been transmitted through sexual contact (MONAR, 2007, p.12). But the stigma remains.

During the communist administration, prostitution was not a significant problem in Poland. But with the opening of borders in 1989, it became an issue. If, at first, the problems arose from Poland's contacts with Eastern European sex-workers, the issue is now completely different. The problem is not at the Eastern frontier anymore, but at the Western one. This means that more people are moving in and out Poland, creating a shift in sex-workers. Since the EU

[8] Adherence refers to the capability of respect ARV treatment program as advised by a doctor in all its aspects.

accession, the region of Zielony Gory and other areas bordering Germany saw their prostitution scene booming. West European clients can easily get sexual services in small border areas, complicating the work of NGOs that are mostly based in big cities. It also means that sex workers are moving. It is not strictly a phenomenon of criminal networks moving their "staff". It is also, for example, the apparition of groups of young male sex-workers, who do not identified themselves with the gay culture, and are traveling from one place to the other, sharing style and language codes. Women prostitutes face a similar situation. And this does not even address the increasingly important issue of elite brothels that are booming in bigger cities, and where nobody really knows what the reality is like within. This provides a good example of the marginalization faced by Polish sex-workers.

Another key issue is xenophobia, encouraged by the recent case of Simon Moll. This popular Nigerian poet, after being used as a symbol of integration and multiculturalism, was found guilty of voluntarily transmitting HIV. A significant anti-foreigner feeling emerged out of the case. Racism has a long history in Poland. A quick look at Samoobrona' speeches, a party in the former governing coalition, proves that racism remains vivid. It also explains why the issue of migrants and HIV/AIDS is not debated publicly, even if it does exist.

3.5. POST-COMMUNIST ESTONIA: HIV POLICY FROM 1989 TO 2000

Post-Communist Estonia, like Poland, lacked "strong stable and strategic leadership, public health expertise and governmental and political support for health promotion" (Andersson, 1998, p. 1597). In many ways, Estonia followed the same path as Poland and other Communist countries, facing the same shortages in terms of resource provision. It also adopted a system of health-care funding based on employers' contributions. This was followed by an intense restructuring of the entire health system, which still left significant room for governmental participation (Habicht & Kunst, 2005, p.777).

HIV/AIDS started being monitored in 1987. If the country now has EU's highest rate of new HIV infections per year, before 2000 it was one of the lowest in Europe. In 2000, numbers of infected cases increased dramatically and rapidly, reaching a peak in 2001 among IDUs. State financed national programmes for HIV/AIDS prevention in Estonia started in 1992. Four national strategies have been published after this: 1993-1996, 1997-2001, 2002-2006, 2007-2011. The first two, which were the two framed outside EU influence, were rather general, which is understandable considering that they were framed before the numbers soared and when HIV was still a phantom menace. The weak pre-accession answer is thus justifiable, making Estonia a good example of how tragic a situation can turn when lack of prevention and ignorance intertwine.

Estonia also followed the same path as other post-communist countries in terms of framing HIV/AIDS as a low priority in the new democratic game. And like the entire population, Estonian authorities have also been affected by the "ethics and moral principles which applied during the Soviet time" (Andersson, 1998, p. 1597). Therefore the adoption of public policies based on public health perspectives and prevention had not been anticipated before the 2001 crisis. Legal institutions and political will only moved after it. But Protestant Estonia did not face the same prejudices on contraception and condom use as had Catholic Poland.

3.5.1. Marginalization in Estonia

In terms of marginalization, Estonia faced a unique situation. In a poll conducted in all of Central and Eastern European countries, most nationals freely associated HIV with gays, except in Estonia. In this Baltic country, most people associated it with IDUs (Goodwin et al., 2003, p.1380). This is no surprise since injection drugs were and are still the main contamination route.

As the issue of same-sex marriage is debated in the Estonian Parliament, we have to admit that MSMs are much less marginalized than in other countries of the region. According Rainer

Kattel, professor of political science from Tallinn University, Estonia has "not really gone through the enlightenment revolution" on this topic. He adds that "Estonia does have latent racism, but it is not violent like other countries. If you are openly gay, or of a different race, people will make mean comments to you, but won't beat you" (BBC, 2007, http:www.news.bbc.co.uk). A report dating from 2002 considers that there is a high level of discrimination against LGQBTT, but still considers that public opinion has changed in the last twelve years. There is greater tolerance and acceptance of alternative life-styles in general (Open Society Institute, 2002, p.60). The same study revealed that Estonian-speaking Estonians tend to see homosexuality more favourably than Russian-speakers. In fact, Tallinn is much more liberal on this issue than any of its neighbours from the Soviet bloc.

Aside from this relative open-mindedness, the Estonian population and medical staff still share the common stereotypes towards IDUs and their lack of adherence to treatment so it would be fair say that opiate users are as marginalized as in other Eastern European countries (Ware, 2005). Political forces did little to deal with the problem until numbers brought international scrutiny. Drug addiction faced a lack of political answer based on an outdated contagious disease laws, discriminatory regulation, and a weak response from civil society (Atlani, 2000, p.1554). Furthermore, political actors have been very good in preventing the message from being passed on, relying on the populist resentment against drug users or prejudices of Russian speaking-Estonian (Atlani, 2000, p.1551).

The HIV prevalence rate is high in Tallinn and other Eastern regions where there is a strong concentration of the Russian-speaking population, which is not surprising when we know that most IDUs are Russian-speaking (Lohmus & Ruutel, 2005). Being poorer, less educated, and more likely unemployed, Russian-speaking Estonians are important subjects in the layers of marginalization. Nevertheless, in the current political crisis, the government refrained from

addressing the issue of Russian marginalization. In fact, the spread of the AIDS virus simply became another thing to blame on the Russians. Many still assume that the pandemic came from the East.

In spite of many laws discriminating its Russian population, particularly the refusal to attribute full citizenship, many studies have concluded that Russians had a comparable levels of health care access as Estonian-speaking citizens, despite their "lower social and civil position" (Labicht, p.786). Nevertheless, primary health care comes too late when we talk about HIV/AIDS. And offering ARV and good testing does not prevent people from getting infected by the HIV in the first place. There are still no governmental prevention campaigns in Russian.

Sex-workers have become an important marginalized group with different risks depending on how they practice their profession. The legal framework evolved quickly, criminalizing pimping, but not prostitution, and a lot of work has been accomplished to help sex workers (Aral, 2005, p.5). Elite sex-workers are often affiliated with networks that will move them around the region. They will often work in brothels in Tallinn within which Estonians will be denied entry, on the basis that it is a small country and that prostitutes fear to be recognized (Aral, 2005, p.5). This is a strong mechanism to avoid marginalization. Those sex-workers could be your neighbours, but you would never find out. With increasing used of the internet, they are even more invisible. But, more importantly, those women know the risks and protect themselves (Aral, 2005, p.31). And they are based in Tallinn, where there are many services available to them. The important group that a strategy should focus on is "street workers", which are less educated and do not have the walls to protect them from marginalization. When they choose this path, they will not get out by themselves (Aral, 2005, p.31).

In sum, what needs to be understood is that the pre-EU accession HIV responses, both in Poland and Estonia, still relied on a modernist approach and on a repressive model of

epidemiology, with a strong concentration of powers within national government's hands, and strong mechanisms of marginalization. This is the challenge of the EU.

CHAPTER FOUR. FINDINGS AND DISCUSSION : DEVELOPMENT OF STRATEGIES POST-ACCESSION

The present chapter aims at answering the research question: how deeply has the EU been able to imprint its postmodern strategy on the new member states' health system. Therefore, we need to ask ourselves two questions: have CEE countries integrated a postmodern approach, and how much is the EU responsible.

We will answer those questions in two parts. First, we will present our findings on how the two case-studies of Estonia and Poland moved towards postmodern health systems. This analysis will be based on the four criteria elaborated during the preceding chapters : inclusion of non-medical strategies that move away from the traditional repressive model (or the panopticon), the capacity of including new narratives and diffuse power among the different actors (particularly civil society), respect of human rights, and capacities of fighting marginalization.

Next the discussion will focus on what the role of the EU is in the integration of postmodernism within national answers to the HIV/AIDS crisis. We will use the same four criteria listed above to make this assessment.

4.1. FINDINGS ON NATIONAL RESPONSES AND METHODOLOGY

The following findings have been based on the analysis of interviews made on a person-to-person basis. The option of email question-answers was also offered, but was not used. .In all, conducted interviews involved 18 activists from Poland (Krakow and Warsaw) and Estonia (Tallinn).

I conducted interviews on a person-to-person basis in Estonia and Poland by myself. I used the questions that can be found in Annex 1. The interviewer felt free to deviate from this list to clarify certain points. Interviews lasted between 45 minutes and one hour, sometimes even more as the interviewer could also spend some times visiting organization facilities.

Interviewed actors were identified based on their active involvement with non-governmental organizations fighting HIV/AIDS. These organizations are either part of European networks or are active in international roundtables, such as meetings with the Global Fund. I constructed a list of such NGOs based on a review of the literature, internet searches, and personal contacts. I contacted 19 pre-selected organizations by either phone or email; of these 11 organizations agreed to answer my questions. Two other organizations agreed to meet at first, and then were unable to answer questions (Polish Res Humanae and Estonian Gay League). Finally, an appointment with Narva Rehabilitation Centre for Alcoholics and Drug Addicts was cancelled due to scheduling and logistical problems.

In Poland, representatives from five different NGOs, based either in Krakow or Warsaw, were interviewed. Among those, there was an association of persons living with HIV/AIDS (Badz z nami), a group defending the rights of LGBQTT (Lambda Warzawa), an organization dealing with drug addiction (Monar), and two associations offering support to street kids (Tada and Parasol). All interviews were carried out between August 23th and August 30th 2007.

In Estonia, all interviews were conducted in the capital city of Tallinn and took place between September 1st and 8th 2007. Among those interviewed were representatives of two organizations of PLWHA (ESPO and Ligo), groups focusing on HIV prevention among particular population groups (Estonian Network of People Living with HIV, EHPV), Convictus and Tugikeskus), and a private initiative to promote health (Terve Esti).

Staff from Integration Projects, a pan-European network of HIV/AIDS NGOs that receives funding from the EU, were also interviewed in Paris. Integration Projects is highly active in both Poland and Estonia.

The actors were interviewed as representatives of an organization. This has been done to ensure that those persons present a view relevant to this study, and to avoid emphasizing the

personal over the institutional process, which is the main subject of this study. The questions used, which the reader can find in Annex I, were also focusing on institutions rather than the individual. Once again, we have to reiterate that the goal is to study if the EU has successfully been able to impose its postmodern strategy, offering among many other effects an opportunity for the development of new narratives. It does not attempt to assess what those narratives are or to offer a comprehensive analysis of the individual psyche.

All representatives of governments or national agencies declined our invitation for an interview. To take into account their point of views, we used the national programmes and different communications published by the government or their agencies. For Poland, we used the 2007-2011 National Program, constituting the white paper on HIV/AIDS, and a review of the 1985-2005 Program written by the National Aids Centre. Other documents, including advertising campaigns and general information documents, have also been analyzed.

For Estonia, we studied various official documents. Many of those have been published by Tervise Arengu Instituut (TAI), the national agency responsible for the implementation and the development of a strategy against HIV/AIDS. These include two national programs, covering the year 2002-2006 and 2006-2015. Other documents from TAI, "The dynamic typology of sex work in Tallinn" as an example, have been used. The Global Fund, with its well documented website, offers diverse and useful publications on Estonia, including its useful Grant Score Card.

More information can be found on the methodology and methods of those interviews in Annex II.

4.1.1. Estonia

Interviews in Estonia were conducted in early September 2007, which was bad timing since all governmental organizations and NGOs were meeting representatives of the Global Fund and the government in order to secure funding for the upcoming months. The parties concluded during this meeting a short term agreement. Governmental actors, who at first expressed their wish to participate in this research, cancelled at the last moment. They then refused to answer questions which had been forwarded to them through email.

4.1.1.1 The end of the panopticon

Estonia made drastic changes since 2000 in its approach to HIV/AIDS. The urgency of the situation, following the 2001 statistical HIV explosion, brought a lot of international attention. The country became one of the only EU-member to receive money from the Global Fund (with Romania and Bulgaria). This grant changed a lot of things for Estonia. It allowed the country to fund needle-exchange and harm reduction strategies, which the government refused to consent to before the first grant was allocated in 2003. Most of the Global Fund grant has been used for initiatives led by civil society, while the government assumed most of the costs associated with treating people living with HIV/AIDS (PLWHA), particularly ARV.

Nevertheless, Estonia achieved major steps away from the repressive model. Tugikeskus, a Tallinn-based NGO, has been sued by the government when it initiated a methadone program. This program has now been fully acknowledged and integrated in the national strategy, with all other harm reduction elements. Sex-workers can now have targeted testing and counselling, including condom distribution or anonymous testing. Once again, those initiatives were civil society-based, and were funded by foreign aid agencies before the Global Fund. Furthermore, the Global Funding grants impose a stringent evaluation with clear objectives, right down to details such as the precise number of people to be trained in peer-support. Those tools offer a clear

indication of what is to be done and how. The Global Fund methods are neither imposed nor done with a stick approach, but rather could be labelled as a carrot approach.

All interviewed actors agreed that a non-scientific answer had been at the core of the national strategy since 2002. Harm reduction and condom distribution was extended to prisons by NGOs like Convictus, an action clearly supported by the national strategy. So far, all civil society-based prevention activities were being funded by the Global Fund, but these new developments seem to indicate that they would now be financed by the government. Gay associations are producing their own material and distributing condoms and lubricant in gay clubs, saunas, and backrooms. They have independent sources of funding in addition to the money coming from the Global Fund.

Finally, the Global Fund evaluated the performance as "very good" in all aspects of developing a prevention programme, including harm reduction (Global Fund, 2005, p.10).

4.1.1.2. New narrative, new power relations

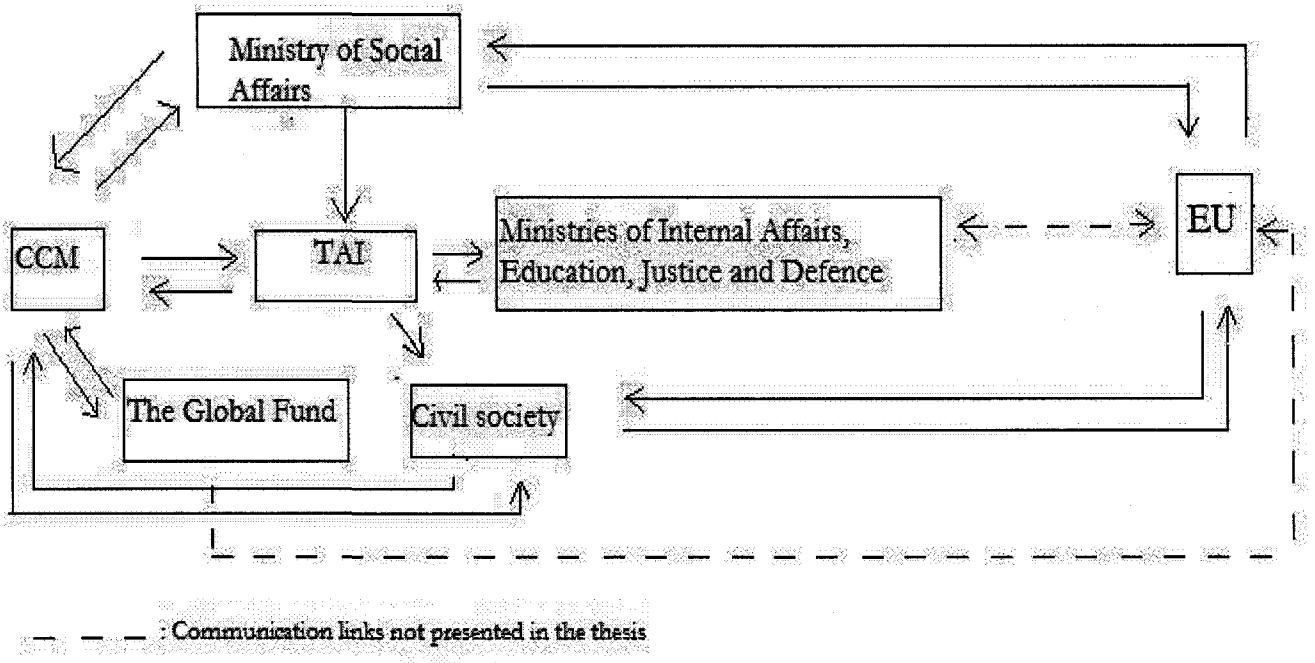
Estonia created the National Institute for Health Development (Tervise Arengut Instituute, TAI) in 2003, a national agency responsible for promoting health in general, and fighting HIV/AIDS more specifically. Under the Ministry of Social Affairs, it coordinated relations with other partners including the Ministries of Internal Affairs, Education, Justice and Defence, civil actors, sub-contractors, and the Global Fund, a clear step towards diffusing power among the different actors

TAI also coordinated the responses to health threats like TB and substance abuse, which are important issues to deal with for effective HIV prevention. In sum, there is a clear acknowledgement that there is no point in working with a strategy which does not tackle issues that increase HIV vulnerability. This is a clear step towards the integration of postmodern thought in a health system that broke with epidemiological strategies strictly based on a medical answer.

The agency incorporated social scientists as well as medical specialists to its staff. In other words, the structure of health policy-making is less vertical than it used to be, and quite obviously includes a non-medical element. Finally, TAI has achieved a certain level of autonomy. In negotiations with the Global Fund and the Country Coordinating Mechanisms (CCM), the national committee responsible to negotiate with the Global Fund, delegates of TAI currently sit beside governmental representatives. The organisation can also initiate policies in certain delineated areas

Figure 1 represents the communication links among Estonian actors on HIV/AIDS, based on an analysis of official governmental documents and interviews.

FIGURE 1. Communication links among Estonian actors on HIV/AIDS



The different NGOs interviewed in Estonia revealed that they had not received money directly from the government's budget. All funding allocated was coming from the Global Fund grant, which ended in May 2007. When the government refused to respect its previous

commitments to ensure the same level of funding, all HIV-related civil society groups came together and launched an international campaign through established European networks to pressure their government to secure funding. This pressure worked, and, in October 2007, the government finally accepted to make available the same amount of funding as Estonians had had with the Global Fund. We still need to see if this commitment will be respected. Nevertheless, UNAIDS considers that this money is not enough, and much more should be injected in health (UNAIDS, 2006, p.2).

More importantly, NGOs are represented in the CCM for the Global Fund. This became the main institutionalized channel of discussion between representatives of the government and civil society. The number of participants is small, and the cooperation is still limited to the contingencies of the Global Fund, but it is a first attempt to come together and communicate, which is not happening anywhere else in the region.

Estonian NGOs developed strong ties with each other, which is also something unique in the region. They work efficiently together, sharing resources and even office space for some. Five different NGOs share a compound in downtown Tallinn. Many came together through this process of presenting projects to the Global Fund and the follow-up meetings that have been held since. Even more importantly, they sporadically improvised a united front when the government announced that it would not respect earlier commitments. Nevertheless, many activists explicitly referred to the scarcity of resources as creating a huge competition among NGOs. One activist framed the metaphor as a ring where everybody is boxing with each other. But, in contrast to Poland, at least there is a ring in which to fight . Most Estonian activists we met got involved in the issue when they discovered they were themselves HIV-positive. They all come from different backgrounds but met because of HIV/AIDS, which explains why most NGOs deal strictly with the issue of HIV/AIDS, in comparison to Poland where NGOs tend to tackle many issues.

Since NGOs had to apply for grants, the Global Fund process led to effective lobbying and improved budget-drafting capacities. By coming together and defending their interests, they forced the government to acknowledge them. They succeeded in creating a critical mass for effective lobbying, showing that the power is not concentrated within governmental hands. But the support from other European NGOs or European networks has been crucial. Estonian NGOs have established different multilateral links with several European networks and bilateral ties with foreign national associations. The 2007 united front against the government was successful because of the webs that had been created with EU funding and support. Thus, the EU sustained the momentum accumulated through the Global Fund process.

But the budget of civil society still comes mostly from international actors (including the EU) or the Estonian government. Estonian NGOs interviewed are still not able to secure their own funding, in spite of different attempts for funding from the private sector (*Terve Eesti* being the sole example).

Another reconfiguration of power came from the inclusion of a new level of governance in health. The city of Tallinn, for example, is funding many projects to help IDUs or sex workers. The city of Narva also funds the answer to HIV/AIDS, funding different civil society initiatives. Therefore, the number of political actors involved in the HIV/AIDS strategy is increasing. There is thus a diffusion of power among different political levels and different organs at the same level. The health system is not the only one with a vertical structure under the Health Ministry.

Power reconfiguration also means that NGOs can work in areas where the government refuses to assume responsibility. Estonian civil society became the main provider of prevention services in Russian language. The government, defending a linguistic and ethnic hard-line against the Russian-speaking Estonians, does not consider the specific needs of this population, according many actors interviewed. NGOs, in such a context, became the main distributor of

Russian-language prevention material. It is an important step, especially considering that the Russian population seems to be more affected by HIV than the Estonian-speaking population. In many associations, Russians and Estonian-speaking people work together in a way that the national government is not able to do. Therefore, civil society became *de facto* the only service provider for an important percentage of the population, definitively proving that the state has lost its monopoly over policy-making.

Both the national strategies and NGOs highlight the importance of increasing self-responsibility in health among the population. Peer-education and outreach programs are now common practice, and are highly emphasized in the national strategy. Estonian actors have been able to create support groups and to provide psychosocial support to different clienteles, including sex workers and detainees within many prisons in the country. The word "responsibility" often came out of the mouths of the interviewees. Mostly through the work of NGOs, Estonia succeeded in creating a context where HIV-positive people are not exclusively submitted to the medical body, and where they actively participate in prevention and solution finding

4.1.1.3. Human rights approach

The last two national programmes clearly emphasize the role of human rights. According the 2002 National programme, "respect for universally recognised human rights is one of the fundamentals of the national programme" (TAI, 2002, p.2). The interviewed actors did not mention any problems in this respect. The Commissioner for Human rights of the Council of Europe, in its last report on Estonia, concluded that the country's answer was satisfactory (CoE, 2007, p.28).

4.1.1.4. Marginalization, stigmatization and vulnerability

The last national programme, covering the years 2006 to 2015, has been drafted conjointly between government representatives and TAI. It was not simply imposed by the Ministry of Health, like in Poland, but rather has been the outcome of consultations with non-governmental actors. The strategy recognizes six more vulnerable groups, within which it wishes to reduce "risk behaviour": youth (15 to 24 years old), injection drug users (IDUs), commercial sex workers, prisoners, Men having sex with men (MSM) and People living with HIV/AIDS (PLWHA). Much more than labelling them, the strategy attempts to target prevention, and does acknowledge simple facts, such as the fact that public advertisement may not be the best way to reach IDUs. In other words, the strategy makes it clear that there is no "one-size-fits-all" prevention strategy, acknowledging that being vulnerable is neither a fixed identity nor simply a behaviour issue. An obvious example is the different strategies needed for sex-workers depending on whether they are on the streets or in "elite brothels". This way of understanding marginalization and vulnerability is definitively postmodern. It could even be said that it is a vulnerable population-based approach to prevention, since the government spends most of its attention on targeted rather than general prevention.

The particular issue of the Russian-speaking population is not addressed at all by the government or TAI. Being Russian is a marginalizing factor, which then increases vulnerability. This Russian identity should not be targeted as a direct source of increasing vulnerability. Since 1991, the Russian-speaking population lost several opportunities to work and get educated because it was clogged in a spiral of marginalization. However, the limits between being Russian-speaking and being vulnerable to HIV/AIDS tend to blur while the situation of the former is worsening due to increasing prejudices from the Estonian-speaking population, which tend to see them as "parasites", according to several activists. In other words, the goal is not to

target them as a "risk group", but more minimally, and as a first step, to translate national prevention campaigns into Russian. The 2006-2015 strategy, although it is available in English, has not been translated into Russian. This is a good indication of what is happening: the government clearly refuses to compromise its strong anti-Russian stance even for the benefits of an efficient HIV/AIDS strategy. So far, only NGOs are working towards a solution that includes the Russian-speaking population.

At the same time, many Estonians share the prejudice that HIV/AIDS is strictly a Russian problem. As a representative of the NGO Tegikeskus said: "We try to explain that it is not a Russian problem. We receive a lot of comments that it is their problem, but only naïve people can now say so". While there is an important increase in heterosexual intercourse transmission, an activist quickly indicated that "sex does not have a language". In fact, the Russian-speaking population remains an important challenge which needs to be addressed in order to build up a successful strategy. All actors labelled it as the main issue now. In sum, the Russian-speaking population is both stigmatized and being ignored by the health system beyond primary health care.

There is no gender component integrated into the strategy yet, even though the rate of HIV-positive women is also increasing quickly. For the NGO LIGO, the needs of HIV-positive women are not sufficiently addressed, often being simplified as an issue of sex-workers or Mother-to-Child-Transmission (MTCT). In comparison to Ukraine, which developed strategies to include and empower women, Estonia lags behind. There is little account of women's specificities in the general Estonian response.

This is symptomatic of the Estonian strategy which does not accept the complexity of the dynamics of marginalization as it would be understood by a postmodern. According to Estonian activists, Russian-speaking women face a higher level of marginalization and discrimination than

Estonian-speaking ones. Therefore, the marginalization that faces a Russian-speaking women is much more important than the one faced by an Estonian-speaking women. Similarly, most activists would also acknowledge that the Estonian-speaking population tends to be more tolerant of MSM than their Russian-speaking fellow-citizens. In short, some identities will worsen marginalization based on another identity. Marginalization is much more complicated than simply being concentric circles. No graphs can reproduce the subtlety and the variability of this phenomenon. But strategies remain framed with little concern for the Russian-speaking population, which lacks representation within health system. Strategies are imposed on them rather than in cooperation with them. In other words, important aspects of marginalization are being left aside by ignoring the Russian voice.

It is thus clear that Estonia moved towards a postmodern health system, and that this shift has been mostly driven by the work of NGOs, which are themselves supported mostly by the Global Fund. Nevertheless, this transition was made possible by the creation of TAI and the inclusion of postmodern strategies, and both elements can be credited to the EU's work. The upcoming discussion will clearly delineate the EU's responsibility.

The coming months will be crucial to see if all those postmodern ideals will remain and if the government will maintain its financial commitment. Certainly the disappearance of the Global Fund will change the relationships among the actors, possibly making the EU an even more important actor.

4.1.2. POLAND

When the Kaczynski brothers formed the governing coalition in 2005 with two radical rightist parties, politics in the country moved to the right, including health policies. Following this election, the new government officially refocused its HIV/AIDS policy on family and abstinence. The new government thus sent an anti-postmodern message. But its message was not

heard by the actors working on HIV/AIDS. This is how we have to understand the Polish case : confrontation among different levels of governance that provide a totally different answer from what the Kaczynski government wanted to see. The upcoming parts will develop this idea.

4.1.2.1. The end of the panopticon

Officially, the Polish government did not embrace as easily as Estonia the approaches that include social science and prevention. In terms of sexual responsibility, the government refused to promote a contraceptive, the condom. There is no mention in the 2007-2011 Polish National strategy at all of condom distribution in the strategy. The only occurrence to the word "condoms" is on page 11, where it says that the use has decreased (PMoH, 2005, p.11). Harm reduction is mentioned for the first time in the annexes of the strategy (PMoH, 2006, p.30). Outreach work and peer-support are excluded from the Polish national strategy. Under the Kaczynski government, drug laws became even harsher, further criminalizing personal consumption, and the government still promotes drug abstinence rather than implementing drug-substitution therapies or harm reduction.

Those two cases represent very well the dilemma that faced the Polish strategy. The strategy failed to emphasize the need for prevention and failed to get rid of the old repressive model. This is the stance of the national government, but this does not mean that others are following those guidelines.

Activists tend to agree that the government is not doing enough on prevention, and is not adopting the proper means to reach the population. It is unclear if this is due to the particular political context or some technocratic blindness, but it does not prevent NGOs from actively seeking the marginalized participation. In the words of an activist from Parasol, an NGO working with street youth, "the problem of marginalized people, like sex workers or IDUs, is that they believe they cannot be helped and that they do not fit in society". All NGOs clearly understand

that there is a relation of trust between "society" and "marginalized groups" that needs to be built, and that a successful HIV/AIDS strategy needs to address this issue. The groups are thus basing their approach on outreach work and peer-support. Monar, the most resourceful and powerful NGO that deals with HIV/AIDS, has developed good outreach strategies for IDUs. Officially, Monar emphasizes "drug abstinence". In practice, its volunteers approach IDUs in parks and streets with the goal of informing them on HIV/AIDS and implementing a needle-exchange initiative. Monar also developed a methadone program in many Polish cities. A similar approach has been developed by NGOs to reach MSMs. Free condoms and lubricants can be found in LGQBTT gathering places, which simultaneously provide information. Their strategy also targets unofficial hang-outs, like parks well-known for being MSM hang-outs such as the Planta Park in Krakow. Outreach work has been developed for sex-workers too. Furthermore, Lambda launched its own ad campaign which directly targets MSM : "*zawsze z gumy*" (always with gum, the slang word for condom). In sum, the official Polish answer is still very concerned with morality, and chose to not develop postmodern strategies despite their proven success, but the civil society, being resourceful enough, were able to shape a totally different reality than what is on paper.

4.1.2.2. New narratives, new power relations

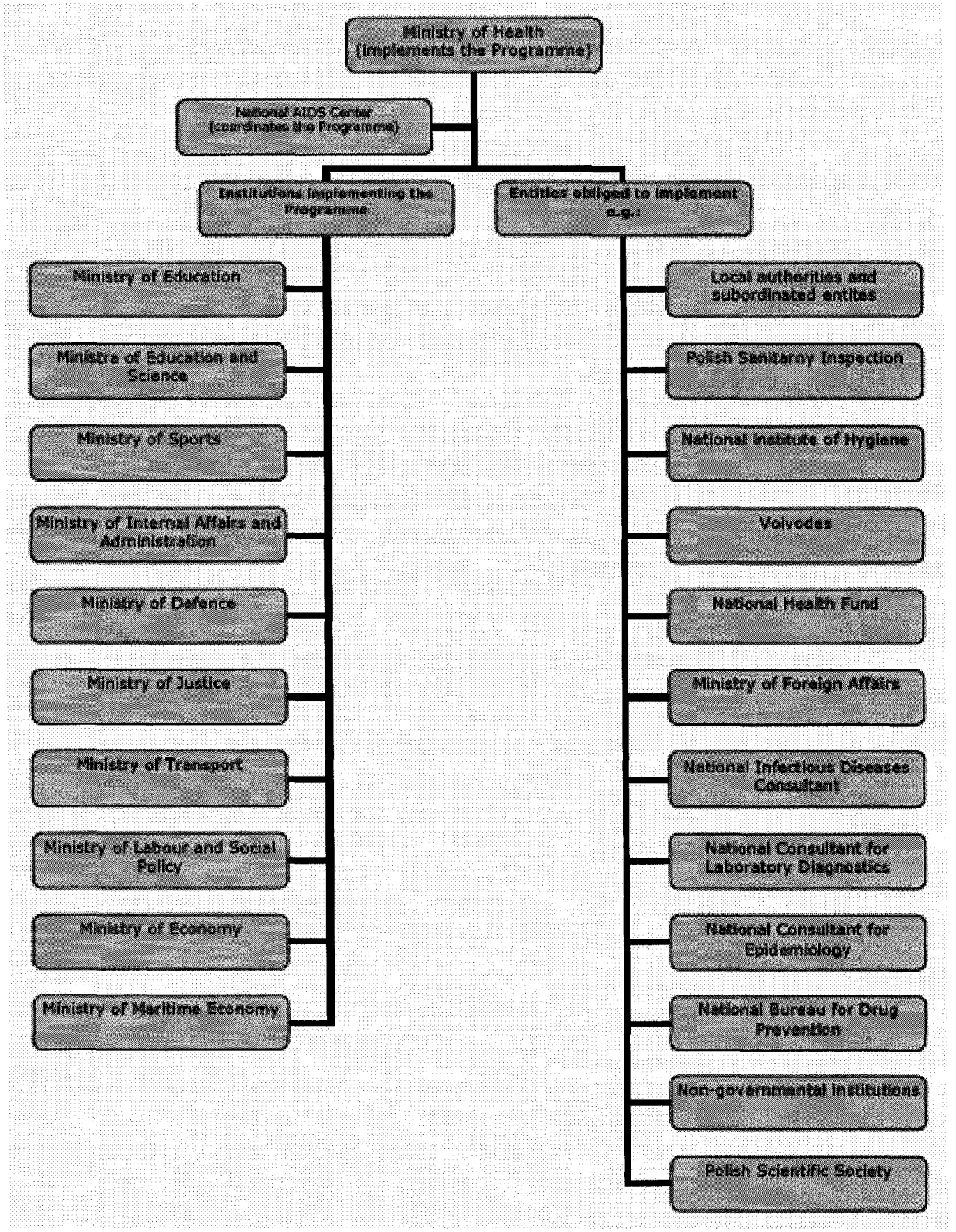
On a year of rule under the brother Kaczynski, all activists came to the same conclusion: overall, the new politicians at legislative/executive levels did not change anything outside of the governmental buildings in terms of HIV/AIDS. This could be the first important proof of the postmodernization of Poland's fight against the pandemic, showing the relative autonomy of civil society groups on what used to be exclusively state matters. In other words, power become more horizontal. It is not because the head, the Health Ministry, that those decisions will be followed blindly. Alas, autonomy is not necessarily strength. Before the election of the Kaczynski government, the Polish inherited an independent National AIDS Centre (*Krajowe Centrum ds.*

AIDS) in 2005 to implement the Polish National Programme for Combating AIDS. The Centre does not frame the National programme for combating AIDS, it simply implements it.

Most actors agree that the agency is limited in its will. In fact, the national agency lacks the resources and the money to meet its commitments. In 2000, 10,25 million zlotys went for HIV prevention. In 2006, the numbers had dropped down to 6,04 million. The Kaczynki government has been responsible for the significant cuts in prevention.

The Polish National AIDS Centre respects the EC recommendation proposing the creation of an independent multi-disciplinary body, something already included in the 2004-2006 Strategy. It is assumed to be "autonomous", but the very vertical diagram (cf. Figure 2) shows that it is dependent on the Health Minister. The national agency is the lackey of the Ministry of Health. The 2007-2011 strategy was framed by the government. According to activists, decisions will come from top to bottom, and there will be a lack of consultation among the different levels of government. No interviewed NGOs have been consulted on the HIV/AIDS strategy, and the issue is not even a source of debate within parliament. The Ministry is mostly filled with medical staff, still assuming that it has full knowledge over the issue. The recent nomination at the head of the National AIDS Centre of Michal Minalto, former president of *Kampania Przeciw Homofobii* (Campaign Against Homophobia), seems to be an opening to NGOs within a very vertical structure. Nevertheless, judging by what has been done so far in terms of changing political structures, Estonia has made a much greater step towards postmodernism than Poland has in terms of diffusing power among different actors.

FIGURE 2. ENTITIES IMPLEMENTING THE POLISH NATIONAL PROGRAMME FOR COMBATING AIDS AND PREVENTING HIV INFECTIONS



Source: Polish Ministry of Healh (PMoH, 2006, p.20)

This being said, if some level of government clearly expressed their reluctance towards a postmodern approach, some others embrace it. In fact, it would be fair to say about Poland that one of its hands ignores what the other one is doing. While Lech Kaczynski served as president of Warsaw and banned gay pride, civil servants from the social committee funded Lambda Warszawa, a LGQBTT group. It still receives money from the *Gmina* (municipal government) for HIV campaigns in spite of the government *modus operandi* of "family and abstinence". Similar ties were developed at different political levels. Monar, an NGO that works with IDUs, developed strong ties with Krakow's *Gmina* and the police. To the latter, Monar offers training on HIV/AIDS and IDUs, and in exchange, the Police does not interfere in the work of the NGO, ensuring there are no obstacles to needle-exchange or methadone programs. Their relationship is so good that in 2007, when outreach workers were in a park for a needle-exchange program, policemen consulted them before to undertake an operations further away in the park to ensure that Monar staff would not perceive this operation as police interference. But unfortunately it is not all NGOs that have the same level of cooperation. One activist from Parasol pointed out that after having sent a grant proposal to the *Gmina* identifying one of the MSM hang-out, the Police raided the location.

Monar also receives grants from the Gmina for its outreach program. There are plenty of other examples of collaboration between civil society groups and different levels of governance, especially the municipal governments. NGOs have succeeded in securing funding through this form of "civil servant activism" within which projects receive funding without public discussion. In opposition to a very conservative political system, a hidden postmodern agenda was developed by civil servants and local politicians who understood issues differently, and who used their personal power to pursue what they judged to be worthy. It is not because a national strategy remains mute on a topic that nothing has been done by the government officials.

Another important issue is that HIV/AIDS prevention often occurs in programs that deal with many issues at the same time. As an example, both Parasol and Stacja, two associations receiving funding to help street kids, have created an HIV/AIDS prevention program within a wide spectrum of initiatives. The same thing is true for Monar and Lambda Warszawa whose first objective is not to fight HIV/AIDS. This also explains why Polish NGOs tend to put a lot of energy in outreach work, the activists often being social workers who became involved in HIV/AIDS almost accidentally, by applying their knowledge of social sciences. Furthermore, prevention on HIV/AIDS can be done at the same time that volunteers officially work on a different issue in the streets. It does not cost anything for an organization that invites street children to their shelter to also talk about condoms. This situation is quite different from the one in Estonia where many more NGOs deal strictly with HIV prevention, not having the wide focus on different issues as their Polish counterparts. Therefore, Polish civil society is more able to address the issue of marginalization and HIV/AIDS through its structure.

Polish NGOs do meet with each other, but are not as cohesive as Estonian NGOs. In Poland, networks are informal. Activists proceed with ad-hoc meetings to share knowledge. They know each other quite well and do not hesitate to cooperate. They have never lobbied their government the same way the Estonian NGOs did in the fall of 2007. They tend to pursue their goals quietly, and keep their projects from public relations as much as possible. Marcin Drewniak from the NGO Parasol would frame it this way: "we don't want to advertise our programs with sex workers, MSMs, or prisoners; we just want to work. We are not making politics". Some groups get involved in politics more than Parasol, but no Polish NGO has launched a public campaign on HIV/AIDS the way Estonian civil society groups did in the spring of 2007.

The national strategy set as an objective to support and promote non-governmental organizations (PMoH, 2006, p.7). This is not surprising considering Poland was the first country

of the region to integrate those civil society groups into the fight against HIV/AIDS. But it was only in the 2004-2006 strategy that this participation became formal. The government finances NGO's work through short-term project-based grants. Groups need to apply for the funding. For activists, this strategy leads to a short-term vision, since they cannot secure funding for longer-term projects. Besides, funding for NGOs from the national government has decreased. In 2003, 97 private of civil society initiatives received funding. In 2004-2005, the number of projects was reduced by a third, following substantial budget cuts by the government. In sum, in comparison with Estonia, NGOs in Poland remain feeble. None of the NGOs I met during the course of this research received money from the national government or were invited by the government to express their point of view. The situation might have been similar in Estonia if it would not have received Global Fund grants, which enforced communication links between civil society and government through the CCM.

Polish NGOs have also been able to profit from the EU accession by communicating with networks of other European actors. This cooperation has been bilateral (with a foreign national organization) or multilateral (through an international umbrella or a multinational network). For example, because of its participation in the Eurasian Harm Reduction Network, Monar has been able to improve its data collection system, its structure, it has been able to share best practices in the quickly-changing field of harm reduction, and it has acquired the possibility to send staff abroad for training. It also developed better outreach approaches with the support of a Dutch NGO, explained one of Monar staff.

In spite of this increasing role for civil society, there is still a low level of responsibility among the general population. Funding of civil society initiative is still either coming from the government or from outside the country. The few attempts for fundraising were a total failure. The NGO *Res Humanae* attempted to gather funds through a public fundraising. They received

only three donations on thousands requests. Poles, when filling their tax declaration, have the possibility to give 1% of their taxes to one NGO of their choice. Monar profits from the initiative. But this funding remains difficult to secure, since it requires a certain level of organization that only Monar, with over 1000 staff members, can ensure. Smaller NGOs cannot profit from this initiative.

4.1.2.3. Human rights approach

Polish national strategies refers to the respect of human rights for many years now (National AIDS Centre, 2007, p.9; PMoH, 2006, p.6). No comments can be found on the report of the Commissioner from Human Rights of the Council of Europe about HIV/AIDS in Poland (CoE,2007a).

4.1.2.4. Marginalization, stigmatization and vulnerability

The 2007-2011 National Programme clearly target vulnerable groups, and propose strong objectives in terms of prevention and treatment. This looks nice on paper, but actions revealed another reality. The Kaczynski government has been quite successful in fostering the process of marginalization, rather than fighting it. Banning gay pride events, enforcing harsher laws on drug consumption, making aggressive declarations against those who do not follow the Catholic and family-oriented policies of the government: this was the credo of Kaczynski's party *Prawo i Sprawiedliwość* (PiS) and its two allies while in power. If the *Platforma Obywatelska* (PO), Donald Tusk's party who won the October 2007 legislative, is offering a pro-European platform, his policies can still be considered very conservative. His party refused to include homophobia in EU anti-discrimination directives, and still supports a strong legal and penal answer to drug substance problems.

The 2007-2011 HIV/AIDS Programme, framed in 2006, respects the style of government at the time of its conception. In the document, an important number of pages present the

epidemiological situation and outline the incentives and institutions behind the strategy. Vulnerability, on the other hand, is only addressed in the annex. Those annexes contain objectives, means and indicators to evaluate the strategy. But prevention is still framed in general terms. In other words, it targets some people, but does not provide an efficient strategy to reach them. This can be illustrated by the ad campaign launched in 2007, "*W życiu jak w tańcu, każdy krok ma znaczenie*[9]" (in life like in dance, steps matter and can be counted). In the ad, we can observe the profile of a young woman. There is no mention of HIV/AIDS, no information on the virus, and no invitation for testing. The TV ad campaign is similarly vague. It shows beautiful young people dancing with the sentence "*Nie daj szansy AIDS*" (don't give AIDS a chance) to the dancing metaphor. An activist said that it looked more like a shampoo ad than an AIDS prevention campaign. There is a clear attempt to offend nobody, but also to elude the core of the problem. In a similar vein, the National Programme puts more emphasis on educating pregnant women than on harm reduction or helping sex-workers. As three activists pointed out, there is a clear attempt to formulate a national strategy that will not shock, focussing on women and family. Once again, the niceties contained in the Programme do not hold the test of the reality. The Programme's objectives are nothing in comparison to the very targeted strategy in Estonia.

In the strategy, we can note the presence of "HIV-mainstreaming", or the attempt to include in all ministries a component of HIV/AIDS prevention. This also remains on paper. This would be promising if one did not know the position of Roman Giertych, former education minister and chairman of the radical right party *Liga Polskich Rodzin* (League of Polish Families, LPR), who said that "homosexual propaganda" should not be allowed in school.

Nevertheless, most activists said their work was getting more and more complicated. There is a growing disappearance of the marginalized from public places. An activist explained

[9] All Polish translations are the author's translations

that he had seen a shoeless and homeless IDU with a cell phone, to call his drug dealer. A similar phenomenon is happening for prostitution and anonymous sex among MSMs with the rise of the Internet. As these vulnerable groups disappear from public places, outreach work becomes increasingly difficult.

As was presented in Chapter III, another important issue is growing mobility, especially among sex workers. They are difficult to reach for HIV prevention. In other words, NGO's outreach work can be quite limited by the incapacity of NGOs to follow those movements.

One last thing must be remembered in the case of Poland. If some conclusions in this part appear very harsh, Poland did move towards a postmodern health system, mostly through the work of its civil society and some individuals that did believe in more than the Kaczynski government *Te Deum.* Since last October, a new government has been in place. It may allow a better fulfillment of the 2007-2011 strategy, or it may even write a new one, free of the fear of hurting certain people's sensitivity. So far, no change has been made.

In sum, Poland is farther from postmodernism than Estonia. Most of the changes have been implemented by active initiatives of particulars, which were able to challenge the lacks of the central government.

4.2.THE EU'S ROLE

While the last part focussed on showing how postmodernism became integrated into national mechanisms, we will now look concretely at the role of the EU in suggesting those changes. Most actors interviewed considered that EU accession had had too little of an impact in the field of HIV/AIDS, but remained positive about the future outcome. From the beginning of the accession process to full membership, the influence has been considerable.

Before examining this influence, we need to clarify one thing about Estonia. One factor has been crucial for the improvement of the Baltic country's response to HIV/AIDS: the urgency

of the situation. If the country would not have faced the 2001 boom, it would not have received the Global Fund grant which injected a lot of money in the answer and supported the development of the current approach. But it would be unfair to see the Global Fund as a significant factor leading to a postmodern approach. Many countries, such as Ukraine, Belarus and Russia, received Global Fund money without moving towards postmodern policies. Like Coker phrased it: "Russia, Ukraine, and Belarus seem to be repeating the ineffective responses of others as they grapple with the development of policy responses to an infectious disease that highlights social and moral fault lines" (Atun, 2004, p.1391). Although "support from the Global Fund, World Bank, and bilateral donors is clearly needed, fundamental cultural, political, and health system shifts are essential if a strategy focus is to be guaranteed" (Atun, 2004, p.1391). Furthermore, in spite of a clear warning with its suspension from the Global fund in 2004, Ukraine still struggles to implement effective changes in its health system (Atun, 2004, p.1390). The Global Fund provides project-based grants. If it allowed the Estonian NGOs to develop their capabilities, it did not provide a direction or a framework to their work. It has no middle or long-term strategy. It does not interfere in the health system as a whole, and does not apply pressure for major reforms. Its role is to support the national answer, not to impose alternatives or to change dynamics among actors.

Imposing alternative frameworks has been the role of the EU, both in Estonia and in Poland, and this is what the present discussion aims at proving. The EU influence can be divided into three areas: destroying the panoptical model, strengthening alternative narratives, defending human rights and fighting marginalization.

4.2.1. The end of the panopticon

By different means, Estonia and Poland have taken considerable steps away from the repressive epidemiological model, and rid themselves of the panopticon perspective on

HIV/AIDS. New member states, when they entered the EU, had to comply with the *Acquis Communautaire*, and other European laws and policies. More precisely, it meant the adoption of all the previous declaration on HIV/AIDS, and the inclusion of many directives, like the one on blood safety and quality regulation (2002/98/EC and 2004/33/EC).

Joint efforts of the European Commission, the European Parliament and the Council succeeded in pushing harm reduction as an EU-backed strategy. Of the ten recommendations made by the European Commission on this issue, Estonia and Poland both adopted 9 out of 10, and this, after the EC pressured the countries. This pressure was crucial for Estonia who refused to include harm reduction in its strategy before 2003. In comparison, in France and the Netherlands, only 5 recommendations became policies, and they were so before the EC proposed them (Commission, 2007, p.16). In other words, the EC only pressured new members on this issue. It is a huge step for national health policy-makers who never had to justify or to comply with other political levels. Most importantly, it is a clear pressure from the EU to update national answers and to include social science within strategies. The technocratic «regard calculateur" (the planning look) is not the sole eye on the debate anymore. This was important since, at the time, the Estonian government refused to include harm reduction in its policies. Even Poland, with an answer mostly defined by medical scientists, adopted it.

This seems an important proof of the EU's postmodern influence on its member states, especially that both Poland and Estonia have complied, according to activists and different documents. Ukraine, in spite of a more explosive situation and many grants from the Global Fund, still has difficulties in implementing effective needle-exchange programs or other harm reduction components (Barcal & al., 2005; Goodwin, 2004). Russia lags even further behind in implementation of such a strategy (East-West Institute, 2003, p.18). The European Union, on this point, successfully pressured the authorities to get rid of the repressive model.

The way Polish and Estonian governments act clearly shows that they understand they are under surveillance. They do not face the invisibility that authorities had under the panopticon model. The 2007-2011 Polish Programme refers to the "better fulfilment of commitments" to EU laws, and proposes to scan and analyse the legislation in place to ensure it conforms to these norms (PMoH, 2006, p.45). The 2006-2015 Estonian strategy also refers to compliance with EU regulations (TAI, 2005, p.3), and reveals the considerable pressure placed on member states from the European institutions to follow the EU's recommendations and laws. EU laws thus become an important tool to fight the repressive model, defending the rights of the ill, rather than supporting the confiscation of their rights. It does so also by forcing countries to be represented in Council of Minister meetings through the OMC. In other words, HIV/AIDS policy-making is not made among a small circle initiated in secret. It is now conceived with a certain public scrutiny, and as an issue that needs all of society's layers to be fought efficiently.

The EU also imposes an answer based on horizontality and with the inclusion of different approaches. In 2003, the European Union, like many other international organizations, adopted the "Three Ones" approach. This approach is based on three factors that should lead a country's fight against HIV/AIDS: an institution coordinating interdisciplinary actions on HIV/AIDS, a national programme, and its own monitoring system. Both Poland and Estonia adopted the "Three Ones" approach. From this emerged two national strategies applied by more or less independent agencies, as we have seen. Those agencies are more able to create multilateral collaboration and to include social science within their work. Furthermore, the new structures imposed by the EU forced a discussion; one between member states and EU authorities, one between civil society and government, and so on. Once again, the Global Fund would have imposed the Three Ones on Estonia, but Estonia adopted it before receiving the Global Fund grand. In Poland, there was no other pressures than the EU . Predictably, Poland integrated its

rights to its policy after the EU adopted the Three Ones approach. Obviously, Estonia went much further than Poland in the development of this structure. The influence of the Global Fund is an important element in this adoption, since one of the conditions to get funding is to create a Country Coordinating Mechanisms (CCM) and develop independent national agencies.

In sum, both countries have abandoned the panopticon model, moving away from approaches based on coercion and enforcement. Even if the Global Fund played an important role in Estonia, the Ukrainian and Russian experiences prove that it was not enough to ensure the rejection of the panopticon.

4.2.2. New narratives, new power relations

New narratives and power relations, both in Estonia and in Poland, have been developed by the activities of NGOs. From the interviews, one of the most important conclusions in terms of EU influence is how the accession allowed NGOs to gain efficiency. Support for networks is an important success for the EU. Civil society groups collaborated with wider networks funded by the EC. The EC directly financed many of those networks, including AIDS Action Europe, Integration Project, Northern Dimension Partnership, and Eurasian Harm Reduction Network (formerly known as the East European Harm Reduction Network). Those networks are more than a simple lobby in Brussels; they transfer knowledge, organize action and provide resources to local NGOs throughout Europe.

Networks and pan-European NGOs have many years of traditions, gaining respect and trust among the European political class. They have systematically been invited to all meetings concerning HIV/AIDS. This was not common practice in the CEE. In Poland even less than in Estonia, governmental officials are not used to sitting at the same table on an equal basis with NGOs. For some the Bremen Conference of the Council of the European Union, which gathered Health Ministers and many representatives of civil society, was an important moment. Some

activists confided that, during those EU meetings, it was the first time they saw high governmental policy-makers. European networks thus force national health policy-makers to consider the point of view of civil society, an important development for governments who still refuse to meet with NGOs.

This influence goes further than simply sitting together during meetings. The common front of Estonian NGOs, and their international appeal against the government, shows that there are now certain mechanisms to constrain the state in its epidemiological response, and that those European networks may lead to successful lobbying. It also shows the strength that NGOs have been able to gain over national policy-makers. Even if the common appeal was motivated by the Global Fund, the pressure has been successful because the message was channelled by the European networks existing through EU support.

HIV/AIDS activists interviewed use "them" to talk about the government. Of course, we can see in this the construction of a dichotomy, but it can also be seen as the creation of an "us". In the process, new identities are being voiced. NGOs are able to frame an "us" for the MSM, IDUs, sex-workers, women, and other groups that used to be marginalized. One of the powerful statements was said by a representative from the Estonian association Ligo: "We represent women, no matter their language, nationality or ethnic origins. We are working for women, that's all". Their inclusive discourse well represents how NGOs have been able to go beyond national politics in order to effectively fight marginalization, creating a new "us" that cannot be framed in a national policy, shaping a voice for the voiceless. Krakow's street worker Marcin Drewniak shares the same concern when talking about MSMs from the Ukrainian border cities or Polish small towns that come to the more liberal Krakow. The "us" here again is not the one framed in the national programme. This "us" provides a common awareness to groups within which members did not syncretize an outspoken identity. It allows new narratives to be developed. The

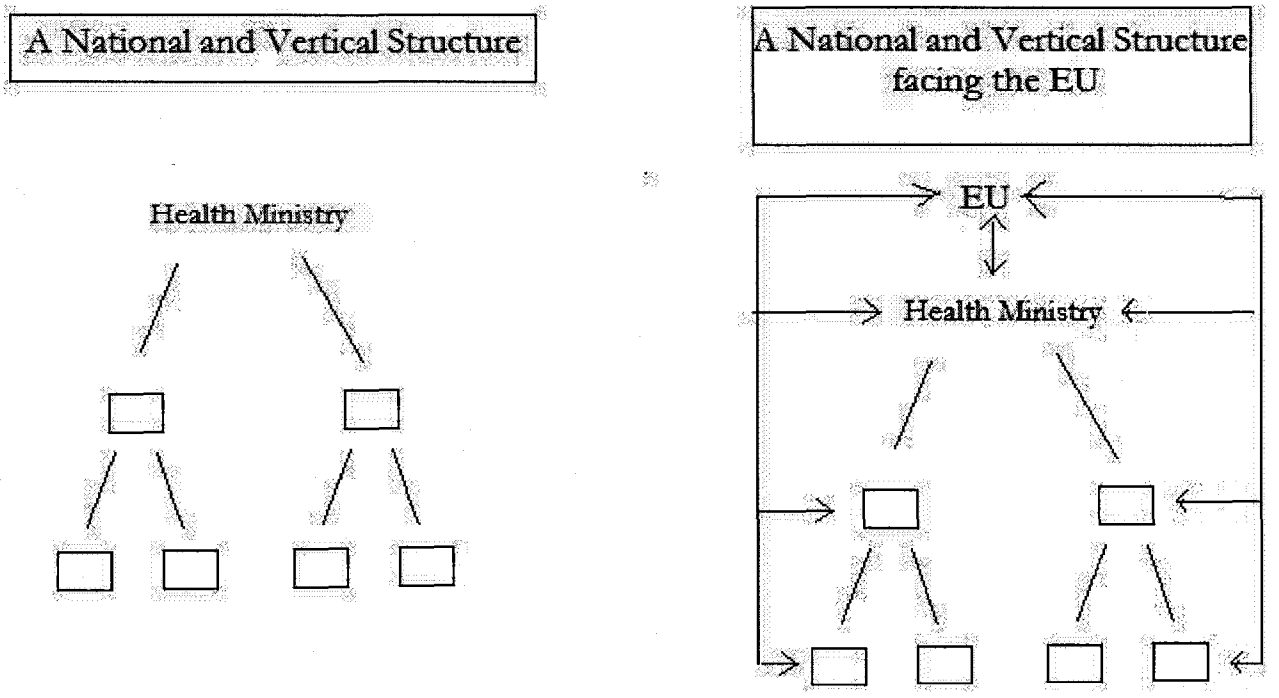
Estonian NGO Turgikeskus, by this identity-building process, is now able to develop strategies targeted specifically to different groups, such as sex workers in the street versus sex workers in elite brothels. This is a good example of how the new way to understand this "us" has emerged. The strategy of "*divide and rule*" does not hold anymore. Through EU-backed networks, NGOs have been able to share those experiences and create common voices and psyches. They can now build a new narrative that does not stop at borders, and can be recognized as such by actors. The Other in one country found a self in the neighbour's Other. It is thus the framing of new narratives, in total opposition to the modernist state monopoly on narrative, protected by national boundaries and immobility.

But the role of the EU in building strong NGOs is much more important than this in terms of providing a postmodern view. The EU's integration means that it is now easier for CEE citizens to move around. Many of the activists met have been educated in other European countries, often through Erasmus for the youngest generation. The different universities and researchers' networks have provided successful channels to share expertise and knowledge among the scientific community. There are also a considerable number of HIV/AIDS activists who work on harm reduction, undergoing training funded by different organizations, such as the Soros Foundation. The increasing mobility, which will be even more drastic with the upcoming extension of the Schengen area, has facilitated this knowledge-transfer. NGOs now share concepts and analytical frameworks, and are more often updated than their governments. The European Union also means a better circulation of knowledge and the increasing availability of information. With the creation of EuroHIV, EuroSurveillance, and ECDC, the state has lost its monopoly on information. The general public has been empowered because it now has the tools to understand the illness, and basic information to become responsible. This could be considered the main pillar of the EU as a postmodern actor: a capacity to diffuse power based on knowledge-

sharing. There is no more monopoly on truth; nobody can impose its single vision on an entire country. Many narratives can live together, since institutions do not choose one over the other.

In sum, even in countries where a very vertical political structure remains in their health system, the EU has been able to provide channels of communication between different branches of this structure that would not have been able to talk together before without passing through the top of the structure. The EU, in addition to important changes within structures, is at the same time building over existing institutions, providing channels for more horizontality in a vertical structure. Both for Poland and Estonia, the EU has been crucial in doing so. Figure 3 presents a graphic version of this argument.

FIGURE 3. The EU method of diffusing horizontality



4.2.3 Human rights approach

The repressive model aimed at seizing the patient's right and responsibilities, transforming the ill into a "case" that must submit to authority, according a postmodern eye. A human rights approach goes against this phenomenon. It aims at empowering the ill to efficiently fight marginalization and stigmatization.

The importance of human rights, in general, is highlighted in all EU documents on HIV/AIDS. The EU automatically links certain practices to human rights. In EU documents, free testing and counselling are presented as human rights issues. Furthermore, the Declaration following the Bremen meeting clearly states that the Council, meaning all member states governmental representatives, will "legislate and guarantee the human rights, including discrimination and stigmatization" (CEU, 2007, p.3). It is the first time that Estonia and Poland clearly iterate the issue of HIV/AIDS as such.

In Europe, accepting the primacy of human rights implies accepting the interpretation of a foreign body, the European Court of Human Rights (ECtHR). The ECtHR's decisions can be easily ignored. But when supported by the EU's institutions, a member state cannot ignore those decisions, since the EU can impose sanctions. As Schimmelfennig said: "nothing short of the high material benefits of [...]EU membership has led to compliance in those transformation countries that violated liberal human rights and basic democratic norms systematically" (Schimmelfenning, 2007, p.128). For the author, the EU was the only organ to "persuade the governments and parliaments of [Estonia and Latvia] to liberalize their citizenship laws and grant minority rights in favor of the large Russian-speaking Minorities", making it a precondition for accession in 1990s with the limitations that would be studied in the next part (Schimmelfenning, 2007, p.128). Similarly, in "Bączkowski and Others v. Poland", the ECtHR unanimously ruled that the 2005 ban on LGBQTT pride parade in Warsaw was a violation of Articles 11, 13 and 14

of the European Convention on Human Rights. This brought tremendous EU focus and attention on the country. This led the European Parliament and the European Commission to undertake action against the Polish state. In this case, the EU became an enforcer of human rights, with a clear impact on HIV/AIDS. No other organizations active in the neighboring countries, including the Global Fund, can enforce human rights as well. This has had considerable impacts in both Estonian and Poland.

4.2.4. Marginalization

The EU offers three different tools to fight marginalization in Estonia and Poland: money, strong institutional responses, and mechanisms to blur the lines of marginalization.

Fighting marginalization is a question of money since it necessitates the creation of social programs to empower marginalized groups. To ensure that the upcoming members would be able to reach the EU's *Acquis communautaire*, Brussels's institutions flood upcoming members with money for social spending through different programs, particularly a program called *Poland and Hungary: Assistance for Restructuring their Economies* (PHARE), which has been extended to all new members in spite of its name. The programme allowed necessary funding for many initiatives often aiming at the marginalized and the poor.

Accession meant the end of PHARE, which provided money that went, both directly and indirectly, to HIV/AIDS programs. For HIV/AIDS activists, it was the end of an important source of funding. The Global Fund justified not renewing its grant to Estonia on the basis that, since it has joined the EU, it was now rich enough to be self-sufficient. It was now expected to contribute to the Fund.

At the same time, accession also meant that the new EU countries could apply for the EU's Structural and Cohesion funds. This allowed Estonia to finance an important project to help IDUs find work. Both Poland and Estonia received grants to increase women's employability.

But those funds are more difficult to get than funds previously available through PHARE and are allocated on a project-proposal basis. Local NGOs do not necessarily have the resources to successfully bid for those grants. It is a complicated process that, according activists, creates a situation where one needs money to get more money.

It is difficult to evaluate if, in the trade-off PHARE/Membership, new member states were able to gain or lose money. Estonia definitively lost with the end of the Global Fund. The country received a total of 10,246,580 US$ from the institution. But accession also brought a booming economy. Acceding countries now face the highest growth rate in the EU, which means more money for the government to put in social affairs.

This being said, the EU also developed direct tools to fight marginalization. EU accession increased institutional capabilities to fight marginalization. The important element of the EU's institutional response is the EU laws against discrimination, and the active participation of both EU political organs and courts. Among others: the European Parliament resolution of April 26th 2007 on homophobia in Europe, the directive 2000/78/EC on discrimination in the workplace (the only EU directive strongly condemning discriminations against LGBQTT), and the different protocols on fighting drugs.

Some actions targeted individual countries. On June 15th 2006, following the assault of a Rabbi in Warsaw, and alerting comments from Polish politicians, the European Parliament adopted a resolution against the general rise in racist, xenophobic, anti-Semitic and homophobic intolerance in Poland (Bernstein, 2006). In the same vein, in 2007 the Parliament decided to open an inquiry into whether the education minister Roman Giertych was in breach of EU anti-discrimination rules by proposing a bill banning discussion on homosexuality in Polish schools. Poland, between 2005 and 2007 has been under constant EU pressure to change its approach. Estonia, on the other hand, has not been a major target of EU's attention.

The EU offers considerable tools to fight gender marginalization. Even if almost all international HIV/AIDS projects include a gender component, they mostly refuse to address the very sensitive issue of reproduction rights and contraception. The ECtHR's last March 20th judgment concluded that Polish abortion laws were against women's right. This was an important decision that put an end to many years of hassle in Brussels's lobby, and that affected all EU countries. It was also the most important decision of a European institution in favor of reproduction rights. It thus constituted a clear step in ensuring that policies promoting abstinence (as supported by USAID or the Vatican) rather than sexual responsibility and condoms would not be tolerated. And it was also an incredible tool for a Union that still did not know what to do with the Polish stance on contraception and reproduction rights, while facing pressure from many European NGOs.

In a similar vein, the EU plays an important role in clearing out the path of detrimental foreign actors, particularly the "Global Gag Rule", or the USAID policy promoting sexual abstinence as a viable method to fight HIV/AIDS. This policy, which targets behaviours rather than assuming the dynamics of vulnerability, has been clearly fought by the different EU strategies (Altman, 2006, p.266). Sexual abstinence has never been part of European strategies: in fact, the EU clearly stands against it. Before 2000, campaigns for abstinence had to be eliminated from both Polish and Estonian practices. Although Poland saw the words "*Abstynencję seksualną*" (sexual abstinence) come back in its national campaign in 2005, it later eliminated them from its national strategy and the successive advertising campaigns. Once again, the Global Fund has shown its relative inaction in this field. Ukraine, receiving a lot of money from USAID, still holds abstinence as a productive strategy to prevent the spread of HIV/AIDS (Glasier, 2006, p.1551). This case could also be taken as an example on limitations of the Global Fund in

influencing national strategies. Fighting abstinence promotion is a clear step towards empowering women, and providing them the tools to be responsible for their own body.

Another important point is how EU accession mutated the dynamics of marginalization within a country. With low-cost flights and other communication links between CEE and other European cities, traveling has never been this easy for nationals of former Communist countries. And with people, ideas travel. Suddenly, Tallinn became a trendy place to go to for gay Fines, boosting the gay scene, and making available a new vision of gay identity to local MSMs. A similar pattern can be observed in the sex-worker *milieu*, where the women who shuffled around Scandinavia came back with new ways to conceive their social identity, based on much more liberal values than the ones expressed by Estonian society. Mobility is thus offering marginalized groups new paradigms of identity and new ways to understand themselves. Today, if one cannot find herself in her society, she can easily find herself in another country. This is crucial for a small society such as Estonia. This has become even more of an issue with Poland which currently has over one million citizens working in Great-Britain.

But at the same time, our study reveals the limits of EU in its fight against marginalization. During the EU accession, Estonia faced considerable pressure to solve the issue of its Russian minority. Every step report on the accession of the Baltic country does refer to the problem. Nevertheless, Estonia entered the EU, and not much pressure to rectify this situation has been set on the country since then. Once again, it is considered normal that the Russian-speaking Estonians are not targeted as vulnerable. But there is no way that we can find a long-term solution to the current HIV/AIDS crisis without addressing the issue of their marginalization. Why is nothing done at the EU level to help Russian speakers? Many other groups representing a marginalized layer, the LGQBTT being one of the most obvious examples, have found strong defenders in EU's institutions. This case, like the case of sex-workers or IDU, proves that the EU

is more efficient in fighting marginalization in those areas where marginalization is a problem in several countries, possibly several EU-15 countries. Besides, the case of the Romas is revealing another aspect. They are not included in any of the EU document on HIV/AIDS. In fact, we do not even know of their situation, even if many Polish and European NGOs believe that the problem is critical. This might reveal that having a "critical mass" is not enough to be able to defend the rights of marginalized. It also needs the support of well-established networks with a certain tradition of effective lobbying. Those not able to do so will not get on the European agenda.

The EU's capacity to fight marginalization is also limited to those cases that are considered "extreme". Like Kurzer said, "regional integration holds the capacity to alter governance structures, even in the realm of morality politics" (Kurzer, 1999, p.143). But, at the same time, there is little evidence that the European integration process "spills over into the field of morality except in those instances in which a country pursues a non-conformist policy course at odds with mainstream European thinking (Kurzer, 1999, p.3). In other words, the EU will act on the most obvious cases, like homophobia in Poland, but will forget the ones that are not able to make the cover of newspapers or that are simply not perceived as gross violations. We can conclude that the EU is able to fight marginalization, but only in those areas where it clearly offends the average member states moral lines.

In sum, for the four aspects studied, it seems that the EU intervention has been much more visible in Poland than Estonia, even if the latter's health system achieved much more progress towards postmodernism. This can be explained by the fact that the EU has been one of the only actors involved in Poland, and that Poland consistently took stances that were considered immoral or outdated by the other EU countries.

But it would be unfair to say that the EU failed to influence the Estonian health system towards a postmodern approach strictly on the basis that it is difficult to single out the influence of the EU in comparison with the influence of the Global Fund. Even if it is to a more subtle extent, the EU did frame the Estonian response. The nature of the EU as an actor is quite different than the one of the Global Fund. Although the Global Fund provided indirectly an unplanned opportunity to change the dynamics among actors in Estonia, its short-term commitment is incompatible with long-term issues like fighting marginalization. Estonia is like a body suffering from an overdose: the Global Fund has injected the necessary adrenaline shot, but the real work will be needed afterwards, and this will be the task of the EU.

4.3. Critique of the current study

In this part, there are three important critiques that should be raised. All the interviews for the present research have been conducted in big cities: Warsaw, Krakow and Tallinn. Even if some actors have been able to summarize the reality outside of these urban areas, it must be acknowledged that studying those realities might reveal a totally different perspective. This is why urban/rural cleavage was also considered a marginalizing factor. There is clearly a different level of marginalization that faces people living outside cities. This study is simply unable to evaluate its extent.

The second critique from the sampling is that they almost all come from civil society. No governmental representatives accepted to participate. Of course, many documents were able to compensate for this lack of participation, but it would have been important to have their experience at the European level included in this work.

Finally, more case studies might be needed to completely understand the issue. The two cases, with the highest HIV prevalence in their respective region, face many statistical similarities. In terms of percentage, the proportion of MSMs and IDUs appears similar, even if

both countries have huge discrepancies in their statistical data. Including other case-studies, like Hungary and the Czech Republic which face a significant infection rate among its MSM, or Romania, with a very concentrated nosocomial infection among hospitalised youth and orphans, would have provided an excellent complement to those two countries.

CONCLUSION

In this thesis, we have seen how regional integration can stimulate a different response to HIV/AIDS policies. To reach this, it reviewed the European Union and its strategy towards the newest member state.

Chapter one has presented the theoretical background justifying a different approach based on postmodern theory. It has explained why a postmodern approach to fight HIV/AIDS is necessary, and what this implies for health system management.

Chapter two has provided an historical perspective of the EU's answer. It looked at how the EU' strategy has been built, and then analysed the different mechanisms that were developed within the Union to fight the pandemic.

Chapter three has delineated the extent of the HIV/AIDS pandemic in the new member states of the 2004 and 2007 enlargement before the EU stepped in, focussing on Poland and Estonia. It also attempted to present a brief picture of marginalization on the two case studies.

Chapter four provided a thorough analysis of our two case studies. It first described how the national answers have been influenced by postmodernism, and then discussed the role of the EU in the move towards a postmodern health system.

This study concludes that the European Union, which built up a postmodernism approach based on the European norms and values, diffuses its strategy within the new member states, although with different levels of success. It does so by contributing to the elimination of the repressive model of epidemiological control, the end of the state monopoly over health policy-making, the imposition of an horizontal structure over actors, the defence of human rights, and the diminution of vulnerability through policies that fight marginalization.

In Estonia, the EU postmodern influence was limited by the Global Fund, even if the country's response faced one of the most important makeovers in the region since 2000. In

Poland, the EU postmodern influence has been considerable, and this was mostly due to low infection rates, which limited pressure from foreign actors. In both cases, it appears that the EU institutions are the most able to sustain a long-term strategy to combat the spread of HIV/AIDS. It also provides an efficient framework to fight marginalization.

This analysis concludes that the EU is an actor, but a somewhat incomplete actor. There are many directions that Brussels should look at to increase its capability to fight HIV/AIDS. For future developments, the EU could look at the Global Fund for a source of inspiration. Its approach has shown to be strong, innovative and successful in Estonia. Understanding the need to address issues of marginalization while at the same time allowing the development of a scientific answer, the multilateral institution has been able to enforce a balanced approach, although myopic and short-term based. The EU has the capability to offer a long-term perspective, something that the Global Fund cannot do. Does the EU wish to develop such capabilities? In spite of a certain commitment within official EU declarations, it is unclear how far the EU vision is reaching in terms of time perspective, and whether those actions will have concrete repercussions.

If our work concludes that the EU played a role in diffusing postmodernism, we have to keep in mind that many countries integrate concepts of postmodernism without the influence of the EU. We can perceive the role of the EU as a guiding one. A country could find its way without EU's help. But, as we have seen in the case of Poland, the EU can become a strong incentive to move towards policies that postmoderns would agree with. Further studies could look more closely on what explains the integration of postmodernism without EU interference, and study the EU role more deeply . A comparative study between one of the newest EU member state and a non-member post-Soviet state, Russia or Ukraine as an example, may offer an opportunity to clearly understand the role of the EU in postmodern influence. The comparison

between Ukraine, Poland and Estonia, which has been alluded to in the present essay, suggests interesting bases for such thorough analysis.

Nevertheless, the EU response is not a miracle. Contrary to Jean Giono's conclusion in *The Horseman on the Roof* on the Cholera epidemic, all the evils are not in the crowd's mind. There is an illness which causes concrete impacts and has physical presence. So far, most EU resources have been used in elaborating protocols and dispersing knowledge. Little has been done to increase the quality of life of the PLWHAs, and not much money has flowed into the countries to support preventive measures. About the European process on HIV/AIDS, one activist said, "the cost of knowing is a bit too high". In other words, the European postmodern approach needs to be complemented with concrete deeds.

Through the last hundred pages, a very theoretical approach to fight HIV/AIDS has been developed. But AIDS remains an illness that still needs to be fought on pure scientific bases and through concrete medical acts. It needs ARVs, an aspect which is already very difficult to deal with. It needs proper care, so that HIV-negative people will not get infected by opportunistic diseases carried by HIV-positive people. In short, elements of the modernist framework remain valid. The whole medical tradition should not be discarded simply because a new paradigm holds. In fact, the European Union will need to develop its "modernist" capabilities too. In light of the recent tragic failure of the vaccine against AIDS, we must face the fact that we still know very little on the retrovirus. Does it really want to go in this direction?

In sum, it seems that the real issue is one of fine balance: balance between modernist and postmodern approaches, medical and social science, theory and practice. This is what Giono called "facing the mirror"; we must now look at the problem for what it is, rather than follow our intuition and our prejudices. We must ask whether the EU is working towards a balance, or it just attempts to justify its incapability to act in certain issues with the creation of postmodern

mechanisms? Is this a way to cover up the fact the EU is not able to gain more modernist structures because of its limited jurisdiction in the health policy area? If balance is needed, the EU will need to work on the other side to reach equilibrium.

There is a need to look at this thesis as posing new questions as well as answers. All the way through, I have attempted to provide critiques of the approaches. These critiques uncover the need for further studies of the fragile relation between modernist and postmodern policies. In the wake of a Bird Flu pandemic, we have to highlight that lessons learns from HIV/AIDS might be of little use. More studies need to be done on how can the EU develop more adequate epidemiological control capabilities.

And postmodernism is not a panacea for HIV/AIDS itself: Lipovetsky clearly emphasizes this while arguing that some citizens adopt destructive and irresponsible behaviors, and that postmodernism increases the dependency of some. Therefore, further studies will need to assess if, in fact, postmodernism is not bringing as many problems as it solves. Those studies will also need to evaluate if the theoretical answers, in the long term, really bring positive outcomes, or if, behind the good intentions, not much is being produced. As Mark Renton said, the main character of Irvine Welsch's novel *Trainspotting*, "it is always easy to philosophize when it is others who have poison in the blood". All those beautiful discussions and theoretical niceties are not enough to stop a pandemic that kills many millions of human beings every year. And we have to see how those actions directly effect the HIV prevalence rate, since most assessments lie more on hope than on well-established proofs.

This research also unveils the important role of "stigmatization" in postmodernism. If the EU has taken strong actions against Poland, it is because the Polish state was taking stances that were clearly against the European Union norms and values. They were a rogue state according to the values widely accepted among the EU member states. But what about those cases that are

neither black nor white? Are the EU postmodern mechanisms still working for those countries in the gray area?

Another important question is how can conclusions of this study be transferred to other regions. Can, for example, the African Union copy and paste the EU's approach, or is it possible only by the particular nature of the organization and the strength of national health systems within the Union? Is such an approach possible in countries that cannot be considered post-materialist? What are the political and social structures that are needed to develop such an approach? More studies need to look at what are the grounds needed for effective transfer of the postmodern mechanisms studied in this thesis.

Postmodernism remains a relatively new framework. Only time will be able to judge its real usefulness, and will offer us answers to many unanswered questions. This piece is an attempt to open new doors in looking at a postmodern EU, but is now opening the way to a new whole undiscovered land. It is crucial to remain lucid on those new opportunities, as promising they might be.

ANNEX I - QUESTIONNAIRE FOR CIVIL SOCIETY GROUPS

- When has your organization been created? Whom? How? Where?
- Raison sociale? Whom does your association target? Who is behind it? What are your objectives?
- What are your sources of funding: Government, Private, EU, Foreign, Other?
- How much funding? How many staff? How many Volunteers?
- Nature of activities/services
    - How many users?
    - Location
    - Facilities?
    - What kind of resources is available?
- Do you provide Testing? Counselling? Which kind?
- Do you have any contacts with government official?
    - How many times per year?
    - Do you attend official national meetings? What is the nature of it?
    - Do you participate in the drafting of the national program?
- Do you feel that the government is collaborative? Listens to you? Takes your point of view into consideration?
- Do you participate in educational programs?
- Are you involved in prevention programs? How? Where? When? Who are the targets?
- Do you see any difference since the accession to the EU?
- Did you have contacts with EU officials or other European organizations? How? When? How often?
- Who is responsible for your agency? Who do you account to in the government? How much funding?
- Do you meet with other NGOs? How many times a year? How would you qualify your relations?
- Do you meet with foreign organizations? European Networks? International organizations? How many times a year? How would you qualify your relation?
- Do you think that the country should implement a mandatory testing for risk groups?
- What proportion of your organization is made up of medical specialist?
- Are there specialists from fields other than medicine? If yes, what is their role?
- Whom would you define as being marginalized? Who is left out of National strategies? What should be done to help them?
- Do you feel that the general population is aware of your cause?
- Do you have any other comments?

ANNEX II: APPLICATION FOR ETHICS REVIEW

Name of the project:
The diffusion of European norms and values as an effective answer to the HIV/AIDS pandemic in Central and Eastern Europe.

Summary of Research Project:
The European Union (EU) is neighbouring some of the countries that faces the world highest increase in HIV prevalence rate: Ukraine, Russia, and Moldavia. In addition new EU Members States admitted in 2004 and 2007 have themselves seen a significant increase in the prevalence rate of HIV/AIDS. Estonia, as one of the latter, is facing the second highest HIV prevalence rate on the European continent. Therefore, it is not a hyperbole to say that the EU is on the verge of an important health crisis.

My project aims at studying the EU's ability to respond to such a crisis. HIV/AIDS is not typical pandemic, and therefore cannot be fought with traditional epidemiological means, like the ones needed for the Bird Flu epidemic, for example. Tackling HIV/AIDS necessitates addressing social and behaviour issues, and other sensitive topics. It also requires a new approach to national health policy-making, and challenges the central role of the medical body in public health policy-making. The EU is very aware of this component, and therefore attempts to build-up a European answer to a pandemic, even if health policy-making remains a national issue that is protected by the Subsidiarity principle. To face those limitations, the EU had to develop strategies based on new approaches involving postmodern theory and the European norms and values.

In sum, HIV/AIDS is imposing the postmodernization of health care in Eastern Central Europe. And, among other things, it necessitates the participation of different actors, including civil society, something that EU strategy is particularly keen on fostering.

The goal of my research is to evaluate the penetration of the EU strategy into the new EU member states. Specifically I want to evaluate how much the national health care policies of Poland and Estonia have succeeded in including different actors in their own strategy, particularly civil society actors.

Methodology and Procedures:

A) A review of relevant literature, including a review of the EU strategy, national healthcare strategies in Europe, HIV/AIDS epidemiological surveys, governmental and para-governmental reports.
B) Identification of the case studies: Poland and Estonia.
C) Development of interview schemes
D) Identification of interviewees and conduct of interviews based on a semi-structured open-ended question interview format.

Deception:
No deception will be used. I am looking for official answers from actors. I am interested with the answers from an institutional perspective, not from the individual persons.

Description of Participants:
Interviewees will be either officials from the national AIDS agency, or actors affiliated with the HIV/AIDS-related civil society. I will not interview HIV-positive persons as such, but only as leaders of civil society groups.

All interviews should be in English, since most actors demonstrated, by their involvement in European networks, a sufficient knowledge of English. An Estonian translator might be used if needed, a PhD candidate in Sociology that already worked with HIV/AIDS-related organizations, and knows both about ethics and the difficulties of the issue. If needed, a Polish translator might be used, but this is very unlikely.

I will be talking to leaders from AIDS-related civil society groups and government officials that are aware of the consequences of their actions. Participants will be asked about their interaction with other actors in the HIV/AIDS sector. They will be questioned on their level of interaction among with other agencies, and will asked to assess the quality of those interactions. Actors will also be questioned on their organizations' activities.

Recruitment Process:
Participants will be contacted by the researcher on the basis of earlier contacts and on the relevance as an actor.

These are organizations that should be interviewed according to earlier talks. They have been selected through a review of literature from the EU documents, and pan-European conferences.

- Paris, France: AIDES (Integration Project)
- Warsaw, Poland : MONAR, Badz z nami, NATIONAL AIDS CENTER, RES HUMANAE, Lambda
- Tallinn and Narva region, Estonia: AIDSi-TUGIKESKUS, ESPO, Narva Rehabilitation Center for Drug Users and Alcoholics, National Institute for Health Development

Remuneration and Employees
No application will be needed, except for possible translation fees.

If an interview cannot be done in either English or French, a translator will be hired.

If such an instance occurs, an Estonian translator might be hired. I already approached a fellow student, which is a PhD candidate in Sociology working on HIV/AIDS-related issues, and who is familiar with research ethics and the difficulties of the issue. If needed, a Polish translator might be used, but this is very unlikely.

The translator's role, if needed, will be only of providing translation. They will not be asked to transcribe the discussion. I will brief the translator in detail about the importance of maintaining the confidentiality of responses, if requested by the interviewee.

Translators will be required to sign the Informed Consent Check List, and with this, provide his/her commitment to keep the context of the interview confidential if the interviewee has requested this.

Risk level
The risk is different depending of whom is interviewed. Governmental or para-governmental employees might face some risks if taking a stand contrary to official governmental position. But it is minimal, since the purpose of the research is to define the governmental position, not to look for controversial declarations.

Civil society officials might also face possible problems if taking a position contrary to the one of the government or the international funding agencies, since most of the revenues of the NGO sector are still secured in great part by the two kinds of institutions. Although, the risk is considered low as the two countries are part of the European Union, which guarantees its citizens basic rights, including freedom of speech. Civil society groups are also participating in many pan-European initiatives, and are, therefore, used to frame a point of view as a public actor, and to face the danger of public scrutiny. Finally, many of those civil society groups have often expressed publicly controversial positions, without having their funding cut or facing any kind of sanctions.

In both the consent form and the letter of information, participants will be made aware that results of the interview will be made public. Participants will thus be conscious of those risks, as low as they are.

Minimizing Risk
Confidentiality will be offered. Therefore, particular attention will be paid to avoiding an outcome where possible critical answers might influence further funding.

If controversial statements are made, I will confirm that I understand the meaning correctly and will remind the respondent at the end of the interview that information from the interview may be made public and be associated with their name if confidentiality is not requested.

Benefits
Benefits will be to provide an assessment on how HIV/AIDS policies have modernized in Central Eastern Europe since the end of Communism.

Anonymity of Participants /Confidentiality of Responses
Those interviewed will not be anonymous. Since interpretation of the material requires taking into account the institutional position of the interviewee, anonymity cannot be provided, as it would make the material pointless for my thesis.

However, participants will be offered the option of confidentiality, which means that particular answers will not be attributed to them. For those who request confidentiality, participants in the publications will be referred with generic terms such as "an official" or an "HIV activist" with careful attention to on ensuring that no information is included that would make it possible to identify the particular individual or their organization. Particular attention will be paid to the fact that the number of actors within a country is limited, and therefore can be easily track if not presented in a generic enough manners.

I will request permission to record interviews. Where permission is granted, interviews will be stored on a memory stick that will not contain the list of contributors. The memory stick will be locked with a password.

Informed Consent

Participants will receive a letter of information prior to the interview, and they will be briefed orally before the interview on what the subject of the interview and the research project.

I strongly believe that written consent will be impossible to get. Thus, I provide you with a better justification for this, but I also provide you with a written consent strategy in the case that you are not convinced that oral consent is adequate

1) ORAL CONSENT STRATEGY

In Poland and Estonia, requiring interviewees to sign an Informed Consent Form will raise suspicions, discomfort and insecurity. The post-Communist bureaucratic culture made them very suspicious of anything that needs a signature. It would be very surprising if they were to accept to sign any document, especially one that is presented by a foreigner. Furthermore, internal rules often requires that documents that leaves the agency or the organization can only be signed by supervisor.

In this context, it will be difficult for the participants to understand that this is a personal consent form, an explanation that will raise even more doubts in a culture that sees signature as something very official, and that needs to be feared.

This process is likely to result in a situation where the participant will refuse to take part in the research strictly because she/he refuses to put her/his signature. This is why I do believe that oral consent is the best approach to avoid those kinds of issues.

Therefore, I propose to use a procedure involving oral consent. The procedure involves the following stages:

a) Provision of the interviewee with the Letter of Information before the interview starts
b) An oral explanation of the rights of the interviewee as outlined in the Informed Consent Form preceding the interview.
c) An indication at the outset of the interview that confidentiality can be assured if the interviewee requests this
d) An inquiry at the completion of the interview as to whether the interviewees wish the content of the interview to be kept confidential.

I intend to fill an Informed Consent checklist for every interview, that will ensure that I respect all the steps, and that participants consent to be interviewed, and are aware that those interviews can be confidential or that they can withdraw from the interview at any point (cf. sample provided). In cases where the interview is audio-recorded the consent will be recorded in this way. In cases where a translator is in attendance, I will have the translator sign the form as a witness to the consent. In cases where there is neither an audio recording nor a translator present, my records, using the consent form, will assure that I have followed proper procedures.

If translation is required, the translator will also sign and comply with the requirement of the checklist, and will confirm that the participant has consent.

2) WRITTEN CONSENT STRATEGY

In the case that the Committee is not convinced that written consent will be impossible to obtain, I have drafted a written consent letter, that I will read to the participant, and then I will ask her/him to sign.

A sample Letter of Informed Consent is attached, as well as an Oral Consent Strategy and an Informed Consent Form.

Photographs
No photographs will be taken.

Audio/video Recording
Interviewed will be taped with a digital audio recorder for personal use. The interviewed will be informed, and will see the recorder.

Participants will be asked if they agree that I audio record the interview. If they refuse, I will transcript the interview myself, and they will not be recorded.

No video recording procedures will be in used.

Security of Data
All data will be transferred on a memory stick as soon as possible, and all remnant files will be destroyed. I will use my personal computer to do so.

Destruction of Data
One copy will be kept in my personal files at home, here in Ottawa. All the other digital copies will be destroyed using software that virtually shreds all documents, to ensure that nobody could access them. I intend to keep a copy of the material as long as it might be needed for the completion of the M.A. thesis.

Ownership of Data
I will remain the owner of the data.

Future use of research Data
The data should be used for my M.A thesis exclusively, but me serve also for scholarly conferences and academic papers too.

Dissemination
Information will be diffused through my M.A. thesis, but might be also used for scholarly articles.

Research Instrument
An open-ended questions questionnaire will be developed, but will be orally proctored. You will find attached a rough copy of the questionnaire.

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