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Political, social and religious dimensions in the fight against HIV/AIDS

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Political, social and religious dimensions in the fight against HIV/AIDS:

Negotiating worldviews, facing practical challenges

Brenda Bartelink
Ulla Pape
(Eds.)

Proceedings of the panel session on HIV/AIDS at the World Conference on Humanitarian Studies in Groningen, 4-8 February 2009 in Groningen, the Netherlands

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Table of Contents

| | |
|--|-----|
| <i>Negotiating worldviews, facing practical challenges: political, social and religious dimensions in the fight against HIV/AIDS</i> | |
| Brenda Bartelink, Ulla Pape | 5 |
| <i>Understanding the situation of poverty-related diseases: multi-level statistics, donor initiatives, and conferences</i> | |
| Nancy Tokola | 17 |
| <i>PEPFAR project implementation and the pursuit of the United States national interest</i> | |
| Ricardo Pereira | 41 |
| <i>Diverging discourses: Civil society and the response to HIV/AIDS in the Russian Federation</i> | |
| Ulla Pape | 57 |
| <i>STI and HIV/AIDS prevention project for Mongolians in the United Kingdom</i> | |
| Bazarragchaa Tsogt, Suvd Batbaatar en Tsegmed Sambuu | 79 |
| <i>Complexity of cooperation in response to HIV/AIDS: the case of Mongolia</i> | |
| Nancy Tokola | 97 |
| <i>Social Protection for HIV-affected Families in Poor Countries: A Policy Recommendations Inquiry after AIDS 2008</i> | |
| Ricardo Pereira | 119 |
| <i>Rivers and stones: citizens with HIV, activism and the Global Fund in Peru</i> | |
| Henry Armas | 133 |
| <i>Development cooperation: a clash of worldviews</i> | |
| Simon Polinder | 149 |

| | |
|---|-----|
| <i>The involvement of religious institutions in promoting sexual reproductive health and rights in education</i> | |
| Martijn Marijnis | 167 |
| <i>Shifting Perspectives: analyzing discourses on faith-based development organisations in the fight against HIV/AIDS</i> | |
| Brenda Bartelink | 185 |
| About the authors | 203 |
| CDS Research Reports | 205 |

Negotiating worldviews, facing practical challenges: political, social and religious dimensions in the fight against HIV/AIDS

Introduction

Brenda Bartelink, Ulla Pape

Travelling to Cameroon, on his first visit to Africa, Pope Benedict XVI stated that distributing condoms does not provide an answer to the tragedy of HIV/AIDS, but on the contrary even increases the problem.¹ It is probably not a surprise to start a book on worldviews and HIV/AIDS with this example, but it is an interesting example nonetheless. The comments of the Pope brought strong and sometimes angry reactions from development agencies and governments, including the Dutch Minister for Development Cooperation, Bert Koenders who called the Pope's statement 'exceptionally harmful'.² It is not our intention to contribute to this debate, or to contribute to essentializing stereotypical images, whether about HIV/AIDS or the Catholic Church. Instead, this volume aims to give insight into the complexities of the fight against the HIV/AIDS epidemic, involving multiple stakeholders, perspectives, motivations and dilemmas. And, if the criticism and discussions on the Pope's expressions have made one thing clear, it is this: that the complexities in the response to the epidemic cannot be seen outside the context of the many worldviews that influence discourses and practices on HIV/AIDS.

This volume presents a number of papers discussed at the panel on 'Worldviews and poverty-related diseases: responses of researchers, donors and aid organizations' at the World Conference of Humanitarian

¹Interview of the Holy Father Benedict XVI on 17 March 2009, Apostolic Journey to Cameroon and Angola, in: The Holy See, Benedict XVI, http://www.vatican.va/holy_father/benedict_xvi/speeches/2009/march/documents/hf_ben-xvi_spe_20090317_africa-interview_en.html.

²<http://www.minbuza.nl/nl/actueel/nieuwsberichten,2009/3/uitlatingen-paus-over-condoomgebruik-buitengewoon-.html>.

Studies, held at the University of Groningen in February 2009. The conference provided a meeting ground for academics and practitioners to reflect on key characteristics of humanitarian studies. In the conference panel on poverty-related diseases we decided to have a closer look on HIV/AIDS, constituting one major human crisis that finds its roots in the consequences of poverty and vulnerability. With the aim to discuss the interrelation between discourses and practices in the fight against HIV/AIDS, the conference panel brought together a great variety of participants from different countries and backgrounds. The papers presented at the panel – reflecting both practical experiences and academic debate – clearly show how intertwined politics, underlying ideological standpoints and HIV/AIDS policies are. With the publication of this volume we wish to show different perspectives on discourse and practices in the fight against HIV/AIDS and contribute to the discussion on the quality of HIV/AIDS policies.

In this introduction we will first introduce the volume's contributions and then discuss the interrelations and differences between them, thereby reflecting upon the discussions that took place during the conference panel and while preparing this volume. The volume is organized into three chapters, referring to the political, social and religious dimensions in the fight against HIV/AIDS. The three dimensions are thereby of different significance. Whereas the political and social dimensions refer to spheres in society, the religious dimension affects the private, public as well as political spheres in society indicating that a clear separation between spheres is often not possible.³

The political dimension

The political dimension comprises of contributions that refer to the state as an actor in the fight against HIV/AIDS, including donor governments involved in fighting HIV/AIDS in foreign nations severely hit by the epidemic. Despite the limitations multilateral organizations experience being dependent on the politics of nation states, these organizations are political actors and not social ones. Thus, the political dimension also refers to the multilateral institutions that influence both discourse and practices on HIV/AIDS. The section on the political dimension starts out with a contribution of Nancy Tokola on 'Understanding the Situation of Poverty-Related Diseases: Multi-Level Statistics, Donor Initiatives, and Conferences'. According to Tokola, the general tendency to exclusively focus on HIV/AIDS often leads to neglecting other poverty related

³ Casanova, Jose (1996) *Public religions in the modern world* Chicago: University of Chicago Press.

diseases. Tokola reveals some of the politics in what has been referred to as the 'Aids industry' by some, making clear that HIV/AIDS is part of a 'terrible square' bringing together HIV/AIDS, Malaria, Tuberculosis and neglected tropical diseases.⁴ Looking at this 'terrible square' highlights the link with poverty and inequality more clearly, than is the case with HIV/ AIDS alone. Thus, the contribution of Tokola at the beginning of this volume sketches the larger framework in which HIV/AIDS has to be seen from a medical perspective; moreover it questions the politics that shape dominant discourses on HIV/AIDS.

Indeed, fighting HIV/AIDS is a political matter as Ricardo Pereira shows in his contribution on 'PEPFAR Project Implementation and the Pursuit of the United States National Interest'. This chapter is dedicated to the interrelationship between HIV/AIDS and security. It focuses on the US President's Emergency Plan for AIDS Relief (PEPFAR). Pereira argues that PEPFAR support is aimed at fulfilling US security goals. Looking at PEPFAR from a Foucauldian perspective, Pereira concludes that the macro-level frameworks of international aid aim at behaviour change on an individual or micro-level. He points at the colonial and post-colonial stereotypes that are continued in the perceived causality between HIV/AIDS and state failure, confirming the authority of development donors over the governments of the countries most affected by HIV/AIDS.

A deconstruction of health politics is a central theme in the contributions that address the political dimension in worldviews and the fight against HIV/AIDS. In his presentation at the conference panel, Bernd Rechel demonstrated political and ideological barriers that prevent the expansion of HIV/AIDS programs in the former Soviet Union. A restrictive political climate, major restrictions towards NGOs by states like Belarus, Russia, Uzbekistan and Turkmenistan, a punitive approach to drug users combined with a negative public attitude have limited the response to the fastest growing epidemic in the world. The contribution of Ulla Pape on 'Civil society and the response to HIV/AIDS in the Russian Federation' focuses on political constraints NGOs face in the fight against HIV/AIDS in Russia. Her contribution shows how the political and social dimension are mutually influencing each other through a case study on how state, church and NGOs cooperate and conflict on HIV/AIDS prevention and sexuality education. It illustrates that the success of the work of NGOs both practically as well as with regard to lobbying and advocacy is highly dependent on the approval of local and state authorities. If, and to what extent NGO activities on HIV/AIDS open up

⁴ Pisani, Elisabeth (2008). *Wisdom of Whores. Bureaucrats, brothels and the business of AIDS*. London: Granta publications.

space for more comprehensive approaches to the fight against HIV/AIDS remains open for further investigation.

The social dimension

The contributions on the social dimension show a vivid civil society, bridging the gaps left by the state in the response to the HIV/AIDS epidemic in many countries around the world. The social dimension can be understood in terms of civil society, as the arena in which ‘conflicts over the balance of power between different societal actors take place’.⁵ That civil society isn’t restricted to the national arena can be seen in the contribution of Bazarragchaa Tsogt on ‘STI and HIV/AIDS Prevention for Mongolians in the United Kingdom’. She shows that the response to HIV/AIDS requires a special focus on migrant communities, in this case the community of Mongolians living in the United Kingdom. Based on a case study of a project on STI and HIV/AIDS prevention for Mongolian migrants in the UK she argues that a contextual analysis of STI and HIV transmission is important, aimed at the specific needs and vulnerability of migrants. Herewith she underlines the importance of (government) support for the activities of migrant NGOs because they are able to reach a specific community and gain insight into their specific needs with regard to information, skills and services to prevent STI/HIV transmission.

While Tsogt reflects on a project for Mongolian migrants in the UK, Nancy Tokola discusses the work of the NGO World Vision in Mongolia. The author presents us with a picture of a Christian based NGO working in a complex web of Mongolian national and international partners. Within these networks, World Vision has to find its own place and develop its own policies with regard to the specifics of fighting HIV/AIDS in a low prevalence country like Mongolia, the policies of the Mongolian government and the wider Asian region, international donors, the Christian identity of the organization and the partnership within a large worldwide network of national World Vision agencies. Like Tsogt’s, Tokola points at the specific vulnerabilities of low-prevalence countries, especially because they are less likely to gain access to international funds to fight the AIDS epidemic while running the risk of enormous increases in infection rates.

In the paper on ‘Social Protection for HIV-affected Families in Poor Countries’, reflecting on policy recommendations put forward at the International AIDS Conference 2008, Ricardo Pereira questions dominant

⁵ Hein, Wolfgang, Bartsch, Sonja and Lars Kohlmorgen (eds.)(2007). *Global Health Governance and the fights against HIV/AIDS*, Basingstoke: Palgrave Macmillan.

discourses on HIV/AIDS that are rooted in a Western-liberal worldview. He explores the concept of social protection for the poor based on a philosophy of community building, in contrast to the concept of partnership that is based on a philosophy of individualism. While the best, most sustainable approach to helping people infected and affected with HIV/AIDS probably lies in the middle, Pereira interestingly shows that there is no such thing as neutrality in the fight against HIV/AIDS.

Social Movements are informal networks of groups and individuals focused on a particular issue which they aim to transform in society.⁶ In 'Rivers and Stones, Henry Armas shows how people living with HIV/AIDS in Peru realized the importance of political awareness and recognition. Necessity participation led to the formation of a social movement and the establishment of an NGO. Moreover, the narratives of people living with HIV/AIDS are an important source on how living with HIV/AIDS leads to new forms of agency, a perspective that is often ignored when looking at HIV/AIDS as a disease. Armas therefore suggest that it is important for organizations to balance a biomedical approach, with a narrative approach of HIV/AIDS.

The religious dimension

The religious dimension is a rather peculiar one in this volume. For example, faith-based organizations sometimes take the form of an NGO while in other cases remain a religious institution.⁷ The idea that the social and religious dimension cannot be separated as such is in line with the reasoning of anthropologists of religion who argue that religion forms an integral part of the public sphere. This argument brings us to a long and intense debate among scholars of religion, and goes against those academics in favour of the secularization thesis. The secularization thesis, which has been influential in many of the social sciences in the previous century, stated that religion is disappearing from the public sphere. While some point at a de-privatization of religion⁸, thus process in which religion is increasing in significance in the public sphere following a decline, others argue that religion has never been absent from the public sphere.⁹ In this volume we see religion as one social phenomenon that

⁶ Hein, *Global Health Governance and the fight against HIV/AIDS*, p. 95

⁷ *Ibid*, p.97.

⁸ Casanova, *Public religions in the modern world*.

⁹ Assad Talal (2003). *Formations of the Secular: Christianity, Islam, Modernity*, Stanford: University of California Press; Salvatore Armando and Marc Levine *Religion, social practice and contested hegemonies: reconstructing the public sphere in Muslim majority societies*, New York: Palgrave Macmillan.

should be studied as such. Therefore we focus on religion influencing both worldviews, as well as practices.

Simon Polinder discusses the religious dimension through the concept of worldviews which often clash. His main point is that people often overlook the involvement of worldviews in the development cooperation and more specifically in the fight against HIV/AIDS. It is worth and necessary to bring different worldviews together. Polinder discusses three such worldviews, a Catholic and evangelical world view, a Northern worldview and an African indigenous worldview, emphasizing that successes and failures in the fight against HIV/AIDS may depend much more on how differences in world views are taken into account than often is admitted. While Polinder presents these worldviews as inherently different and even conflicting, he comes up with a more constructive perspective on processes of modernization. Multiple modernities as a perspective on modernization is suggested as a better alternative for the dominant Western idea of modernity (or the Northern view in Polinder's words) as a way to overcome clashes, challenges and discrepancies.

In his contribution on 'The Involvement of Religious Institutions in Promoting Sexual Reproductive Health and Rights in the Education', Martijn Marijnjs explains how faith-based organizations (FBOs) encounter specific challenges when working on sexual and reproductive health issues, because it means looking for ways to integrate their values with evidence based approaches. This chapter is based on the practical experience of a network of (mainly) FBOs working on HIV/AIDS and education. Unlike more theoretical approaches, practical experience doesn't always allow a strong conclusion. Yet, what is interesting in chapter 9 is that it gives an insight into a grassroots process that is addressing the same questions as many of the other contributions in this volume.

In chapter 10, the book is completed with a contribution from Brenda Bartelink in which an attempt is made to bring theoretical approaches and empirical data together for an analysis of discourses on FBOs and HIV/AIDS. The author points at the characteristics of recent discourses on FBOs and HIV/AIDS that often provide an instrumental perspective by emphasizing the important role of FBOs in the fight against HIV/AIDS. However, two brief case studies point at another type of discourse, exclusively produced by FBOs and religious actors themselves. Based on these case studies Bartelink argues that discourses constructed with the aim of developing a religious, theological view on HIV/AIDS might be an important or even crucial foundation for FBOs to be able to develop practical programs and activities focused on HIV/AIDS prevention.

While religion is an important dimension in the fight against HIV/AIDS, the contributions on the religious dimensions show that FBOs make up an important part of the social dimension in many countries. Moreover discourses on religion (Polinder) and FBOs (Marijn, Bartelink) are influenced by the political attention that has been devoted to FBOs by programs such as PEPFAR. Here we come full circle, as we see the three dimensions addressed in this volume coming together again. Now let us move to part two of this introduction and go a bit deeper into the interrelationships and discussions between different contributions in order to find some common threads.

Discourses and practices

When using the word *discourse* in this volume, we refer to ways of speech and social actions in a pragmatic rather than a semantic sense.¹⁰ We refer to those structures of power, that people, communities and organizations have to deal with, and which influence whatever becomes accepted as an approach to HIV/AIDS prevention at a certain time. The interrelationship between discourses and practices makes it hard to distinguish between the two at times. Practices inform discourses, but get their meaning from certain discourses as well. Yet, treating the fight against HIV/AIDS only as a discourse might mean losing sight of the distinction between discourses and practices. Moreover, one runs the risk of looking at the fight against HIV/AIDS only ‘as a monolithic enterprise heavily controlled from the top’.¹¹ In this volume we therefore explicitly bring together contributions based on and informed by, different positions with regard to the fight against HIV/AIDS. Some contributions focus more on discourses, while others are explicitly based on practical experience. Furthermore others draw upon the analysis of discourses as well as practices. Thus, both power and agency are taken into account, hence the emphasis on negotiation in the title.

The contribution of Ricardo Pereira on PEPFAR can serve as an illustration of those power relations in the fight against HIV/AIDS. The author points out that the authoritative approach accepted by all major aid organizations is influenced by a specific Western, liberal worldview. This discourse on HIV/AIDS might be more generally accepted, but is in itself not more neutral than the Roman Catholic perspective. While the statements of the Pope make the Catholic perspectives on HIV/AIDS

¹⁰ Bauman, Gerd (1999). *The Multicultural Riddle*, New York: Routledge.

¹¹ Grillo, R.D. (1997) “Discourses of development: The View from Anthropology”. In Grillo, R.D. *Discourses of Development: Anthropological Perspectives*. Oxford, pp. 1-34.

appear to be rather fixed and unchangeable, practices of Catholic (inspired) organizations show more flexibility on the grassroots level. However, it must be noted that the statement of the Pope on condom distribution makes some Catholic organizations working on the fight against HIV/AIDS in East Africa worry about the restrictions they will face in their work in sexual education and HIV/AIDS prevention. Thus, taking the discourse approach to the study of worldviews in the fight against HIV/AIDS means ‘we have to show how it involves multiple and ever changing realities and narratives’.¹² That is how practices come into the picture, and the challenges resulting from the practical experience in the fight against HIV/AIDS have to be considered while discussing more theoretical and analytical concepts such as worldviews and discourses.

Worldviews

The concept of ‘worldviews’ has a long intellectual history within the humanities. It has been used fairly pragmatically, as a way to bring together our work on HIV/AIDS from various disciplines, academic traditions and focused on different dimensions. However, it is also a matter of conscious choice to bring these different, overlapping and sometimes conflicting dimensions together under the concept of worldviews.

Worldviews refers to the relationship between human beings and the world in which they live, and looks at the meanings they attach to this relationship.¹³ Thus the concept of worldviews enables us to bring political, social and religious dimensions together while treating them as different, but mutually influential social phenomena. While worldviews also apply to individuals, in this volume we explicitly use it in a collective sense. A worldview that is accepted by a certain community, whether local, national or transnational, influences the discourses on HIV/AIDS constructed by those communities.

The contributions in this volume are all grouped along different dimensions in the fight against HIV/AIDS; political, social and religious dimensions. However, one can question to what extent these dimensions can be discussed separately. In fact, in some contributions we see political and religious dimensions overlapping and influencing each other. In the contribution of Tokola (2) we see how the work of World Vision Mongolia on HIV/AIDS is influenced by national political choices that do

¹² Gardner, K. (2000) “Dominant Paradigms Overturned or ‘Business as Usual’? Development Discourse and the White Paper on International Development.” *Critique of Anthropology*. Vol. 20, 1, pp. 15-29.

¹³ Braun, Willi (2000) *Guide to the Study of Religion* London: Cassel.

not allow them to be registered as an international NGO. She points at the Christian identity of World Vision Mongolia as one of the reasons. While Tokola's paper gives insight in the complex webs of power that influences the work of World Vision in Mongolia, Polinder focuses on conflicting worldviews in the response to the epidemic. His provoking argument, challenges the idea that Western scientific thinking (referred to as the Northern worldview in Polinder's contribution) is secular and rational. While his contribution contrasts with others in this volume, because of the emphasis on clashes, he argues that worldviews need be taken into account by development actors because it can give insight into why efforts to fight HIV/AIDS fail. This brings us to a point that is stressed in other contributions as well: to understand the worldviews that influence the fight against HIV/AIDS, development actors have to become aware of their own worldviews first.

Practical challenges

Being actively involved in HIV/AIDS programs or looking at the epidemic from a more distant theoretical perspective, both practitioners and academics are aware of the practical challenges in the fight against HIV/AIDS. Those practical challenges on the level of individuals and communities are part of the everyday reality non-governmental organizations (NGOs) have to deal with. Marijn's shows how HIV/AIDS programs at schools are confronted with the influence of the epidemic on the educational sector in East African countries. Not only children and their families suffer from the consequences of HIV/AIDS, teachers are also severely affected. A lack of trained teachers is a serious problem to the educational sector in countries in which general populations are hit by the AIDS epidemic. In her paper on 'STI and HIV/AIDS prevention programs for Mongolians in the United Kingdom', Bazarragchaa Tzotg focuses on another practical challenge: migration. From her practical experience as NGO director, the author can show how the situation of Mongolian migrants in the UK contributes to their vulnerability to HIV/AIDS

Another practical account can be found in Henry Armas paper on citizens' participation in Peru. Dealing with the practical challenges of living with HIV in Peru can empower people to become active participants in social movements. However, this empowerment needs to be seen in the context of the limited choices people living with HIV/AIDS have. While Pereira (2) critically supports a more comprehensive approach of social protection of vulnerable families in developing countries, as a way to move out of dominant paradigms.

Armas gives an interesting insight into how such transformations can take place in practice. He shows how the necessity resulting from living with HIV/AIDS leads to the construction of new discourses. Such necessity participation becomes especially powerful as transformative processes, when it is taken up and supported by development organizations. Thus, while discourses and world views influence practices and lead to certain challenges on a practical level, practical challenges and the answers that result from that lead to shaping new discourses as well.

Negotiating

Whatever approach to HIV/AIDS is chosen by a certain organization, it is always the outcome of a process of negotiation between different views, and agenda's and demands. The difference between practical and ideological challenges is often not clear-cut. As Pape shows NGOs in Russia have not been able to influence discourse change in Russia, due to a lack of political will to foster this change. The many practical challenges that Russian NGOs face are not only influenced by a lack of political will and support, but also by moral discourses of the Russian orthodox church condemning sex education and harm reduction programs.

That sexuality is sensitive for FBOs may not come as a surprise, recently many publications have pointed at negative views on sexuality by pointing at the negative and blame laden way in which sexuality is discussed for example in South African churches.¹⁴ Yet, a taboo on sexuality is not only typical for religious actors in the fight against HIV/AIDS. A neglect of sensitive issues such as sexuality and drugs is also characteristic of the policies and approaches of many secular institutions active in the fight against HIV/AIDS.¹⁵ The necessity to bring the connection between HIV/AIDS and sexuality to the floor again, ignored in the poverty perspective on HIV/AIDS that has been embraced by many actors, has also been referred to as an evidence based approach. Marijn's contribution distinguishes between two approaches of FBOs on sexual and reproductive health and rights; evidence based and value based. FBOs involved in the Shareframe project tend to hold on to value-based approaches even though this is not in line with the needs of the young people in their target groups. Hesitance to take up evidence based approaches, however, cannot only be seen in the context of a clash of worldviews but also has to do with a lack of capacity and experience in

¹⁴ Marshall, Mandy and Nigel Taylor 'Tackling HIV and AIDS with faith-based communities'. *Gender & Development*, 14, 3 (November 2006).

¹⁵ Pisani, Wisdom of Whores.

designing evidence based policies and programs. Thus, the process of negotiation is influenced by other factors, than worldviews alone.

The contribution of Bartelink shows that religious institutions are practically involved in the fight against HIV/AIDS. Churches may avoid certain practical challenges on the basis of morality, but these morals might as well press a religious institution to adjust its worldview in such a way that it supports an open attitude towards sensitive issues around sexuality. While this doesn't necessarily mean that a religious institution will engage fully in a comprehensive approach, including giving information and services on condom use for example, they indeed deal with one of the most sensitive issues in the fight against HIV/AIDS openly. In addition to Polinder, not only worldviews or clashes between them should be taken into account by development actors, but attention should be paid to how churches and other faith based organizations deal with sensitive issues in shaping their own (religious) perspective on HIV/AIDS.

Every contribution to this volume, each one in its own way, reflects on challenges experienced in or influencing the fight against HIV/AIDS. In conclusion we can say that it is not only the outcome, but the process of negotiating between different identifications and worldviews that is interesting for both academics and professionals involved in the fight against HIV/AIDS. Because, what this volume has set out to show is that the complexities of the fight against HIV/AIDS are rooted in worldviews as well as in practical challenges. The process of negotiation and the result thereof in policies, programs and activities can best be understood by taking into account the political, social and religious dimensions that inform them.

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Understanding the situation of poverty-related diseases: multi-level statistics, donor initiatives, and conferences

Nancy S. Tokola

This paper provides a foundational overview of the statistics, donor initiatives, and conferences constructed by multi-level organizations in response to the three main poverty-related diseases (PRD): HIV/AIDS, tuberculosis and malaria. Over past decades, methodologies have evolved for estimation of PRD statistics, indicating the scope of the situation against which programs must acquire resources for managing responses. The paper overviews the joint UNAIDS/WHO-published *AIDS Epidemic Update 2007*, the UNAIDS-published *2008 Report on the Global AIDS Epidemic*, the *WHO Report 2008: Global Tuberculosis Control – Surveillance, Planning, Financing*, and the joint WHO/UNICEF-published *World Malaria Report 2005*.

The sixth Millennium Development Goal, formulated in 2000, aims to “have halted by 2015 and begun to reverse” the spread of HIV/AIDS and the incidence of malaria and other major diseases. International strategic policy and practical frameworks have included “Universal Access to Prevention, Treatment, Care and Support” (co-opted from HIV/AIDS by other PRD); HIV/AIDS “3 x 5 Initiative”; “Stop TB Partnership”; and “Roll Back Malaria”. Such frameworks require funds and professional capacity development for administration, implementation, monitoring, and evaluation.

The understanding of poverty-related diseases is advanced through international conferences, regional congresses, and national seminars. On 09 June 2008 in New York, the UN Global Leaders Forum set the theme of “One Life, Two Diseases, One Response” in order to address interactions of HIV/AIDS and tuberculosis. During 13-14 November 2008 in Brussels, the European Commission sponsored an international conference on “Challenges for the Future: Research on HIV/AIDS, Malaria and Tuberculosis”. This paper reviews these important events.

In sum, the paper addresses two questions: How does the understanding of PRD influence their visibility to researchers, policy-makers, practitioners, and donors and, in turn, how does their visibility influence the extent to which a comprehensive response to PRD is achievable in developing countries?

Epidemiology: Foreshadowing the Answers

Epidemiology is “the study of the distribution and determinants of diseases and injuries in human populations”¹ or “the study of how often diseases occur in different populations and why”.² Epidemiologists present information statistically as absolute numbers or as rates, which can be expressed mathematically as fractions, decimals, or percentages. Incidence rate is the number of new cases in a population at risk (without immunity) during a specified period of time (such as a calendar year). Prevalence rate is the “number of existing cases” (new cases plus past cases of the disease with persisting illness) in the total population at a given point in time.³

HIV/AIDS became visible as newly emerging pathologies in 1981, when U.S.-based outbreaks were reported to the U.S. Centre for Disease Control and Prevention. Throughout the 1980s, HIV morbidity (illness) and AIDS-associated mortality (death) escalated from epidemic (“number of cases exceeds that expected on the basis of past experience for a given population”⁴) to pandemic (“higher than normal incidence and prevalence rate” regionally or globally⁵). In contrast, tuberculosis, malaria, and “neglected tropical diseases” (NTD) were recognized as ancient conditions, with tuberculosis being pandemic and with malaria and NTD being endemic (“continuously present” as “a normal level of prevalence to a specific population”⁶; confined to particular geographic areas which have the ecological conditions to support sustained interactions of infectious agents, their vectors, and their non-human and human hosts). Throughout the 1990s, activists campaigned to pull HIV/AIDS into the forefront of attention by media, intergovernmental organizations, local and national governmental organizations, and non-governmental organizations (NGO) in order to motivate resource mobilization for

¹ Mausner, Judith S. and Bahn, Anita K. (1974). *Epidemiology: An Introductory Text*. Philadelphia: W.B. Saunders, p. 21.

² Coggon, D., Rose, Geoffrey, and Barker, D.J.P. (1993). *Epidemiology for the Uninitiated*. Third edition. London: BMJ, p. 1.

³ Mausner, *Epidemiology*, pp. 126-127.

⁴ *Ibid.*, p. 22.

⁵ Linardakis and Khachatryan (1998). *Biostatistics and Epidemiology*, p. 45.

⁶ *Ibid.*, p. 44.

research, to influence policy, and to provide goods and services for practitioners. If HIV/AIDS, tuberculosis, and malaria formed a “Terrible Triangle” of global communicable disease burden, then HIV/AIDS claimed the apex of attention on this triangle. NTD were hidden in remote communities in developing countries. If HIV/AIDS, tuberculosis, malaria, and NTD can be viewed as a “Terrible Square”, then NTD can become more visible. Indeed, tuberculosis, malaria, and NTD – statistically combined – account for approximately 12% of the global disease burden⁷ and, therefore, should attract attention for research and development (R&D) of vaccines, diagnostics, and medications. In November 2008, Médecins Sans Frontiers explained that, “because the people affected by such diseases are poor, and unable to afford expensive health products, they do not represent a commercially viable market”.⁸

The following morbidity statistics cover the estimated averages of incidence and prevalence rates for the “Terrible Square” globally by the end of 2007, the most recent available figures for comparability. There were 33 million people living with HIV (prevalence).⁹ There were 13.7 million prevalent cases of active tuberculosis, 9.27 million incident cases of active tuberculosis, 500,000 incident cases of multiple-drug resistant tuberculosis (MDR-TB, with 27 countries having 85% of these cases), 40,000 incident cases of extensively drug-resistant tuberculosis (XDR-TB, with 55 countries having at least one case each), and 2 billion people having latent tuberculosis infection¹⁰ (with 5-10% risk for re-activation during a lifetime¹¹). There were 3.3 billion people living in the 109 malaria endemic countries, with reporting of 247 million malarial febrile clinical episodes (incidence).¹² Finally, over 1 billion people were infected with one or more NTD.¹³

In summary of this “Terrible Square” of global communicable disease burden, by the end of 2007, the 33 million statistic for people

⁷ Médecins Sans Frontiers (2008): *Cough Up for TB! The Underfunding of Research for Tuberculosis and Other Neglected Diseases by the European Commission*, Geneva: MSF, p. 3.

⁸ Ibid., pp. 6-7.

⁹ UNAIDS (2008). *Report on the Global AIDS Epidemic*, Geneva: UNAIDS.

¹⁰ WHO (2009): WHO Report 2009: Global Tuberculosis Control: Epidemiology, Strategy, Financing, pp. 1-2, http://www.who.int/tb/publications/global_report/2009/en/index.html, accessed on 10 March 2009.

¹¹ Tuberculosis Alliance Vaccine Initiative (2008). *Tuberculosis: A Huge Cost to Humanity*, Brussels: TBVI, pp. 1-5.

¹² Roll Back Malaria Partnership (2008): “The Global Malaria Action Plan: Key Facts, Figures, and Strategies”, p. 2, http://www.rollbackmalaria.org/gmap/GMAP_Advocacy-ENG-web.pdf, accessed on 05 January 2009.

¹³ World Health Organization (2008): “Neglected Tropical Diseases”, http://www.who.int/neglected_diseases/diseases/en/, accessed on 14 December 2008.

living with HIV is in stark contrast to the approximately 2 billion people (one-third of the world population) having latent tuberculosis infection, 3 billion people (one-half of the world population) living in malaria-endemic areas, and 1 billion people (one-sixth of the world population) diagnosed with NTD. Yet, globally, HIV/AIDS outstrips the media attention and funding for R&D and for both clinical and public health interventions aimed at controlling, eliminating, and eventually eradicating these diseases.

A foundational message of this paper is that PRD, both communicable and non-communicable, should be perceived as problems which have their root causes in “social and economic inequality, discrimination and marginalization”. The health sector alone cannot tackle PRD, which require multi-sectoral cooperation.¹⁴ Through the subsequent five sections, this paper overviews the classification of diseases, the general frameworks for prioritising PRD, the main publications on the situations of communicable PRD, the international strategies for responding to these PRD situations, and the recent international conferences for debating these situations and responses to communicable PRD.

Classification of Diseases

This second section of the paper provides a general classification of diseases based on biological causation and then a specific classification of diseases based on level of nation-state development, which influences the visibility of PRD.

Medical researchers and practitioners categorize diseases into two general categories: 1) communicable diseases (contagious or infectious diseases) and 2) non-communicable diseases. Communicable diseases are caused by infectious agents, which are categorized as prions (self-replicating proteins), viruses, bacteria, fungi, protozoa (one-celled organisms), or helminths (worms). The infectious agent is specific to the disease. HIV, a retrovirus, is the causative agent of AIDS. The predominant strains are HIV-1, which is globally distributed, and HIV-2, which is confined to western Africa and to migrants from this area. *Mycobacterium tuberculosis*, a rod-shaped bacterium, is the causative agent of tuberculosis in humans. *Plasmodium*, a genus of protozoa, is the causative agent of malaria; there are four species of *Plasmodium* infecting humans: *P. falciparum*, *P. ovale*, *P. malariae*, and *P. vivax*. Across the 109 malaria-endemic countries, approximately forty species of *Anopheles*

¹⁴ Tarantola, Daniel (2001). “Facing the Reality of AIDS – a 15-year process?” *Bulletin of the World Health Organization*, 79/12, p. 1095.

mosquitoes can serve as vectors in transmitting *Plasmodium* to humans, since the female mosquito must obtain a blood meal in order for her eggs to mature.¹⁵ There are examples of NTD within each of the categories of infectious organisms. NTD have “overlapping geographical clusters”, in which different types of NTD occur in the same geographical area. Similar to malaria, some of the NTD require a biological vector for transmission to humans. Due to lack of compliance with medication regimens by human hosts, the genetic material of any of these infectious organisms can mutate, resulting in drug-resistant strains.

Non-communicable diseases are malformations and malfunctions attributable to inherited, acquired (including injuries from accidents), or multi-factorial causes. Many non-communicable conditions (such as autoimmune diseases, cancers, cardiovascular diseases, type II diabetes, and tobacco-related illnesses) are considered “chronic diseases of aging” because members of the population have sufficient longevity for cumulative damage to result in overt manifestation of the disease.

Collectively, communicable and non-communicable diseases can be categorized into three types according to incidence in developed versus developing countries. Considering visibility, Type I classification highlights both communicable and non-communicable diseases, whereas Type II and Type III classifications highlight communicable diseases. Considering funding for R&D and for the delivery of goods and services to vulnerable populations, Type I diseases are well funded, Type II diseases are “neglected”, and Type III diseases are “very neglected”. Type I diseases are “incident in both rich and developing countries, with large numbers of vulnerable population in each”. Examples of Type I communicable diseases are hepatitis B and measles. Examples of Type I non-communicable diseases are cardiovascular diseases, diabetes, and tobacco-related disorders. Type II diseases are “incident in both rich and developing countries, but with a substantial proportion of the cases in the poor countries”. Examples of Type II communicable diseases are HIV/AIDS and tuberculosis because “more than 90 percent of cases are in developing countries”. Type III diseases are “overwhelmingly or exclusively incident in developing countries”. Examples of Type III communicable diseases are NTD.¹⁶

¹⁵ Centre for Disease Control and Prevention (2008): “Malaria: Geographic Distribution”, http://www.cdc.gov/malaria/distribution_epi/distribution.htm, accessed on 20 August 2008.

¹⁶ WHO (2006): “CIPIH Report”, World Health Assembly Commission on Intellectual Property Rights, Innovation and Public Health, Geneva: WHO.

The World Health Organization (WHO) classifies seventeen communicable diseases as NTD, in alphabetical order as follows:¹⁷ Buruli Ulcer, Chagas diseases (American trypanosomiasis), Dengue haemorrhagic fever, Dracunculiasis (guinea worm disease), Fascioliasis (liver fluke), Human African trypanosomiasis (African sleeping sickness), Leishmaniasis (cutaneous and visceral), Leprosy, Lymphatic filariasis, Malaria, Neglected zoonoses (organisms transmitted from non-human animals to humans), Onchocerciasis (African river blindness), Schistosomiasis, Soil-transmitted helminthiasis, Trachoma, Tuberculosis, and Endemic Treponemes (such as Yaws, Pinta, and endemic syphilis). Note that this NTD list includes malaria and tuberculosis, but not HIV/AIDS.

General Frameworks for Prioritization of PRD

This third section of the paper explores two general frameworks through which PRD situations become visible (or remain invisible): the well-known Millennium Development Goals (MDG) from 2000 and the less familiar Copenhagen Consensus from 2004. Visibility of PRD motivates responses by donors, researchers, policy-makers, and practitioners. These frameworks emphasize the interaction of PRD and nation-state development.

During the Millennium Summit in September 2000, through the *Millennium Declaration*, world leaders acknowledged the impact of poverty through its broader ramifications on human populations, leading to the formulation of eight global MDG, eighteen targets time-bound for 2015, and forty-eight indicators measuring progress from baseline 1990 data.¹⁸ The eight goals are interdependent, and the links to PRD are evident across these goals and their associated targets.

MDG 1 (“eradicate extreme poverty and hunger”) is the foundational goal because of focusing on basic survival. MDG 2 (“achieve universal primary education”) and MDG 3 (“promote gender equality and empower women”) are goals in themselves but also are key means for achieving the other goals.

There are three designated health-related MDGs: MDG 4 (“reduce infant mortality”), MDG 5 (“improve maternal health”), and MDG 6 (“combat HIV/AIDS, malaria, and other diseases”). MDG 4 has only

¹⁷ World Health Organization (2008): “Neglected Tropical Diseases”, http://www.who.int/neglected_diseases/diseases/en/, accessed on 14 December 2008.

¹⁸ Sachs, Jeffrey (2005). *Investing in Development: A Practical Plan to Achieve the Millennium Development Goals*. Geneva: United Nations Millennium Project Report to the UN Secretary-General; London: Earthscan Publications, pp. xviii - xix.

Target 5: to “reduce by two-thirds, between 1990 and 2015, the under-five mortality rate”. For children under five years old, this target is partially achievable through immunization against preventable communicable diseases. MDG 5 has only Target 6: to “reduce by three-quarters, between 1990 and 2015, the maternal mortality rate”. For women in their reproductive years, this target is partially achievable through access to clinical services such as diagnosis and treatment of sexually transmitted infections (STI) and provision of barrier contraception such as condoms. MDG 6 has two targets: to “have halted by 2015 and begun to reverse” the spread of HIV/AIDS (Target 7) and the incidence of malaria and other major diseases (Target 8).¹⁹ In Target 8, the delineation of these “other major diseases” is the responsibility of the particular nation-state.

MDG 7 (“ensure environmental sustainability”), with its three targets, overtly focuses on preservation of environmental resources (Target 9) but less visibly also addresses the combating of PRD through access to safe drinking water and basic sanitation (Target 10) and through improving the lives of slum dwellers (Target 11). Poor sanitation causes pollution of drinking water supplies. Slum dwellers suffer from poor sanitation and consequently from unsafe drinking water harbouring water-borne infectious organisms and their vectors, but slum dwellers further suffer from overcrowded living conditions enabling the transmission of air-borne pathogens such as the tubercle bacillus. Slum dwellers may be excluded from civil registration and consequently from social entitlements to education and health services necessary for prevention and treatment of PRD.

MDG 8 includes targets for financial systems, debt relief, good governance, essential drugs, and information and communication technologies (ICT), all of which promote mobilization of resources for responding to PRD.

In 2001, the WHO Commission on Macroeconomics and Health reported on its financial analysis of responding to disease burdens in developing countries. WHO determined that “the least-developed countries would have to spend US\$30-40 annually per person for health in order to cut by half the premature deaths due to AIDS, malaria and other widespread diseases: this would save the lives of 8 million people per year”. However, WHO asserted: “Even with an increase in the health expenditures of the poor countries from US\$50 billion to 90 billion by the year 2015, there still remains a financing gap”. The CMH concluded: “The financial benefit of this global effort” [to fill the financial gap] would be many times greater than the investments”, since the “increased

¹⁹ Ibid.

productivity and greater economic growth are estimated to be at least US\$360 billion per year”.²⁰

In 2002, the “Global Fund to Fight AIDS, Tuberculosis and Malaria” – the “Terrible Triangle” – was established as a public/private partnership in order to support country-specific plans for achieving MDG 6. Statistics reinforced this decision to focus on communicable PRD. In 2002, out of a global population of approximately 6 billion people, there were 57 million deaths from all causes of disease, communicable and non-communicable. 20% of these deaths were in children under age 5 years, and 98% of these child deaths were in developing countries. Communicable diseases accounted for 60% of all child deaths. Further, communicable diseases represented seven out of the top ten overall causes of child deaths.²¹

In 2004, Bjorn Lomborg, a Danish economist and head of the Danish Environmental Assessment Institute,²² designed his Copenhagen Consensus Project around this central question: “How should a limited amount of new money for development initiatives, say an extra \$50 billion, be spent? Would it be possible to reach an agreement on what should be done first?”²³

Lomborg gathered together a panel of eight expert economists, including three Nobel laureates. The panellists reviewed the documents of UN agencies and constructed a short list of ten “development challenges”, in alphabetical order as follows: civil conflicts, climate change, communicable diseases, education, financial stability, governance, hunger/malnutrition, migration, trade reform, and water/sanitation.

Thereafter, the panellists issued a call for “challenge papers”, which took the form of project proposals for responding to each of these ten issues with rationales, plans, and budgets. Out of 38 proposals on a long list, the panellists prioritized 17 proposals on a short list, most significantly as follows: Rank 1 (opportunity to control HIV/AIDS), Rank 4 (opportunity to control malaria), Ranks 6, 7, and 8 (opportunity to improve water/sanitation), and Rank 13 (opportunity to scale up basic health services). These Copenhagen Consensus results reinforced the

²⁰ WHO (2001): “Investing in Health for Economic Development: Report of the Commission on Macroeconomics and Health”,
<http://www.who.int/whosis/menu.cfm>

?path=whosis,cmh&language=english, accessed on 10 December 2008.

²¹ Mills, Anne and Shillcutt, Sam (2004). “Copenhagen Consensus Challenge Paper: Communicable Diseases”, pp. 62-114, in: Lomborg, Bjorn (ed.) (2004). *Global Crises, Global Solutions*. Cambridge: Cambridge University Press.

²² “Special Report Copenhagen Consensus: Putting the World to Rights”, *Economist*, 05 July 2004, pp. 59-61.

²³ Lomborg, Bjorn (ed.) (2004). *Global Crises, Global Solutions*. Cambridge: Cambridge University Press, pp. 1-9.

visibility of PRD in the three health-related MDGs (MDG 4, 5, and 6) and in MDG 7.

Statistics on Communicable Poverty-related Diseases

This fourth section of the paper addresses the key publications offering statistics on the situations of the communicable PRD forming the “Terrible Square”. In developing countries, 90% of avoidable deaths are caused by communicable diseases.²⁴ This statistic serves as a rationale for focusing on communicable PRD, even though non-communicable PRD are significant causes of morbidity and mortality in poverty-embedded, resource-poor settings.

Statistics on HIV/AIDS

The Africa Region has 10% of the global population and greater than 70% of the global HIV/AIDS burden.²⁵ WHO and UNAIDS track the regional and global pandemics. Whereas WHO has a general health mandate, UNAIDS has a specific health mandate for tracking the HIV/AIDS pandemic. Annually, WHO independently authors its own organizational publication, the *World Health Report*. Biannually since 1998, UNAIDS has independently authored its own organizational publication, the *Report on the Global AIDS Epidemic*. While UNAIDS mounts a multi-sectoral response to HIV/AIDS, WHO is responsible for the health sector response to HIV/AIDS.²⁶ Annually since 2001, UNAIDS and WHO have co-authored the *AIDS Epidemic Update*, which is published just before World AIDS Day on December 01.²⁷

During 25-27 June 2001, the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS issued the “Declaration of

²⁴ Mills, Anne and Shillcutt, Sam (2004) “Summary of Copenhagen Consensus Challenge Paper on Communicable Diseases” 16 May 2004, pp. 1-6, http://www.copenhagenconsensus.com/Admin/Public/DWSDownload.aspx?File=Files%2FFiler%2FCC%2FPapers%2FCommunicable_Diseases.

²⁵ Kibaki, Mwai (2002): “Welcome Remarks by President of Republic of Kenya: 13th International Conference on AIDS and Sexually Transmitted Infections in Africa”, Nairobi, Kenya, 21 September 2002, http://www.kenyaembassy.org/site/news/press_32.htm, accessed on 25 January 2009.

²⁶ UNAIDS (2007). *Towards Universal Access by 2010: Scaling Up Priority HIV/AIDS Interventions in the Health Sector*, p. 5.

²⁷ UNAIDS (2008). “AIDS Epidemic Update Report Archive”: reports for the years from 2001 until 2007, <http://www.unaids.org/en/KnowledgeCentre/HIVData/EpiUpdateArchive/>, accessed on 15 August 2008.

Commitment on HIV/AIDS”.²⁸ The UNGASS Declaration requires a biannual *Country Progress Report* to be submitted by signatory nation-states. An increasing number of UN Member States have been submitting these reports: 102 out of 189 Member States in 2004, 122 out of 191 Member States in 2006, and 147 out of 192 Member States in 2008.²⁹ In 2002, the UNAIDS Monitoring and Evaluation Division devised the “Country Response Information System”(CRIS) in order to guide the national HIV/AIDS surveillance processes necessary for construction of these UNGASS reports. CRIS is a means to harmonize data collection, analysis, and reporting. Since 2003, UNAIDS has recorded this data into the “Global Response Database”, which disaggregates by age and gender at national level and at regional level.³⁰

Since 2003, UNAIDS has reported HIV/AIDS statistics as an estimated average accompanied by “plausibility bounds”. “Plausibility” refers to “the degree of uncertainty associated with estimates”; the “bounds” constitute the minimum-to-maximum range around the average, with wider range indicating greater uncertainty.³¹ During 2003, 2005, 2007, and 2009, UNAIDS has been conducting a global series of training workshops in order to build capacity in countries to produce these estimates.³²

Consider the following HIV prevalence estimates reported by UNAIDS for people living with HIV (PLH) (adults and children): 40 million PLH at end of 2001, 42 million PLH at end of 2002, 440 million PLH at end of 2003, 39.4 million PLH at end of 2004, 40.3 million PLH at end of 2005, 39.5 million PLH at end of 2006, and then surprisingly a significant downsizing of the pandemic to 33.2 million PLH at end of 2007.³³

Observe that, between the end of 2006 and the end of 2007, suddenly there was a 16% reduction based on the estimated averages,

²⁸ Declaration of Commitment on HIV/AIDS”, United Nations General Assembly Special Session (UNGASS) on HIV/AIDS, 25-27 June 2001, New York:.

²⁹ UNAIDS (2008). *2008 Report on the Global AIDS Epidemic*, p. 3.

³⁰ UNAIDS (2008). “CRIS: Country Response Information System”, <http://www.unaids.org/en/KnowledgeCentre/HIVData/CRIS/cris.asp>, accessed on 31 August 2008.

³¹ UNAIDS (2008): *2008 Report on the Global AIDS Epidemic*, pp. 214-215, http://data.unaids.org/pub/GlobalReport/2008/jc1510_2008_global_report_pp211_234_en.pdf, accessed on 18 August 2008.

³² UNAIDS (2008): “Methods and Assumptions for Estimates”, <http://www.unaids.org/en/KnowledgeCentre/HIVData/Methodology/>, accessed on 18 August 2008.

³³ UNAIDS (2008). “AIDS Epidemic Update Report Archive”, <http://www.unaids.org/en/KnowledgeCentre/HIVData/EpiUpdateArchive/>, accessed on 15 August 2008.

with 6 million fewer PLH counted in the global HIV prevalence calculations. Retrospectively, in September 2008, a journalist of *Time* magazine reported: “At the time, the UN came under fire from critics for inflating its estimates [prior to 2007] in order to exaggerate the urgency of the epidemic – and to spur bigger donations”. However, the *Time* journalist clarified: “In large part, such massive miscalculations have less to do with politics than with the simple fact that epidemiology involves an inordinate amount of guesswork. Routine re-evaluations of existing data often result in data shifts, sometimes huge ones, which global health experts and epidemiologists have come to expect”.³⁴

The *AIDS Epidemic Update 2007* explained: “The single biggest reason for this reduction was the intensive exercise to assess India’s HIV epidemic, which resulted in a major revision of that country’s estimates”; further, there were major revisions in sub-Saharan Africa, specifically in Angola, Kenya, Mozambique, Nigeria, and Zimbabwe. The collective revisions in these six nation-states resulted in the downsizing of the global HIV pandemic. UNAIDS concluded that the differences in 2006 and 2007 annual estimates “result largely from refinements in methodology, rather than trends in the pandemic itself”.³⁵

Statistics on Tuberculosis

Over 90% of tuberculosis morbidity and mortality occurs “in low- and middle-income countries, comprising 76% of the world’s population”.³⁶ Since 1997, WHO has published annually its *WHO Report: Global Tuberculosis Control*. The *WHO Report 2008: Global Tuberculosis Control – Surveillance, Planning, Financing* analyzed data submitted in 2006 (a two-year lag). The *WHO Report 2009: Global Tuberculosis Control – Epidemiology, Strategy, Financing* analyzed data submitted in 2007 by 196 out of the total nation-states and territories in the world.³⁷ These reports have profiled twenty-two high-burden countries in which 80% of the global tuberculosis cases occur: Americas (Brazil), Eastern Europe and Central Asia (Russian Federation), ten countries in Africa,

³⁴ Blue, Laura (2008). ‘Global Malaria Estimates Are Reduced’ *Health & Science* section, *Time* online, 18 September 2008, <http://www.time.com/time/health/article/0,8599,1842102,00.html>, accessed on 15 November 2008.

³⁵ UNAIDS (2007): *AIDS Epidemic Update 2007*, December 2007, Geneva: UNAIDS.

³⁶ AERAS Global TB Vaccine Foundation (2007). *Developing New Tuberculosis Vaccines for the World: 2006/2007 Progress Report*. Rockville: AERAS, pp. 1-2.

³⁷ WHO (2009): *WHO Report 2009: Global Tuberculosis Control - Epidemiology, Strategy, Financing*, http://www.who.int/tb/publications/global_report/2009/en/index.html, accessed on 10 March 2009.

and eleven countries in Asia.³⁸ However, these reports warn that “[e]stimates for all years are re-calculated as new information becomes available and technologies are refined, so they may differ from those published previously”.³⁹

Since 1996, WHO and the International Union against Tuberculosis and Lung Disease (IUATLD) have partnered for a “Global Project” to publish reports entitled *Anti-tuberculosis Drug Resistance in the World*, based on surveys conducted in an increasing number of participating countries (1997 report: 35 countries surveyed during 1994-1997; 2000 report: 58 countries surveyed during 1996-1999; 2004 report: 77 countries surveyed during 1999-2000; 2008 report: 93 countries surveyed during 2002-2007).⁴⁰

Statistics on Malaria

In general, out of the 109 malaria-endemic countries, 35 countries (30 in sub-Saharan Africa and 5 in Asia) report 98% of the global deaths from malaria. Five of these sub-Saharan Africa countries – Democratic Republic of the Congo, Ethiopia, Nigeria, Tanzania, and Uganda – account for 50% of the global deaths from malaria.⁴¹ Before 2003, the international community made rough estimates on the global situation of malaria. Then in 2005, WHO and the United Nations Children’s Fund (UNICEF) partnered to publish the *World Malaria Report 2005*, the “first comprehensive” effort to provide global malaria statistics. This landmark report used 2003 clinical data (a two-year lag) collected on malarial febrile episodes and malarial mortality in endemic nation-states. Statistical modelling was based on forty-year-old techniques to evaluate vegetation coverage in order to estimate *Anopheles* mosquito population sizes and, indirectly, *Plasmodium* infections in the human populations.⁴²

Then in 2008, WHO and UNICEF partnered again to publish the *World Malaria Report 2008*, which used 2006 clinical data and a re-evaluation of vegetation coverage based on urbanization and deforestation particularly in Asia and more particularly in India. This re-

³⁸ Ibid.

³⁹ WHO (2008). WHO Report 2008: Global Tuberculosis Control, Annex 1, p. 191.

⁴⁰ World Health Organization and International Union against Tuberculosis and Lung Disease (2008): *Anti-tuberculosis Drug Resistance in the World*, http://www.who.int/tb/publications/mdr_surveillance/en/index.html, accessed on 10 August 2008.

⁴¹ Roll Back Malaria Partnership (2008): “The Global Malaria Action Plan: Key Facts, Figures, and Strategies”, “Key Tools for Malaria Prevention and Treatment”, p. 9.

⁴² World Health Organization and United Nations Children’s Fund (2005). *World Malaria Report 2005*. Geneva: WHO and UNICEF.

evaluation resulted in the successive downsizing of India national statistics, Asia regional statistics, and thus global statistics for malaria.⁴³

Statistics on Neglected Tropical Diseases

The scope of this paper does not permit covering all 17 of the NTD designated by WHO. There is no global notification system for NTD to enable accurate estimation of rates. However, the statistics of two visible successes should motivate increased resource mobilization for the other NTD. A more visible NTD, leprosy, caused by *Mycobacterium leprae*, is endemic in 122 countries. Since 1985, accessibility of multi-drug therapy has led to the elimination of this ancient disease in 116 countries. A less visible NTD, dracunculiasis, caused by the guinea worm, is transmitted through unsafe drinking water. With escalation of prevention and treatment measures, the number of cases has decreased over the past two decades from 3.5 million cases to 4,619 cases (as of 2008), indicating the transition from elimination to eradication.⁴⁴

Yaws, caused by the bacterium *Treponema pertenuae*, is a “forgotten disease” in sub-Saharan Africa and Asia. Transmitted through direct skin-to-skin contact in overcrowded living conditions, approximately 75% of cases are diagnosed in children (particularly age 6-10 years), with risk of stigmatizing disfigurement from ulcerations and granulomas. This disease can be cured by one dose of injected benzathine penicillin. During 1950-1970, a joint WHO and UNICEF campaign led to a 95% decrease in yaws prevalence in 46 countries, constituting elimination and near eradication. Thereafter, local healthcare systems took responsibility, national political will declined, and lack of resources led to escalation of yaws. WHO estimated the prevalence of yaws as 2.5 million cases in the 1990s.⁴⁵

Specific Strategies for Responding to PRD

This fifth section of the paper overviews the main strategies adopted by the international community for responding to the situations of communicable PRD within the “Terrible Square”. Ideally, these responses progress from control to elimination to eradication.

⁴³ Ibid.

⁴⁴ World Health Organization (2008): “10 Facts on Neglected Tropical Diseases”, http://www.who.int/neglected_diseases/en/, accessed on 14 December 2008.

⁴⁵ World Health Organization (2009): “Yaws: A Forgotten Disease”, http://www.who.int/neglected_diseases/diseases/yaws/en/index.html, accessed on 14 December 2008.

Strategies: Control of HIV/AIDS

December 01 is World AIDS Day. In 1988, it was initiated for the first time in order to advocate internationally for increased understanding of and funding for the escalating HIV/AIDS pandemic. In 1997, the new UNAIDS took over the administration of WAD by devising the World AIDS Campaign (WAC). In 2004, WAC transitioned to the status of an independent NGO, initially based in Amsterdam, The Netherlands but with an office in Cape Town, South Africa as of 2007.⁴⁶

During 21-26 September 2002 in Nairobi, a working group of the “13th International Conference on AIDS and STIs in Africa” (ICASA) devised “a set of guiding principles for optimizing the use of resources and improving the country-level response to AIDS”. Thereafter, on 25 April 2004 in Washington, D.C., at the “Consultation on Harmonization of International AIDS Funding”, multi-level representatives approved the “Three Ones Principles”, for which UNAIDS became the “facilitator and mediator”. The “Three Ones Principles” are as follows: one national HIV/AIDS strategy, one national coordinating authority, and one national monitoring and evaluation system.⁴⁷

In December 2003, the World Health Assembly, the WHO governing body, launched the “3 x 5 Initiative”, with the goal of treating 3 million people living with HIV/AIDS (PLHA) in developing countries by 2005 with antiretroviral therapy (ART).⁴⁸ The “3x5 Strategy” motto was “Making it happen”. The three core principles were “urgency, equity and sustainability”. The five strategic pillars were as follows: 1) “global leadership, strong partnership and advocacy”, 2) “urgent, sustained country support”, 3) “simplified standardized tools for delivering ART”, 4) “effective, reliable supply of medicines and diagnostics”, and 5) “rapidly identifying and reapplying new knowledge and successes”.⁴⁹ At the start of this initiative, there was a funding gap of US\$ 5.5 billion. WHO issued progress reports in June 2004, December 2004, and June 2005. By June 2005, only 1 million PLHA in need were receiving ART –

⁴⁶ World AIDS Campaign (2008): “History of the WAC”, updated on 07 May 2008, <http://www.worldaidscampaign.org/en/WAC/About-Us/History-of-the-WAC>, accessed on 05 June 2008.

⁴⁷ UNAIDS (2005). *The “Three Ones” in Action: Where We Are and Where We Go from Here* (Geneva: UNAIDS), p. 7.

⁴⁸ WHO (2005). “3x5 Initiative”, <http://www.who.int/3by5/en/>, accessed on 15 March 2008.

⁴⁹ WHO (2003). “Treating 3 Million by 2005: Making It Happen”, <http://www.who.int/3by5/publications/documents/isbn9241591129/en/>, accessed on 15 March 2008.

one-third of the target.⁵⁰ By December 2006, only 28% of PLHA in need were receiving ART.

For the HIV/AIDS response in 2006, WHO, UNAIDS, and UNICEF jointly launched a new initiative called “Universal Access to Prevention, Treatment, Care and Support”, with the goal of “universal coverage” (interventions for 80% of the population at risk) by 2010. By December 2007, only 31% of PLHA in need were receiving ART.⁵¹ In 2008, international donors invested US\$ 13.7 billion in this HIV/AIDS Universal Access initiative, but the funding required to meet the goal by 2010 is US\$ 25 billion – a funding gap of US\$ 11.3 billion in the midst of a global economic crisis.⁵²

Notably, during 02-04 May 2006, the “Special Summit of African Union on HIV/AIDS, Tuberculosis and Malaria” met in Abuja, Nigeria, in order to formulate “Africa’s Common Position to the UN General Assembly Special Session on AIDS” (scheduled for June 2006). The high-level representatives expanded the Universal Access mandate beyond HIV/AIDS to include tuberculosis and malaria.⁵³

Strategies: Control of Tuberculosis

In 2000, WHO launched the “Stop TB Partnership”, which in turn that same year launched the first World TB Day on March 24, commemorating the day on which Dr. Robert Koch had isolated the tubercle bacillus in 1882. The Stop TB Partnership set the goal of globally eliminating tuberculosis by 2050. “Elimination” is achieved when the TB incidence is less than one case per one million people in a country.

As of January 2009, the Stop TB Partnership “Partners’ Directory” listed 828 partner organizations.⁵⁴ Three Partners’ Forums have launched three successive phases of the “Global Plan to Stop TB”: 2001–2005,

⁵⁰ WHO (2005): Progress on Global Access to HIV Antiretroviral Therapy: An Update on “3 by 5”, <http://www.who.int/3by5/fullreportJune2005.pdf>, accessed on 15 March 2008.

⁵¹ WHO (2008): “Universal Access by 2010”, <http://www.who.int/hiv/topics/universalaccess/en/index.html>, accessed on 15 March 2008.

⁵² Dyer, Clare (2009). “Funding the HIV/AIDS Needs to Double to Ensure Universal Access to Drugs”. *BMJ*, vol. 338, p. 583.

⁵³ African Union (2006). “Special Summit of African Union on HIV/AIDS, Tuberculosis and Malaria”, Abuja, Nigeria, 02-04 May 2006 – “Africa’s Common Position to the UN General Assembly Special Session on AIDS” – “Theme: Special Summit to HIV/AIDS, Tuberculosis and Malaria Services by 2010”, Addis Ababa: African Union.

⁵⁴ WHO (2009). “Stop TB Partnership Partners Directory”, January 2009, <http://www.stoptb.org/partners/>, accessed on 08 December 2008.

2006 –2010, and 2011-2015.⁵⁵ In 2000, for enabling the national health authorities of epidemic countries to incorporate this planning, the Stop TB Partnership designed the Tuberculosis Control Assistance Program (TBCAP), administered by the partner United States Agency for International Development (USAID).

In 1996, WHO introduced its “DOTS Strategy” as the means to control tuberculosis locally, nationally, regionally, and globally.⁵⁶ DOTS is “Directly Observed Treatment - Short Course”. WHO defines “DOTS Coverage” as “the percentage of the national population living in areas where health services have adopted DOTS”. The aim is to detect at least 70% of smear-positive cases (microscopic observation of tubercle bacilli in a sputum smear) and successfully to treat at least 85% of detected cases with DOTS.⁵⁷ In 2006, WHO reported DOTS coverage as 93% globally, 100% in South-East Asia, 100% in Western Pacific, 98% in Eastern Mediterranean, 93% in Americas, 91% in Africa, and a surprisingly low 67% in Europe.⁵⁸ That same year, for the tenth anniversary of its original DOTS Strategy, the Stop TB Partnership made revisions by constructing a six-point strategic commitment for scaling up the global response to TB. These six points are as follows: 1) “Pursue high-quality DOTS expansion and enhancement”, 2) “Address TB/HIV, MDR-TB, and the needs of poor and vulnerable populations”, 3) “Contribute to health system strengthening based on primary health care”, 4) “Engage all care providers”, 5) “Empower people with TB, and communities through partnership”, and 6) “Enable and promote research”.⁵⁹ For the global response to tuberculosis, “[t]here exists a current funding gap for TB control of US\$ 0.9 billion that is increasing to 1.2 billion in the wake of the increased appearance of drug-resistant TB cases”.⁶⁰

Considering TB/HIV co-infection, in 2004, UNAIDS and the Stop TB Partnership joined forces for the campaign “Fight AIDS, Fight TB, Fight Now”.⁶¹ In a speech given to support the Stop TB Partnership at the

⁵⁵ Ibid.

⁵⁶ WHO (2006): “The Stop TB Strategy”, http://www.who.int/tb/strategy/stop_tb_strategy/en/, accessed on 20 April 2008.

⁵⁷ WHO (2008) WHO Report 2008: Global Tuberculosis Control, p. 187.

⁵⁸ Ibid, p. 290.

⁵⁹ “WHO Launches New Stop TB Strategy to Fight the Global Tuberculosis Epidemic: DOTS Strengthened by a Six-point Strategy to Achieve the 2015 TB-related Millennium Development Goal”. *Lancet*, vol. 367, 17 March 2006, pp. 877-878.

⁶⁰ Tuberculosis Vaccine Initiative (2008): “Tuberculosis: A Huge Cost to Humanity”, pp. 1-5.

⁶¹ Stop TB Partnership and Joint United Nations Programme on HIV/AIDS (2004): “Fight AIDS, Fight TB, Fight Now TB/HIV Information Pack”, <http://www.stoptb.org/news/archives/iacxv/TBHIVInformationPack.asp>, accessed on 16 November 2008.

“XV International AIDS Conference” in Bangkok in July 2004, Nelson Mandela asserted: “But we cannot win the battle against AIDS if we do not also fight TB. TB is too often a death sentence for people with AIDS. We have lost ground in the fight against TB in the face of a spreading AIDS epidemic.” Further, Mandela asserted: “The world has made defeating AIDS a top priority. This is a blessing. But TB remains ignored”.⁶² Complicating the fight against TB/HIV co-infection, a major concern is that “the current TB drug regimen is not compatible with certain common antiretroviral therapies used to treat HIV/AIDS.”⁶³

For TB/HIV co-infections, the *WHO Report 2009: Global Tuberculosis Control* made the following observations from 2007 data: 1) “Among the 15 countries with the highest estimated TB incidence rates, 13 countries are in Africa, a phenomenon linked to high rates of HIV co-infection”; 2) “In 2007, as in previous years, the Africa region accounted for most (79%) HIV-positive TB cases, followed by South-East Asia Region (mainly India) with 11% of total cases”; 3) during 2007 alone, 14.8% of incident TB cases were diagnosed with HIV (1.37 million TB/HIV co-infections out of 9.27 million TB infections).⁶⁴

Strategies: Control of Malaria

Considering the global response to malaria, in 1998, WHO, UNICEF, United Nations Development Program (UNDP), and World Bank launched Roll Back Malaria (RBM) with the motto “Right Drugs, Right Place, Right Time”. Thereafter, on 25 April 2000, at the “African Summit on Malaria” in Abuja, Nigeria, African leaders from 44 malaria-endemic countries signed the “Abuja Declaration on Roll Back Malaria in Africa” and declared April 25 to be “Africa Malaria Day”.⁶⁵ In May 2007, the World Health Assembly declared April 25 to be “World Malaria Day”.⁶⁶

⁶² Mandela, Nelson (2004). “Remarks by Nelson Mandela on TB/HIV: Media Briefing on ‘Confronting the Joint HIV-TB Epidemics’”, XV International AIDS Conference, Bangkok, 15 July 2004, www.stoptb.org/news/archives/iacxv/MandelaSpeech.asp, accessed on 10 January 2009.

⁶³ TB Alliance (2006): “The Urgent Need for New TB Drugs”, www.tballiance.org, accessed on 15 November 2008.

⁶⁴ World Health Organization (2009): *WHO Report 2009: Global Tuberculosis Control*, pp. 9-10, www.who.int/tb/publications/globalreport/2009/en/index.html, accessed on 10 March 2009.

⁶⁵ Roll Back Malaria Partnership (2009): “African Summit 2000”, <http://www.rollbackmalaria.org/globaladvocacy/africansummit2000.html>, accessed on 05 January 2009.

⁶⁶ WHO (2009). “World Malaria Day”, <http://www.who.int/mediacentre/events/annual/malaria/en/index.html>, accessed on 05 January 2009.

The RBM Partnership conducts forums for guiding strategies and services. In 2004, the RBM Partnership established its Malaria Medicines and Supplies Service.⁶⁷ Control of malaria requires the following “tools” for prevention of parasite transmission and for case management of malaria patients: long-lasting insecticide-treated bed nets and indoor residual spraying to prevent contact with anopheline mosquitoes, intermittent preventive treatment during pregnancy, traditional microscopic diagnosis or rapid diagnostic tests (RDT), Artemisinin-based Combination Therapies (ACT) for malaria patients infected with *P. falciparum*, and chloroquine and primaquine treatment for patients infected with *P. vivax*.⁶⁸

Although malaria is an ancient disease, in 2005 the RBM Partnership launched “the first single comprehensive blueprint for global malaria control and elimination”,⁶⁹ the Global Strategic Plan (2005-2015), containing the Global Malaria Action Plan (GMAP) for all 109 endemic countries. The RBM/GMAP goals are to achieve global malaria “control” (“universal coverage” through interventions) in the short term by 2010 (Universal Access deadline), “elimination” (zero mortality in patients) in the medium term by 2015 (MDG deadline), and “eradication” (zero transmission of the parasite by mosquito vectors) in the long term (undesignated deadline).⁷⁰ The RBM Partnership had already adopted the “Three Ones Principles” when, in April 2008, the UN Secretary General called for the adopting of “Universal Access”⁷¹ in order to achieve “universal coverage” (80-100%) through malaria prevention amongst the population at risk and through treatment for malaria patients, requiring “Scaling up for Impact” (SUFU) and strengthening of healthcare systems.⁷²

For the global response to malaria, international funding increased from US\$ 51 million in 2003 to US\$ 1.1 billion in 2008 (through contributions from Global Fund, World Bank, and the U.S. President’s Malaria Initiative).⁷³ However, as of 2008, there was a US\$ 4.2 billion funding gap; from 2009 to 2020, the collective 109 endemic countries

⁶⁷ Roll Back Malaria Partnership (2004): *RBM Brochure*, www.rbm.who.int/docs/rbm_brochure.pdf, accessed on 05 January 2009.

⁶⁸ Roll Back Malaria Partnership (2008): *The Global Malaria Action Plan: Key Facts, Figures, and Strategies*, p. 6, www.rollbackmalaria.orggmap/GMAP_Advocacy-ENG

-web.pdf, accessed on 05 January 2009.

⁶⁹ *Ibid*, p. 5.

⁷⁰ *Ibid*, pp. 9-11.

⁷¹ *Ibid*, p. 23.

⁷² *Ibid*, pp. 4-9.

⁷³ *Ibid*, p. 3.

will require US\$ 16.6 billion in order to support the projected ten times need for access to the intervention tools.⁷⁴

In December 2008, in New York City, the United Nations General Assembly approved a resolution to establish the “Decade to Roll Back Malaria”.⁷⁵ Also in December 2008, in Washington, D.C., the new “Centre for Interfaith Action on Global Poverty” hosted the “Leadership Consultation on Scaling up Faith Community Impact against Malaria” in order “to promote greater collaboration on malaria control among diverse faith groups” in conjunction with international development and public health initiatives.⁷⁶

Strategies: Control of Neglected Tropical Diseases

NTD have overlapping geography because of overlapping environmental and public health conditions: insect vectors, sub-standard housing, unsafe drinking water, poor sanitation, and limited access to health care. Consequently, in 2006, the “WHO Strategy Integrated Approach” clustered the highest-burden NTD in order to implement preventive chemotherapy. The first NTD cluster intervention piloted by WHO included: lymphatic filariasis, onchocerciasis, schistosomiasis, soil-transmitted helminthiasis, and trachoma.⁷⁷

Conferences on Poverty-related Diseases

This sixth section of the paper offers a brief overview of important conferences focusing attention on HIV/AIDS, tuberculosis, malaria, NTD, and co-infections. During 19-20 April 2007 in Geneva, WHO hosted the first ever “Global Partner’s Meeting on Neglected Tropical Diseases: A Turning Point”, with the theme “Neglected Tropical Diseases: Hidden Successes, Emerging Opportunities”.⁷⁸

On 09 June 2008 at UN Headquarters in New York, the UN HIV/TB Global Leaders Forum set the theme of “One Life, Two Diseases,

⁷⁴ Ibid, pp. 12-13.

⁷⁵ Roll Back Malaria Partnership (2008): “UN General Assembly Adopts New Draft Resolution on the Decade to Roll Back Malaria”, 22 December 2008, www.rollbackmalaria.org, accessed on 05 January 2009.

⁷⁶ Roll Back Malaria Partnership (2008). “Roll Back Malaria Partnership: Faith Community Pledges Greater Collaboration on Malaria Elimination”, 16 December 2008, <http://www.rollbackmalaria.org>, accessed on 05 January 2009.

⁷⁷ WHO (2007): Report of the Global Partner’s Meeting on Neglected Tropical Diseases: A Turning Point, 19-20 April 2007, p. 2, http://whqlibdoc.who.int/hq/2007/WHOCDS_NTD_2007.4_eng.pdf, accessed on 15 November 2008.

⁷⁸ Ibid.

One Response” in order to address interactions of HIV/AIDS and tuberculosis. Subsequently, this Forum informed the “UNGASS High Level Meeting” held at UN Headquarters in New York during 10-11 June 2008. During 13-14 November 2008 in Brussels, the European Commission sponsored the international conference “Challenges for the Future: Research on HIV/AIDS, Malaria and Tuberculosis”. Three working groups separately covered HIV/AIDS, tuberculosis, and malaria. The author of this paper was a delegate in the HIV/AIDS working group. During the closing plenary session, the three working groups aligned in concluding that R&D is under-funded, that only through re-commitment to the basic sciences will new vaccine candidates be found for prevention of infections, that NTD deserve greater attention, and that public health programming must focus on accessibility to available prevention and treatment modalities for vulnerable communities.

During 10-11 March 2009, Chatham House hosted an international conference entitled “Rethinking Global Health: Political and Practical Challenges from Foreign and Security Policy”. This conference focused on the infrastructural and technical capacities of healthcare systems in developing countries, the accessibility of more effective health-related goods and services for vulnerable populations, the risks of transnational spread of communicable diseases, production of counterfeit medicines, and the increasing influence of private organizations, such as the Bill and Melinda Gates Foundation, in setting the global health agenda.

Conclusion

In the first introduction of this paper the author posed a research question: How does an understanding of the situation of PRD influence their visibility to researchers, policy-makers, practitioners, and donors and, in turn, influence the extent to which a comprehensive response to PRD is achievable in developing countries?

The second section of this paper placed communicable PRD within the MDG framework, reinforced by the Copenhagen Consensus prioritization exercise. The third, fourth, and fifth sections of this paper overviewed the published statistics, strategies, and conferences associated with HIV/AIDS, tuberculosis, malaria, and NTD. Coordinated responses adopted by the international community for combating the “Terrible Triangle” – the “Three Ones Principles” and the “Universal Access” initiative – have not been applied to NTD.

Visualizing a “Terrible Square” can motivate the international community of donors, researchers, policy-makers, and practitioners to mobilize the resources needed to construct well-functioning healthcare

systems in which interventions can reach the vulnerable members of poverty-embedded communities. Dr. Margaret Chan, the WHO Director-General, stated that the MDG framework recognizes “the two-way link between health and poverty” and that “neglected tropical diseases express this link between health and development”.⁷⁹ In conclusion, although the scope of this paper has precluded discussion of non-communicable PRD, the focus on communicable PRD has been justifiable.

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⁷⁹ World Health Organization (2007): Report of the Global Partner’s Meeting on Neglected Tropical Diseases, Opening speech by Dr. Margaret Chan, WHO Director-General, p. 1, http://whqlibdoc.who.int/hq/2007/WHO_CDS_NTD_2007.4_eng.pdf, accessed on 25 February 2009.

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PEPFAR project implementation and the pursuit of the United States national interest

Ricardo Pereira

Since the late 1990s the HIV/AIDS epidemic has been considered an issue of national and international security. Explored by activists and academics since the mid to late 1990s, arguably to grab public attention about the disease and raise funds for prevention and treatment programs, the 'HIV-security nexus' first received large scale recognition on January 10 2000, under the auspices of a United Nations Security Council session, the first ever dedicated to a health issue. This nexus is based on the presumption that, where it proliferates endemically, HIV/AIDS provokes socio-economic disruption due to the high number of deaths and drastic reductions in quality of life, and therefore also has a large impact on labor productivity and political governance. Such disruption leads to social chaos and eventually violence, reinforcing, namely in Southern and Eastern Africa, where gloomier figures on AIDS are found, an already frail picture of domestic stability, with transnational consequences as well.

Since September 11, 2001, and the launch of United States-led 'war on terror,' HIV/AIDS has been broadly inserted in counter-terrorist calculations, namely the vast orphanage it is bound to precipitate. According to some influent literature,¹ as victims of AIDS due to the premature death of their parents, orphans might engage in, or be attracted to, extremist associations. The fear of an expanding 'global jihad,' exploiting social vulnerabilities, is mostly associated with the worst-affected African countries of Muslim majority, or where Muslims maintain 'large minorities,' such as Nigeria or South Africa. After the

¹ Lyman, Princeton N.; Morrison, J. Stephen (2006). *More than Humanitarianism: A Strategic U.S. Approach Toward Africa*. New York: Council on Foreign Relations; Garrett, Laurie (2005). *HIV and National Security: Where are the Links?* New York: Council on Foreign Relations; Schneider, Mark; Moodie, Michael (2002). *The Destabilizing Impacts of HIV/AIDS. First Wave Hits Eastern and Southern Africa; Second Wave Threatens India, China, Russia, Ethiopia, Nigeria*. Washington DC: CSIS.

January 2000 Security Council session, an increasing number of major states have been integrating HIV/AIDS's social impacts in their security and strategic texts, allocating further funding to a number of multilateral and bilateral public-private initiatives. Despite the centrality of public health and philanthropic discourses, programs such as the Joint United Nations Program for HIV/AIDS (UNAIDS), the Global Fund to Fight AIDS, Malaria and Tuberculosis, and the United States' President Emergency Plan for AIDS Relief (PEPFAR), have been advancing a global security purpose, extensively disseminated in official reports and leadership speeches.

My argument in this contribution is that global instruments against HIV/AIDS serve an intense security agenda whose purpose and practice outshine what governmental and program leaders argue in their HIV-security articulation. Taking the case of PEPFAR, the very intervention in HIV/AIDS for the sake of prevention and treatment, together with an array of related activities in health and development, constitutes, in itself, a manifestation of securitization. Promoting 'hope' and 'responsibility,' PEPFAR, moreover, capacitates psychologically and materially towards 'self-reliant economic growth' and eventual global marketplace integration and competition. This is securitization through integration in liberal modes of production and trade. Such securitization is explainable by the dramatic increase in the volume of funds available to organizations involved, and politico-symbolic support which is allocated to the whole infra-structure of transnational, multilevel public-private partnerships. Securitization is pursued by a will to re-engineer and normalize behaviours - at the sexual level, but also in terms of political economy - and augment popularity for the United States.

The case of PEPFAR appears particularly telling, since the launch of PEPFAR roughly coincided with the launch of the Iraq invasion in 2003, and thus appears as another 'war front' against terrorism and other underdevelopment-related issues, such as state failure and collapse in the peripheries of the world system. Apart from that, it is eminently a bilateral program that, although still connected to multilateral arrangements (it finances the U.S. part of the Global Fund and is informed by UNAIDS' data), reifies the post-September 11 bilateral stance of the U.S. government pursued until very recently.²

² According to a statement issued by the White House, PEPFAR and other global health programs, such as the President's Malaria Initiative, were integrated in a single Global Health Initiative (The White House [2009]: Statement by the President on Global Health Initiative, http://www.whitehouse.gov/the_press_office/Statement-by-the-President-on-Global-Health-Initiative/, accessed on 13 May 2009), presumably as a response to a latest report by the Government Accountability Office's (GAO) report demanding improvement in coordination, efficacy and cost-

This paper is divided into three parts. The first part articulates the AIDS-security response and the 2006 concept of counterinsurgency of the United States army, providing an understanding of it based on Michel Foucault's readings of biopolitics and governmentality. The second part describes the governance infra-structure of the response rooted on a sophisticated concept of partnership for PEPFAR, revealing continuities from the colonial experience. The third part concentrates on ongoing debates around an emerging actor in PEPFAR, the United States Africa Command (AFRICOM), with regard to understanding the securitization agenda involved in HIV/AIDS intervention.

AIDS-Security: response and biopolitics

As the epidemic enters its 25th year, HIV/AIDS remains high on the agenda in international politics. The numbers speak for themselves. According to the latest figures advanced by UNAIDS, which aggregates world records on the disease and constitutes the main source of information, in 2007 there were 2.7 million new HIV infections and 2 million HIV-related deaths, with Sub-Saharan Africa remaining the region most heavily affected by HIV, accounting for 67% of all people living with HIV and for 75% of AIDS deaths in 2007.³ As a result, HIV/AIDS is a cause of concern for Western countries, which link it to the set of 'fatalities' that liberal globalization brought about, as the world's major donor the United States demonstrates,⁴ although Russia,

effectiveness among the various development-related agents' budgets (GAO [2009]. Foreign Aid Reform Comprehensive Strategy, Interagency Coordination, and Operational Improvements Would Bolster Current Efforts. Washington, D.C.: United States Government Accountability Office).

³ UNAIDS (2008): 2008 Report on the global AIDS epidemic, http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp, accessed on 30 January 2009, p. 30.

⁴ The White House (2006). The National Security Strategy of the United States of America. Washington, D.C.: The White House, p. 47: "[these] new flows of trade, investment, information, and technology are transforming national security. Globalization has exposed us to new challenges and changed the way old challenges touch our interests and values, while also greatly enhancing our capacity to respond. Examples include: Public health challenges like pandemics (HIV/AIDS, avian influenza) that recognize no borders. The risks to social order are so great that traditional public health approaches may be inadequate, necessitating new strategies and responses."

China, India and Brazil, not to mention badly affected South Africa, have also started to pay attention, in their different ways.⁵

Hence, pursued measures aimed at mitigating and preventing HIV dissemination and its impacts – actual and presumable – are regarded as security policies. This obviously includes usual public health measures, both medical and socio-psychological, which are funded and taught as “good practices” worldwide, namely where the epidemic is most prevalent, i.e. Southern and Eastern Africa. Yet, in this paper, that understanding proceeds from an analysis which takes into account historical-political continuities, in the relationship between the African regions and the former colonial West. Two sets of continuities exist, on the one hand, the post-colonial, particularly post-Cold War, relations in terms of state building and development, and, on the other hand, the particular history of public health in those African areas while they were mostly under European rule.

This assessment is fundamental in order to understand Western political discourse linking the HIV/AIDS pandemic, and even endemic, proliferation and its foreseeable socio-economic effects at the national, regional and global level. This construction of foreseeable realities is, indeed, built upon speculative thought. This thought is speculative, since the few studies carried out so far negate any connection between HIV and state failure.⁶ It derives more from intuition than evidence.⁷ Arguably, this line of thinking arises because it is conditioned by a persistent unbearable unacceptability of “underdevelopment and barbarism” in the peripheries, by the “civilized” Western world.⁸

HIV/AIDS touches all dimensions of life. It is a medical-viral issue, and it is a social issue too. It can be thus described as ‘totalitarian,’ as well as a chronic disease, since infected people have to cope with it for the rest of their lives. Most HIV-concerning activities are focused on prevention, counselling, treatment and other sensitization tasks, and are

⁵ It is not the purpose of this contribute to analyse any other national experience but the United States. Any of these experiences deserve – and they are deserving – abundant research currently.

⁶ McInnes, Colin (2006). “HIV/AIDS and Security”. In: *International Affairs*, (vol. 82), No. 2, pp. 315-326; Sato, Asuza (2008). *Is HIV/AIDS a Threat to Security in Fragile States?* New York: Netherlands Institute of International Relations Clingendael and Social Science Research Council; Barnett, Tony; Dutta, Indranil (2008). *HIV and State Failure: Is HIV a Security Risk?!* New York: Netherlands Institute of International Relations Clingendael and Social Science Research Council.

⁷ Barnett, Tony; Prins, Gwin (2006). “HIV/AIDS and security: fact, fiction and evidence – a report to UNAIDS”. *International Affairs*, vol. 82, 2, pp. 931-952.

⁸ Duffield, Mark (2002). “Social Reconstruction and the Radicalization of Development: Aid as a Relation of Global Liberal Governance”. In: *Development and Change*, (vol. 33), No. 5, pp. 1049-1071.

strictly oriented to HIV/AIDS epidemiological results. Yet, these activities are incorporated within a broader platform, which seeks to restore political and economic wellbeing. As a result, HIV/AIDS, as the Millennium Development Goals initiative shows, is considered a development issue. In my view, these manifold elements are analyzed in a more complete way through the readings of French sociologist and historian Michel Foucault on bio-politics and governmentality, which require an assessment of liberal power and its reach and expression. It also demands an understanding of security focusing on human beings, and not on state-centric modelling, although states are not excluded. They are also included into the equation.

The end of the Cold War has seen the emergence of the United States as the world's sole superpower and with it the hegemonic expansion of the liberal creed in the world. Despite militaristic incursions and other aggressive behaviour throughout the Bush Administration, this was also a time for increased financial and political support of 'soft power' measures in some peripheries of the world, namely in Southern and Eastern Africa. PEPFAR is perhaps, the best example of such an effort, together with the Millennium Challenge Account or the President's Malaria Initiative. To a large extent, the U.S. liberal tradition of free market, representative democracy and philanthropy was continuously advanced, even if tactics included more use of military force and less diplomatic skill. This is why Foucault's readings have become so appealing in recent years.⁹

For Foucault, liberal power goes genealogically back to the 18th century and the beginning of a shift from Absolute power to Liberal power in Europe, in which the nature of the power exercised by the sovereign, starts to be located less in the capacity of taking life, but in the ability of "either fostering life and impede it to the point of death."¹⁰ The object of such power consists of human beings at the aggregate level, as well as life in general.¹¹ Designated as "biopower," it expresses the increasing scientific effort of measuring and regulating all dimensions of life: birth, mortality, education, employment, and criminality. Biopower is therefore 'totalitarian' in the way that it is aimed at the totality of the population and the totality of life manifestations. Contrary to previous absolutist regimes, biopower needs to be rationalized and justified. In this

⁹ In the specific domain of HIV/AIDS politics, see Elbe, Stefan (2005). "AIDS, Security, Biopolitics". *International Relations*, vol. 19, 4, pp. 403-419 and Elbe, Stefan (2008). "Risking Lives: AIDS, Security and Three Concepts of Risk". *Security Dialogue*, vol. 39, . 2-3, pp. 177-198.

¹⁰ Foucault, Michel (1984). "Bio-Power". In: Rabinow, Paul (ed.). *The Foucault Reader*. New York: Pantheon Books, pp. 258-272.

¹¹ *Ibid.*

regard, the medical practice was very important in terms of consolidating this regime of power at its knowledge level.¹² The concept of biopower is linked to the concept of biopolitics, that started to be used by Foucault later, and basically means the agent of the former. It is supplemented by the concept of governmentality, that is, a discursive-material device of security embodying rationalities and technologies of government, comprising of “discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, and scientific statements, philosophical, moral and philanthropic propositions.”¹³ Yet, those technologies do not necessarily use violence to force people to do as the sovereign wishes.¹⁴ In liberal societies that would be very difficult to manage in relation to the system’s own sustainability. Frequently control is exerted through “ideological manipulation or rational argumentation, moral advice or economic exploitation.”¹⁵ The target is, nevertheless, the anatomic body in its most comprehensive political sense and at very different levels, from the professional setting to the dietary/beauty regime.¹⁶

One can distinguish two interconnected levels of biopolitical securitization: a ‘macro’ and a ‘micro.’ Whereas the former is linked to the architecting of formal institutions (state building) and the political economy they serve (development), the latter is associated with intervention at the individual level. Both though at different levels, target the normalization and re-engineering of social behaviours. Actions regarding conflict prevention and state reconstruction in the world’s peripheries (‘macro level’) are put into place in a search for reducing perceived indigenous inabilities to govern themselves through further surveillance and reliance on the West-led international community,¹⁷

¹² Foucault, Michel (1994). *Birth of the Clinic: An Archeology of Medical Perception*. New York: Vintage Books.

¹³ Foucault, Michel (1980). “The Confessions of the Flesh”. In: Gordon, Colin (ed.) *Power/Knowledge. Selected Interviews and Other Writings. 1972-1977*. New York: Pantheon Books, p. 184.

¹⁴ Lemke, Thomas (2001). “The Birth of Bio-Politics – Michel Foucault’s Lecture at the Collège de France on Neo-Liberal Governmentality” In: *Economy & Society*, (vol. 30), No. 2, pp. 190-207.

¹⁵ Lemke, Thomas (2000). “Foucault, Governmentality, and Critique”. *Rethinking Marxism Conference*. Amherst, MA, p. 5.

¹⁶ *Ibid.* 13.

¹⁷ Bickerton, Christopher (2007). “State-building. Exporting state failure”. In: Bickerton, Christopher et al. (eds.). *Politics Without Sovereignty. A critique of contemporary international relations*. London: University College London Press, pp. 107-108.

aided by humanitarian and development apparatus.¹⁸ State failure is the usual description and prescription for such inability.¹⁹ At the ‘micro level,’ normalization is developed through attempts at modifying sexual behaviour, through the so-called ‘ABC strategy’ (abstinence until marriage, be faithful to your partner and correct and consistent use of condoms), counselling and propaganda (public group and peer speeches, media, street advertisements and other mass communication means), medication, through anti-retrovirals and other therapies, and bodily interventions, such as male circumcision. ‘Hope’ and ‘responsibility’ are key values to be inculcated among clients. These values ultimately serve as pillars for local societal self-reliance in the global marketplace, as will be briefly described in the next section.

When inserted into a security framework of prevention of state failure and extremism, in times of a global war on terror in regions where it goes pandemic and endemic, HIV/AIDS intervention constitutes a liberal counterinsurgency technology.²⁰ Arguing in favour of the U.S. Africa Command (AFRICOM) as a humanitarian player, Ward Casscells, the assistant secretary of defence for health affairs, thus clarifies the role health care provision plays in the stability effort: “humanitarian assistance, disaster relief and other activities designed to win the hearts and minds of local populations are important counterinsurgency measures.”²¹

PEPFAR infrastructure: “partnership compact”

The United States President’s Emergency Plan for AIDS Relief constitutes the largest financial bilateral initiative ever to fight a single disease. It emerges as a manifestation of philanthropy and bi-partisanism,

¹⁸ Duffield, Mark (2005). “Governing the Borderlands: Decoding the Power of Aid”. In Wilkinson, Rorden (ed.). *The Global Governance Reader*. London and New York: Routledge, pp. 204-216.

¹⁹ Pureza, José Manuel et al. (2007). “Do States Fail or Are They Pushed? Lessons Learned From Three Former Portuguese Colonies”. In: *Oficina do CES*, No. 273, <http://www.ces.uc.pt/publicacoes/oficina/273/273.php>.

²⁰ U.S. Army (2006). *Counterinsurgency*. Washington, DC: Department of the Army, p. 19: “The purpose of America’s ground forces is to fight and win the Nation’s wars. (...) All full spectrum operations executed overseas—including COIN operations—include offensive, defensive, and stability operations that commanders combine to achieve the desired end state.”

²¹ Buxbaum, Peter (2009): *Soft power with guns*, <http://www.isn.ethz.ch/isn/layout/set/print/content/view/full/73?id=95415&lng=en>, accessed on 18 January 2009.

bringing together both liberal NGOs and Christian conservative groups.²² Established by the United States Leadership Against HIV/AIDS, Tuberculosis and Malaria Act of 2003 and reauthorized by the Tom Lantos and Henry J. Hyde United States Global Leadership Against HIV/AIDS, Tuberculosis, and Malaria Reauthorization Act of 2008, PEPFAR is managed by the Office of the U.S. Global AIDS Coordinator. It gathers several governmental agencies – Agency for Development (USAID), Peace Corps and Departments of State, Defence, Trade, Labor and Health and Human Resources, and places a strong emphasis on partnership establishment between governmental and nongovernmental agencies of the United States and fifteen priority countries.²³ PEPFAR is a program former President Bush has been personally engaged in, arguably responding to its strong religious constituency,²⁴ namely the Evangelicals.²⁵

This relationship generated intense disputes during the whole period of the Bush Administration, given the strong emphasis on preventive strategies based on abstinence until marriage and marital faithfulness, where condoms are to be used as a last resort. In fact, faith-based organizations, more enthusiastic about abstinence and faithfulness promotion were systematically favoured by PEPFAR. In contrast, organizations advocating contraceptive measures based on condom distribution, faced difficulties in obtaining PEPFAR support. Furthermore, the Bush Administration significantly reduced support for family planning-related purposes.²⁶

According to the latest report of the GAO on PEPFAR, budgetary allocations for the 2003-2008 five-year period accounted for treatment (55%), palliative care (15%), prevention (20%) and orphans and

²² Dietrich, John W. (2007). “The Politics of PEPFAR: The President's Emergency Plan for AIDS Relief”. In: *Ethics & International Affairs*, (vol. 23), No. 3, pp. 277-292.

²³ The full list includes Botswana, Cote d'Ivoire, Ethiopia, French Guyana, Haïti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, Vietnam and Zambia. PEPFAR's website presents many other countries, where PEPFAR is implemented through USAID and U.S. embassies.

²⁴ Fletcher, Michael A. (2006): Bush Has Quietly Tripled Aid to Africa, http://www.washingtonpost.com/wpdyn/content/article/2006/12/30/AR2006123000941_pf.html, accessed on 1 April 2007.

²⁵ In the midst of his lowest scores in domestic popularity, President Bush was awarded a medal by the coalition PEACE, led by Evangelical Pastor Rick Warren.

²⁶ At the time of writing the new Obama Administration has just reversed policies with regard to family planning and other related activities.

vulnerable children (10%).²⁷ This accounted for \$15 billion US dollars in that period. With regard to the reauthorization, \$48 billion was approved by the Congress, “including approximately \$5 billion for malaria and \$4 billion for tuberculosis.”²⁸ As we can see, despite possible changes in the coming future, PEPFAR, and the overall global health commitment by the U.S. government, has been tremendous and definitely ambitious.

PEPFAR’s governance model is rooted around the idea of partnership. According to sociologists Luc Boltanski and Ève Chiapello, partnership materializes the neo-liberal ideal of “society by project” as the “new spirit of capitalism” of the last twenty years.²⁹ Through the newest management sciences, flexibility is facilitated in the division of labor, in order to counter political decisions and institutional rigidities. In development-related work globally “governance at a distance”³⁰ through ‘projectization’ is a key feature, as donor-imposed management tools (the project cycle management) exemplify. It is a sophisticated policy solution, insofar as it conciliates the maintenance of guidance control, with rhetoric on country ownership. Country ownership is defined as “recipient governments [being] urged to take ownership of development policies and aid activities in their country, to establish their own systems for coordinating donors, and only to accept aid that suits their needs.”³¹ Thus, it is an encompassing working platform built to mobilize all available stakeholders – governmental and nongovernmental entities, transnational and local organizations, and ‘peoples’ in general. On the U.S. side, one finds a long list of U.S.-based nongovernmental organizations, as well as the governmental institutions mentioned above. PEPFAR’s latest annual report to Congress calls this sort of “future” partnership the “partnership compact.”³²

²⁷ GAO: Government Accountability Office (2008). *Global HIV/AIDS. A More Country-Based Approach Could Improve Allocation of PEPFAR Funding*. Washington, D.C.: United States Government Accountability Office, p. 10.

²⁸ Oomman, Nandini (2008): *PEPFAR Reauthorization: Where Did All the Evidence Go?* http://blogs.cgdev.org/globalhealth/2008/07/pepfar_reauthorizati_2.php, accessed on 17 August 2008.

²⁹ Boltanski, Luc; Chiapello, Ève (2001). *Le nouvel esprit du capitalisme*. Paris: Gallimard.

³⁰ Duffield, *Governing the Borderlands*, 208-210.

³¹ Renzio, Paolo de et al. (2008). *Reforming Foreign Aid Practices: What country ownership is and what donors can do to support it*. Oxford: University College Oxford, p. 1.

³² PEPFAR (2009). *Celebrating Life: The U.S. President’s Emergency Plan for AIDS Relief*. Washington, DC: Office of the U.S. Global AIDS Coordinator, p. 58: “To build on the success the American people’s partnerships have achieved to date and reflect the paradigm shift to an ethic of mutual partnership, the USG [United States government] is working with host countries to develop Partnership Compacts: agreements that engage governments, civil society, and the private sector to address

PEPFAR's rationale revolves around the belief that hopelessness is the fundamental illness caused by the HIV/AIDS complex. Feelings of hopelessness out of death, fall in quality of life and social stigma are perceived as key psychological factors which menace the 'social fabric' and feeds extremism. Expression of support against hopelessness is mandatory in the task of raising local popularity for the United States, and hence contributing to national security, as stated by President Bush on 2008 World AIDS Day,³³ and later U.S. Global AIDS Coordinator Mark Dybul during the U.S. presidential transition period.³⁴

Yet, hopelessness is not something one can fight back just by preventing and treating AIDS medically. HIV/AIDS as global policy must be incorporated in a more comprehensive set of practices, namely in terms of development, and state and peace building support. In fact, reconstruction of hope is not just a mission to be targeted at the individual or peer level (as the ABC strategy might possibly suggest), but mostly at the aggregate one. The fight against AIDS is all but another front, in the attempt to reconstruct whole societies in a specific way. Hope is presented in different, yet interrelated ways. As an expression of liberal creed, hope is achieved through the stimulus and celebration of merit and self-esteem, as PEPFAR's latest report to Congress finely exemplifies with the Malawian case of the "'Great Guy' Hope Kit."³⁵ Hope is also

the issues of HIV/AIDS. The goal of Compacts is to advance the progress and leadership of host nations in the fight against HIV/AIDS, with a view toward enhancing country ownership of their programs. [...] PEPFAR will continue to be part of this new era of development that champions friendship and respect, mutual understanding and accountability – and trusts in the people on the ground to do the work.”

³³ Ibid., p. 17: “America is committed – and America must stay committed – to international development for reasons that remain true regardless of the ebb and flow of the markets. We believe that development is in America's security interests. We face an enemy that can't stand freedom. And the only way they can recruit to their hateful ideology is by exploiting despair – and the best way to respond is to spread hope.”

³⁴ Dybul, Mark (2009). *The Global Fight Against HIV/AIDS*, <http://www.state.gov/r/pa/ei/coffee/113121.htm>, accessed on 8 January 2009: “Our future is Africa's future and Africa's future is our future. So there's very much that long-term vision for a stable world in which we play a role and have a role. And it's in our self-interest. (...) [These programs] have changed how people view America. (...) people know what we stand for when we stand with them. And eight of ten of the countries in the world with the highest approval rating of the United States, sometimes higher than the United States itself, are in Africa. (...) These programs touch lives.”

³⁵ PEPFAR, *Celebrating Life*, p. 37: “In the Chikwawa District of Malawi, PEPFAR supported the development of a Bambo Wachitsanzo 'Great Guy' Hope Kit, which uses participatory approaches to promote discussion around small actions that men can take to prevent HIV/AIDS. After attending a Bambo Wachitsanzo Open Day

realized through local economic self-reliance and integration in the global marketplace, yet in a process closely and carefully monitored, as U.S. Congressional Commission on Foreign Assistance Reform remarks.³⁶

In previous writing (Pereira, 2008), I argued that global health instruments' implementation were driven by Western goals of international security, and supported by a political history of colonial exploitation, in which medical administrative authorities and tropical medicine played prominent roles. Here, with regard to transnational partnerships a similar argument is to be explored as well. According to Bill Cooke (2003), methodologies of development management, namely by the establishment of the World Bank, hold a "direct genealogical link with indirect rule"³⁷ applied to colonial contexts in Africa and Asia.³⁸

AFRICOM: Debates around an emerging actor

As already mentioned, the Department of Defence is another stakeholder in PEPFAR's efforts. Yet, until quite recently its participation has been little remarked upon. The discreet participation of the U.S. Military has mostly concentrated on vaccine research and development, prevention,

focusing on knowing one's status, practicing safe sex, and reducing the number of sexual partners in his village, Lyson Mandere and his wife went for voluntary HIV counseling and testing. In March 2008, Mandere was awarded the "Bambo Wa Chitsanzo Certificate," which is awarded by the community to "Great Guys" who have demonstrated exemplary characteristics. Many people in his community now follow his example and his actions."

³⁶ The HELP Commission Report on Foreign Assistance Reform (2007). Beyond Assistance. Washington, DC: The HELP Commission Report on Foreign Assistance Reform, pp. 56-57: "While one goal of U.S. foreign policy is to promote good governance and human rights in the developing world, an equally challenging objective is to assist countries in their efforts to create sustainable economic growth. A new, flexible business model should include a broader "basket of tools" than solely foreign aid, and should allow for flexibility on some policies that can affect development. The new business model also needs to focus on building local management capacity and leadership skills in order to help countries promote growth. (...) By adopting policies and programs based on collaboration and joint commitment, America will enhance the ability of people in the developing world to sustain pro-growth policies able to propel their countries toward political, civil, and economic stability. Partnership requires a long-term commitment from both parties. When all agree on common priorities and make investments that are commensurate, everyone is accountable for the results, and sustainability is achieved through mutual accountability."

³⁷ Cooke, Bill (2003). "A new continuity with colonial administration: participation in development management". In: *Third World Quarterly*, (vol. 24), No. 1, p. 47.

³⁸ See in my other contribution to this volume section "A Critique of Liberal Development and Aid Governance."

treatment and care, and clinical trials in Nigeria, Thailand, Tanzania, Uganda and Kenya.³⁹ In those countries, these activities have been oriented to army staff as well as civilians. The Navy, in particular, has been targeting its work on reducing HIV/AIDS incidence among U.S. uniformed personnel stationed in selected African countries, as well as its local allies and other partnering army structures.⁴⁰ Yet, as AFRICOM was launched in 2007, the possibility of an upgrade of Department of Defence's participation in development-related activities generated a heated debate where development and military officers and Congress representatives exchanged views on the purposes of U.S. anti-AIDS intervention.

AFRICOM was unveiled by President Bush on February 6, 2007, primarily as a means to intensify the global war on terror, as well as to resolve interconnected issues of political economy, namely access to mineral resources and growing rivalry perceived by Chinese business influence in Africa. This decision reflects a major shift in U.S. Policy in regard to attention paid to the continent, emerging from relative obscurity in the 1990's, to an ever increasing central role after the start of the 'war on terror,'⁴¹ together with the issues of energy resources, humanitarian crises, armed conflicts, and HIV/AIDS.⁴² But, rather than showing aggressive force, AFRICOM is meant to pursue a mission of conflict prevention and collaboration in several areas of public governance. Actually, AFRICOM is presented as another partnership in the current U.S.-Africa relationship, aimed to assist peacekeeping and counter-terrorist operations and the implementation of other U.S. Agency programs.⁴³ USAID and embassies are fundamental arms in the partnership architecture, facilitating liaisons between the perceived "tougher" U.S. representatives and African governments and societies. As AFRICOM's command surgeon Colonel Schuyler Geller mentioned, "USAID is the lead agency for development (...) but you can't do development in an unstable environment. We see our role in those areas

³⁹ U.S. Military HIV Research Program (2008): Global Efforts | U.S. Military HIV Research Program, <http://www.hivresearch.org/global-efforts/>, accessed on 29 June 2008.

⁴⁰ Kates, Jen et al. (2009). *The U.S. Government's Health Policy Architecture*. Menlo Park, CA: The Henry J. Kaiser Family Foundation, p. 14.

⁴¹ Buchanan, Robert B. (2008). *USAFRICOM: Operational Considerations are Paramount in Selecting a Headquarters Location*. Newport, RI: Naval War College, p. 17.

⁴² Ploch, Lauren (2008). *Africa Command: U.S. Strategic Interests and the Role of the U.S. Military in Africa*. Washington, DC: Congressional Research Service.

⁴³ Committee on Foreign Affairs of the House of Representatives (2007). *Africa Command: Opportunity for Enhanced Engagement or the Militarization of U.S.-Africa Relations?* Washington, DC: U.S. Government Printing Office, p. 17.

as providing initial support.”⁴⁴ Actually, Theresa M. Whalon, Deputy Assistant Secretary of Defence for Africa, has mentioned at a House of Representatives’ hearing that AFRICOM’s goal is not to militarize development aid, but “to establish an institutional basis for continued coordination and collaboration.”⁴⁵ At the same hearing, she added that AFRICOM has been keen to meet with African representatives, both politicians and NGOs, in order to learn about their position on the implementation of the command.⁴⁶

Yet, Democrat Congressmen, such as Donald Payne, John Tierney, Stephen Lynch and others take AFRICOM sceptically. Their scepticism is based on the perspective that a serious backlash against U.S. presence in the continent may occur given the local perception that AFRICOM serves objectives of militarization and energy exploitation of the continent.⁴⁷ A first sign of such a backlash has had to do with a general unwillingness by African countries to host any AFRICOM headquarters in their territories, meaning that, for the time being, AFRICOM headquarters remains at the U.S. base in Stuttgart, Germany. Nonetheless, development workers may be targeted by violent groups, since they are regarded as an intrinsic part of the military-security machinery.⁴⁸

⁴⁴ Buxbaum, *Soft power with guns*.

⁴⁵ Committee on Foreign Affairs, *Africa Command*, p. 23.

⁴⁶ *Ibid.*, p. 25.

⁴⁷ Representative Payne has stated that “I believe that we have a moral obligation to assist the region’s efforts to overcome [...] momentous challenges. To the extent that establishing a command where our relationship with Africa is the priority rather than an afterthought can help to eliminate some of these problems, a unified approach seems like a good approach and I support it. [...] Africans themselves seem somewhat skeptical and perhaps downright cynical about the intentions of this new command and so it appears as though we have started out on the wrong foot. There are some who think this effort is a reaction to the presence of the Chinese in Africa. There are others who believe that we are establishing forward locations from which to fight the global war on terror. Still others are convinced that the United States is intent on protecting oil resources on the continent. I suspect that there is an element of truth to each of these rumors. [Department of Defense’s] increasing involvement in foreign aid and foreign assistance is something that I am concerned about. Congress has granted the Department of Defense new authorities to implement security assistance programs in coordination with the State Department. However, as a February GAO report indicates, the degree of coordination has not been good at all.” (*Ibid.*: 1-2)

⁴⁸ Ironically or not, in a visit paid in late April 2008 to Somalia aimed to improve local governance and to end the regional armed conflict Representative Payne himself escaped a violent strike by local rebels near a Mogadishu airport (Boyd, Herb [2009]: “Congressman Donald Payne Narrowly Escapes Harm In Somalia,” <http://www.seattlemedium.com/News/article/article.asp?NewsID=95954&sID=3&It>e, accessed on 13 May 2009).

Regardless of what has or will happen with AFRICOM and its participation in development-related efforts, the ‘unpleasant’ scenario of militarized development aid seems to confirm the security/power agenda that development, and HIV/AIDS notably, embodies, and that many in Africa acknowledge. The question at stake is whether one will observe a “step further” of such tendency through changes in labor division between actors in the partnership compact and the social constructions that emerge, locally and else.

Conclusion

In this contribution my argument is that HIV/AIDS intervention, namely PEPFAR-supported, aims to safeguard U.S. national security goals. Rather than just a political statement as referred to in a speech by President George W. Bush and U.S. AIDS Global Coordinator Mark Dybul aimed at mobilizing popular support, this intervention is per se fulfilling that task. Engagement and fulfilment is analyzed through the lens of Michel Foucault’s concepts of biopolitics and governmentality, which draw from an historical assessment of the nature of liberal power. Together with biopolitical control at the ‘macro level,’ through state building by the West-led international community and broad frameworks of international aid, there is a will to, at the ‘micro level,’ obtain surveillance through the individual/peer/group normalization of behaviours and values. Modification of sexual behaviour is one facet of this program. Another has to do with fostering hope, strongly emphasized in PEPFAR reporting, and responsibility, which in turn provide the basis of liberally-informed local self-reliance towards necessary economic growth and integration in the global marketplace. This understanding of security is eminently ‘totalitarian,’ as the concept of biopolitics stands for, and is informed by an equally ‘totalitarian’ power sustained in philanthropic ideals, as well as national interest principles, in turn informed by intuition and social construction. Rather than being initially obvious, the connection between HIV and state failure is, in fact, an intuition that certainly builds on colonial and post-colonial continuing visions of incapable indigenous government. Recently launched AFRICOM has generated debates which exacerbate the hypothesis that development-related activities are security-driven. The feeling of ‘discomfort’ shared by some Congress representatives in the face of potential manifestations of cynicism – if not outright dissatisfaction and anger – by societies under intervention confirms it.

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Diverging discourses: Civil society and the response to HIV/AIDS in the Russian Federation

Ulla Pape

Worldviews and ideological standpoints as well as cultural norms and religious beliefs have a strong impact on the response to the global HIV/AIDS epidemic. Prevention programs always build upon a certain perspective on social behaviour; they make explicit and implicit statements, what kind of social behaviour is desired and how a change of behaviour can best be achieved. However, there is little understanding about the interrelation between the discourses, shaping views on HIV/AIDS, on the one hand and the practical response to the epidemic on the other hand.

This article proposes to investigate the interrelation between discourses and practices in the response to the HIV/AIDS epidemic by focusing on the example of the Russian Federation. With a rapidly growing HIV/AIDS epidemic over the past decade, Russia represents a case where government policies so far have had only limited success in tackling the epidemic. This raises the question about barriers and obstacles in the formulation and implementation of response strategies. Although the Russian government understands that a continuous growth of HIV-infection will confront the country with far-reaching political, economic and social implications, policies remain largely inconsistent and inadequate. The objective of the article is to understand, why Russia falls short in responding to the HIV/AIDS epidemic by looking at societal discourses and investigating competing views on HIV/AIDS in Russia.

The concept of *discourse* has been widely applied in the humanities and social sciences, it can be understood as ‘linguistic action, undertaken by social actors in a specific setting determined by social rules, norms and conventions’¹. For the purpose of this article, I define *discourse* as statements societal actors make with regard to the HIV/AIDS epidemic in

¹ Wodak, Ruth and Michał Kryżanowski (ed.) (2008). *Qualitative Discourse Analysis in the Social Sciences*, New York: Palgrave Macmillan, p. 5.

Russia, including views on underlying causes of the epidemic and required response strategies. *Practices*, on the other hand, are defined as actions with regard to the fight against HIV/AIDS. Discourses on HIV/AIDS are not neutral, but reflect the power dynamics within society, as different actors compete to highlight what their understanding on the situation is and what they view as an adequate response to the epidemic.

The Russian discourse on HIV/AIDS reveals a great variety of contrarious interpretations. Different actors in society, including political decision-makers, the church as well as civil society organisations (CSOs), strive to frame the issue of HIV/AIDS by expressing their views in public debate. As the epidemic is closely associated with societal prejudices and stigma, particularly regarding sexual relations and drug use, the discourse on HIV/AIDS in Russia has become highly politicised. Participating in the public debate, societal actors do not only present possible solutions to the problem, but also defend their basic views on society. Moreover, actors use the issue of HIV/AIDS in order to position themselves, e.g. as crisis manager or guardian of morals. Competing views on HIV/AIDS have a strong impact on the response, as strategies to tackle the epidemic require the negotiation of different positions and approaches in society.

In investigating discourses and practices, the article will focus on the role of civil society. The article aims to show what the different discourses on HIV/AIDS in Russia are and to what extent civil society organisations (CSOs) have been able to transform discourses and change practices concerning the response to HIV/AIDS. Special attention will be paid to three key areas of HIV/AIDS prevention: (1) sex education and HIV/AIDS prevention programs for young people, (2) harm reduction programs for injecting drug users (IDUs), and (3) social support and empowerment of people living with HIV (PLWH). Those three areas have been identified as essential in the formulation of a successful response to the HIV/AIDS epidemic in Russia. First, sex education and HIV/AIDS prevention programs for young people provide necessary information and raise awareness within the age group that is most at risk to contract HIV-infection in Russia. Second, harm reduction programs, including needle exchange, can be regarded as an indispensable tool for preventing HIV-infection among IDUs, constituting one of the most vulnerable groups regarding HIV/AIDS in Russia. Third, the involvement of PLWH via social support and empowerment forms an essential component in the response to HIV/AIDS, as stigma and discrimination with regard to HIV-infection is commonly seen as a barrier in effectively dealing with the epidemic.

The structure of the article is the following. First, the Russian HIV/AIDS epidemic and the government's response will be described, followed by an investigation of the role of civil society in the response to

HIV/AIDS. Second, the discourse on HIV/AIDS in Russia will be characterised, before discussing the interrelation of discourse and practices in the key problem areas of HIV/AIDS prevention.

Russia's HIV/AIDS crisis

Neglected for a long time, the HIV/AIDS epidemic has grown into a serious political, economic and social problem in the Russian Federation. According to the *Joint United Nations Program on HIV/AIDS* (UNAIDS), Russia has the biggest HIV/AIDS epidemic in all of Europe with an estimated number of 940,000 people living with HIV.² An important driver of the epidemic in Russia has been the increasing number of injecting drug users among young people.³ Other specifically vulnerable groups include prison inmates, sex workers (SW) and men who have sex with men (MSM). In combination with an already diminishing population, the Russian HIV/AIDS epidemic, thus, forms a threat to economic development and national security. Different estimations on the future evolution of the epidemic predict that HIV/AIDS will have a negative impact on Russia's economic development by 'increasing morbidity and mortality among the economy's most productive age groups, while at the same time driving up health and social protection costs.'⁴

The underlying factors enabling the spread of HIV/AIDS in post-Soviet Russia are complex. As well as a sharp increase in drug use, sexual behaviour has significantly changed after the collapse of the Soviet Union. Widespread stigma and discrimination against those groups in society which are most at risk, contributed to the spread of HIV and made prevention efforts more difficult. Moreover, the emergence of the HIV/AIDS crisis is closely linked to the transition process, which seriously affected health care provision in Russia. In a period of decline and serious under-funding, Russian health care institutions have been unable to effectively respond to the emerging HIV/AIDS epidemic.

The case of Russia shows the enormous difficulties societies face in negotiating HIV/AIDS response strategies. For a long time, the Russian government has neglected the unfolding epidemic. HIV/AIDS was seen solely as a health problem rather than being interpreted as 'a

² Fleck, Fiona: 'Eastern Europe and Russia face world's fastest growing HIV epidemic', *BMJ*, 328: 486 (28 February 2004).

³ Ibid.

⁴ Sharp, S. (2006), 'The Economic Impact of HIV/AIDS in Russia: Current Trends and Perspectives, in: Twigg, J. (ed.), *HIV/AIDS in Russia and Eurasia*, Vol. 1, New York: Palgrave Macmillan, p. 90.

phenomenon, which impacts on all aspects of public life'.⁵ This limited understanding has resulted in a lack of funding and coordination in the response to the epidemic. A turning point in the government's perception of the epidemic was reached in April 2006, when president Putin declared HIV/AIDS to be a national security threat and called for a scaled-up response.⁶ This statement at a meeting of the State Council represented an important policy shift, as it clearly indicated the political will to tackle the epidemic. As a consequence, federal spending on HIV/AIDS programs was significantly increased in the following years.⁷

However, although the Russian government has more than once declared its commitment to realize an effective national response to the HIV/AIDS,⁸ the reality shows a somewhat different picture. Necessary prevention strategies, such as harm reduction programs for IDUs or information campaigns for young people, are not in place or are conducted on a limited scale that does not allow them to make a real impact on the epidemiological development of HIV-infection.

These examples show that Russia is far from finding workable solutions to overcome the HIV/AIDS epidemic. Despite its declared intentions, the Russian government fails to deliver a comprehensive national response. On the contrary, most efforts in the field of HIV/AIDS remain scattered and contradictory. Although the urgency of the problem has been politically acknowledged, there is little consensus about *how* effective HIV/AIDS prevention program can best be realized. Apparently, many questions still remain unanswered and obstacles exist that hamper the adoption of a comprehensive and effective response to HIV/AIDS in Russia. In order to understand those obstacles one needs to take into account the different views on HIV/AIDS that exist in Russian society. In

⁵ Davis, Christopher and Ben Dickinson (2004): 'Priorities, government institutions and foreign assistance in the fight against HIV/AIDS in Russia', *Public Administration and Development*, 24, pp. 31-40, p. 31.

⁶ Putin, Vladimir (2006): 'Opening Remarks at State Council Presidium Meeting on Urgent Measures to Combat the Spread of HIV-AIDS in the Russian Federation', 21 April 2006, available at: Official Web Portal of the President of Russia, <http://www.kremlin.ru/eng/text/speeches/2006/04/21/2148_type82912type82913_104797.shtml>. For the debate on the securitization of HIV/AIDS in Russia see: Sjöstedt, Roxanna (2008): "Exploring the construction of threats: The securitization of HIV/AIDS in Russia", *Security Dialogue*, 39,7, pp. 7-29.

⁷ Funding for HIV/AIDS programmes grew from \$4 million per year in the early part of the decade to \$150 million in 2006; Twigg, Judyth (2007): HIV/AIDS in Russia. Commitment, Resources, Momentum, Challenges. A Report of the Task Force on HIV/AIDS, Washington: Center for Strategic and International Studies, p. 9.

⁸ Speech of Minister of Health and Social Development Tatyana Golikova at the Second Eastern Europe and Central Asia AIDS Conference, 5 May 2008, <<http://2008.eecaac.org/en/index.phtml>>, (accessed on 12 December 2008).

the following we will investigate the role of civil society in the response to HIV/AIDS, before focusing on the societal discourse and its interrelation with practices concerning HIV/AIDS.

Civil society and HIV/AIDS

In the global response to HIV/AIDS, civil society plays an important role. On the one hand, civil society actors, such as NGOs, play an active part in the formulation and implementation of policies; while on the other hand, the involvement of civil society itself constitutes a norm in the global response to the epidemic. According to the UNGASS Declaration of Commitment on HIV/AIDS, the ‘full involvement and participation of civil society actors in the design, planning, implementation and evaluation of programs is crucial to the development of effective responses to the HIV/AIDS epidemic’.⁹ As a main international institution, UNAIDS acknowledges the essential role of civil society. It is believed that the active participation of NGOs makes prevention strategies more effective, since NGOs can fulfil a bridge function to the most vulnerable and hard-to-reach populations, and thereby guarantee that HIV/AIDS prevention becomes rooted in local communities.

In his opening speech at the State Council presidium meeting in April 2006, President Putin acknowledged the need to involve civil society in the response to the HIV/AIDS epidemic in Russia: ‘We need more than words; we need action, and the whole of Russian society must get involved.’, and also ‘we need to get the business community, political parties and civil society more actively involved in this information and prevention work.’¹⁰ The need to interact with civil society actors has also been emphasized by health care officials in Russia, as acknowledged by chief sanitary physician Onisheko: ‘Taking into account that HIV/AIDS first and foremost is a social problem and that its solution depends on behaviour change, those measures can only be successful with the consolidated efforts of the state and civil society.’¹¹

⁹ Declaration of Commitment on HIV/AIDS, United Nations General Assembly Special Session on HIV/AIDS, 25 – 27 June 2001.

¹⁰ Putin, Valdimir (2006), ‘Opening Remarks at State Council Presidium Meeting on Urgent measures to Combat the Spread of HIV-AIDS in the Russian Federation, April 21, available at: President of Russia Official Web Portal, <http://www.kremlin.ru/eng/text/speeches/2006/04/21/2148_type82912type82913_104797.shtml>, (accessed on 1 March 2009).

¹¹ Onishenko, Gennadiy (2004). ‘Decree ‘On the activation of measures, focusing on the fight against the spread of HIV-infection in the Russian Federation’, January 14, available at: Federal AIDS Centre, <<http://www.hivrussia.org/doc/05.shtml>> (accessed on 2 March 2009).

Civil society actors have been active in the response to HIV/AIDS from the beginning of the epidemic. Today, approximately 300 Russian NGOs are active on local, regional and national level.¹² The biggest and probably most well-known AIDS-service NGOs in Russia are the members the NGO-consortium of the Globus project, including the *Open Health Institute* (OHI), the *AIDS Foundation East-West* (AFEW), *Focus-Media*, *Population Services International* (PSI) and *AIDS Infoshare*. Those Moscow-based NGOs have a network of partner organisations in Russian regions, with which they are conducting HIV/AIDS prevention programs. AIDS-service NGOs in the regions vary from small initiatives to big grass-root organisations with their own access to international donor organisations, such as the St. Petersburg NGO *Humanitarian Action*.

A useful approach for analysing the role of NGOs in the response to HIV/AIDS is the concept of *agency*, which has been developed by Hakan Seckinelgin in order to gain a better understanding of NGOs as actors in the policy field of HIV/AIDS.¹³ According to Seckinelgin, NGOs are institutionalised within the international policy process of HIV/AIDS, and have, thus, gained *agency*, which is understood as ‘the capability to do things according to certain values and policy priorities’.¹⁴ Applied to the context of domestic policy of Russia, we can ask, to what extent NGOs have agency to transform discourses on HIV/AIDS and assert influence on the domestic decision-making process concerning the response to HIV/AIDS?

Voices in the discourse

In order to investigate discourses on HIV/AIDS, one needs to locate and understand the different positions. In the following, the main stakeholders in the discourse on HIV/AIDS in Russia are investigated by examining both political and societal actors.

The main state institution responsible for the response to the epidemic, is the *Federal AIDS Centre*, which is in charge of the epidemiological surveillance of HIV infection as well as of HIV/AIDS prevention, clinical diagnosis and medical care in the Russian

¹² Twigg, J. and Skolnik, R.: *Evaluation of the World Bank’s Assistance in Responding to the AIDS Epidemic: Russia Case Study*, Washington, D.C.: The World Bank, 2005.

¹³ Seckinelgin, Hakan (2008). *International Politics of HIV/AIDS. Global Disease – Local Pain*, London: Routledge.

¹⁴ *Ibid*, p. 65.

Federation.¹⁵ The *Federal AIDS Centre* was already established in Soviet times, when the first case of HIV-infection was diagnosed in 1987. It operates on the basis of the 1995 Federal AIDS law¹⁶ and consists of a network of regional and municipal AIDS centres.¹⁷ In the past, the discourse on HIV/AIDS was restricted to health care institutions and did not reach the level of political decision making. The response to the epidemic was given low priority, and funding for HIV/AIDS programmes was insufficient to make a real impact on the epidemic.¹⁸ This changed after HIV/AIDS had been declared a national security threat in 2006. The creation of the *Commission on Prevention, Diagnosis and Treatment of HIV/AIDS* shows that the Russian government has reassessed its approach and started to view HIV/AIDS as a priority.¹⁹

International organisations have played an essential role in initiating this change of perception. The different scenarios on the macro-economic implications of HIV/AIDS, presented by the World Bank, the UNDP and the ILO between 2002 and 2004,²⁰ which predicted a steep decrease of Russia's GDP as a consequence of the epidemic, served as a particular wake-up call for Russian decision makers.²¹

¹⁵ Statute of the Federal AIDS Centre of the Ministry of Health of the Russian Federation, available at *Federal AIDS Centre*, <<http://www.hivrussia.org/about/index.shtml>> (accessed on 11-03-2008).

¹⁶ Federal AIDS Law, No 38-F3, 30 March 1995, available at *Federal AIDS Centre*, <http://www.hivrussia.org/doc/08.shtml>.

¹⁷ Federal AIDS Centre, <http://www.hivrussia.ru> (accessed on 12 March 2008).

¹⁸ Wallander, Celeste A. (2006). 'Russian Politics and HIV/AIDS: The Institutional and Leadership Sources of an Inadequate Policy, in: Twigg, Judyth L. (ed.). *HIV/AIDS in Russia and Eurasia*, Vol. 1, New York: Palgrave, pp. 33-55.

¹⁹ Policy Resource Center on HIV/AIDS: 'Commission on Prevention, Diagnostics and Treatment of HIV/AIDS by the Russian Government', <<http://hivpolicy.net/topics/?id=40&page=119>> (accessed on 26 March 2009).

²⁰ In his article on the economic impact of HIV/AIDS in Russia, Shombi Sharp presents three models, developed by the World Bank, UNDP and ILO; Sharp, Shombi (2006). 'The Economic Impact of HIV/AIDS in Russia: Current Trends and Perspectives', in: Twigg, Judyth L. (ed.). *HIV/AIDS in Russia and Eurasia*, Vol. 1, New York: Palgrave, pp. 77-102. For more information on the different models see also: Rühl, C., V. Pokorvsky and V. Vinogradov (2002). 'The Economic consequences of HIV in Russia', World Bank, Moscow, May 15, <http://www.worldbank.org.ru>; Sharp, S. (2004). 'Modelling the Macroeconomic Implications of a Generalised AIDS Epidemic in the Russian Federation', annex 1 in: UNDP. *Reversing the Epidemic: Facts and Policy Options*, Bratislava: UNDP; ILO (2004) *Social Policy costs and Consequences of HIV/AIDS in the Russian Federation: an ILO Model*, Moscow: ILO.

²¹ Sharp, Shombi (2006). 'The Economic Impact of HIV/AIDS in Russia: Current Trends and Perspectives', in: Twigg, Judyth L. (ed.). *HIV/AIDS in Russia and Eurasia*, Vol. 1, New York: Palgrave, pp. 77-102.

The societal discourse on HIV/AIDS, on the other hand, has largely been influenced by the way the Russian media has reported on the issue. During the 1990s, HIV/AIDS had mostly been portrayed as a problem affecting marginalised groups of society, particularly drug users and sex workers. Frequent reports on HIV/AIDS as the ‘plague of the 20th century’ stoked fears within society rather than contributing to information and awareness raising. Even today reliable information on HIV-infection and associated risks is scarce in Russian media with many reports containing misleading information.²² An exception are information campaigns, as for instance the ‘Stop AIDS’ campaign, conducted by the *Global Business Coalition on HIV/AIDS, Tuberculosis and Malaria*.²³ Private information campaigns, however, have limited coverage in Russia’s regions, as many regional TV stations require payments for broadcasting information on HIV/AIDS.²⁴

A prominent voice in the discourse on HIV/AIDS is the Russian Orthodox Church (ROC), which has developed a vision on its role in the ‘Conception of the participation of the ROC in overcoming the spread of HIV/AIDS and working with people living with HIV/AIDS’, adopted by the Holy Synod in October 2004.²⁵ In this conception, the ROC recognized HIV/AIDS as ‘one of the most serious threats to the CIS countries’ and assured its participation in the efforts to overcome the epidemic.²⁶ According to the conception, the underlying causes for HIV/AIDS are to be seen in ‘an unprecedented growth of sin and lawlessness, loss of fundamental spiritual values, moral traditions and guidelines in society.’²⁷ The ROC sees its own role in a ‘spiritual and moral appraisal of the HIV/AIDS epidemic’²⁸, as it has ‘an opportunity to offer a real alternative to the widespread vice of today, including drug use, amorality and lack of spirituality’, as the deputy chairman of the Moscow

²² In 1999, the Russian newspaper “Moscow News” reported about a supposed cure for HIV-infection, the so-called “Armenicum” without questioning the reliability of the information on the “magic cure”; Moscow News (1999): “Magic Cure for AIDS discovered in Armenia”, 03-03-1999. “Armenicum” later became a symbol for unreliable reports on HIV-infection.

²³ The Global Business Coalition on HIV/AIDS, Tuberculosis and Malaria (GBC), <<http://www.gbciimpact.ru/en/>> (accessed on 2 April 2009).

²⁴ Interview deputy director of the Regional AIDS Centre in Tomsk, 4 December 2008.

²⁵ Moscow Patriarchy (2004): ‘Conception of the participation of the Russian Orthodox Church in overcoming the spread of HIV/AIDS and the work with people living with HIV/AIDS’, <<http://www.mospat.ru/archive/9596-1.html>>, (accessed on 30 March 2009).

²⁶ Ibid.

²⁷ Ibid.

²⁸ Ibid.

Patriarchy's department for external church relations Vsevolod Chaplin explained during the official presentation of the conception.²⁹ In his words, the response to the HIV/AIDS epidemic should be based on the 'Christian principle 'Hate the sin, but love the sinner''.³⁰ In 2005 the ROC specified its cooperation with the state organisations and with public organisations.³¹ Religious organisations and parishes are today involved in HIV/AIDS prevention as well as in programmes for palliative care and support.

Some Russian organisations are categorically opposed to HIV/AIDS prevention programmes, including the *All-Russian Parents' Assembly*, a Russian NGO focusing on family values and education.³² The organisation views foreign-funded AIDS-service organisations as a harmful Western influence and a threat to well-being of the Russian people. In May 2008, the *All-Russian Parents' Assembly* held a conference on HIV/AIDS, to which it invited notorious AIDS denialists from around the world. The conference resolution disclaimed the causal relationship between HIV-infection and AIDS and called on the Russian government to stop all HIV/AIDS programmes.³³ Whereas the organisation does not have impact on the political decision-making process on the federal level, the activities of its branches are able to assert influence on the regional and local level.

Key problem areas of HIV/AIDS prevention

In the following the paper will discuss the discourse on HIV/AIDS focusing on three key areas of prevention, which are essential in the response to the epidemic in Russia: (1) sex education and HIV/AIDS prevention programme for adolescents, (2) harm reduction programmes

²⁹ Moscow Patriarchy, 'In Moscow the presentation of Conception of the participation of the Russian Orthodox Church in overcoming the spread of HIV/AIDS and the work with people living with HIV/AIDS to place', <<http://www.mospat.ru/center.php?page=27487&newwin=1&prn=1>>, (accessed on 30 March 2009).

³⁰ Ibid.

³¹ World Council of Churches, 'State, religious and public organizations discussing the problems of HIV/AIDS – prospects of cooperation, final document, Moscow, Russian Federation, 18-19 April 2005', <<http://www.oikoumene.org/en/resources/documents/other-ecumenical-bodies/church-statements-on-hiv-aids/19-04-05-moscow-international-conference.html>> (accessed on 14 March 2009).

³² All-Russian Parents' Assembly, <<http://oodvrs.ru./mainnews/index.php>>, (accessed on 9 March 2009).

³³ All-Russian Parents' Assembly (2008), 'Resolution of International Conference. The Problem of HIV and AIDS and the Family Well-Being of the Nation', <http://oodvrs.ru/article/index.php?id_page=21&id_article=645> (accessed on 1 March 2009).

for IDUs, and (3) social support and empowerment of people living with HIV.

Sex education and HIV/AIDS prevention

The HIV/AIDS epidemic mainly affects young people in Russia. According to UNAIDS, 80 percent of people living with HIV (PLWH) in Russia are between 14 and 30 years old.³⁴ HIV/AIDS prevention programmes for adolescents are therefore an essential element in the response to the epidemic. The education sector is critical in providing information, as programmes at schools reach the majority of teenagers. Moreover, they allow for an interactive discussion among peers and can be integrated in broader health programmes. In Russia, however, no systematic sex education courses exist in the curriculum of secondary schools or institutions of higher education. According to a survey, conducted by the St. Petersburg youth centre Yuventa in 2004, 61 percent of local teenagers have little or no sex education.³⁵ A steep increase in STI incidence among adolescents since the early 1990s shows widespread sexual risk behaviour in this age group. Syphilis rates, for instance, rose from 4,2 to 144,1 per 100,000 population from 1987 to 2002.³⁶

Attempts to introduce comprehensive sex education in Russian schools has failed due to conservative resistance. In 1996, a coalition of different groups such as the religious *Pro-Life* movement, parents associations, the Russian Orthodox Church and the Russian Communist Party prevented the start of a pilot project, initiated by the Russian Ministry of Education in cooperation with the United Nations Population Fund (UNFPA) and the UNESCO.³⁷ The project, which aimed to introduce a curriculum for sex education into secondary schools, came under heavy attack in the mass media for being a 'Western ideological subversion of Russian children'.³⁸ A broad campaign against the project was started, which Russian sexologist Igor Kon called an 'anti-sexual

³⁴ UNAIDS: Global Summary of the AIDS Epidemic, December 2006, http://www.unaids.ru/en/HIV_data, accessed on 27 May 2008.

³⁵ 'Infections Linked to a Lack of sex Education in Russia', in: *Medical News Today* <<http://medicalnewstoday.com/articles/7751.php>> (28 April 2004).

³⁶ Twigg, Judyth and Richard Skolnik (2005): *Evaluating the World Bank's Assistance in Responding to the AIDS Epidemic: Russia Case Study*, World Bank: Washington D.C, p. 6.

³⁷ Kon, Igor, 'Sexual culture and politics in contemporary Russia', in Štulhofer, Aleksandar and Theo Sandfort (ed.) (2005). *Sexuality and Gender in Postcommunist Europe and Russia*, New York: Haworth Press, pp. 111-124.

³⁸ Chervyakov, V. and Kon, I. (2000) 'Sexual Revolution in Russia and the tasks of sex education', in: *AIDS in Europe*. Ed. By Theo Sandfort, pp., 119-134, p. 133.

crusade'.³⁹ The Russian Orthodox Church opposed the programme as being a harmful influence from the West. Church representatives announced that Russia was not in need of any sex education programmes, as this task had always been fulfilled by the church.⁴⁰ The campaign was also supported by the Communist Party of the Russian Federation, which at that time held a majority in the state Duma. According to Kon, the party deliberately used the topic in order to excite anti-Western sentiments in the Russian electorate.⁴¹ Moreover, the campaign was accompanied by reports in leading Russian newspapers, denouncing sex education programmes as 'subversive activities, paid for by Western secret services', in order 'to promote homosexuality'.⁴² The Ministry of Education finally cancelled its previous approved programme.⁴³

Since 1996, no more attempts have been made to introduce a general sex education course into the curriculum of secondary schools. NGOs working in the field of HIV/AIDS prevention have described the educational sector as extremely conservative and difficult to deal with.⁴⁴ Despite a rapidly growing HIV/AIDS epidemic since the late 1990s, many political and societal groups are still opposed to sex education and HIV/AIDS programmes. In 2006, a representative of the Moscow city parliament, Mrs. Stebenkova, appealed to the Russian President Putin to restrict the activities of foreign AIDS-service organisations, as 'they are guilty of spreading AIDS by promoting safe sex'.⁴⁵ The deputy blamed foreign-funded NGOs, such as the consortium of the Globus project, for fuelling the epidemic rather than stopping it.⁴⁶ In an open letter to the Russian president, patriarch Alexey II, head of the Russian Orthodox Church, accused NGOs of being 'agents of moral corruption that operate to promote Western commercial interests'.⁴⁷ In his letter, the patriarch

³⁹ Kon, Igor, 'Sexual culture and politics in contemporary Russia', in Štulhofer, Aleksandar and Theo Sandfort (ed.) (2005). *Sexuality and Gender in Postcommunist Europe and Russia*, New York: Haworth Press, pp. 111-124, p. 115.

⁴⁰ Ibid, p. 117.

⁴¹ Ibid.

⁴² Ibid, p. 119.

⁴³ Ibid, p. 118.

⁴⁴ Interview with representative of the NGO Open Health Institute, February 2007.

⁴⁵ Vasil'ev, Yurij (2006): 'Герой неделю Проигравший. Кондомоборец, in: *Ogonek*, 24 April, available at *Eastview*, <<http://dlib.eastview.com/sources/article.jsp?id=9387512>> (accessed on 12 December 2008).

⁴⁶ Swanson, Elizabeth (2006). 'City MPs demand crackdown on foreign AIDS Centres', in: *Moscow News*, 21 April, available at *Eastview*, <<http://dlib.eastview.com/sources/article.jsp?id=9357702>>

⁴⁷ 'Russian Orthodox Patriarch Criticizes Western Anti-AIDS Programs', in *Associated Press*, available at *The Body*. The complete HIV/AIDS resources, <<http://www.thebody.com/content/art24276.html/ts+pf>>.

said that ‘under the guise of promoting a healthy lifestyle and AIDS prevention among the young generation, programmes are being spread, which cannot be deemed anything other than a sexual and moral corruption of children.’⁴⁸ Russian parents’ organisations, such as the *Russian Parents’ Assembly*, also campaign against HIV/AIDS prevention programmes. In 2008, the association accused AIDS-service NGOs of aiming to aggravate Russia’s demographic crisis.⁴⁹ The organisation appealed to the Russian government to revise its policy on HIV/AIDS and to stop the activities of foreign-funded AIDS-service organisations.⁵⁰

Due to societal opposition, the introduction of sex education and HIV/AIDS prevention programmes has been deferred in Russia. The topic of sex education is not raised in the political debate anymore, although many representatives in the health care system are in fact in favour of a different approach. According to a representative of the Moscow-based NGO *Transatlantic Partners Against AIDS*, health care specialists and politicians are disinclined to raise the topic of sex education in schools, as any initiative in this direction is associated with a political risk.⁵¹

As a result, the implementation of sex education and HIV/AIDS prevention programmes in schools is limited to local programmes. In the framework of the Globus project, the Russian NGO *Health and Education* developed a programme for teaching healthcare issues in schools, including information on HIV and STI. The scope of the programme, however, was limited to the ten regions of the Globus project. Moreover, it was left to the participating schools, as to whether they would actually introduce courses into their curriculum. Another example of a local initiative is the NGO *Siberian AIDS Aid*, which in cooperation with the municipal department for education provides interactive workshops on HIV/AIDS and STI prevention, drug use prevention and reproductive health to students of secondary schools in the city and region of Tomsk. Even on the local level, *Siberian AIDS Aid* needs to guard itself against criticism. In order to participate in the programme pupils need the written consent of their parents. Moreover, the NGO has clearly defined the content and form of the course with the municipality and the participating schools, including clear distinctions between different age groups. Also in other Russian regions, HIV/AIDS prevention programmes in secondary schools are initiated by local NGOs. Often, so-

⁴⁸ Ibid.

⁴⁹ All-Russian Parent’s Assembly: ‘Open letter of the parents of Russia’, available at <http://oodvrs.ru/article/index.php?id_page=21&id_articles=329> (accessed on 22 January 2009).

⁵⁰ Ibid.

⁵¹ Interview with representative of the NGO TPAA, 10 October 2008.

called youth-friendly clinics, offering medical and social services for adolescents, such as Yuventa in St. Petersburg, are involved in those programmes.⁵² HIV/AIDS prevention is thereby often included in a broader programme of health promotion. Local sex education and HIV/AIDS prevention programmes depend on the approval of local authorities and schools. Furthermore, the implementation is down to the initiative and activism of local NGOs and schools. Many programmes have to deal with limited financial resources, mostly provided by foreign donors. On the whole, it is thus often a question of chance, whether teenagers receive any information on reproductive health and HIV/AIDS prevention during their school time.

Due to lack of comprehensive programmes in schools, young people rely on information provided by the media. Media reports concerning reproductive health and HIV/AIDS, however, often contain unreliable information. Many reports convey a misleading picture of HIV-infection and associated risk behaviour. Particularly outside the urban centres, young people have limited access to reliable information on HIV/AIDS. State-funded HIV/AIDS information campaigns, such as the 'Stop AIDS' campaign do not reach all regions in Russia, as regional TV channels do not broadcast HIV/AIDS prevention spots, or ask for additional payments from AIDS-service organisations in order to include them in their programme. This is contradictory to legal provisions that stipulate that public health promotion is to be broadcasted free of charge.

We can conclude that there is no comprehensive approach to sex education and HIV/AIDS prevention in the Russian educational system. The dominating voices in the discourse are opposed to sex education and HIV/AIDS prevention programmes in schools. Consequently, young people in Russia do not have sufficient access to reliable information on HIV-infection or reproductive health in general in order to make well-informed and responsible decisions. The lack of societal consensus about the form of sex education and HIV/AIDS prevention for young people shows that Russian society is still struggling to find a workable answer to the challenge posed by the HIV/AIDS epidemic.

Harm reduction programmes

Risky drug use practices among IDUs, such as needle sharing and the use of non-sterile equipment, has been the main driver of the HIV/AIDS epidemic in Russia. According to UNAIDS, two thirds of newly registered HIV cases in 2006 of which the mode of transmission was

⁵² St. Petersburg Youth Clinic Yuventa, <www.iuventa-spb.ru> (accessed on 10 January 2009).

known were due to injecting drug use.⁵³ In order to halt the HIV/AIDS epidemic in Russia, prevention programmes for injecting drug users (IDUs) therefore require special attention. In order to prevent HIV-transmission among IDUs, international organisations as UNAIDS recommend a combination of comprehensive measures that are focused on mitigating the harm associated with drug use, so called harm reduction strategies.⁵⁴ Recommended harm reduction programmes include needle exchange, substitution therapy, voluntary HIV counselling and testing as well as other related health intervention for IDUs.⁵⁵ According to UNAIDS, the efficacy of harm reduction strategies is supported by overwhelming evidence.⁵⁶ However, harm reduction programmes remain subject to controversial debate in many countries, which is partly due to the fact that it is extremely difficult to conduct programmes for active drug users and assess their impact.

Due to traditionally conservative drug policies, Russia has been highly reluctant in providing harm reduction strategies. Legally, such strategies are treated inconsistently. Whereas substitution therapy is banned by Russian law, needle exchange programmes are permitted under certain conditions. In the following, the focus will therefore be on needle exchange programmes. Needle exchange programmes aim at preventing HIV-transmission among IDUs by providing them with the opportunity to exchange their used needles for new, sterile ones. Most programmes combine needle exchange with information on risk, behaviour and consultations regarding drug-related health issues. Organisations emphasize that such programmes allow them to directly contact the difficult-to-reach high-risk group of active drug users, in order to provide information and eventually prepare for drug rehabilitation. In Russia, needle exchange programmes can be conducted on the local level provided that the State Narcological Service and the health care authorities give approval to the respective programme.

Local projects are implemented by a number of Russian NGOs, working with IDUs. The biggest coalition is the *Russian Harm Reduction Network*, which has been founded with the aim to 'promote drug-related harm reduction strategy in order to combat the HIV/AIDS epidemic and other adverse consequences related to drugs, strengthen public health, and

⁵³ UNAIDS (2008). *Epidemiological Update 2008 Eastern Europe and Central Asia*, Geneva: UNAIDS.

⁵⁴ UNAIDS (2009). 'People, who use injecting drugs', <<http://www.unaids.org/en/PolicyAndPractice/KeyPopulations/InjectDrugUsers/>> (accessed on 17 January 2009).

⁵⁵ Ibid.

⁵⁶ Ibid.

realize the civil rights of drug users and all citizens of Russia.’⁵⁷ The network consists of many NGOs, which conduct programmes for IDUs on a local level. One example is the St. Petersburg NGO *Humanitarian Action*, which started one of the first projects for IDUs in Russia.⁵⁸ The mobile project of the NGO combines different strategies, including needle exchange, condom distribution and health promotion. Also, in other regions, as for instance Tomsk, needle exchange services are provided. In most cases, the projects are conducted by AIDS-service NGOs, in some cases they cooperate with local health institutions. In the city of Moscow, however, needle exchange projects are not in place due to the disapproval of local authorities.

In total, the scope and coverage of needle exchange programmes in Russia is far from being sufficient. One reason is the unclear legal situation of needle exchange. Programmes require the approval of both health institutions as well as the local branches of the State Narcological Service. The local branches of the State Narcological Service, however, do not have an internal mechanism to officially decide upon the approval of needle exchange programmes.⁵⁹ In some regions, as for instance in Tomsk or in St. Petersburg, AIDS-service NGOs succeeded to negotiate an unofficial tolerance of their projects by the regional branches of the State Narcological Service. This has the consequence that the respective programmes lack official approval and run the risk of being closed down in case of difficulties or changing attitudes by the authorities. In other cities, as for instance in Orenburg or Kaliningrad, societal opposition led to the closure of needle exchange programmes.⁶⁰ Opponents of harm reduction strategies argue that needle exchange promotes drug use and forms a risk factor for young people. The *Russian Parents’ Assembly*, for instance, has denounced the approach as being ‘degenerated’ and ‘harmful’.⁶¹ The region of Kaliningrad had one of the first needle exchange projects for IDUs in Russia. This project, however, was closed after negative media reports about the activities of the responsible NGO.⁶²

In general, we can conclude that IDUs have limited access to HIV/AIDS prevention, treatment and care. Moreover, IDUs face

⁵⁷ Russian Harm Reduction Network, <<http://harmreduction.ru/>> (accessed on 31 January 2009).

⁵⁸ Humanitarian Action Fund, <www.hap.ru> (accessed on 14 January 2009).

⁵⁹ Interview with representative of the NGO ‘Positive Wave’, St. Petersburg, 06 October 2008.

⁶⁰ Interview with representative of the Russian Harm Reduction Network, Moscow, 2 February 2007.

⁶¹ All-Russian Parents’ Assembly: ‘Open letter of the parents of Russia’, available at <http://oodvrs.ru/article/index.php?id_page=21&id_articles=329> (accessed on 12 March 2009).

⁶² Interview with NGO ‘Yula’, Kaliningrad, 12 October 2008.

discrimination in the health care system and are often denied services and treatment by medical personnel. This also holds true for the AIDS Centres. In fear of being prosecuted, IDUs are often afraid to approach state institutions. Because of their marginalisation, they form a hard-to-reach target group. Services for this risk group are limited in scale and coverage, and are entirely dependent on the activism of local organisations. The lack of a well-defined legal platform regarding harm reduction strategies poses an obstacle to comprehensive HIV/AIDS strategies for IDUs.

Support and empowerment for PLWH

Stigma and discrimination against people living with HIV (PLWH) play a major role in the HIV/AIDS epidemic. The 2001 UNGASS Declaration of Commitment on HIV/AIDS states that ‘the realization of human rights and fundamental freedoms to all is essential to reduce vulnerability to HIV/AIDS’ and calls for the ‘full participation of people living with HIV/AIDS’.⁶³ According to UNGASS, respect for human rights of PLWH helps deliver an effective response to the epidemic, which is also emphasized in the principle of the ‘Greater Involvement of People living with HIV’ (GIPA).

Despite the growing number of PLWH in Russia, their voices in decision-making processes remain largely unheard. Attempts to support the PLWH community are largely rhetoric, as human rights are violated on a regular basis. HIV-infection is highly stigmatised and associated with marginalised groups of society. As a consequence, PLWH face widespread discrimination. Most common problems reported by PLWH include violations of medical confidentiality, problems in the labour market, as well as with state institutions responsible for granting social allowances or other services.⁶⁴

As HIV-infection is associated with stigma in Russian society, many PLWH fear that their diagnosis might become known in their social environment. They are afraid that if family members, employers, colleagues, or neighbours find out about their HIV-status, it will possibly have far-reaching consequences in their personal life. The confidential treatment of the HIV diagnosis and other medical information, thus, is a major concern for PLWH in Russia. However, the rule of medical confidentiality is not guaranteed in many clinics and AIDS centres. Many

⁶³ Declaration of Commitment on HIV/AIDS, United Nations General Assembly Special Session on HIV/AIDS, 25 – 27 June 2001, § 58, available at http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf.

⁶⁴ Interview with representative of the NGO ‘Positive Wave’, St. Petersburg, 06 October 2008.

PLWH report violations with regard to confidential treatment of their diagnosis by medical personnel.⁶⁵

Moreover, the AIDS Centres as separated institutions also contribute to the isolation of PLWH in Russia. The system of federal and regional AIDS Centres forms one big institution that encompasses all state services in the field of HIV/AIDS. People, diagnosed with HIV-infection, are required to register with the regional AIDS Centre, which will then be responsible for all services to the patient. Even for medical treatment, not directly linked to HIV-infection, PLWH are usually referred to their AIDS Centre. Many AIDS Centres are located in separate buildings, which constitutes a psychological barrier for patients. Many PLWH are afraid to be publicly recognized as 'AIDS patients', particularly in small towns.

Another problem for PLWH is their position in regards to the labour market. Employment in state services requires a negative HIV-status. Following the state example, a growing number of Russian companies have stipulated that their prospective employees must be prepared to undergo HIV tests. Although discrimination on the basis of HIV infection is forbidden according to Russian AIDS law⁶⁶, the practices in the labour market paint a different picture. Many PLWH are afraid that they will lose their job, if their diagnosis becomes known to their employer. Also in other spheres of life, such as housing, PLWH deal with discrimination.

AIDS-service NGOs provide services to PLWH, which range from psychological counselling and social support to the provision of information concerning juridical questions. Moreover, AIDS-service NGOs conduct awareness campaigns that aim to strengthen the tolerance towards PLWH in society. One example of this approach is the HIV/AIDS awareness campaign of the NGO *Focus-Media*, which is realized in the framework of the GLOBUS project. In many AIDS centres, self-help initiatives have been established by PLWH with the aim to provide mutual support. In some regions, PLWH have been able to create their own organisations, which provide a broad range of services to their members. One example is the NGO *Positive Wave* in St. Petersburg, which was founded with the objective "to enhance the life quality of PLWH".⁶⁷ On the national level, self-help initiatives of PLWH have established the *Russian Association of People Living with HIV*, representing the interests of PLWH in Russia.⁶⁸

⁶⁵ Shagi, <<http://shagi.infoshare.ru/>>

⁶⁶ Federal AIDS Law, No 38-F3, 30 March 1995, available at *Federal AIDS Centre*, <http://www.hivrussia.org/doc/08.shtml>.

⁶⁷ Positive Wave, St. Petersburg, <<http://positivewave.org/>>.

⁶⁸ Russian Association of People Living with HIV, <<http://www.positivenet.ru/>>

Many self-help initiatives of PLWH have a religious orientation. Some groups maintain close links with the Russian Orthodox Church, or other religious communities such as evangelical free churches. In its 'Conception of the Russian Orthodox Church's Participation in the Fight against the Spread of HIV/AIDS and the Work with People Living with HIV/AIDS', adopted by the Holy Synod in 2004, the church emphasized its commitment to take an active part in the response to the epidemic.⁶⁹ The church particularly addresses those, who are directly affected by HIV/AIDS, and calls upon its members to involve PLWH in parish life.⁷⁰ According to the church, 'the attempts of people living with HIV/AIDS should not be met with indifference, or worse, disdain and condemnation.'⁷¹ Many Orthodox priests participate in local programmes that provide social support and care to PLWH and IDUs.

Although a number of NGOs, such as *Positive Wave* in St. Petersburg offer legal support for PLWH, many questions regarding the protection of their rights still remain unanswered. The legal problems of PLWH are mostly treated on an individual level without setting up general advocacy strategies to enhance human rights protection. In general, one can say that mutual support and civic engagement of PLWH in Russia is still poorly developed. Advocacy for the interests of PLWH remains weak, as questions of discrimination and human rights violations have largely been untouched. In most institutions, PLWH are seen as patients, receiving services, rather than as citizens, who are entitled to rights. On the other hand, most people, who are affected by the epidemic, do not see a real opportunity to improve their situation by uniting with others. As a result, the involvement of PLWH in the response to the HIV/AIDS epidemic and their self-empowerment is only at the beginning.

Concluding remarks

The article investigated the societal discourse concerning HIV/AIDS prevention in Russia. It thereby focused on three key areas, which are essential for overcoming the HIV/AIDS epidemic. In all three key areas we can observe shortcomings. Comprehensive HIV/AIDS response strategies are not in place or are too limited in scale.

⁶⁹ Moscow Patriarchy (2004): 'Conception of the participation of the Russian Orthodox Church in overcoming the spread of HIV/AIDS and the work with people living with HIV/AIDS', <<http://www.mospat.ru/archive/9596-1.html>>, (accessed on 30 March 2009).

⁷⁰ Ibid.

⁷¹ Ibid.

First of all, sex education and HIV/AIDS prevention programmes in the educational sector are long overdue in Russia. Due to a lack of systematic educational programmes a sufficient level of information and awareness regarding HIV/AIDS among young people cannot be guaranteed. Second, harm reduction programmes are limited in scale and coverage. Unclear legislation and a lack of government support hamper the implementation of harm reduction programmes. All existing programmes are restricted to the local level and depend on the unofficial tolerance of the State Narcological Service and the activism of local NGOs. As a result, IDUs, who constitute a main risk group with regard to HIV-infection in Russia, do not have sufficient access to HIV/AIDS prevention and related health services. The situation of PLWH, finally, is characterized by stigma and discrimination, both of which are major factors in the growth of the HIV/AIDS epidemic in Russia. Support programmes of AIDS-service NGOs and self-help initiatives are too weak to bring a significant change in the situation of PLWH.

In all three areas, discourses are influenced by societal groups, which are opposed to specific HIV/AIDS programmes. While NGOs play an important role in providing services, they have so far not been able to successfully transform discourses on HIV/AIDS, which would allow for a change in policy.

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STI and HIV/AIDS prevention project for Mongolians in the United Kingdom

Bazarragchaa Tsogt, Suvd Batbaatar and Tsegmed Sambuu

In 2007, the Mongolian Association of the United Kingdom (MAUK) designed and implemented a one-year STI/HIV/AIDS prevention project within the Mongolian community of the UK. The goal of the project was to assess the STI/HIV/AIDS knowledge and the risky practices of Mongolians in the UK and to organise STI/HIV/AIDS prevention activities based on community needs involving community members using their own resources. This paper gives an overview of the project activities and its implementation and survey results. Furthermore, it discusses the importance of a multisectorial community-specific approach handling STI/HIV/AIDS prevention activities by taking into consideration certain needs which have arisen from a behavioural survey conducted as part of the project activities.

The Mongolian Association of the United Kingdom (MAUK) is a non-profit association established in 1998. The aims of MAUK¹ are to unite Mongolians living in the UK; to provide the support that Mongolians require in a host country; to promote and organise, social, cultural and traditional events, especially national holidays, in order to keep Mongolians closer to their socio-cultural roots; and to host an annual meeting of Mongolian intellectuals in order to capture their knowledge, experience and skills for the development of Mongolia.

“Tсахим Уртуу Холбоо” (TUH) is based in Ulaanbaatar, Mongolia and is the first nongovernmental organization (NGO) that has been implementing STI/HIV/AIDS prevention activities for Mongolians living abroad. In 2006, TUH became an implementing partner for a five-year project supported by the Global Fund country office and the Mongolian Ministry of Health. As a long-term commitment, TUH began to provide

¹ MAUK (2006): Vision and mission statement of the Mongolian Association of the United Kingdom, May 2006, www.mongolchuud.co.uk, accessed on August 2007.

HIV/AIDS awareness raising sessions for Mongolians who were leaving the country as workforce for South Korea and then for those Mongolians already working there.

Background: HIV/AIDS in Mongolia

Although, in the global context, Mongolia is among the HIV/AIDS low prevalence countries (< 500 infected adults over age 15 years per total population), the incidence of people living with HIV (PLH) has been increasing since the first case was officially reported in 1992. Between 1992 and the end of 2006, thirty people had tested positive for HIV, and four people had progressed to AIDS and have already died.² However, these numbers seriously underestimate the real extent of the HIV/AIDS epidemic in Mongolia, and the Government of Mongolia is well aware of this situation.

Mongolia has a small population, at 2.6 million people, and thus as a nation-state is at risk for crises that could undermine population development, with due regard for the human rights of individuals and groups within the population. Mongolia has certain vulnerabilities that may predispose the general population to HIV infection. These vulnerabilities include: (1) Increasing HIV prevalence in the two populous neighbouring countries, China³ and Russia,⁴ (2) Poverty (36% of the population being poor or in extreme poverty,⁵ living well below minimum subsistence levels according to social statistics), (3) Unemployment⁶ (14% of work force being unemployed), (4) Existence of risky sexual behaviour among young people⁷ and especially among people having their first sexual intercourse⁸, (5) High prevalence of

² National Centre for Health Development (2006). *Health Indicators 2006*. Ulaanbaatar, p.9.

³ UNAIDS and WHO (2008). *Asia: AIDS epidemic update-regional summary 2007*. Geneva: pp.1-4.

⁴ UNAIDS and WHO (2008). *Eastern Europe and Central Asia: AIDS epidemic update- regional summary 2007*. Geneva: pp. 3-5.

⁵ National statistical office, World Bank and UNDP Mongolia (2004). *Main report of Household income and expenditure survey/Living standard measurement survey*. Ulaanbaatar: National Statistical office, pp. 6-10.

⁶ National statistical office and Asian Development Bank (2004). *Main report of labour force survey*. Ulaanbaatar.

⁷ Bazarragchaa Tsogt et al. (2003). A strategic assessment of policy, program and research issues related to reducing the recourse to abortion and improving the quality of care of abortion and family planning services in Mongolia. Ulaanbaatar: Munkhiin Yseg, pp. 43-45.

⁸ National Infectious Disease Centre and STI/AIDS Reference Centre (2006). *Sentinel Surveillance of HIV and syphilis-2002-2005*. Ulaanbaatar.

sexually transmitted infections (STI) among the general population (with STIs accounting for approximately 35.3% of all infectious diseases⁹ officially reported in Mongolia in 2006, showing the possibility of increased risk for sexual transmission of HIV), (6) Dramatic increase in internal migration from countryside to cities (because of disasters caused by harsh winters decimating livestock, thus jeopardising the income of many herder families in the countryside and leading to the expansion of new settlements called “ger districts” on the outskirts of the capital city Ulaanbaatar), and (7) Extensive external migration¹⁰ to Asian, European, and American industrialised countries. An unofficial source claims that more than 100,000 Mongolian people, which is 4% of the total population, are living outside of the country, with the highest numbers in South Korea, Japan, United Kingdom (UK), Germany, and the USA. To date, there is no reliable government data on the number of migrants abroad.

Most of these mobile populations travel to support their families in the home country. One Mongolian working abroad may be supporting three to four family members in Mongolia. Moreover, most of these migrants constitute the potential work force of Mongolia. No policy or program exists to protect the rights and health of Mongolians in foreign countries. In contrast, many officials view the transposition of workforce abroad as one way of dealing with economic problems in Mongolia, through the bolstering of the Mongolian economy with foreign-acquired funds.

Low population density and the chronically dire socio-economic situation combined to motivate young people to flee the country in search of better living conditions in industrialised countries. An increase of HIV infection might threaten the national security of Mongolia in the longer term.

Project background

The UK has a population of over 60 million people, with Gross National Income per capita of 33,650 USD.¹¹ The UK is contending with a relatively small HIV epidemic in comparison with some other

⁹ National Centre for Health Development (2006). *Health indicators*. p.30.

¹⁰ Solongo A. (2007). Growth of internal and international migration in Mongolia. Migration, development and poverty reduction 8th International conference of Asia Pacific migration network. May 25-29. Fuzhou, Fujian province, China.

¹¹ WHO (2006): United Kingdom statistics, 2006, <http://www.who.int/countries/gbr/en/>, accessed on 2 August 2007, updated on 9 September 2009.

industrialized countries in the world, with an estimated 77,400 people¹² (2008) – 0.2% of the population – currently living with HIV.

London is the epicentre of the epidemic, accounting for almost half of all HIV diagnoses in the UK. There is an estimated 10,000 Mongolians living in the UK, with the majority living in London. A survey of 112 Mongolian migrants conducted by MAUK in July 2007 showed that almost 50% were aged between 20-29 years and 29% were aged between 30-39 years.¹³ Although this survey comprised a relatively small number of people, it shows that approximately 79% of the participants are young people aged between 20-39 years, confirming the trend of the young workforce leaving Mongolia.

There are many general factors that put Mongolians at a high risk of poor health in foreign countries. The majority of migrants travel alone, separated from their families or regular partners. Loneliness, homesickness, and anonymity may lead people, especially young people, to take risks that they would not have taken at home in Mongolia. Misconceptions about host country norms and the pressure to “fit in” may also lead young people to take increased risks with regards to social behaviour, especially sexual behaviour -- not using a condom, having multiple sexual partners, combining alcohol and sexual intercourse, experimenting with illicit drugs. Thus, an immediate prevention programme among these Mongolian migrants was needed as an important part of an HIV control strategy for both Mongolia and the UK.

Objectives of the project

The objectives of the project were (1) to conduct a behavioural survey and (2) to contribute to the decrease in risky behaviours among these Mongolians while they reside in the UK, and (3) to contribute to the decrease in risk of HIV and STI transmissions involving Mongolian citizens leaving the UK and returning to Mongolia.

Implementation of the project

Project preparation started as soon as funding was secured through TUH from the Global Fund country office in August 2007. A project team of five people (two people from MAUK and PHI and one from TUH) was established to communicate between the two countries and to organise

¹² Health Protection Agency (2008). *HIV in the United Kingdom: 2008 report*. London. p.3.

¹³ Mongolian Association of the United Kingdom. (2007), Unpublished internal survey. London.

and manage the project, though the main coordination depended on MAUK in London, where the project was to be implemented. Preparation was intense and involved team members meeting online on a regular basis, at least every other day, to discuss all issues related to the project.

The main focus of the project preparation stage was sensitisation of the community members, especially those people who have business engagements with the community. The support of the Mongolian Embassy officials was essential and readily offered. Situation analysis of the community helped to choose the project sites as the freight forwarding centre, pub, and karaoke bar, where Mongolians regularly meet for socialisation and gather together to celebrate different events. Invitations with a brief description of the project were sent to these people inviting them for a discussion at the Embassy meeting room in London. These meetings were informal and at the same time were designed to give a short theoretical background of STI/HIV/AIDS and the situation in Mongolia and to explain what the project could do to prevent spread of infection in the Mongolian community. There were always two-way dialogues to address the concerns of establishment owners, who thought that the project might intervene with their businesses, and to build an understanding of the aims of the team.

The MAUK web page (www.mongolchuud.co.uk) was the main tool for the community members to learn about the project and its progress. This web page runs in the Mongolian language and is accessible to all Mongolians across the UK. The project stages and implementation were regularly updated, and a job opportunity to recruit survey assistants within the project was advertised on this page. Three people from Manchester and Nottingham responded and volunteered to become survey data collectors. Thus, the web based information was important to involve local people in the project.

Email Yahoo! group networking of Mongolians was part of electronic information dissemination not only at the beginning of the project but also during the main activities. MAUK board members expanded existing Yahoo! group emails of Mongolians during the traditional holiday sport and cultural celebration “Naadam” in July 2007, which brought together Mongolians from different cities of the UK. New members were added to the list to receive news and information about MAUK activities including the project. Self-registration to join the email group was operated to expand the list further.

For general locations, the project included three cities in England (London, Manchester and Nottingham) where most of the Mongolians live. For specific sites, each Mongolian community in these cities had its own way of socializing, and these differences were taken into account

carefully. In London, for example, there are two sites: the so-called “Mongol pub” near Paddington station and the “FM karaoke bar” in Shepherds Bush, both of which serve traditional Mongolian food, play Mongolian songs and organize events for Mongolians. These sites are especially busy during weekends and on Tuesday evenings. Thus, they were optimal sites for targeted activities. In Manchester, most of the Mongolian community consists of younger people, who study in a college that provides English language courses and subsequent professional training. In Nottingham, in contrast, many Mongolians live with their families or partners, and socialising takes place in the form of home visiting or house parties during the weekends and holidays.

Main project activities

The three main activities of the project included (1) a behavioural survey, (2) the promotion of STI/HIV/AIDS awareness, and (3) the distribution and dissemination of information materials.

Behavioural survey

The project team conducted a behavioural survey¹⁴ at the beginning of the project implementation. This survey was the first study which investigated the sexual behaviour of Mongolians living in the UK. The aim of the survey was to investigate the knowledge and attitudes of Mongolians on STI/HIV/AIDS and their sexual behaviour in order to identify barriers and opportunities for addressing the development of appropriate preventive interventions for the project. This was a cross-sectional study with random selection of participants who gave an oral consent to participate in the study. Three cities in England: London, Manchester and Nottingham were chosen for the project, based on the estimation that the biggest number of Mongolians were living in those cities. Study participants were any Mongolian aged 15-49 years old living in these three cities. Mongolians in these cities have similarity in their lifestyles and their communication with each other. In each city they have places to meet for socialization and for celebrating traditional and other holidays together. They usually live in the same area, close to each other, and often share the same flat. Many of them together or study in the same college or school.

There are limited studies that investigated knowledge, attitude and practice on HIV/AIDS of Mongolians living abroad. The sample size

¹⁴ Bazarragchaa Tsogt, Tsegmed Sambuu and Suvd Batbaatar (2008). Study report about knowledge, attitude on STI/HIV/AIDS and sexual behaviour of Mongolians living in the UK. London.

calculation for this study in the UK was based on an unpublished report of Mongolians living in South Korea.¹⁵ Specifically, this calculation was based on the percentage of people who answered correctly three main ways of transmission of HIV infection (29%) and the percentage of people who used condoms during their last sexual intercourse (52%). Using the Statcal programme of Epi-Info 6.0 software, we estimated 500 people as the study sample.

Ten people volunteered for data collection, and they were reimbursed for each completed questionnaire. Two volunteers came from Manchester, one from Nottingham and the remaining seven from London. A one-day training course on data collection was held in October 2007. The volunteers were given a detailed explanation of each question, trained in randomly selecting survey participants, and instructed on research ethics. There were discussions about the best way of finding people in each city in order to invite and encourage their participation.

Data collection took place between December 2007 and January 2008. During the pilot study, when the team tested the questionnaire, many subjects preferred to complete the questionnaire privately because of sensitive questions contained in the sexual history section. This issue was discussed during the data collectors' one-day training and it was agreed to allow participants privately complete the questionnaire instead of having a face-to-face interviewer-led questionnaire. Data collectors were strongly advised to spend enough time with the participants to explain the questionnaire properly in order to avoid incompleteness of responses and assure the participants rights concerning privacy and confidentiality.

The teams used behavioural survey guidelines¹⁶ and the survey protocol was approved by the Scientific Committee of the Public Health Institute (PHI) in November 2007. The structured questionnaire was designed to be used with both male and female adults who are 15 years of age or older. Questions contained single and multiple answer choices and open questions. Eleven sections were included in the questionnaire, as follows: (1) Background characteristics; (2) Marriage; (3) Sexual history: numbers and types of partners; (4) Sexual history: regular partners; (5) Sexual history: non-regular, non-commercial partners; (6) Sexual history: commercial partners; (7) Knowledge and attitudes towards STIs; (8) Knowledge and attitudes towards HIV/AIDS; (9) Sources of information; (10) Patterns of alcohol and drug use; (11) Treatment seeking behaviour.

¹⁵ Association of Mongolian Public Health Professionals (2007). KAP survey of Mongolians working in South Korea. Unpublished report. Ulaanbaatar.

¹⁶ Family Health International and Impact- Implementing AIDS prevention and care project (2000). *Behavioral Surveillance surveys. Guidelines for repeated behavioral surveys in populations at risk of HIV.*

Mean and standard deviation (SD) were calculated to describe age and number of years in the UK, with 95% confidence interval (CI). Median and interquartile range (IQR) were calculated to describe non-parametric data. The Chi-squared test for independence, with Yates's correction, was used to test differences between proportions. If an expected cell was below 5, the Fisher's exact test was used. Spearman's Rank Order Correlation (rho) was used to calculate the strength of the relationship between continuous variables. Logistic regression was employed to see what effect predictor variables had on the outcome of the study, and the Odds Ratio (OR) was produced. A p-value of less than the alpha criterion of 0.05 was considered to be statistically significant.

A total of 504 people completed the questionnaire; 14 questionnaires were incomplete and were not included in the analysis, 24 questionnaires did not have both variables age and sex of participants. Thus, statistical analysis included the questionnaires of 490 participants. The refusal rate was minimal (2.1%).

Background characteristics of participants

There were more female participants than males (56.9% versus 43.1%), with almost similar mean age of 30.10 ± 8.62 years (95%CI ± 1.2) for male and 30.54 ± 8.16 years (95%CI ± 0.98) for female participants. 45.9% of participants belonged to the age group between 20-29 years old and 29.4% to the age group 30-39 years old – together comprising 75.3% of all participants. Educationwise, 66.4% of participants had university education, 16.2% vocational education, 16.8% secondary school education, and only 0.7% primary education.

The mean age of the first sexual intercourse was 19.65 ± 3.31 years (95% CI ± 0.3). In any age group. men had their first sexual intercourse earlier than women, with mean age for men 18.9 ± 3.35 years (95%CI ± 0.5) versus mean age for women 20.23 ± 2.78 years (95%CI ± 0.36) (one way ANOVA=17,56, df=20, p<0.0001). Interestingly, the younger the respondents, the earlier they had their first sexual intercourse. Respondents age 19 years and below had first intercourse at 17.38 years for males and 17.4 for females; Respondents between 20-29 years had first intercourse at 17.69 years for males and 19.68 years for females. Respondents age 30-39 years had first intercourse at 20.04 years for males and 20.75 years for females. Respondents age 40 and over had first intercourse at 21.09 years for males and at 20.95 years for females.

Considering the nuptiality rate of participants, 47.8% were married and 52.2% were single. The mean age of first marriage was 23.42 ± 3.67 years (CI ± 0.55), with no statistical difference observed between genders.

Not all married people can bring their spouses to the UK. Therefore, participants were asked about living and sexual arrangements with partners. 40.1% of respondents reported not being married and not living together with a sexual partners. 22.5% of respondents were married and living with their spouses. 8.5% of respondents were married but not living with their spouses. 6.9% of respondents were married, but were living with sexual partners other than their spouses.

When asked about sexual partners in the last 12 months, 86.5% of married respondents had regular (spouse or live-in sexual partners) compared to 61.2% of single respondents having regular sexual partners; 51.3% of married respondents had non-regular (not married to and have never lived with and did not have sex in exchange for money) sexual partners compared to 22.9% of single respondents having non-regular sexual partners. Accessing of commercial sexual partners was 1.6% for married respondents versus 4.6% for single respondents.

The median number of non-regular sexual partners in the last 12 months for men was two [IQR: 1-10] and for women was one [IQR: 1-9]. However, the majority of them had 1-3 non-regular sexual partners (88.8% of men and 96.7% of women). In any age group, men had more non-regular partners than women, although the result was not statistically significant (Spearman's rho=-0.72, p=0.05).

Condom use

74.2% of participants reported knowing where to buy male condoms. However, condom use during the last sexual intercourse was low, at 42.8% for males and 37.4% for females. Participants' educational level and the number of years living in the UK were likely to be related to the knowledge of places of getting male condoms. Participants with secondary education were three times more likely not to know where to get male condoms compared to university educate participants (OR=3.5, CI [1.65-7.42], p=0.001); participants living less than one year in the UK five times more likely not to know (OR=5.4, 95%CI [2.31-12.93], p<0.0001), and those living 1-2 years in the UK four times more likely not to know (OR=4.6, 95% CI [1.80-11.74], p=0.001) where to get male condoms.

Source of information

The majority of participants (53.6% of males and 46.4% of females) reported not getting any information about STI/HIV/AIDS. Participants stated that they wanted to get general information about STI/HIV/AIDS but also that they needed the contact information for clinics which could

provide free services (counselling, diagnosis, and treatment). Participants expressed preferences for means of obtaining this information, as follows: through the internet (28.1%), in the form of leaflets (21.6%), text messaging (21.3%), as a part of promotion activities (16.3%), and other (12.7%).

Knowledge and attitudes

In general, 94% of participants had heard about HIV/AIDS, and 88.2% of participants had heard about STIs. There were misconceptions about HIV transmission among participants. 19% of participants believed that a mosquito bite can transmit HIV and 32.5% of participants did not know whether this information was right or wrong. Further, 13.1% of participants did not believe that having one faithful sexual partner could protect from HIV infection and 21.2% of participants did not know whether this was right or wrong; 11.7% of participants did not think that abstaining from casual sex could protect from HIV infection and 15% of participants did not know. 3.8% of participants said that a sharing plate when eating could transmit HIV infection and 22.7% of participants did not know. Moreover, one in five participants reported having negative attitudes about people living with HIV.

The knowledge about STI signs and symptoms, such as discharge or itchiness, was correlated to gender. For example, the majority of women only knew about symptoms occurring in women while the majority of men only knew about symptoms occurring in men ($p < 0.0001$). Further, 3.3% of respondents reported that they could recognize that a healthy-looking person was infected with STIs. In contrast, 58.7% of respondents reported that they could not recognize that a healthy-looking person was infected with STIs. Finally, 38.0% of respondents did not know whether a healthy person was infected or not.

STI occurrence

Respondents were asked whether they had any of the common signs and symptoms, occurring during STIs other than HIV, such as genital ulcer or discharge, in the last 12 months, rather than asking about specific STIs. 35 (7.1%) respondents reported either genital ulcer or discharge in the last 12 months. These signs and symptoms were not related to age, education, marital status, or time spent in the UK. However, twice the number of signs and symptoms were reported by male respondents compared to female respondents ($\chi^2 = 6.22$, $p = 0.01$).

Treatment seeking behaviour

Out of 7.1% respondents reporting signs and symptoms of STIs, concerning the timing of treatment-seeking behaviour after appearance of the first signs and symptoms of STIs other than HIV, 16.7% reported seeking treatment in health facilities more than one month later, 46.7% within one month, and 36.7% within one week. Again out of this 7.1%, concerning the asking of friends or relatives for advice, 75% of advice-seekers were men and 25% of advice-seekers were women. Finally, concerning the actual receiving of treatment, 46.2% were male and 53.8% were female. However, 28.1% of these respondents reported not completing the full course of treatment.

Prevention activities

The project was launched on December 01, 2007, World AIDS Day. It was important to create an HIV/AIDS awareness environment in those Mongolian-frequented establishments by placing posters, balloons and prevention messages. The team used its own resources to download posters from the related internet sites, created preventive poster messages and decorated white balloons by painting red ribbons on them. Everyone who come to this evening was given an AIDS “red ribbon” to show solidarity with the world in the fight against this epidemic and to commemorate those who died of AIDS.

On World AIDS Day the team organised HIV/AIDS awareness raising events in two popular gathering places (“Mongol pub” and “FM karaoke bar”) focusing on the promotion of good sexual health and safe sex. The programme of the evening started with the opening speech of the MAUK chair, who highlighted MAUK activities emphasising the project. Then the inspirational speech by the Ambassador of Mongolia in the UK Mr. Davasambu D. stressed the importance of HIV prevention in Mongolia as a sparsely populated country that could be in danger of epidemic escalation in absence of appropriate measures to halt the spread of this infection. The Ambassador gave the full support of the Mongolian Embassy to MAUK. The project consultant’s message “Thinking globally, acting locally” added a powerful meaning to the MAUK work.

The evening continued by conducting traditional British type “pub quizzes” with a HIV/AIDS theme to add and test knowledge of participants. The winners of the quizzes received books by famous Mongolian authors, and all participants were given souvenirs. Everybody in attendance received four types of preventive information materials in the Mongolian language and three condoms. These Mongolian language IEC materials were sent by TUH from Mongolia specifically for

awareness raising events. These awareness raising events were attended by around 160 people altogether.

London: annual meeting

The “Annual Meeting of Mongolians” is a big event organised by MAUK with the collaboration of the Embassy of Mongolia in London. During such meetings, Mongolian intellectuals get together for a one-day discussion of priority issues in all spheres of Mongolian life. The main issues are the economic development and the cultural traditional heritage of Mongolia. As part of this project, for the fourth annual meeting, held in London during May 2008, the team members presented the results of the behavioural survey and welcomed a discussion. Moreover, during this meeting, poster boards showing past HIV awareness raising events were displayed, and distribution of free IEC materials (leaflets), with condoms were enclosed in the meeting’s information pack.

Manchester: new year celebration event

The project team has recognized the importance of organizing HIV/AIDS awareness raising in collaboration with traditionally recognized special occasions, when more people are likely to gather, rather than organizing separate events. Thus, during the 2008 New Year celebration event of Mongolians in Manchester, two team members from London were invited to have a brief talk about the project, and IEC materials and condoms were distributed for the participants of this event.

Nottingham: at home

Considering the peculiarities of Mongolians residing in Nottingham, a box of four types of Mongolian language IEC materials, along with condoms and posters, was sent by the “Mongol Centre’s” freight collection van. This decision was made during the project preparation stage. In Nottingham, a person who volunteered to take part in distribution of preventive leaflets was informed.

Distribution and dissemination of Information materials

A result of the behavioural survey showed that almost 80% of participants wanted to receive general information about HIV/AIDS and other STIs. Moreover, participants indicated in the survey that they preferred Mongolian language information. The project team developed eleven leaflets: nine on common STIs – including HIV-infection, one on

registering with a General Practitioner (GP) in the UK, one on tuberculosis, a common opportunistic infections related to HIV/AIDS. All leaflets were designed as pocket-sized expandable document containing prevention messages, colourful pictures, bilingual Mongolian/English description of common signs and symptoms of STIs, and important contact addresses of Mongolian businesses, including MAUK and the Embassy. Particular attention was paid to incorporating UK-specific information into these leaflets; the cover pages featured famous British places and objects, such as the red double-decker bus and Big Ben, in order to normalise the sensitive subjects contained in the leaflets and to make interested parties less embarrassed about picking up these leaflets.

The most important information items presented on these leaflets were the contact addresses of clinics in London, Manchester and Nottingham that provide free, confidential advice, counselling, testing and treatment in the UK. Before the leaflets were printed, they all went through the scrutiny of IEC experts in Mongolia.

28.1% of survey participants preferred to receive HIV/AIDS information via the internet. Thus, the project team developed web based information simultaneously with the leaflets, both containing similar themes and contents. This specific information appeared on the webpage of MAUK (www.mongolchuud.co.uk) under the “Health” subheading in the “News” section, with regular updates. To capture wider community members, the project team used the Mongolian email Yahoo! group and sent prevention IEC materials every fortnight.

In August 2008, the project team organised a dissemination workshop in Ulaanbaatar. The project team overviewed the design, implementation, and reporting mechanisms of the project, while presenting the results of the behavioural survey and motivating discussion. Representatives of government, non-government and intergovernmental organisations attended the workshop (UNAIDS, Health Science University of Mongolia, National AIDS Programme, Public Health Institute, “TUH” NGO, “Focus” NGO and Global Fund Mongolia Office)

In Mongolia, at the beginning of the project, the team published two previews.^{17,18} Thereafter, an extensive summary of the behavioural survey,¹⁹ was published in an academic volume of the Public Health

¹⁷ Bazarragchaa Ts. (2008). “Mongolians in World AIDS Day in London”. In: Tshim Ulaach, TUH organisational journal, (22) No.01, p.41.

¹⁸ Bazarragchaa Ts. (2007). “STI/HIV/AIDS prevention project for Mongolians in the UK”. In: Mongolian Journal of Infectious Disease Research, (18) No. 5, p. 79.

¹⁹ Suvd B., Bazarragchaa Ts. and Tsegmed S. (2008). “Knowledge, attitude and practice towards STI/HIV/AIDS of Mongolians living in the UK”. In: Academic Volume of Public Health Institute dedicated to 40th Anniversary of the PHI “Public health problems in developing countries” conference proceedings, p. 169-171.

Institute. The purpose of these publications was to inform about the work of MAUK for STI/HIV/AIDS prevention – as a model for what other expatriate Mongolian communities in other industrialized countries could accomplish and acquire possible support from Mongolia for the Mongolian community in the future.

Discussion of the project

MAUK was the first organisation to implement a public health project focusing on the prevention of HIV/AIDS and STIs among Mongolian citizens living in the UK. This innovative project has demonstrated worthwhile community-based activities serving two countries, Mongolia and the UK. In the focus cities – London, Manchester, and Nottingham – this project has the potential outcome and impact of reducing STI/HIV/AIDS incidence and prevalence, not only amongst Mongolian citizens but also amongst UK citizens. Other Mongolian communities in other countries should have the capacity to implement such a prevention project within a multicultural society, similar to the UK.

Planning and preparation formed the keystone of the project, especially the sensitising meetings for representatives of the main sites where the project activities would take place. In the designated communities, the involvement of business-oriented organisations motivated utilization of their resources during project implementation and perhaps has the potential of motivating post-project activities for a sustainable, community-owned response.

The presence of UK-educated public health professionals on the Board of MAUK has played a crucial role in the initiation and implementation of this project. Their knowledge of the subject matters enabled efficient, effective management of the project. In particular, their dual knowledge of the health systems of both Mongolia and the UK greatly facilitated the conducting of the behavioural survey and the subsequent producing of prevention IEC materials for the community through an evidence-based approach.

Yahoo! Messenger has proved to be an efficient connector between the two partner organisations, MAUK and TUH. The majority of team members had never met each other before the beginning of this project, but they nevertheless managed to communicate, plan and implement the project activities online, despite a time difference of eight hours.

Availability and accessibility of information are the main requirements of prevention programmes. Although the behavioural survey indicated the types of formats towards which the respondents would be receptive for receiving information, the project could not

accommodate all modalities. For example, 21.3% of participants requested receiving prevention information by text messaging, which was not possible through this project because this modality required time and resources beyond the scope of the project. Although the duration of this project was only one year, MAUK took the need for future interventions into consideration. After project completion, MAUK was able to launch a mobile text messaging database. The first MAUK text messaging task was to make an announcement about the scheduling of the “Fifth Annual Meeting of Mongolians” in May 2009.

The regular work of MAUK is bringing together Mongolians through meetings and special events. The project activities were complementary to and integrated in the regular work. For example, the project team used the existing MAUK web page to convey STI/HIV/AIDS prevention information. However, this project has motivated MAUK to add new tasks to its existing portfolio. For example, MAUK launched this project on World AIDS Day 2007 and then, one year later, even though the project had ended, MAUK (in partnership with the Mongolian Embassy in the UK) organized a pub-based event on World AIDS Day 2008 for Mongolians in London. An innovative activity was to make a three-minute television programme of this event, by “London-MN Studio”, in order to motivate Mongolian communities living in other industrialised countries to consider following the good model of MAUK for prevention in their own communities. This programme was broadcast on a private Mongolian television station, “NTV”, which dedicated broadcasting to World AIDS Day in Mongolia. Furthermore, this programme was uploaded to the MAUK webpage for viewing by a broader Mongolian audience.

The main difficulties with managing this project were the lack of time and the limited budget. The team members worked voluntarily outside of their main job obligations, which sometimes made meeting the deadlines of the project difficult. However, this project demonstrated the great gains that can be achieved on a very limited budget with dedicated team members. The project team wishes to acknowledge the time and effort which the MAUK Board members generously volunteered for this project, which has benefited Mongolians in their host country. Further, the public-private partnership of the Global Fund enabled the specific partnering of two organisations, MAUK and TUH NGO, for protecting the right to health of Mongolians abroad.

Conclusion

Nationality-contextualized and country-contextualized activities are required to halt STI/HIV transmission in low-prevalence settings such as Mongolia and the UK. Government support – especially bilateral governmental support – is needed for NGO initiatives, focusing on respecting the rights, particularly the right to health, of migrant populations abroad -- in the context of this project Mongolian migrants residing in the UK.

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Complexity of cooperation in response to HIV/AIDS: the case of Mongolia

Nancy S. Tokola

Mongolia is an isolated, landlocked, poverty-embedded, democratic nation-state in East Asia, bordered by the Russian Federation to the north and the People's Republic of China to the south. After 70 years of Soviet domination, Mongolia began its political-economic-social transition in 1990. Politically, since then, the communist Mongolian People's Revolutionary Party has predominated over coalitions of democratic parties in national presidential and parliamentary elections, resulting in an illiberal democracy. Economically, Mongolia transitioned from a planned economy with collectivization to an open market with privatization. However, over these past two decades of transition, 36% of the Mongolian population has struggled to live below the poverty line. Socially, 90% of Mongolians are literate, and religious affiliations are 90% Buddhist, 6% Muslim, and 4% Christian, with ancient Shamanistic practices persisting across all three main religions.¹

HIV/AIDS is a development issue, and diverse organizations, especially civil society organizations, have pivotal roles across the Asia-Pacific Region. The author of this paper, a medical doctor and researcher, moved to Mongolia with her U.S. diplomat spouse in September 2003. Over the subsequent four years, she witnessed the escalation of the HIV/AIDS epidemic in Mongolia while contracted successively to World Vision Mongolia, World Vision International, the United Nations Children's Fund (UNICEF), and the Health Sciences University of Mongolia (HSUM). Further, she partnered for programming with local and national government officials, the "Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria", the World Health Organization (WHO), the United Nations Population Fund (UNFPA), international non-

¹ U.S. Department of State Bureau of East Asian and Pacific Affairs (2009): "Background Notes: Profile Mongolia", February 2009, <http://www.state.gov/r/pa/ei/bgn/2779.htm>, accessed on 25 February 2009.

governmental organizations (NGO), national NGOs, and a network of 32 local NGOs.

Mongolia's vulnerability to HIV/AIDS

The HIV/AIDS epidemic has grown slowly in this vast, traditionally nomadic, pastoral nation-state. With population of 2.9 million people (2008 estimate) and lowest population density in the world at 1.5 people per square kilometre, Mongolia has experienced recent waves of rural-to-urban migration, to the extent that approximately half of the population lives in urban centres, especially the capital city Ulaanbaatar (1 million people).²

Mongolia has open borders with Russia and China. During 1999-2000, Russia “experienced the world’s biggest increase in HIV infection”; unprotected sexual intercourse by men who have sex with men (MSM) and by heterosexual partners contributed to 80% of HIV transmission in the late 1980s and early 1990s; however, injecting drug use (IDU) has contributed to 90% of HIV transmission since 1996.³ As of 1998, all mainland provinces of China have reported HIV cases, and HIV transmission has occurred in over 60% of cases through IDU, approximately 10% of cases through blood/blood products, and at least 8% of cases through unprotected sexual intercourse.⁴ By the end of 2007, UNAIDS estimated the average numbers of people living with HIV/AIDS (PLHA) (adults and children) as follows: 33,000,000 million globally, 1,500,000 in Eastern Europe and Central Asia Region (940,000 in Russia), and 740,000 in East Asia (700,000 in China versus < 1000 in Mongolia).⁵ The combined estimates of PLHA for Russia and China, 1,640,000 PLHA, is equivalent to over half the population of Mongolia, landlocked between these two huge neighbours.

The more advanced HIV/AIDS epidemics in Russia and China have increased the risk of HIV transmission for Mongolian cross-border traders, young military recruits assigned to border stations, and associated

² Ibid.

³ Vinokur, Anatoly, Godinho, Joana, Dye, Christopher, and Nagelkerke, Nico (2001). *The TB and HIV/AIDS Epidemics in the Russian Federation*, World Bank Technical Paper No. 510. Washington, D.C.: International Bank for Reconstruction and Development/World Bank, pp. v, 31-32.

⁴ Guomei, Xia (2004). *HIV/AIDS in China*. Beijing: Foreign Languages Press, pp. 5-7.

⁵ Joint United Nations Programme on HIV/AIDS (2008): *2008 Report on the Global AIDS Epidemic*, 29 July 2008, Annex 1: HIV and AIDS Estimates and Data, 2007 and 2001 Geneva: UNAIDS,

http://data.unaids.org/pub/GlobalReport/2008/jc1510_2008_global_report_pp211_234_en.pdf, accessed on 15 August 2008.

sedentary communities along transportation routes within Mongolia. With approximately two-thirds of Mongolian citizens being under age 30 years and with increasing concentration of the population in urban areas,⁶ the Mongolian population is vulnerable to sexually transmitted infections (STI) and co-infection with HIV. During this decade, the rate of condom usage by the reproductive-age population has been less than 30%,⁷ and STIs have accounted for up to 43.6% of all infectious diseases reported by the Mongolian National Centre for Communicable Diseases.⁸

HIV/AIDS in Mongolia and state response

In 1987, the Government of Mongolia opened the STI/HIV/AIDS Reference Centre. In August 1992, the National Centre for Communicable Diseases officially reported its first HIV case (MSM who had travelled abroad).⁹ In conjunction in 1992, the Government of Mongolia established the National AIDS Committee (chaired by the Prime Minister since 1997) and designed the National HIV/AIDS Programme (expanded to include STI in 1998). In 1994, the State Great Khural (Parliament) approved the Law on HIV/AIDS Prevention, which detailed the responsibilities of individuals and organizations within Mongolian society. In June 1997, the Government of Mongolia and the UN agencies signed a “Memorandum of Understanding” in order to strengthen the national HIV/AIDS response.¹⁰ In December 1997, Mongolia officially reported its second HIV case (female sex worker).¹¹ In 1998, the Government of Mongolia established the Information, Education, and Communication (IEC) Committee and approved its IEC strategy for raising awareness in the population.¹²

During 25-27 June 2001 at UN Headquarters in New York City, the landmark UN General Assembly Special Session (UNGASS) on HIV/AIDS issued the “Declaration of Commitment on HIV/AIDS”,

⁶ U.S. Department of State (2009). “Background Notes: Profile Mongolia”.

⁷ Government of Mongolia (2004). *Health Indicators Survey 2004*. Ulaanbaatar: National Centre for Health Development, p. 77.

⁸ *Ibid.*, p. 29.

⁹ Government of Mongolia (2006). *United Nations General Assembly Special Session (UNGASS) Country Progress Report Mongolia* (first UNGASS report). Ulaanbaatar: Government of Mongolia, pp. 2-3.

¹⁰ Government of Mongolia and World Health Organization (1999). *Mongolia: Health Sector Review*, June 1999. Ulaanbaatar: Government of Mongolia and WHO, p. 50.

¹¹ Government of Mongolia (2006). *United Nations General Assembly Special Session (UNGASS) Country Progress Report Mongolia* (first UNGASS report), p. 2.

¹² Government of Mongolia and World Health Organization (1999). *Mongolia: Health Sector Review*, June 1999, p. 51.

which requires Member States to submit an *UNGASS Country Progress Report* every other year.¹³ In July 2001, Mongolia officially reported its third HIV case (female cross-border trader).¹⁴

In January 2002, the Mongolian Ministry of Health requested that the Joint United Nations Programme on HIV/AIDS (UNAIDS) regional office should conduct an external review of the Mongolian HIV/AIDS response. In this UNAIDS report, the section on “Activities of Non-governmental Organizations” listed only three civil society organizations: Mongolian Family Welfare Society (established in 1994 for provision of reproductive health services), National AID Foundation (established in 1998), and Mongolian Red Cross Society (conducting HIV/AIDS programming since June 2002). This UNAIDS report served as the basis for drafting the successful project proposal submitted later in 2002 for the HIV/AIDS-designated Global Fund Round Two.¹⁵

In January 2003, Mongolia officially reported its fourth HIV case (female who had travelled abroad).¹⁶ In March 2003, the Mongolian Public Health National Committee approved the “National Strategy to Respond [to] HIV/AIDS in Mongolia”, which included sections on sentinel surveillance, behaviour change and communication (BCC), client-friendly services for diagnosis and treatment, cooperation with the National Program for Infectious Disease Control in its STI/HIV/AIDS Prevention Sub-program (2002-2010), and cooperation with the Global Fund Projects on HIV/AIDS and tuberculosis.¹⁷

During February - March 2004, the Mongolian Ministry of Health appointed the United Nations Theme Group (UNTG) on STI/HIV/AIDS

¹³ United Nations Department of Public Information and Joint United Nations Programme on HIV/AIDS (2001). “Declaration of Commitment on HIV/AIDS”, Resolution A/RES/S-26/2, 27 June 2001, United Nations General Assembly Special Session (UNGASS) on HIV/AIDS, 25-27 June 2001, published August 2001. New York City: UN DPI and UNAIDS, pp. 1 - 48.

¹⁴ Government of Mongolia (2006). *UNGASS Country Progress Report Mongolia*, p. 2.

¹⁵ Government of Mongolia (2003). “Global Fund Grant Original Proposal: HIV/AIDS Round Two Project: Strengthening National Prevention and Care Programmes on HIV/AIDS in Mongolia”, Grant Number MON-202-GO2-H-00, Start Date 01 August 2003. Ulaanbaatar: Ministry of Health.

¹⁶ Government of Mongolia (2006). *UNGASS Country Progress Report Mongolia*, p. 2.

¹⁷ Government of Mongolia and United Nations Development Program (2003). “National Strategy to Respond to HIV/AIDS in Mongolia” (bilingual Mongolian/English), 21 March 2003, Ulaanbaatar: Mongolian Ministry of Health Public Health National Committee and UNDP, pp. 1-12.

to conduct an internal review of the HIV/AIDS response in Mongolia.¹⁸ Thereafter, the new HIV/AIDS Response Program of World Vision Mongolia became active in this UNTG. During 22-23 March 2004, the “National Seminar on AIDS and Communicable Diseases” formed three working groups – medical, legal, and behaviour change and communication (BCC) – in order to discuss the need for changes in the 1994 Law on HIV/AIDS Prevention. The designated National HIV/AIDS Coordinator (Dr. Nancy Tokola) of World Vision Mongolia served in the BCC working group. In the plenary session, the most controversial discussion concerned whether HIV testing should be voluntary, mandatory, or compulsory, especially at points of entry into Mongolian territory, (border stations and airports). As a consequence, the revised law included an amendment for protection of human rights.¹⁹

In October 2004, Mongolia officially reported its fifth HIV case (MSM).²⁰ Also in October 2004, the Great State Khural adopted the eight Millennium Development Goals (MDG) but with Mongolian contextualization, including different numbering of targets.²¹ Instead of the global version of MDG 6 (“combat HIV/AIDS, malaria and other diseases”), the State Great Khural approved a Mongolian version (“combat STI/HIV/AIDS, tuberculosis and other diseases”). Mongolian MDG 6 Target 9 is to “have halted by 2015 the spread of HIV/AIDS” and Target 10 is to “reverse the spread of tuberculosis by 2015”. Further in October 2004, Mongolia submitted its first MDG national report to the United Nations Development Program (UNDP).²²

Throughout 2005, for the HIV/AIDS-designated Global Fund Round Five,²³ the core project proposal writing team consisted of three

¹⁸ United Nations Theme Group on STI/HIV/AIDS (2004). “Internal Review of the National HIV/AIDS Programme Implementation in Mongolia”, 15 February - 17 March 2004. Ulaanbaatar: United Nations, pp. 1-14.

¹⁹ Government of Mongolia (2006). *UNGASS Country Progress Report Mongolia*, pp. 4, 6.

²⁰ *Ibid.*, p. 2.

²¹ Government of Mongolia (2004). “Parliament Resolution on the Millennium Development Goals of Mongolia”, Resolution Number 25. Ulaanbaatar: State Great Khural, pp. 1-6.

²² Government of Mongolia (2004). “National Report: Implementation of the MDGs in Mongolia”. Ulaanbaatar: Government of Mongolia; United Nations Development Program (2008): “MDG Profile: Mongolia”, *MDG Monitor: Tracking the Millennium Development Goals*, updated 26 August 2008, http://www.mdgmonitor.org/factsheets_00.cfm?c=MNG, accessed on 15 November 2008.

²³ Government of Mongolia (2006). “Global Fund Grant Original Proposal: HIV/AIDS Round Five Project: Expanding Targeted National HIV/AIDS Prevention”, Grant Number MON-506-GO4-H, Start Date 01 July 2006. Ulaanbaatar: Ministry of Health.

officers from the Mongolian Ministry of Health, one UNICEF officer, and two representatives of civil society -- the Executive Director of National AIDS Foundation and the National HIV/AIDS Coordinator of World Vision Mongolia.

Mongolia officially reported its sixth HIV case (male tuberculosis patient) in March 2005, its seventh, eighth, and ninth HIV cases (two MSM and one unknown route of transmission) in April 2005, and its ninth HIV case (MSM) in June 2005²⁴ -- constituting an escalation of the HIV epidemic for Mongolia. By 2005, three of the four original PLHA had died of AIDS.²⁵

In 2006, Mongolia submitted its first *UNGASS Country Progress Report of Mongolia*, which recorded the number of officially reported HIV cases as 16. For this report, the National Centre for Communicable Diseases provided a table detailing – for each case – the date of HIV diagnosis, the route of and/or risk factors for HIV transmission, tuberculosis status, and year died of AIDS as applicable. Out of these 16 cases, MSM accounted for 8 cases, and female sex workers accounted for 1 case. For the other 7 cases, one mode of transmission was unknown, two male PLHA were detected through screening for tuberculosis, and one female PLHA was detected through screening of pregnant women.²⁶ Amongst organizations in Mongolia responding to this growing HIV/AIDS epidemic, there was an acknowledged need to approach most-at-risk populations (MARP) for raising awareness on condom use in order to prevent further HIV transmission.

In December 2007, Mongolia submitted to the UNDP its second MDG national report, estimating 58.3% of targets as achieved or achievable by 2015 (including the STI/HIV/AIDS Target 9 of MDG 6) and estimating 41.7% of targets as slow achievers or regressing (including the tuberculosis Target 10 of MDG 6).²⁷

In January 2008, the Government of Mongolia submitted its second *UNGASS Country Progress Report of Mongolia*, with 36 officially reported HIV cases and an estimated 475 unreported (hidden, undiagnosed) HIV cases. This report did not present a case-by-case,

²⁴ Government of Mongolia (2006). *UNGASS Country Progress Report Mongolia*, p. 2.

²⁵ Ibid.

²⁶ Ibid.

²⁷ Government of Mongolia (2007). “Second National Report: The Millennium Development Goals Implementation”, Report Number DDC 361.61 M-81. Ulaanbaatar: Government of Mongolia; United Nations Development Program (2008): “MDG Profile: Mongolia”, *MDG Monitor: Tracking the Millennium Development Goals*, updated 26 August 2008, http://www.mdgmonitor.org/factsheets_00.cfm?c=MNG, accessed on 15 November 2008.

detailed, enumerated table but instead offered categorized percentages of cases. The epidemic remained concentrated among MSM and female sex workers. More specifically, 88% of male HIV cases were amongst MSM, and 60% of female HIV cases were amongst female sex workers. Further, 55.5% of the HIV cases occurred in the 25-34 year old group, and 74% of the cases occurred in males. Most of these HIV cases occurred in Ulaanbaatar, which was home to one-third of the Mongolian population. Of the 20 HIV cases reported during 2006 and 2007, 75% of these PLHA were diagnosed with a co-infection (10% of which was tuberculosis).²⁸

On 01 February 2008, the State Great Khural approved the “Millennium Development Goals-based Comprehensive National Development Strategy” for phase one (2007-2015, achieving the MDG targets) and for phase two (2016-2021, establishing a knowledge-based economy). In Section 4.5, “Healthcare Sector Development Policy”, the first strategic objective focused on strengthening the capacity of clinics to combat STIs, HIV/AIDS, and tuberculosis, especially in rural areas.²⁹

HIV/AIDS Response of World Vision Mongolia

World Vision was founded as a Christian faith-based organization in East Asia in 1950 and, over subsequent decades, grew into an international NGO. The core values of World Vision are as follows: 1) We are Christian, 2) We are committed to the poor, 3) We value people, 4) We are stewards, 5) We are partners, and 6) We are responsive. World Vision International has a Partnership Office, located in the USA, which sets policy at its top level, relays strategic decision-making through regional level offices, and tends to respect the socio-cultural contextualization of strategy for planning interventions through 130 national level offices. For local community development, World Vision national offices support urban and rural Area Development Programs (ADP), which have semi-autonomous staff focused on improving the security of vulnerable children and their families. The funding for programming emanates from international donations to “Child Sponsorship” and from nineteen World Vision Support Offices in developed countries. Each ADP has a fifteen-

²⁸ Government of Mongolia (January 2008). *United Nations General Assembly Special Session (UNGASS) Country Progress Report Mongolia* (second UNGASS report), Reporting period January 2006 - December 2007, published January 2008. Ulaanbaatar: Government of Mongolia, pp. 4, 10.

²⁹ Government of Mongolia (2007): “Millennium Development Goals-based Comprehensive National Development Strategy”, Draft, December 2007. Ulaanbaatar: Government of Mongolia), pp. 21-22, 59, http://www.siteresources.worldbank.org/INTMONGOLIA/Resources/NDS_DRAFT_ENG.pdf, accessed on 15 August 2008.

year lifecycle, with a World Vision exit strategy centred on handing control over programming to a community-based organization (CBO).³⁰

Under the jurisdiction of the World Vision Asia-Pacific Region Office (Bangkok, Thailand), World Vision Mongolia began its operations with a small office in Ulaanbaatar in 1995 and registered as a local NGO with the Mongolian Ministry of Justice in 1997. Thereafter, as a Christian faith-based organization in a predominantly Buddhist nation-state, World Vision Mongolia has repeatedly applied for international NGO status with the Mongolian Ministry of Foreign Affairs, which has consistently refused the application, despite concerted negotiations (ostensibly because of religious issues).

The National Office of World Vision Mongolia acquired a budget of US\$ 2 million in 1998 and then launched its first ADP in 1999. In 2004, World Vision Mongolia had a budget of US\$ 14 million and 16 ADPs. By 2006, World Vision Mongolia had a budget of US\$ 25 million, 25 ADPs, the status as the largest NGO in Mongolia, and the frustration of continued designation as a local instead of as an international NGO.³¹

HIV/AIDS Response Programme of World Vision Mongolia

The second half of fiscal year 2004 (01 March - 30 September 2004) was a preparatory period during which the physicians working for World Vision Mongolia constructed a comprehensive health strategy, which included the existing five-year Nutrition Program, the new five-year Tuberculosis Control Program, and the new three-year HIV/AIDS Response Program.

During fiscal year 2005 (01 October 2004 - 30 September 2005), the World Vision Mongolia HIV/AIDS Response Program team implemented the “Foundational Project for Prevention and Advocacy Response to HIV/AIDS”. This project began with a situation analysis. After two months of field team selection and training, the interviewers used three sets of Knowledge, Attitude, Practice (KAP) questionnaires – HIV/AIDS, STIs, tuberculosis – in 230 randomly selected households in each of the 16 ADPs, covering both urban and rural communities. The statistical report guided onward programming, not only for the new HIV/AIDS Response Program but also for the new Tuberculosis Control Program. Access to the results of this situation analysis is restricted for internal use by World Vision Mongolia staff.

³⁰ World Vision International,
<http://www.wvi.org/wvi/wviweb.nsf/maindocs/E7809E562722923A88257375007659B0?opendocument>, accessed on 19 December 2008.

³¹ World Vision Mongolia (2007). *World Vision Mongolia: 2006 Annual Review*. Ulaanbaatar: World Vision Mongolia.

Further, this foundational project focused on internal (intra-organizational) partnering for empowerment of staff members across the World Vision Mongolia National Office and the ADPs. The HIV/AIDS Response Program team conducted a series of focus group discussions amongst these staff members in order to learn about personal attitudes towards HIV/AIDS and to map diverse community networks for future inter-organizational partnering.

In June 2005, the National HIV/AIDS Coordinator of World Vision Mongolia led the Asia-Pacific Region delegation at a World Vision International HIV/AIDS strategy planning meeting in Johannesburg, South Africa. As the forty delegates took turns reporting the number of PLHA in the countries in which they were serving, the collective delegates expressed disbelief that Mongolia had only nine officially reported HIV cases at that time, despite the realization that each officially reported HIV case may indicate over fifty hidden cases in a low prevalence country.

For World AIDS Day 2004, the World Vision Mongolia HIV/AIDS Response Program funded newspaper reporting which correctly educated the public about routes of HIV transmission, discussed behaviour change for mitigating risks of transmission, and emphasized respect for the privacy of PLHA. Throughout 2005, the HIV/AIDS Response Program funded a ten-part national radio drama series, an eighteen-episode radio program series, and short-message radio spots through Mongolian National Radio in order to raise awareness of HIV/AIDS prevention in relation to sexual intercourse, blood safety, parent-to-child transmission (especially with the eleventh HIV case being reported in a Mongolian pregnant woman in July 2005), and human rights (especially for combating stigma, discrimination, invasion of privacy, and professional breaches of confidentiality).

Throughout fiscal year 2005, the National Office team internally partnered with the ADP teams within the HIV/AIDS Response Program in order to conduct HIV/AIDS awareness raising for former street children sheltered in the World Vision Mongolia “Lighthouses”, for children incarcerated in the Youth Prison (boys) and the Women Prison (girls), for medical doctors and nurses in community clinics, for school medical staff, and for Mongolian church leaders. Respecting the established inter-faith “Religious Leaders Initiative” being promoted by UNICEF-Mongolia,³² World Vision International adopted the “Channels

³² United Nation Children’s Fund (2003). *Buddhist Leadership Initiative: Strategy and Monitoring & Evaluation Framework*, January 2003. Bangkok: UNICEF East Asia and the Pacific Regional Office; United Nation Children’s Fund (2004). *What Religious Leaders Can Do about HIV/AIDS: Action for Children and Young People*. New York: UNICEF.

of Hope Initiative” for inter-faith approaches to the HIV/AIDS response. However, the World Vision Mongolia HIV/AIDS Response Program team was disappointed that discussions amongst Mongolian Christian leaders serving in communities associated with the ADPs expressed reluctance to partner with religious leaders of other faiths.

During fiscal year 2006 (01 October 2005 - 30 September 2006), the World Vision Mongolia HIV/AIDS Response Program team implemented the “Expanded Project for HIV/AIDS Prevention, Care, and Advocacy Response to HIV/AIDS”. This project funded awareness-raising workshops for the journalists of print and broadcast media stations (promoting the drafting of a code of conduct), the teachers and children in the public school systems associated with the ADPs, the employees of the national north-south railway system, and the administrators and guards of the national prison system. Also, this expanded project funded interactive (call-in) FM radio broadcasts designed to attract young listeners in the communities. Significantly and expensively, this project funded an STI continuum of care component (diagnosis, treatment, care, and support) for over 400 people in especially vulnerable populations: children in shelters, female detainees/prisoners, and the staff of these institutions.

Through this expanded project of the HIV/AIDS Response Program, World Vision Mongolia externally partnered with many local NGOs (both Christian and secular) in order to support their responses to HIV/AIDS. In particular, for the “Population Development, Human Rights, and Reproductive Health NGO Network” (“RH Network”), consisting of 32 local NGOs, partnership involved financing meetings and sharing activities. The RH Network proved to be a strong partner for prevention and advocacy initiatives, especially amongst MARP. Five local NGOs working with MARP in Mongolia were members of the RH Network: Positive Life NGO (for PLHA), Youth and Health NGO (for MSM), Women’s Association Trust and Faith NGO (for outreach to female sex workers), Anti-drug Association NGO, and Association against Alcohol and Drug Abuse. Significantly, this expanded project gave monthly support to the Positive Life NGO and its Positive Life Centre so that PLHA could have a secure, private office for support group meetings.

During fiscal year 2007 (01 October 2006 - 30 September 2007), ownership of the HIV/AIDS response of World Vision Mongolia gradually shifted from the National Office team to the ADP teams, since the local-level Health Programme Coordinators had been trained for internal organizational partnering and for multi-level external partnering over the previous two years of programming.

World Vision International in the Asia-Pacific Region

Within World Vision International, the strategic framework for responding to HIV/AIDS is called the “Hope Initiative”. During 2004-2006, National HIV/AIDS Coordinators from each national office in the Asia-Pacific Region participated in the “Hope Initiative” project for designing a comprehensive toolkit. Workshops in Bangkok, Thailand, in July 2004 and in Phnom Penh, Cambodia, in July 2005 encouraged a participatory approach to learn about diverse cultural enablers and constraints for HIV/AIDS prevention, treatment, and care/support across this vast region. During January - February 2006, World Vision International contracted Dr. Nancy Tokola to be the final editor of this toolkit, entitled *World Vision Resource Guide for HIV/AIDS Programming in the Asia-Pacific Region*. Thereafter, World Vision International provided funding for each national office to translate the toolkit into the language(s) of the country, especially for implementation by the ADPs.

In 2004, the International Federation of Red Cross and Red Crescent Societies (IFRC) designed the “Code of Good Practice for NGOs Responding to HIV/AIDS” (“the Code”).³³ At the “Seventh International Congress on AIDS in the Asia-Pacific” (ICAAP), held in Kobe, Japan, during 01-05 July 2005, the IFRC hosted a meeting to build interest in the Code. The World Vision Mongolia National HIV/AIDS Coordinator questioned why World Vision International was not one of the fifty original signatory organizations, even though the Geneva-headquartered World Council of Churches (WCC) was an original signatory.

In mid-July 2005, at the World Vision Asia-Pacific Region toolkit workshop in Cambodia, the World Vision Mongolia National HIV/AIDS Coordinator questioned a Geneva-based World Vision International HIV/AIDS advocacy expert on this Code signatory issue without gaining a solid answer. Conjectures ranged from disagreements over the condom component of the ABC approach (for prevention of sexual transmission of HIV) to disagreements over the Harm reduction approach (for prevention of blood transmission of HIV through needle/syringe exchange programs and medication substitution therapy for IDU).

As of February 2009, the Code Steering Committee consists of the following international organizations: CARE International, Global Network of People Living with HIV/AIDS, International Council for AIDS Service Organizations, IFRC, International HIV/AIDS Alliance,

³³ International Federation of Red Cross and Red Crescent Societies (2004): “Code of Good Practice for NGOs Responding to HIV/AIDS”, 110 pages, <http://www.ifrc.org/what/health/hivaids/code>, accessed on 20 February 2009.

and International Planned Parenthood Federation. There are 408 signatory organizations, but World Vision International is still not among them.³⁴

HIV/AIDS Prevention Approaches

To support the prevention workshops and advocacy initiatives of World Vision Mongolia, the HIV/AIDS Response Program team constructed a comprehensive course designed with bilingual text (English/Mongolian) and with Mongolian-contextualized illustrations (for example, traditional *deels* for dress and traditional *gers* for housing). The IEC Committee of the Mongolian National Centre for Health Development approved these materials prior to mass printing of forty pages in the form of a desktop flipchart and a wall-mountable set of large posters. Only one out of these forty pages provided education on condoms by offering information on the lower-case “c” of the “ABc” approach for prevention of HIV transmission.

In the late 1990s, the “ABC” approach originated as a slogan designed by the Government of Botswana for display on billboards: “Abstain, Be faithful, Condomise”.³⁵ The UNAIDS version of the ‘ABC’ approach evolved as follows: A = “Abstinence or delaying first sex”; B = “Being safer by being faithful to one partner or by reducing the number of sexual partners”; C = “Correct and consistent use of condoms for sexually active young people, couples in which one partner is HIV-positive [discordant couple], sex workers and their clients, and anyone engaging in sexual activity with partners who may have been at risk of HIV exposure”.³⁶

In 2002, during the conservative Administration of U.S. President George W. Bush, the U.S. Government formulated the President’s Emergency Plan for AIDS Relief (PEPFAR) to tackle the HIV/AIDS epidemics of resource-poor developing countries. PEPFAR adopted the conservative “ABc” approach as follows: A = “Abstinence for youth, including the delay of sexual debut and abstinence until marriage”; B = “Being tested for HIV and being faithful in marriage and monogamous relationships”; c = “Correct and consistent use of condoms for those who

³⁴ Code of Good Practice for NGOs Responding to HIV/AIDS (2009): “Signatories”, 21 pages, <http://www.hivcode.org/signatories-to-the-code/?p=20>, accessed on 20 February 2009.

³⁵ Kanabus, Annabel and Noble, Rob (2008): “The ABC of HIV Prevention”, 20 November 2008, <http://www.avert.org/abc-hiv.htm>, accessed on 10 December 2008.

³⁶ Joint United Nations Programme on HIV/AIDS (2004). *2004 Global Report on the Global AIDS Epidemic*. Geneva: UNAIDS.

practice high-risk behaviours” (namely “prostitutes, sexually active discordant couples, substance abusers, and others”).³⁷

Founded in 2003 in Uganda, ANERELA+ is the African Network of Religious Leaders living with or personally affected by AIDS. In August 2008, at the “XVII International AIDS Conference” in Mexico City, ANERELA+ launched INERELA+, the International Network of Religious Leaders living with or personally affected by AIDS. Combined, ANERELA+ and INERELA+ have 3,500 members across five continents. Early in its operations, the religious leaders of ANERELA+ devised the SAVE Approach. The acronym expands as follows: S = “Safer practices”, A = “Available medications”, V = “Voluntary Counselling and Testing” (VCT), and E = “Empowerment through education”.³⁸

In April 2006, the international NGO, Christian Aid, declared its support for the SAVE approach by asserting that the ABC approach is “not well suited to the complexities of human life”.³⁹ Then in summer 2006, Christian Medical Fellowship (CMF) suggested that HIV/AIDS programmers who utilize “catchy acronyms to encompass complex realities” are generating “falsely opposed positions” (conservative versus liberal) which can be detrimental to the HIV/AIDS response. CMF asserted that “ABC is highly effective for a general population” (especially through alignment with “Safer Practices” in the SAVE approach), but not for sex workers.⁴⁰

The 100% Condom Use Program (100% CUP) originated in the Asia-Pacific Region, specifically in Thailand. In the Asia-Pacific Region, up to 90% of the HIV/AIDS pandemic has been driven by heterosexual transmission, especially amongst MARP, including sex workers and IDU. Thailand reported its first HIV case in 1984 and experienced rapid escalation throughout the remainder of the 1980s. In response, within the Thai Ministry of Health in 1989, medical officer Dr. Wiwat Rojanapithayakorn designed and locally piloted 100% CUP in order to tackle the sexual transmission of HIV between sex workers and clients, many of whom were also IDU. The two premises of the program were the “power imbalance between male clients and female sex workers in any

³⁷ United States Government (2004). *The President’s Emergency Plan for AIDS Relief: U.S. Five Year Global HIV/AIDS Strategy*, February 2004. Washington, D.C.: Office of the US Global AIDS Coordinator.

³⁸ ANERELA+ and INERELA+ (2008): <http://www.anerela.org/> --> <http://www.cpsajoburg.org.za/hivaids/anerela1.html>, accessed on 26 January 2009.

³⁹ Christian Aid (2006): <http://www.christian-aid.org.uk/news/media/pressrel/060321p.htm>, accessed on 10 December 2008.

⁴⁰ Fouch, Steve (2006): “SAVE versus ABC: The Alphabet Wars of AIDS Prevention”, *Triple Helix*, summer edition, p. 5, <http://www.admin.cmf.org.uk/pdf/helix/sum06/36newsreviews.pdf>, accessed on 10 December 2008. [Note: Christian Medical Fellowship (CMF)]

negotiation about condom use” and the “economic disincentive for sex workers to use condoms” when clients could offer double payment for sex without condom. To establish balance and to create incentive, the program offered the designation of “safe sex establishment” to owners/managers who insisted that clients consent without negotiation to the “correct and consistent use of condoms” with the establishment-based sex workers. By 1991, 100% CUP became the Thai national policy for preventing HIV transmission in sex establishments, both direct (brothels) and indirect (bars, karaoke, massage parlours, bath houses).

The 100% CUP approach has concerted motto, guidelines, monitoring, strategies, and means of sustainability.⁴¹ The 100% CUP motto is “No condom - No sex”. This motto is supported by three guidelines for condom use: 1) “100% of the time”, 2) “in 100% of risky sexual relations”, and 3) “in 100% of the sex entertainment establishments in a large geographic area such as a town, district, province or country”. The implementation of 100% CUP is monitored through five levels of activities from the perspectives of the owners/managers of sex establishments: 1) “verbal indication of support” for condom use, 2) “permitting condom posters in entertainment establishments”, 3) “onsite education/outreach in entertainment establishments”, 4) “ensuring condom availability in entertainment establishments”, and 5) “ensuring ‘No condom - No sex’” in the interaction between sex workers and their clients.⁴²

Nation-states adopting 100% CUP into their HIV/AIDS prevention policies must incorporate the following six components into their strategies in order to mitigate their epidemics: 1) “high-level political commitment”, 2) “multi-sectoral institutional structures”, 3) “promotion and accessibility of quality condoms”, 4) “identification and collaboration with sex entertainment establishments”, 5) “monitoring of condom use” in these establishments, and 6) “evaluations of the outcome and/or impact” by promoting VCT both for STI and HIV through surveillance systems.⁴³

Throughout the 1990s, in Thai sex establishments near the border with Cambodia, Cambodian clients would cross the border in order to use these “safe sex establishments”, a financially lucrative incentive for the Thai sex establishment owners/managers to maintain their adjective

⁴¹ World Health Organization Western Pacific Regional Office (2004). *Responding to Questions about the 100% Condom Use: An Aid for Programme Staff*. Manila: WHO/WPRO.

⁴² World Health Organization Western Pacific Regional Office (2004). *Experiences of 100% Condom Use Programme in Selected Countries of Asia*. Manila: WHO/WPRO, pp. 24-32.

⁴³ *Ibid*, pp. 5-7.

“safe”. In 1998, the Government of Cambodia locally piloted 100% CUP, which became national policy in 2000.⁴⁴ With the success of 100% CUP in Thailand and Cambodia, other nation-states in the Asia-Pacific Region began locally to pilot and then nationally to adopt this program: The Philippines in 1999, Vietnam in 2000, Myanmar in March 2001, China in June 2001, Mongolia in July 2002, and Lao People’s Democratic Republic in July 2003.⁴⁵

Initially, these developing nation-states were dependent upon external funding (such as from Global Fund) for condom procurement, especially as 100% CUP expanded from local level to national level. As 100% CUP matured in these developing nation-states, sustainability became dependent upon successful social marketing of condoms. In Mongolia, the international NGO, Marie Stopes International, produces condoms with the brand name “Trust” and promotes social marketing by sex workers.

100% CUP in Mongolia

Dr. Wiwat Rojanapithayakorn, the designer of 100% CUP, left his employment in the Thai Ministry of Health and joined the WHO Western Pacific Region Office (WPRO), through which he accepted a position as medical officer for WHO-Mongolia, through which he launched 100% CUP in Mongolia. In Mongolia, national policy makers ambiguously claim that sex work is neither legal nor illegal. However, until the launch of 100% CUP, Mongolian sex workers had limited access to health care services due to fear of being detained by police. In July 2002, with support from the HIV/AIDS-designated Global Fund Round Two, Mongolia piloted 100% CUP in one of its twenty-one *aimags* (provinces). Nationally, 60% of female sex workers had been diagnosed with at least one STI. However, in Darkhan-Uul Aimag, bordering the Russian Federation, 78% of female sex workers had been diagnosed with at least one STI, which substantially increased the risk of HIV co-transmission. Further, during 2002-2003, establishment-based (as distinguished from freelance) sex work increased by 15% in Darkhan-Uul Aimag. Through 100% CUP in this province, these establishment-based sex workers received official “green cards”, giving them greater access to health care services and deterring police interference. By mid-2003, these sex

⁴⁴ World Health Organization Western Pacific Regional Office (2003). *Guidelines for Scaling-up the 100% Condom Use Programme: Experience from Cambodia*. Manila: WHO/WPRO, pp. 1-2.

⁴⁵ World Health Organization Western Pacific Regional Office (2004). *Experiences of 100% Condom Use Programme in Selected Countries of Asia*, pp. 24-31.

workers demonstrated significant decreases in STI incidences for trichomoniasis, syphilis, and gonorrhoea.⁴⁶

With support from the HIV/AIDS-designated Global Fund Round Two (since 2003) and Round Five (since 2006), Mongolia has aimed for national coverage by adding five provinces per year to 100% CUP, with all twenty-one aimags scheduled to be fully implementing this HIV/AIDS prevention policy and program by 2008.⁴⁷ Nation-wide strengthening has continued through the HIV/AIDS-designated Global Fund Round Seven (since 2008).⁴⁸

HIV/AIDS Response through Partnerships in Mongolia

After the Millennium Summit in September 2000, experts formulated 18 targets and 48 indicators for the eight MDGs during 2001. Thereafter, in January 2002, the international community established the Global Fund as a public-private partnership to finance country-specific programming. The three imperatives of the Global Fund are as follows: 1) “Raise it” (through pledges), 2) “Spend it” (through calls for project proposals), and 3) “Prove it” (through strict performance-based monitoring and evaluation of programming).⁴⁹ The money derives from pledges made by the governments of developed nation-states and by private organizations. Between 2001 and June 2008, the U.S. Government pledged US\$ 4 billion, all other nation-states pledged US\$19 billion, and private foundations pledged US\$20 billion. However, by mid-2008 only US\$ 2.5 billion, US\$ 10 billion, and US\$ 10.5 billion had actually been distributed by these respective donors.⁵⁰

In Mongolia, the Project Coordinating Unit (PCU) in the Global Fund Projects Office, located within the Ministry of Health building, has actively pursued financing from Global Fund headquarters in Geneva in order to mount comprehensive, coordinated responses both to tuberculosis and to HIV/AIDS. The process of applying for Global Fund

⁴⁶ Ibid, pp. 21-22.

⁴⁷ Ibid, p. 31.

⁴⁸ Government of Mongolia (2008). “Global Fund Grant Original Proposal: HIV/AIDS Round Seven Project: Maintaining Low Prevalence in Mongolia through Scaling up Universal Access for HIV/AIDS Prevention, Treatment, Care and Support for Most-at-Risk Populations and Strengthening the Health Sector”, Grant Number MON-708-GO5-H, Start Date 01 July 2008. Ulaanbaatar: Ministry of Health.

⁴⁹ Global Fund to Fight AIDS, Tuberculosis and Malaria (2008). *The Global Fund: Who We Are, What We Do*. Geneva: Global Fund.

⁵⁰ Global Fund to Fight AIDS, Tuberculosis and Malaria (2008): “Pledges and Contributions”, <http://www.theglobalfund.org>, accessed on 10 January 2009.

grants through strict project proposal formats has motivated the Ministry of Health, other Ministries, local government officials, intergovernmental agencies, and civil society organizations to strive for harmonization of programming.

Each Global Fund round has a five-year implementation period requiring extensive funding. Through grant proposals submitted between 2003 and 2008, for the collective responses to tuberculosis (Rounds One⁵¹ and Round Four⁵²) and to HIV/AIDS (Round Two, Round Five, and Round Seven), Mongolia has requested from Global Fund a total of US\$ 30,886,718 but has received approval for only US\$ 21,466,720. In 2008, the financial need for the HIV/AIDS response in Mongolia was US\$ 5.3 million, with only US\$150,000 available from domestic sources. Similarly in 2009, the financial need for the HIV/AIDS response is US\$ 5.4 million, with only US\$ 152,000 projected to be available from domestic sources.⁵³

WHO medical officers had served as key drivers in drafting the early Global Fund project proposals, both for tuberculosis and for HIV/AIDS. However, for the HIV/AIDS-designated Round Five project proposal in 2005, Mongolian multi-level teams, consisting of governmental, intergovernmental and civil society organisations, were able independently to accomplish the rigorous researching and writing, objective by objective. Dr. Wiwat Rojanapithayakorn, who had transferred from Ulaanbaatar to Beijing with WHO early in 2005, provided a one-week consultancy prior to final submission of this project proposal in June 2005. Thereafter, he travelled from Beijing to Ulaanbaatar for leading a one-day seminar on 100% CUP during the 13-16 June 2006 “National HIV/AIDS Seminar”, focusing on progress of the Global Fund projects.

⁵¹ Government of Mongolia (2003). “Global Fund Grant Original Proposal: Tuberculosis Round One Project: “Acceleration of Directly Observed Treatment Short Course (DOTS) in Mongolia”, Grant Number MON-102-GO1-T-00, Start Date 01 May 2003. Ulaanbaatar: Ministry of Health.

⁵² Government of Mongolia (2005). “Global Fund Grant Original Proposal: Tuberculosis Round Four Project: “Strengthening the National Response to Tuberculosis in Mongolia”, Grant Number MON-405-GO3-T, Start Date 01 April 2005. Ulaanbaatar: Ministry of Health.

⁵³ Global Fund to Fight AIDS, Tuberculosis and Malaria (2008): “Country Program: Mongolia”, <http://www.theglobalfund.org/programs/country/?lang=en&countryid=MON>, accessed on 10 January 2009.

Local NGOs in Mongolia

World Vision Mongolia may be registered as a local NGO by the Ministry of Justice, but its wealth is in sharp contrast to the meagre budgets of other local NGOs in Mongolia. Founded in 2001, the RH Network accepted sponsorship by UNFPA in 2002 and gradually grew in membership across Mongolia. As RH Network members, each of the 32 local NGOs (as of 2008) is expected to adapt its own original list of organizational mandate-specific goals by mainstreaming (inserting HIV/AIDS response elements into original goals), by integrating (adding new goals focused on HIV/AIDS response), and by actively participating in RH Network-directed HIV/AIDS programming. The co-chairs of the RH Network are Focus NGO (mandated for media advocacy) and Adolescence Future Centre NGO (mandated for operation of a reproductive health clinic).

In mid-2006, the Mongolian Ministry of Health, as Principal Recipient of the HIV/AIDS-designated Global Fund Round Five, awarded Sub-recipient status to the RH Network for one of the four objectives (“to scale up HIV/AIDS advocacy, human rights protection, and de-stigmatization”).⁵⁴ Subsequently, as an RH Network member organization, the Mongolian Scout Association became one of four NGOs admitted to membership in the 20-member Mongolian Country Coordinating Mechanism (CCM) of the Global Fund.⁵⁵

During 24-27 October 2006, UNFPA-Mongolia sponsored the “Low to Zero: First Asia-Pacific Regional Conference on Universal Access to HIV Prevention, Treatment, Care and Support in Low Prevalence Countries”. This high-level meeting featured the twelve HIV/AIDS low prevalence countries in the Asia-Pacific Region: Bangladesh, Bhutan, Brunei Darussalam, Fiji, Democratic People’s Republic of Korea, Lao People’s Democratic Republic, Malaysia, Maldives, Mongolia, Sri Lanka, The Philippines, and Timor Leste. A co-chair of the RH Network, Ms. Tuya Badarch, served as a coordinator in

⁵⁴ Tokola, Nancy and Badarch, Tuya (2006). “Memo from RH Network to UNFPA-Mongolia: Rationale in Applying for Sub-recipient Status for Objective 4 of HIV/AIDS-designated Global Fund Fifth Round Project: ‘Scaling up Targeted National HIV/AIDS Prevention Programs in Mongolia’”, 10 April 2006. Ulaanbaatar: Population Development, Human Rights, and Reproductive Health NGO Network.

⁵⁵ Global Fund to Fight AIDS, Tuberculosis and Malaria (2008): “Country Program: Mongolia”, <http://www.theglobalfund.org/programs/country/?lang=en&countryid=MON>, accessed on 10 January 2009.

the Conference Secretariat. The international consultant of the RH Network, Dr. Nancy Tokola, served as the rapporteur.

Building on this success, in early-2007, UNFPA-Mongolia awarded the RH Network the status of implementing partner for US\$ 60,000 of programming in its Five-Year Work Plan (2007-2011), specifically for “reproductive health care service delivery points”, “reproductive rights and gender equality versus gender-based violence”, “data collection and data analysis to inform policy”, and “accountability”.

During 19-23 August 2007, at the “Eighth International Congress on AIDS in the Asia-Pacific” (ICAAP) held in Colombo, Sri Lanka, the executive director of Focus NGO represented the RH Network by speaking at the Civil Society Forum, with a presentation entitled “The Role of Civil Society in HIV Low Prevalence Settings”. Usually, local NGOs are the implementing partners for conducting on-the-ground work of HIV/AIDS response projects. However, the directors and staff of these local NGOs might not be receiving either salaries or office support because of contractual restrictions embedded in the project financing mechanisms. Civil society serves as the empowered bottom-up voice of communities at risk for HIV/AIDS. However, top-down understanding of the practical circumstances of civil society organizations is essential for a sustainable HIV/AIDS response in Mongolia.

Conclusion

This paper on the situation of and response to the HIV/AIDS epidemic in Mongolia has explored the complexity of interactions regarding policies, strategies, programs/projects, and monitoring/evaluation/reporting mechanisms. Diverse organizations have brought their own philosophies, missions, and visions to the HIV/AIDS response, some complementary to and others conflicting with the socio-cultural sensitivities of the Mongolian population. For World Vision Mongolia, with its Christian-based core values, its wealth, and its status as the largest NGO in the country, the HIV/AIDS Response Program posed challenges at the interface of spiritual and secular operations.

The Global Fund has provided major financial resources for mounting comprehensive responses both to tuberculosis and to HIV/AIDS in Mongolia. The Global Fund process has motivated diverse, otherwise unconnected organizations to accept coordination for the sake of harmonized programming in partnership. At the civil society level, the RH Network is a model of integration, mainstreaming, and participation.

The Asia-Pacific Region has twelve nation-states, including Mongolia, with low prevalence of HIV/AIDS. Low prevalence hides

vulnerabilities which should motivate increased resource mobilization for intervention in the national epidemics and thus the regional pandemic. Otherwise, eventually, the absolute numbers Asia-Pacific PLHA could rival the absolute numbers of sub-Saharan Africa PLHA.⁵⁶

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Social Protection for HIV-affected Families in Poor Countries: A Policy Recommendations Inquiry after AIDS 2008

Ricardo Pereira

This article aims to discuss a set of policy recommendations put forward by South Africa-based AIDS expert Linda Richter during a plenary session of the latest International AIDS Conference (AIDS 2008), which took place on 3-8 August 2008 in Mexico City. With approximately 24,000 delegates from all over the world, this meeting gathered a vast array of actors involved in the global governance of HIV/AIDS: natural and social scientists; economists and funding managers; medical and social workers; governmental, intergovernmental and nongovernmental leaders; activists of specific groups (people living with AIDS, gays, lesbians, transsexuals, sex workers); pharmaceutical companies; religious representatives.

From the myriad of personal and institutional agendas pursued at AIDS 2008, the most prominent and common one to emerge concerned the absolute necessity of keeping HIV/AIDS a central preoccupation for governments, businesses and societies, in order to secure support for research, prevention and treatment. As such, in the closing session, Julio Montaner, president of the International AIDS Society, co-organizer of AIDS 2008, addressed thankful words to “President Bush and the American people” for the major financial commitments made through the President’s Emergency Plan for AIDS Relief (PEPFAR). Yet – perhaps to the surprise of some – his speech was received by a mixture of applause and booing from the audience. How does one comprehend such an embarrassing situation? In my view, this is explainable by the fact that, despite the urgency to respond to the epidemic, many involved in the global “HIV/AIDS industry”¹ acknowledge that many global health and development programmes are embedded in, and ultimately serve, broader

¹ Pisani, Elizabeth (2008). *The Wisdom of Whores. Bureaucrats, brothels and the business of AIDS*. London: Granta Books.

imperial agendas, no matter how generous they appear. My reflection on Richter's speech was inspired precisely by that 'discomforting' episode at AIDS 2008.

Richter's recommendations in the report *No Small Issue: Children and Families* invited the questioning of the political economy of global AIDS governance² in a way that no other at the AIDS conference did. Unlike the innumerable approaches focused on specific aspects of the epidemic, Richter puts forward a perspective which reaches beyond AIDS, as it advocates a comprehensive system of social protection in poor donor-dependent countries. Although they remain committed to the main development agenda, I still take these policy recommendations as interesting inputs for a discussion centred on perspectives of emancipation of affected societies, not only from the epidemic-related threats, but also from permanent external dependency, which I observe as similarly 'epidemical.'

In fact, Richter's perspective demands critical discussion, when taking into account broader political issues of contemporary global governance, such as leading liberal approaches to development *and* aid, as well as Western security-driven agendas of intervention, *but also* emancipative "national project" post-aid agendas. After reviewing these different topics in the next three sections, I conclude by suggesting that a paradigm based upon an emancipative community-based rationale, aimed to address contingencies imposed by AIDS itself, and other issues alike shall continue to be researched towards more appropriate and sustainable responses.

² I utilize the definition of governance put forward by Dodgson, Richard et al. (2002). *Global Health Governance. A Conceptual Review*. London and Geneva: London School of Hygiene & Tropical Medicine and World Health Organization, p. 6: "In broad terms, governance can be defined as the actions and means adopted by a society to promote collective action and deliver collective solutions in pursuit of common goals. This a broad term that is encompassing of the many ways in which human beings, as individuals and groups, organize themselves to achieve agreed goals. Such organization requires agreement on a range of matters including membership within the co-operative relationship, obligations and responsibilities of members, the making of decisions, means of communication, resource mobilisation and distribution, dispute settlement, and formal or informal rules and procedures concerning all of these. Defined in this way, governance pertains to highly varied sorts of collective behaviour ranging from local community groups to transnational corporations, from labour unions to the UN Security Council. Governance thus relates to both the public and private sphere of human activity, and sometimes a combination of the two."

Support for children and families affected by AIDS

Assessing the current state of affairs in HIV/AIDS intervention in the hardest-hit regions, which are simultaneously some of the world's poorest places, Linda Richter states that children have been left relatively unprotected by AIDS programs. When compared to services exclusively oriented to adults, support of mother-to-child AIDS transmission prevention care has been much smaller.³ Thus, families face the burden of providing necessary relief to their members, constituting further hardship in an already impoverished situation.⁴ Eventually, HIV/AIDS prevention and treatment should target children and adults equally, as part of a larger strategy, aimed at augmenting the community's resilience to the disease and its impacts on income productivity. Given this scope of intervention, Richter recommends a re-conceptualization, centred, not on HIV as *infecting* a particular individual, but on HIV as *affecting* not only the person infected, but all others attached to the infected. In fact, one does not have to be actually infected to suffer the painful consequences of AIDS.⁵

Richter also has trouble with the definition of "orphan", which derives from a Western-centred view, i.e. "a child under 18 who has lost *one* or *both* parents."⁶ This definition is inaccurate, since it does not capture the reality of children and their family environments in non-Western regions.⁷ Thus, the author reinforces a family-based approach as

³ Richter, Linda (2008). *No small issue: Children and families*. Bernard van Leer Foundation, pp. 12-13: "The current response is largely composed of temporary or *ad hoc* projects with limited outreach that are often poorly designed and underfunded. These efforts undoubtedly alleviate some of the distress experienced by children and families. But small, localized projects can only take us so far. To have a bigger impact requires larger and more systemic responses – responses which support families and address the pervasive poverty in which so many of them live. Putting needed resources into the hands of affected families should be urgently considered in order to expand the impact of small scale programmes currently reaching only very small numbers of children. Families are the crucial link in providing sustainable assistance for children over the long-term and, in turn, building stronger communities that can be more resilient to HIV."

⁴ Ibid, p. 11: "Everywhere, HIV-affected households typically experience a worsening of their socioeconomic status; they frequently become indebted, sell assets and reduce their consumption, especially of food. They spend more on the health care of sick members and suffer a loss of income as a result of declining productivity."

⁵ Ibid, p. 6: "Children are *infected* by HIV and they are also *affected* – affected, that is, by the devastating impact of the epidemic on their families and the communities in which they live."

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⁷ Ibid: "In Western countries, the usual meaning of an orphan is a child who has lost both parents; in much of Africa, it is someone without family or close kin."

a more adequate and effective strategy of epidemic containment. Eventually, financial support should be directed to households and hence diverted from intermediaries, namely orphans' institutions. Supporting children at family level is to be pursued through the development of a comprehensive system of support whose goal is to more thoroughly prevent disease driven poverty. Accordingly, this proposal is "based on the development agenda, it is affordable and feasible and consists of income transfers directly to households and not intermediaries."⁸ Supported by an International Labour Organization's study, Richter argues that "every developing country, no matter how poor, can afford to support a social protection package for children affected by HIV, AIDS and extreme poverty."⁹

Liberal Development and Aid Governance

HIV/AIDS touches all dimensions of life and is particularly lethal in countries and regions where people already live in sub-standard conditions. HIV/AIDS is both a medical and social issue, contributing to poverty and exclusion, due to reductions in quality of life and to social stigma. Therefore, a comprehensive and effective AIDS strategy – a strategy that mitigates, reduces and ideally puts an end to all dimensions that undermine both infected and affected people's quality of life – needs to be introduced.

To an extent, the Millennium Development Goals embody such broader thinking. Yet, persistent complications and disagreement between actors combine to make the achievement of these goals difficult. Often donor states are blamed by international non-governmental and governmental organizations for failing with in commitments to higher financial support of poverty-eradication projects. Yet, a broad consensus is found among all those conflicting actors at the political-economic level. Such consensus revolves around the arguably best working business model to be implemented, i.e. donor-dependent public-private¹⁰ partnerships embracing any single stakeholder (foreign, transnational, local).¹¹ It is precisely the 'working solution' that the public-private

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⁹ Ibid.

¹⁰ By private I mean a whole range of actors, from private companies to nongovernmental organizations, both of national and transnational scope.

¹¹ For instance, a very recently published report on global health by Oxfam International exemplifies it. See: Oxfam International (2009). *Blind Optimism. Challenging the myths about private health care in poor countries*, February 2009, http://www.oxfam.org.uk/resources/policy/health/downloads/bp125_blind_optimism_private_health_care.pdf, p. 6.

partnership promises that I am critically calling into question. Does it mean taking practical steps towards dealing with problems, such as the high figures of HIV-affected people in countries already ridden by mass poverty and often violence? Or does it primarily seek to facilitate the coordination or harmonization of disparate institutional power relations and agendas?

According to French sociologist Luc Boltanski,¹² ‘partnership’ materializes the neo-liberal ideal of “society by project” as the “new spirit of capitalism” of the last twenty years. Through ‘scientific’ management, the envisaged goal of flexibility is facilitated in the division of labour in order to counter political decisions and institutional rigidities. “Governance at a distance”¹³ through ‘projectization’ is a key feature, as donor-imposed management tools such as the project cycle management clearly show. However, this seems to be particularly obvious in the Sub-Saharan case vis-à-vis, for instance, the Asian case.¹⁴

The idea of partnership is a clear-cut product of the contemporary liberal approach to social affairs in globalization, which can be observed inside and outside the Western world. Current models which fight against social exclusion in Western societies consist of such infra-structures as ‘partnerships,’ ‘platforms,’ ‘networks,’ ‘alliances,’ ‘campaigns,’ ‘coalitions’ that gather all sorts of state and non-state actors and are adapted to, or inspired by, equivalent transnational anti-poverty initiatives in the Global South. This type of public-private partnership, composed by state development agencies, nongovernmental organizations, charities, private companies and celebrities, tend to be reproduced home and abroad, though reframed to suit the specific environment. An analysis of today’s dominating partnership idea leads to conclusions around the retreat of politics in social and foreign development work. Political deliberation (not necessarily the state institutions themselves) is put aside, and the focus is instead on the technicalities of the issue.¹⁵

¹² Boltanski, Luc (2008). "Approches sociologiques d'une forme contemporaine de domination". *Crítica do Contemporâneo*. Porto.

¹³ Duffield, Mark (2005). "Governing the Borderlands: Decoding the Power of Aid". In: Wilkinson, Rorden (ed.). *The Global Governance Reader*. London and New York: Routledge, pp. 204-216.

¹⁴ Warah, Rasna (2008). "The Development Myth". In: Warah, Rasna (ed.). *Missionaires, Mercenaries and Misfits: an anthology*. Central Milton Keynes: AuthorHouse, p. 10.: “The exclusive international focus on the country may have to do with the fact that African problems are easier to ‘compartmentalise.’ Whether it is Aids, famine or conflict, Africa offers a canvas that can be painted into neat little boxes.”

¹⁵ Cooke, Bill (2003). "A new continuity with colonial administration: participation in development management". In: *Third World Quarterly*, (vol. 24), No. 1, p. 48: “Managerialist representations of management as a neutral, technical means-to-an-

After the independences and the self-determination processes of the formerly colonized peoples, and corresponding repudiation of the concept of colony, transnational partnerships emerged as the reframed engagement tool displayed by the West. As Bill Cooke explains, methodologies of development management, namely by the World Bank establishment, hold a “direct genealogical link with indirect rule”¹⁶ applied in colonial contexts in Africa and Asia. Benign concepts such as local empowerment and country ownership are relevant in such continuity. One can see similarities in the programmatic purpose of colonial and contemporary policies. Indirect rule addressed “the need for imperial rule to be sustained (...) in terms of obligation first, exploitation second.” Whereas the former implies “the need to train, to build capacity, the importance of the rule of law and the absence of corruption, the role of education in progress, flexible labour markets, fair revenue collection, and espoused support for the rural poor,”¹⁷ the latter goes for “material” concerns, which British “colonial architect” Lord Lugard believed would benefit “all mankind.” In turn, country ownership is defined as “recipient governments [being] urged to take ownership of development policies and aid activities in their country, to establish their own systems for coordinating donors, and only to accept aid that suits their needs.”¹⁸ Although current ‘recipes’ of ownership invite recipient countries to play active and decisive roles, persistent power disparities in the donor-recipient relationship are still acknowledged, to the point of Western donors being advised to refrain from their latent and impatient will to reshape recipient countries’ governance.¹⁹ This manifestation makes explicit the “denialism” that today’s Western “empire” experiences.²⁰ Unlike the racist and overtly exploitative colonial past, today’s rule is

end set of activities and knowledge conceal its status as a product of broader social (at every level from the global to the personal) power relations, and in particular, its role in sustaining these.”

¹⁶ Ibid., p. 47. Indirect rule draws from imperial colonial government, mostly British inspired, and is based on the idea that colonized native chiefs and leaders are not dispensable; they rather instrumental in colonial rule indeed. According to Cooke, today’s leading institutions of global governance ‘work’ postcolonial leadership in a very similar fashion. Hence, the argument he puts forward in terms of a genealogy, or continuity, in global policy making, in which country ownership or empowerment are imposed tools by the global development establishment, which assure control over postcolonial leadership though claiming to be merely technocratic.

¹⁷ Ibid, p. 49.

¹⁸ Renzio, Paolo de et al. (2008). *Reforming Foreign Aid Practices: What country ownership is and what donors can do to support it*. Oxford: University College Oxford, p. 1.

¹⁹ Ibid.

²⁰ Chandler, David (2006). *Empire in Denial: The Politics of State-Building*. London: Pluto.

achieved through a sophistication of power transmission and control embedded in the very policy programs and language.

Richter's critique of the Joint United Nations Programme on HIV/AIDS's (UNAIDS) Western-centred definition of orphan is particularly revealing of the imbalance in power relations at the knowledge level within the current governance model. In the same way, Rachel Bray reported on a number of ethnographic studies carried out in Southern Africa highlighting the role orphans and vulnerable children play, not as delinquents, but as care-givers to their relatives and members of the community. Thus, Bray denounces the Western prejudice on the idea of an orphan as a child growing alone and "without family."²¹ Despite the merits of Richter's recommendations, there is one specific problem in her governance model that I would like to debate. Her suggestion of income transfers as part of the "development agenda" concur with current mainstream policy recommendations aimed to be sponsored by the international community under the auspices of new, or reformulated, partnership schemes.²² Yet, in Richter's community-based approach the ultimate goal for such money transfers is not subject to clarification, apart from helping the poor and disadvantaged to cope with capitalist contingencies. Is it the case of plain donor paternalism, empowerment, i.e. developmentalist buzzword for liberal, self-reliant, self-made modes of production, or something *else* aimed at constructing or maintaining locally-run safety nets? Excluding the paternalist hypothesis, the fundamental difference between self-reliance and safety net has to do with which "life" is to be realized by development actors, that is, the difference between what Mark Duffield has distinguished between "non-secure," self-reliant life, and "secure," interdependent life.²³ For Duffield, self-reliance, as a liberal strategy for achieving

²¹ Bray, Rachel (2003). *Predicting the social consequences of orphanhood in South Africa*. Cape Town: University of Cape Town, p. 42: "Young people are considered vulnerable, but also rebellious and potentially delinquent. For these reasons, there is a perceived need to organise and control the young in order to prevent social disorder. Families are generally promoted as a way in which society can maintain such control over children, meaning that children who are outside 'the family norm' are even more dangerous."

²² Barrientos, Armando; Holmes, Rebecca (2007) *Social Assistance in Developing Countries Database*. London: Overseas Development Institute; Harvey, Paul; Holmes, Rebecca (2007). *The potential for joint programmes for long-term cash transfers in unstable situations*. London: Overseas Development Institute, Institute, Overseas Development (2007) *Linking social protection and the productive sectors*. London: Overseas Development Institute, Shepherd, Andrew et al. (2004) *DFID paper on social protection*. Department for International Development.

²³ Duffield, Mark (2008). "Global Civil War: The Non-Insured, International Containment and Post-Interventionary Society". In: *Journal of Refugee Studies*, (vol.

sustainability in the Global South's modes of production and consequent integration in the global marketplace of goods and services, proves insufficient, namely in contexts of disaster.²⁴ Thus, it demands external relief intervention and future dependence through larger, longer term development programs, as the United Nations Children's Fund's (UNICEF) post-catastrophe slogan "Building Back Better" interestingly co-substantiates.²⁵ Therefore, a paradigm fully addressing the manifold contingencies and risks, with an aim to secure life and emancipate poor countries, needs to be searched outside a strict pervasive liberal ontology.

Security Rationales and Emancipative Horizons

AIDS exceptionalism is an expression widely used in policy analysis to describe today's emergency-like engagements.²⁶ It captures both the need to act in an emergency and the corresponding high allocations of funding and politico-symbolic support for such actions. But AIDS exceptionalism also induces 'post-structural' realist readings of securitization of non-military issues,²⁷ such as migrations and epidemics, dominated by an idea of state of exception, as derived from Carl Schmitt's idea of head of state-ordered suspension of civil order and liberties in the superior interest of the state, in the face of national existential threats.²⁸ Often the HIV/AIDS-security nexus is drawn out of the causality established between AIDS

21), No. 2, p. 150. "For developed, or what metaphorically could be called insured life, the contingencies of capitalist existence are ameliorated through risk-reducing and compensatory benefits funded through contributory social insurance, general taxation, private insurance and personal savings (McKinnon 2004). (...) Underdeveloped life is, from a biopolitical perspective, non-insured."

²⁴ Ibid, p. 151: "An expansive humanitarian assistance constantly invokes the need for a consolidating developmental self-reliance. Self-reliance, however, regularly collapses into humanitarian emergency which again enjoins a repeat of the governmental process of expansion and consolidation (Duffield 2007: 42–51)."

²⁵ United Nations Children's Fund (2005): Building Back Better: A 12-month update on UNICEF's work to rebuild children's lives and restore hope since the tsunami, [http://www.reliefweb.int/rw/RWFiles2005.nsf/FilesByRWDocUNIDFileName/SOD-A-6JM9ZB-unicef-tsunami-01dec.pdf/\\$File/unicef-tsunami-01dec.pdf](http://www.reliefweb.int/rw/RWFiles2005.nsf/FilesByRWDocUNIDFileName/SOD-A-6JM9ZB-unicef-tsunami-01dec.pdf/$File/unicef-tsunami-01dec.pdf), accessed 24 March 2009.

²⁶ Stillwaggon, Eileen (2008): Strengthening Health Systems through the AIDS Response, XVII International AIDS Conference, Mexico City.

²⁷ Buzan, Barry et al. (1998). *Security: A New Framework for Analysis*. Boulder, Colorado: Lynne Rienner Pub.; Vieira, Marco António (2007). "The Securitization of the HIV/AIDS Epidemic as a Norm: A Contribution to Constructivist Scholarship on the Emergence and Diffusion of International Norms." In: *Brazilian Political Science Review*, (vol. 1), No. 2.

²⁸ Schmitt, Carl (1996). *The Concept of the Political*. Chicago: University of Chicago Press.

endemic dissemination in specific countries, and the rise of socio-economic destabilization and hopelessness, which may lead to the breakdown of the social tissue and even fanaticism, notably against Western interests.²⁹ At the public level, the former executive-director of UNAIDS Peter Piot, former U.S. global AIDS coordinator Mark Dybul and current secretary-general of the World Health Organization Margaret Chan have been championing in recent years a discourse articulating several elements, such as dissemination and predicted social impact in governance and security.³⁰

However, it should be stressed that, rather than being a novelty in international politics, this trend has emerged from a historical process of political and cultural experiences of domination in the 19th and 20th centuries. This goes back to the development of tropical medicine and the installation of medical authorities in the former colonial world, meant to support Western economic exploitation, and whose legacies not only remain today but provide contemporary Western strategies in the former colonial world with an important infra-structure of intervention.³¹ In this regard, the concept of biopower is particularly instrumental in understanding, how populations and spaces are secured, and therefore expand the project of security, and the extent of what is at stake through intimate HIV/AIDS interventions, at both psychological and body levels. Biopower was coined by Michel Foucault and is defined as the sovereign power to enhance life or reduce it to the point of death through a range of technologies (medical, social, political) intervening at the individual and societal level.³²

²⁹ Garrett, Laurie (2005). *HIV and National Security: Where are the Links?* New York: Council on Foreign Relations; Lyman, Princeton N.; Morrison, J. Stephen (2006). *More than Humanitarianism: A Strategic U.S. Approach Toward Africa*. New York: Council on Foreign Relations; Schneider, Mark; Moodie, Michael (2002). *The Destabilizing Impacts of HIV/AIDS. First Wave Hits Eastern and Southern Africa; Second Wave Threatens India, China, Russia, Ethiopia, Nigeria*. Washington DC: CSIS.

³⁰ Piot, Peter (2005): Remarks at the Council on Foreign Relations Meeting on "HIV and National Security," 18 July 2005, http://www.cfr.org/publication/8428/hiv_and_national_security.html, accessed on 24 March 2009; Dybul, Mark (2009): The Global Fight Against HIV/AIDS, <http://www.state.gov/r/pa/ei/coffee/113121.htm>, accessed on 8 January 2009; Chan, Margaret (2009): The impact of global crises on health: money, weather and microbes, http://www.who.int/dg/speeches/2009/financial_crisis_20090318/en/print.html, accessed on 22 March 2009.

³¹ Pereira, Ricardo (2008). "Processes of Securitization of Infectious Diseases and Western Hegemonic Power: A Historical-Political Analysis". In: *Global Health Governance*, (vol. 2), No. 1, http://www.ghgj.org/Pereira_2.1.securirization.htm, accessed on 30 January 2009.

³² Foucault, Michel (1984). "Bio-Power". In: Rabinow, Paul (ed.). *The Foucault Reader*. New York: Pantheon Books.

Hansjörg Dilger suggests that for a long time, rather than being an integral part of the biopolitical institutionalizing apparatus, Africans were largely defined by their exclusion and reduction to plain labour force in the colonial machinery.³³ Yet, in the later stages of colonial domination, Western medical intervention extended also to indigenous populations, namely through vaccination and other immunization campaigns.³⁴ Development as a means of empowering individuals towards self-reliant modes of production and insertion in the global market is a modern form of biopolitical, surveillance control.³⁵ In the particular case of HIV/AIDS, and applying the Foucauldian analytical apparatus, the proclaimed AIDS-security nexus is arguably driving global intervention in the same direction.³⁶ This understanding arises only from general analyses of post-September 11 anti-terrorist campaigning, but – most importantly, in my view – from post-colonial “state failure.”³⁷ Therefore, policy prescriptions bear a striking resonance with former colonial times’ models of governance, such as the one U.S. foreign policy influent scholar Stephen

³³ Dilger, Hansjörg (2007). “Population Politics and HIV/AIDS in the Neoliberal Age,” Sixth Berlin Roundtables on Transnationality, Thema: Population Politics, Migration and Human Rights. Wissenschaftszentrum Berlin, p. 1: “Biomedical practice was *not* (author’s emphasis) shaped by what Foucault in relation to the formation of nation-states in 19th century Europe called the emergence of bio-power, a process which involved the relocation of power from repressive institutions *into* (author’s emphasis) the bodies of individuals who were thought to produce and reproduce society by applying knowledge about social organisms and biological processes to themselves and towards others. The colonial enterprise saw individual Africans rather as parts of an undifferentiated whole characterized primarily by its “otherness” and “deviance” and which had to be disciplined for the benefit of those in power and the colonial subjects themselves.”

³⁴ Dilger mentions the arrival of missionary medicine as part of the shifting tendency from otherness to biopolitical inclusion.

³⁵ A number of critical authors have been advancing extensive analysis on development aid, human rights and statebuilding interventions as a function of Western global surveillance power practice on the world peripheries in the light of Michel Foucault’s concept of biopower. See: Duffield, Mark (2007). *Development, Security and Unending War*. Cambridge; Malden: Polity Press; Jabri, Vivienne (2007). *War and the Transformation of Global Politics*. Basingstoke: Palgrave; Douzinas, Costas (2007). *Human Rights and Empire: The Political Philosophy of Cosmopolitanism*. London: Routledge Cavendish.

³⁶ Elbe, Stefan (2008). "Risking Lives: AIDS, Security and Three Concepts of Risk." In: *Security Dialogue*, (vol. 39), No. 2-3, pp. 177-198.

³⁷ Failed states are those that “cannot or will not safeguard minimal civil conditions for their populations: domestic peace, law and order and good governance, [where] the basic functions of the State are no longer performed” See: Jackson, Robert [2000]. *The global covenant: human conduct in a world of states*. Oxford: Oxford University Press, p. 296; Zartman, William [1995]. *Collapsed states: the desintegration and restoration of legitimate authority*. Boulder: Lynne Rienner, p. 5.

Krasner prescribed on “shared sovereignty.”³⁸ Krasner proposes a colonial-like administration resolution for what he perceives as local incapability to respond to manifold governance issues, and hence advocates an “indirect rule” case. Such a resolution hardly seems consistent with a sovereign community-building infra-structure which includes a long term social protection to tackle problems locally, referred to in the last analysis, of poverty and livelihood sustainability.

An alternative perspective to the predominant international establishment has recently been advanced, though it does not represent either a novelty or a rupture from developmentalism as an ideology, that is, something close to post-development or intellectual refusal of development as idea and policy.³⁹ In late October 2008, in the midst of the financial turmoil in the United States, which brought about recalculations of foreign aid by Western countries, Ugandan economist and then-executive director of the intergovernmental think-tank South Centre,⁴⁰ Yash Tandon, appeared on an Al Jazeera talk show on the impact of the financial crisis in Africa. He argued that the crisis would not severely affect the continent, as this could be a historic opportunity

³⁸ Krasner, Stephen (2004). "Troubled Societies, Outlaw States, and Gradations of Sovereignty". Christopher H. Browne Center for International Politics Speaker Series. Philadelphia: "Gradations in sovereignty could be put in place through either treaties or unilateral commitments in which national leaders accepted partial sovereignty or shared sovereignty. Partial sovereignty would involve limitations on a state's freedom of action with regard to policies or institutions. Political authorities might, for instance, make a commitment to external actors that they would limit the kinds of weapons that they would develop, the security pacts that they would join, or the legal system that they would adopt. Shared sovereignty would involve the ongoing participation of external actors in national institutions and policy making. Shared sovereignty would be put in place by a contractual agreement between the state and an external party that could only be terminated with the agreement of all of the signatories, or after specific conditions had been met."

³⁹ Warah, *The Development Myth*, pp. 3-20.

⁴⁰ "The South Centre [...] is an intergovernmental organization of developing countries established by an Intergovernmental Agreement (Treaty) which came into force on 31 July 1995 with its headquarters in Geneva. [...] Broadly, the Centre works to assist in developing points of view of the South on major policy issues, and to generate ideas and action-oriented proposals for consideration by the collectivity of South governments, institutions of South-South co-operation, inter-governmental organizations of the South, and non-governmental organizations and the community at large. In order to meet its objectives, and within the limits of its capacity and mandate, the Centre also responds to requests for policy advice, and for technical and other support from collective entities of the South such as the Group of 77 and the Non-Aligned Movement." (South Centre [2009]. 15 May 2009, www.southcentre.org/

[index.php?option=com_content&task=view&id=13&Itemid=80](http://www.southcentre.org/index.php?option=com_content&task=view&id=13&Itemid=80), accessed 15 May 2009.

for ending aid dependence.⁴¹ His comments, derived from his 2008 book *Ending Aid Dependence*,⁴² represented in the context of the financial crisis, a very different perspective from most developmental nongovernmental organizations' rushed attitude to counter the peril of reducing aid commitments by Northern governments. The relevance of Tandon's views to this discussion on social protection systems is derived from the liberation project embedded in his proposal. In his own words, he asserted that aid is like a drug one is addicted to; when one drops out of it, the experience is painful in the immediate, but in the longer term it offers a potential for collective emancipation.

For Tandon, emancipation is rooted in what he calls "the national project" that starts with a fundamental questioning by recipient societies of the role Western development aid has been playing in terms of facilitating, primarily, post-colonial economic exploration by the Global North. This implies, in his view, a re-transformation of mindsets by those societies,⁴³ in which the picking up of specific 'aid packages' should serve, firstly, the national project.⁴⁴ Tandon links the "national project" to the independence struggles of the 20th century and the internationalist tradition of the non-aligned movement. His project seeks the creation of domestic markets, South-South solidarity and the ongoing quest for self-determination.⁴⁵

Yash Tandon's prescription underlines the idea that development aid is not apolitical, as the Western partnership-rooted model ascertains. In fact, Tandon acknowledges that there needs to be national political engagement in order to produce an aid package tailor made for the project of emancipation. In my view, this is a promising step towards the realization of a structural comprehensive protection for families, infected and affected, (or are prone to infection) by HIV/AIDS. He shares the understanding that anti-poverty efforts are not pure technocracy and need

⁴¹ Tandon, Yash (2008). Riz Khan. Al Jazeera. 23 October 2008, <http://southcentretv.blip.tv/file/1396424>, accessed 30 January 2009.

⁴² Tandon, Yash (2008). *Ending Aid Dependence*. Geneva: South Centre Fahamu Books.

⁴³ Ibid., pp. 67-77.

⁴⁴ Tandon distinguishes five types of aid: ideological; commercial or non-developmental; military and political; provision of global public goods; and solidarity.

⁴⁵ "The national project (...) is not solely a nationalist strategy, but a strategy for local, national, regional and South-South self determination, independence, dignity and solidarity. It is the essential political basis for any strategies to end aid dependence. The national project is the continuation of the struggle for independence. It is a project that began before countries in the South got their independence from colonial rule, continued for several decades after political independence, and then, in the era of globalization, it appeared to have died a sudden death." (Ibid., p. 66).

to be informed of local realities and expectations, which moreover may not be consistent with hegemonic liberal ontologies.

As discussed above with regard to Richter's connection to mainstream development agendas, it can, in turn, be argued that Yash Tandon's proposal is also reliant on Western modernity's socio-political modes. Utilizing the language of Weberian social-contractual state organization and developmentalism, it might limit, if not contradict, the critique of contemporary liberal development. Yet, it can be seen as illustrating the fundamental distinction between what can be termed as a postmodern deconstructionist inquiry and the Critical Theory emancipative approach.⁴⁶ Despite the imperativeness of the critique of Western modernity's 'totalitarianism' of knowledge, cultural and political economy,⁴⁷ modern nation-states are still the central political communities in the international arena, allowing the realization of sovereign community-based democratic deliberation.⁴⁸ However, it should be noted that "the national project" Tandon puts forward does not prescribe, unlike the 'Krasnerian' state-building establishment, any particular form of statehood and remains open to future developments.

Conclusion

Linda Richter's policy recommendations are appealing as they advocate a comprehensive response to AIDS and its effects at the family and community level. Rather than a 'compartmentalised' focus on adults, on one side, and vulnerable children, on the other, Richter proposes an all-inclusive approach centred on the overarching issue of poverty through income transfers to families and communities.

I pursue this reflection in terms of questioning the development-related political economy in Richter's proposal. Thus, I discussed the issue of donor-led public-private partnership as an infra-structure of response. The partnership model not only proceeds from the colonial administration model (indirect rule) but also appears as the liberal means of managing the "new spirit" of globalized capitalist relations in the last twenty years. Therefore, though looking like a plain technocratic intervention and politically "neutral" and based on benign concepts such as "local empowerment" and "national ownership," partnership stands for

⁴⁶ I mean the research agenda pursued by the post-Second World War Frankfurt School scholars (Sheehan, Michael (2005). *International Security: An Analytical Survey*. Boulder, CO: Lynne Rienner Publishers, p. 152).

⁴⁷ Jones, Richard Wyn (1999). *Security, Strategy, and Critical Theory*. Boulder, CO: Lynne Rienner Publishers, pp. 130-137.

⁴⁸ Chandler, David (2009). "Critiquing Liberal Cosmopolitanism? The Limits of the Biopolitical Approach". In: *International Political Sociology*, (vol. 3), pp. 53-70.

an evident political philosophy of individualism, expressed through promotions of self-reliance. Richter's proposals of social protection based on cash transfers to affected families reflect this mainstream policy. But can its community-centred dimension nurture an alternative policy instead?

As discussed, the difference between self-reliance, on one side, and a community-centred approach, on the other, together with the paternalist hypothesis, lies at the core of the income transfers question. Recommendations on transferring resources directly to families and communities, and not to intermediaries, are positive steps towards a better community-oriented policy. But what is the final aim of that orientation? Yash Tandon's proposal of "the national project" offers a contribution towards the research of a paradigm which grounds a sense of collective entity outside a strict liberal perspective, in which local realities and expectations may not be consistent with an ontology oriented to West-led global market integration. In this regard, the complex case of HIV/AIDS is particularly telling given the structural effects that Linda Richter's report attentively indicates.

In a time of global capitalist crisis and, indeed, unsustainable external mechanisms of prevention and treatment, it is relevant to research a paradigm which accommodates a collective policy approach to severe societal problems. As a 'totalitarian' epidemic, in the way that it constrains the totality of life of both infected and affected, it offers the possibility of exploring policy solutions addressing the totality of the problem. Possibly, a balanced mixture of foreign aid and local political sovereign deliberation consolidates path-breaking solutions to move from the totalitarianism of HIV/AIDS and colonial reminiscences into the totality of life possibilities.

Rivers and stones: citizens with HIV, activism and the Global Fund in Peru

Henry P. Armas

This paper explores the experiences of participation by people living with HIV/AIDS in CONAMUSA (Coordinadora Nacional Multisectorial en Salud or Multi-sectorial National Coordinator on Health), an organization that works as the local counterpart of the Global Fund to Fight AIDS, Tuberculosis and Malaria (GF) in Peru. The central argument of this paper is that the political stories of these leaders are marked by stigma and urgency and both contribute to a particular form of political action: necessity participation. The paper also examines the role of support groups as promoters of political awareness¹.

Does the particular condition of people living with HIV/AIDS (PLHA) affect the ways in which they participate and exercise their citizenship? What are the challenges and possibilities of participation as full citizens of PLHA? This case study on the Global Fund (GF) in Peru may help to clarify these questions. According to UNAIDS, there are 93,000 PLHA in Peru and around 52% of them receive Antiretroviral (ARV) treatment². However, there are many problems related to the inequality of access to this treatment. Approximately 20% of infected people in Lima, the capital, don't receive treatment and this amount grows to 70% in provinces.

The growing concern on the participation of PLHA is shared by international organizations, governments and civil society groups alike.

¹ This research would not have been possible without the invaluable collaboration of the courageous activists who took part in the fieldwork. I feel particularly grateful to Edward Armas, the facilitator of the workshops, who helped me to keep a reflective attitude during this process. I would also like to express my gratitude to John Cameron, Rosalba Icaza and Manine Arends for their guidance through this academic (and emotional) journey and to the HIVOS-ISS Civil Society Building Knowledge Programme, which made possible this research.

² UNAIDS (2008): Peru, <http://www.unaids.org/en/CountryResponses/Countries/peru.asp>, accessed on 12 February 2008.

This concern, for example, has been reflected in the emergence of GIPA (The Greater Involvement of People Living with HIV). According to UNAIDS³, GIPA is a principle that aims to realize the rights and responsibilities of PLHA, including their right to self-determination and participation in decision-making processes that affect their lives. It was formalized at the 1994 Paris AIDS Summit (42 countries agreed on the Principle) and later, in 2001 by 189 UN member countries. The 2006 Political Declaration on HIV/AIDS unanimously adopted by 192 Member States at the 2006 High Level Meeting on AIDS also advocated this Principle.

WHO'S WHO?

Global Fund to Fight AIDS, TB and Malaria: A foundation, the result of the efforts of different multilateral and bilateral donors to increase the efforts to fight against these diseases. As a partnership between governments, civil society, the private sector and affected communities, the GF represents an innovative approach to international health financing. The operation of the GF is different than other institutions (like WHO, the World Bank or UNAIDS) that oversee implementation of programmes with a large number of staff. The GF doesn't implement programmes, as it relies on Country Coordinating Mechanisms (local stakeholders that are formed by civil society organizations, the representatives of relevant State Ministries or NGOs).

CONAMUSA: The Peruvian partner (Country Coordinating Mechanism or CCM) of the GF. Its structure relies on the participation of government sectors, representatives of different sectors of civil society, including organisations of PLHA. CARE PERU is the administrator of the fund, and CONAMUSA is the institution responsible for elaborating proposals to achieve these objectives and supervise activities done by the GF. Currently there are 4 main platforms (that group other organizations) that participate in CONAMUSA. There are also many organizations that consider themselves as "independents", they are not affiliated to any platform and their level of involvement in the decision making processes around the representatives of PLHA is lower.

The main research question that this paper addresses is: What are the challenges and possibilities of participation as full citizens of PLHA

³ UNAIDS (2007) 'The Greater Involvement of People Living with HIV (GIPA)' [electronic version], *Policy Brief*: 4, http://data.unaids.org/pub/BriefingNote/2007/JC1299_Policy_Brief_GIPA.pdf, accessed 1 September 2008.

under the Global Fund scheme in the Peruvian case? The answer is related to topics such as the absence of participation of certain groups, the forms of participation of those groups that decided to be involved with CONAMUSA and the challenges that PLHA raise to the theories of citizen participation.

The methodology combined metaphor analysis and the use of focus groups. On the one hand, metaphors are a key element to shape reality and negotiate power as they express values and ideologies that spread out through language. Their use in informal conversations, homes, media, school or on the street affects the public arena in a constant process of meanings negotiations. In the case of HIV/AIDS, metaphors transform a mere disease into a cultural product with plenty of meanings. In “AIDS and its metaphors”, Susan Sontag⁴ reflects on the use of HIV/AIDS as symbol of latency, divine punishment, poverty, change (mutation) or invasion. Even more, guilt is accentuated through metaphors, maintained not only in everyday language but also through scientific language.

On the other hand, focus groups facilitate the gathering information on a collective basis. Focus groups provide a safer space for informants, encourage diversity of ideas and language and help to reduce the power of the researcher⁵. In this case, focus groups used participatory techniques which were complemented by individual semi-structured interviews. These techniques were: a) “The river of my participation”, participants were asked to draw the river of their lives to tell the story of their participation, discussing personal stories of activism, their diagnosis and their political action regarding CONAMUSA; and b) “Choosing images”, participants were asked to choose a combination of images to depict their experience participating in CONAMUSA.

The field work phase to gather primary data in Lima, Peru, was developed between July and August 2008. Five focus groups were organized with the four main networks (platforms) of PLHA: Peruanos Positivos, Alianza en Acción +, Plataforma Callao and Red Peruana de Mujeres Viviendo con VIH/SIDA. Fourteen interviews were done, from which eight were selected according to their relevance to the research objectives. I gathered information from different actors - PLHA, NGOs, the Ministry of Health and other state and academic actors -related to CONAMUSA to triangulate information. Finally, an interview with a key informant related to the GF Board was conducted in Amsterdam, The Netherlands.

⁴ Sontag, S. (1991) 'AIDS and Its Metaphors', in *Illness as metaphor and AIDS and Its Metaphors*. London: Penguin Books.

⁵ Laws, S. (2007) *Research for Development. A practical guide*. London: SAGE.

Two Theoretical Approaches

In this paper I will refer to two approaches in the analysis of our findings: Andrea Cornwall and her research on how power is related to (participatory) spaces and Sarah White and her forms of participation.

Cornwall⁶⁷ uses space as an entry point to analyze participation and theorize on power. Participation as space can be a useful device to unveil power practices. Participation spaces are not neutral as they gather people from different backgrounds, which have different ideas of meanings and power. These spaces are the settings where power is exerted and to distinguish them, Cornwall introduces the notion of “invited spaces”⁸. If power holders can create participatory spaces and invite different groups of society to participate, “invited spaces” can express already existing power relationships (the decision of who is invited or not is political). Due to this, it’s important to have “sites of radical possibility”, i.e. independent groups that can create opportunities for marginalized actors to gain capabilities and organize an agenda.

Sarah White states that not every kind of participation is positive as under certain circumstances, participation can even perpetuate unequal relationships and injustice. However, if the conditions are available, participation can also create the capacity in people to claim for their rights. White distinguishes 4 kinds of participation⁹: Nominal Participation (referred to the mere presence of people without voice in participatory spaces), Instrumental Participation (people are used as instruments to execute decisions taken by others, people have no voice but they participate building bridges, schools or health centres, in a basis of communitarian work with no power in the decision making process), Representative Participation (people have a voice and they have power in the decision making process) and Transformative Participation (people not only have a voice in the decision making process but participation is evaluated in terms of capabilities developed in people and processes, not only results). This classification establishes a hierarchy of values in which processes are more important than results. Therefore, it is a refusal of the search of efficiency usually related to market-oriented and logical positivist approaches.

⁶ Cornwall, A. (2002) 'Making spaces, changing places: situating participation in development.' IDS Working Paper 170: 35.

⁷ Cornwall, A. (2004) 'Space for transformation? Reflections on issues of power and difference in participation in development', in H.A.G. Mohan (ed.), *Participation: From Tyranny to Transformation* (pp. 75-91). London: Zed Books.

⁸ Ibid.

⁹ White, S.C. (2002) 'Despolitizando el desarrollo: los usos y abusos de la participación', in *Desarrollo, ONG, y Sociedad Civil Barcelona: Intermón Oxfam*.

In the following lines I will analyze the research results using two wide notions: space and time in participation. Finally, I will discuss how these issues raise theoretical challenges in the final section.

Participation and Space: A Geography of Activism

This section will start showing the results of the “Choosing Images” technique used in the focus groups. This information will be used to analyze the features of the CONAMUSA space, through its participation forms using Sarah White’s approach. After this, I will address some topics that have spatial connotations.

| List of Images (Choosing Images Technique) | |
|---|--|
| Figure 1 | A man with a padlock on his mouth |
| Figure 2 | A person carrying a heavy load with just a bicycle |
| Figure 3 | A human figure used as a puppet |
| Figure 4 | A group of people standing up with a hand on their chests, like singing a national anthem. |
| Figure 5 | Two male construction workers digging in the ground |
| Figure 6 | A crowd that together raises a giant fist |
| Figure 7 | Female workers with masks in a factory selecting grain |
| Figure 8 | Two hands holding a little plant |
| Figure 9 | Two persons (man and woman) in front of arrows pointing to different directions |
| Figure 10 | Four human figures of different colours under a crown |
| Figure 11 | A question mark |

Predominant Forms of participation in CONAMUSA

Not many highly ranked elements of nominal participation were found. However, instrumental, representative and transformative participation elements were present. References to instrumental participation can be related to the excess of work depicted in figure 2: “the human resources team is like the bike: so small compared to the load that it has to carry”. Another instrumental element is the possibility of manipulation of the representatives (figure 3) by other actors in CONAMUSA due to different knowledge: “you have to know a lot on the topic, you know that there are numerous technicians and professionals”. NGOs appear as power holders and this has to be understood in a wider landscape of negative perceptions about NGOs in the country. Also, the lack of clarity in this space’s rules (accountability, elections, etc.), affects the process of representation.

Elements of representative participation were suggested mainly by Peruanos Positivos (as the two PLHA representatives in CONAMUSA are from this platform). This group said: “we have a participation in which you can hear these voices and the existing problems”(figure 6). Also, Peter Van Rooijen, ex representative in the GF Board, chose figure 6 to describe the experience of the PLHA delegation in the GF, giving a similar meaning. It is interesting to note the use of metaphors such as “voice”, “to hear”, and “force”. In these cases, representation is portrayed as something tangible that has to be noticed, perceived. Tangible results are the best way to corroborate this presence.

Transformative participation can be traced in different themes. One of them is the sustainability of the process, framed by some informants as a sensation of hope or being part of something new and different. For a Health Ministry representative (José Luis Sebastián), there is hope (figure 8) in CONAMUSA as “in our country there is a disposition to sow something new”. The little plant figure was also used to describe an incipient process at global and national levels. Political skills and abilities are required for a sustainable multi-sectorial space. Transformative participation is related to these learning processes. Different metaphors of space were used (e.g. expand, grow, small). The emphasis on the country as CONAMUSA’s scenario helps to realize on the insufficient work in the regions so far.

The effects of funding: the activist-consultant dilemma

Along the stories of different forms of participation, different tensions in the CONAMUSA model were identified. One of them is the activist-consultant dilemma. When the GF projects began in Peru, they involved many activists working as consultants who appeared in sub-receptor organizations in different GF projects. On the one hand, those projects needed the experience and social networks of the activists and it represented recognition of their experience. On the other hand, this situation implied less time for advocacy activities as these jobs involved more than one consultancy at the same time and constant travelling. The situation wouldn’t have been problematic if new activists had been found to fill the void left by the departing consultants.. As it will be discussed later, after HAART (Highly Active Antiretroviral Treatment), less people got involved in activism and GAMs (Grupos de Ayuda Mutua or support groups) were not the space that they used to be. All this happened in the middle of a wider context of tension between NGOs and communities in Peru.

But let’s reflect now with a different frame. If the effect of turning activists into consultants weakens the movement, it’s relevant to ask if the

negative consequences are a collateral effect of the model itself. Studying development interventions in Lesotho, Ferguson reflected on the negative consequences of development interventions. According to Ferguson¹⁰, the deployment of development can contribute to the de-politicization of a space. He uses the metaphor of an anti-gravity machine to explain how some interventions can suspend politics.

Is the CONAMUSA model performing together with the stigma and individualizing bio-medical approaches to disassemble a rising social movement? To examine this machinery implies to go much further than CONAMUSA and the GF as the model may not be an intended purpose of a person or a particular institution. Good intentions may be lost by a power architecture that disguises itself and that hides among the numerous details of the model structure (that is why it's important to realize about these mechanisms). Institutions are not monolithic and there are always different factions and practices, spaces for dissidence and a constant process of negotiation of paradigms. "Sites of radical possibility" play a key role in the dismantling of this anti-politics machinery as they can generate activists that could help to re-politicize this space. That is why independent groups are important.

The importance of the sites of radical possibility to deal with the challenges that "invited spaces" represent, such as the advocate-partner issue in a multisectorial model¹¹ or the activist-consultant dilemma cannot be overlooked. GAMs may play this role. These spaces are crucial to re-politicize an HIV/AIDS agenda.

Before the treatment, GAMs were regarded as groups to perform a death process with a certain dignity and peace. They were a key space that provided not only emotional support but also information and the opportunity to get together with peers, they provided spaces that turned political in a later stage, they enabled PLHA to meet other people with the same diagnosis and who may have faced this situation successfully and they also helped to identify problems and to use the group dynamics to solve them.

Nowadays, GAMs have become weaker. Some informants have stated that people don't participate like before, and that the original purpose has changed. The lack of participants was attributed in certain focus groups to the post-HAART moment in activism and to policies concerned with individualizing biomedical approaches that prioritized

¹⁰ Ferguson, J. (1990) *The anti-politics machine. "Development," depoliticization, and bureaucratic power in Lesotho.* Cambridge: Cambridge University Press.

¹¹ A multi-sectorial model implied to gather State and civil society actors to work together. Some activists regret the private-public partnership as they consider that this model limits their possibilities for public critiques and advocacy. For others, this implies a less confrontational and more dialogical style.

medicalised solutions instead of collective action. Although GAMs provide an initial opportunity to re-politicize HIV/AIDS, there comes a point at which they are not enough to overcome structural problems. That is when it is time to move to other spaces.

Participation and Time: Facing Limitations

We are made of time¹². The entire human experience is based on it. Decisions about time shape our world and define who we are. In participation theories, time has been usually framed as a cost. However, time (as an essential element that shapes people's lives) is much more than a cost as it determines people's decisions about their participation and how participation is experienced by them, especially in the case of PLHA. Following a reflection on time, this section will be focused on the constraints to participate in the activists' stories.

Navigating through Participation Rivers

The rivers technique, with its waterfalls, eddies, rapids, backwaters, tributaries and branches, showed life stories of political awareness and action. Every story was unique and time was used differently in each case. However HIV/AIDS was a common element that gave this time a new sense (not only scarcity but also transcendence). Some key moments were identified.

To know about **life before the diagnosis** was important to reflect on the previous political story of people who are participating now in activism. While some people had strong political stories of participation (e.g. in political parties or in neighbourhood organizations), other people stated that getting HIV changed their political life completely as they didn't have an active participation before.

The diagnosis was seen as a crucial moment in all the focus groups that changed not only the participants' lives but also their stories of participation. Recurrent metaphors refer the diagnosis as: "a cut in the life", "an interrogation mark" or "darkness" as they didn't know what was waiting for them. A fall, storms and "the harvest of what we sowed" depicted feelings of anger, depression, sadness and suicide thoughts. However, the hardest experiences were related by people living in the provinces (given that the stronger discrimination in smaller cities increased loneliness feelings). In consequence, during the diagnosis period, participation decreased and isolation feelings appeared.

¹² I am grateful to Giuseppe Campuzano for his inspiring reflections on time. Conversation on 15 April 2001.

The involvement in activism and in CONAMUSA related spaces was linked to the GAMs. But to take part in activism beyond GAMs was a major step as the involvement in a wider organization was referred to as a “growing river”, a dream that came true or clarity in a confusing process (“I found light”). With these stories, stones and rocks symbolized difficulties that coexisted with new opportunities e.g. CONAMUSA was referred many times as a difficult space where activists had to deal with “turbulences” (tensions) which also helped them to strengthen their river (experience). Also, CONAMUSA’s role on free HAART was regarded as “a sun”.

The activists represented their current moment with fish, blue tones, trees, fruits and families. In some cases, roses represented people alive and eddies represented organizations working and interrelating with other groups under a shining sun. There was a “normalization” of HIV in everyday life. However, people referred also to the need of constant support to deal with the difficulties of their activists’ roles. It can be said that in general, stigma is a major barrier to participation, but there are many other difficulties, such as the lack of resources, the post-HAART moment, conflicts among groups, lack of information, personal circumstances (courage, personal stories of activists) and the civil society history in a specific context.

Antiretrovirals and politics

Another element that influenced the experience of PLHA participation is the universal access to HAART (Highly Active Antiretroviral Treatment), available in Peru since May 2004. The impact of this policy in the PLHA activism was notorious. Two periods can be distinguished: before and after HAART.

CONAMUSA was created in May 2002. Many informants say that before HAART (before the GF) “there was more activism”. In that time, The Union for Life (El Colectivo por la Vida) appeared with a clear objective: to get free access to treatment for PLHA. This clarity and the possibility to gather efforts around a single agenda were some factors of its success. The Union conducted different activities to exert pressure on the State through legal and social action and this coincided with the beginning of the GF presence in Peru.

The GF created the possibility, with CONAMUSA, to engage the Peruvian State in the HAART policy, covering the first year (2004) of the treatment and transferring completely that responsibility to the State in the third year. The impact of this was enormous in terms of activists’ health and political action. For the PLHA community it was a long awaited victory.

Steven Robins has reflected on the different effects of framing ARVs under a mundane medicalised approach or charged with an aura of a quasi-religious miracle. Research comparing the UK (where HIV may be considered a chronic illness like diabetes) and South Africa (where the narratives of Lazarus effect and “God’s gift of life” are strong) led, among other reasons, to different consequences in activism. While in the UK, a biomedical approach favoured individual treatment and the de-politicization of the HIV/AIDS movement, a more collective response and a different frame of ARV treatment in South Africa, allowed the movement continuation after the HAART distribution.¹³

In the Peruvian case, many informants referred that once HAART arrived, the activists went away. The access to medicines finished a “necessity” period in activism. Once the necessity was covered, the agenda changed and activism decreased. New patients had more possibilities to have access to medicines, to be reinserted at their workplaces or to deal with the disease in their families’ environment, without getting involved in activism. They had more choices. But the HAART introduction also framed HIV/AIDS under a stronger biomedical approach. Besides this, the new post-HAART moment coincided with the formalization of CONAMUSA’s legal framework and the GF projects’ implementation in which activists were greatly involved. The ARV effect on activism shows that citizenship identities around HIV/AIDS can be fluid and difficult to predict (and therefore to plan) by international AIDS policies.

Necessity as a Catalyst for Participation

Given all these constraints, why do PLHA participate? Many reflections during the focus groups or interviews suggested the idea of necessity as a deeper level of motivation. As an activist mentioned: “How do you create an activist? First, as there were no medicines (...) they started to create GAMs and that was a support. With time, some people stopped just hugging each other and started to demand rights (...) necessity made us activists”.

Furthermore, as the context of participation was a necessity, the activists lacked free choices to define the conditions and forms of their participation. This “necessity participation” challenges the common notions of what a good citizen is supposed to do. In the case of HIV, to participate was not in any activist’s plans. As somebody mentioned:

¹³ Robins, S. (2005) 'From "medical miracles" to normal(ised) medicine: AIDS treatment, activism and citizenship in the UK and South Africa', IDS Working Paper 252.

“Here the State invisibilized the issue, then there was the necessity that we, the activists had to pay for that. It was like paying something to make the problem of HIV/AIDS visible, but with your face. Many of us had to appear in the media, but nobody would have liked to be known making public your diagnosis (...) Now it is different, nobody has the idea of becoming an activist, because if I receive my diagnosis and I have the medicine, then I do my normal life... They made us activists by force”.

Participation has costs, but in the case of PLHA, the cost can be very high. Activists had to “pay” (a cost, something from them given to others) with their “face” (revealing their diagnosis publicly). Nobody planned as a life project to become an “HIV activist” having their own diagnosis as a political tool of identity. The disclosure of their condition exposed them to something more than discrimination: stigma. The consequence is a perverse dilemma: PLHA are discriminated against because the opportunities to participate (get information, claim rights) are few; but at the same time, if they participate, they are exposed to deeper levels of stigma and exclusion, putting at risk their health and lives. However, not-participating also implied risk for their lives.

Another element to consider is that necessity is time. Before HAART the diagnosis meant a death sentence, a race against time. The political action was marked by this element – urgency, desperation, necessity, lack of time. After HAART there is a change in the level of necessity and an evident change in the level of activism. With HAART there is time. Even more important: the *perception* of time is different. This new way to perceive time (and therefore life) affected participation as it had been argued previously.

Conclusions: Challenging Theories

The evidence found has raised new questions and has posed challenges to current participation theories, which could be grouped around two issues:

Necessity Participation

The decision to become an activist was hard and costly. If every participation experience represents a cost, in the case of HIV/AIDS this cost was very high. To become an activist implies to turn discrimination into stigma (a public mark that separates). This way, participation implies that PLHA will have a public mark and become more vulnerable. Rai¹⁴

¹⁴ Rai, Shirin. (2008) 'Civic Driven Change: Opportunities and Costs', in Alan Fowler & Kees Biekart (eds.), *Civic Driven Change. Citizen's Imagination in Action* (pp. 103-117). The Hague: Institute of Social Studies.

reflects on the high costs that participation may entail and the different effects on volunteers' work. These costs cannot always be foreseen and it is important to approach programmes for change so that those who step forward to take on the burdens of activism do so with the information, knowledge and support that is appropriate to the task.

Despite its high price, in the case of PLHA, participation was a necessity to get medicines and survive. Participation was not only difficult, but even unwanted. That is why necessity participation implies an enormous amount of courage and generosity. As one activist said, "when you are a child, you don't dream to become an activist living with HIV".¹⁵ Beyond the idealistic models of platonic citizens that fulfil their human activity through political action, many people participate for necessities. There is certain amount of necessity behind every form of participation. But what makes necessity participation different? This specific form of participation appears when the life of the people involved is at risk unless they participate. In this context, participants are able to accept high costs for their participation.

Rai¹⁶ reflects on the complexities of freedom when volunteers decide to participate as agents. For her, freedom itself is difficult to define because of the way in which we approach the interplay between structure and agency. For some it is rational choice which determines the exercise of agency – maximizing advantage and minimizing risk – while for others, rationality is itself framed by dominant social relations and is therefore open to question.

However, even with freedom limitations, it is fair to say that necessity participation can promote the creation of capabilities. Also, the level of involvement among activists is deeper than in other cases in which life is not at risk. The HAART gave the activists more opportunities to choose about their participation and indeed, many continued participating. In necessity participation, some people will continue participating once the necessity has gone, as they discover that their participation can have an effect in their lives beyond the necessity. Necessity participation can encourage the emergence of necessity identities, which can be fluid as these identities may disappear when necessity is overcome as in the post-HAART period in Peru (this may be different in other contexts when there are other factors intervening in the continuation of activism).

But what is the relevance of necessity participation for development organizations? A first issue is the importance of time in participation. The negative consequences of HAART on the HIV/AIDS

¹⁵ Personal conversation with one PLHA activist. July 18th 2008.

¹⁶ Rai, Civic Driven Change.

social movement are in part due to politics-without-time to generate long-term political agendas. They may bring benefits in the short-term but may also have negative consequences in the long term. In CONAMUSA, time is related to two problems: the activist-consultant dilemma (no time to involve new activists) and the post-HAART political decline (no time to generate a long-term agenda). The amount of money that Peru received from the GF for HIV and tuberculosis related projects is now \$69,088,979¹⁷. It is evident that the GF affected activism, changing power relationships, dynamics and practices in civil society. Taking into account the importance of time, may lead to sequenced funding alternatives to have time for adaptation and new ways of organization. A second issue is the importance of different narratives about HIV/AIDS, which can bring different results and can avoid the reductionism of mere biomedical approaches. A third issue is power inequality in participatory spaces as necessity participation, implies participants under necessity don't have the same power, or time, as other actors. Therefore, the big challenge is to change necessity participation into a transformative process, once the urgent agenda is covered and this will require participants to think and work in the context of a deeper social transformation (e.g. on HIV/AIDS prevention, sexual diversity or to change the construction of AIDS as a stigmatizing disease).

But is the necessities' frame a good approach for the participation experience of PLHA? Discussing the findings of this document with people working in HIV/AIDS issues, I discovered that many of them have thought about this particular type of participation and some of them even called it "survival" participation. However, I consider that the "necessity" frame provides a flexible term that makes it possible to talk about levels in this necessity and to think in a continuum instead of a binary (yes or no) concept (like the "survival" frame may suggest). However, it's fair to say that it is not just about necessities but about how these necessities are framed, as these frames are crucial for people to understand (make sense of) their own activism. I am aware that the word "necessity" brings heavy baggage in terms of meanings in development debates. Nevertheless, I think this is exactly why this term may be more interesting as it can enrich the debate.

¹⁷ The Global Fund (2008): The Global Fund.
<http://www.theglobalfund.org/Programs/Portfolio.aspx?countryID=PER&lang=en>,
accessed on 22 September 2008.

The importance of micro-participation

One activist talked about her experience in GAMs and other activism spaces as a ladder. This suggested the idea of different levels of participation. This research on CONAMUSA led to a period of reflection on the GAMs. The relationship was clear: activism in the inter-institutional level is related with what happens in a micro level.¹⁸ Therefore, it is plausible to think in a system of different levels of participation with different possibilities and limitations: GAMs, independent activist's groups, platforms, COREMUSAS (Coordinadora Regional Multisectorial en Salud or Multi-sectorial Regional Coordinator on Health) and CONAMUSA. They all influence each other.

The reasons why GAMs can be the foundation of other levels of activism lie in the personal dimensions of politics. It was Carol Hanisch who coined the phrase "the personal is political" in 1969, during a feminist movement debate on: if the consciousness-raising groups were just "personal therapy" on personal problems and "not political".¹⁹ Coincidentally Hanisch made a fierce defence of therapy groups as a means of political therapy.

If the therapeutic is political, then GAMs, a space originally considered as "just therapeutic" can be an opportunity for awareness and action. GAMs may be the sites of radical possibility to which Cornwall refers. It is important that citizens have spaces for interaction with others, especially those who are more excluded and disempowered. GAMs also defy the typical biomedical approach seen in a doctor-patient relationship that has a clear power inequality and a de-politicizing medical discourse that can isolate. GAMs brought the opportunity to work with individuals departing from a personal level of awareness. Some participants and groups moved then to a macro-political level of awareness.

The UNAIDS Policy Brief on the GIPA Principle mentions different levels of participation's benefits that can be compared with the levels proposed here: self-esteem in an individual level, change of perceptions at an organizational level and facing prejudice in the community and on a social level.²⁰ However, the mechanisms that can enable the mobility from one level to other are not clear. Also, the importance of GAMs as an opportunity for political awareness and participation should be recognized by GIPA.

¹⁸ I took the idea of participation levels from Alex Shankland. Conversation on 3rd November 2004.

¹⁹ Hanisch, C. (2006) 'The Personal is Political. Introduction', <http://scholar.alexanderstreet.com/pages/viewpage.action?pageId=2259>.

²⁰ UNAIDS (2007) 'The Greater Involvement of People Living with HIV (GIPA)' http://data.unaids.org/pub/BriefingNote/2007/JC1299_Policy_Brief_GIPA.pdf.

What is the relevance of the notion of micro-participation for development organizations? The levels of participation and the importance of GAMs bring different implications. Firstly, it is important to reinforce the GAM system to engage new activists in CONAMUSA. With that, it is possible to have political sustainability in the model, face the activist-consultant dilemma and create alternative ways of organization when the funds are affecting the political environment. Secondly, it is crucial to have democratic frameworks in the different levels to have a sustainable PLHA representation in CONAMUSA. It is important to have clear election rules not only in the CCM, but also encourage clear rules in its constituents. It is also important to renovate the CONAMUSA Presidency with different state and civil society actors being eligible. Additionally, this representation has to be less generic, giving space for more diversity as the situation of gays, transgenders or sex workers is different. Thirdly, different levels of participation imply a focus on capabilities to enable mobility between levels. A constant element in the interviews and focus groups is the importance of capabilities regarding technical, organizational and political issues. Many informants have complained about the lack of training opportunities for activists. Therefore, it is important to develop a human resources policy, investing in PLHA education. Only by this, the PLHA movement can propose solutions, influence policies and gain legitimacy.

A final word

GAMs, time, activists, metaphors, ARV, participation – these words have shaped this paper giving sense to voices, memories and hopes. These words have also been promises of citizenship. But participation can be an elusive promise and in the case of HIV/AIDS it can represent the difference between life and death. Citizenship built in this particular scenario can not only bring change but also can raise questions and defy paradigms. HIV/AIDS has plenty of metaphors and meanings. One of the most terrible and dehumanizing ones is the categorization of PLHA as “others”. This research is an effort to recognize this group with dignity (the same dignity that any other human group deserves), understanding the stories of PLHA as possibilities of the human experience. What does it mean to be human under the conditions of HIV/AIDS? Only by understanding this research in this way, links can be developed with other groups of civil society. Only in this way, dignity can become a common ground (and not just a mere euphemism for pity).

Development cooperation: a clash of worldviews

Simon Polinder

In order to illustrate the title of this paper, I would like to start with a small story from some missionaries in the north of Nigeria. It shows how development cooperation can be understood as a clash of worldviews. Missionaries in Nigeria were worried about the level of infant mortality due to stomach infections transmitted in drinking water. They explained to ‘converts’ at the mission that the deaths were due to tiny animals in the water, and that these animals would be killed if they only boiled the water before giving it to the children. Talk of invisible animals was greeted with some scepticism: the babies went on dying. Finally a visiting anthropologist suggested a remedy. There were, he said, evil spirits in the water; boil the water and you could see them going away, bubbling out to escape the heat. This time the converts believed the story.¹

Today, many development organizations deal with the so-called gap between the North and the South.² Nongovernmental organizations (NGOs), policymakers at the ministries of Foreign Affairs, the International Monetary Fund (IMF), the United Nations and the World Bank are all striving for, at least, less difference in welfare between the North and the South. They all intend to extend the ‘success’ of the North, often also called the West, to the rest of the world. Most economists agree that the welfare of the North has been the result of modernization. That means that western institutions face the question to what extent countries that aspire towards the same living standard as those in the North need to

¹ Appiah, Kwame Anthony (1992). *In my father's house. Africa in the philosophy of culture*. Oxford: Oxford University Press, pp. 134, 135.

² The North consists of North America, Europe, Russia, Australia and Eastern Europe. The South is composed of Latin America, the Middle East, Africa, China and South Asia. In: Goldstein, Joshua S. and Jon C. Pevehouse (2008). *International Relations*. New York etc., 4th edition: Pearson Longman, p. 20. In this paper I use the word North over against the South, but in many cases it can also be read as the West, meaning Western Europe and North-America.

go through the same historical process. Does modernization require westernization?³

This question can be answered in many ways. The answer given can be of importance for policies regarding countries in the South. If people believe in a universal course of history, which has often been expressed by Northern countries to date, they would stimulate or force others to do so. The IMF and the World Bank are examples of such a policy. Organizations that do not believe in the 'superiority' of the West or of any culture at all, would admire local cultures as they are. They hesitate to intervene in order to change certain cultural habits or structures. Many answers to the question above move between these two opposite positions. Before we can answer the question whether modernization requires westernization we really need to understand what is happening between the North and the South. That is the aim of this article. The first issue that I deal with is how the relationship between the North and the South can be seen as a clash of worldviews. This paper uses the relationship between the Middle Ages and modernity as a framework to understand the relation between the North and the South. This does not mean that I equate the Middle Ages with the developing world and modernity with the North, but as a framework it is very useful to use that historical period, because it functions as a mirror.

This paper takes the thoughts of the philosopher Rene Descartes (1596-1650) as its starting point. Descartes' search for absolute certainty ended in a scientific world picture that has determined western culture until today to a large extent. It determines many aspects of our present day thinking. It influences our ideas about rationality, religion and development: issues that are very much relevant in our understanding of modernization and that are important for the relations between the North and the South.

The leading question of this paper is how the misunderstandings between the West and South can be explained as a clash of worldviews, understood as a pre-scientific comprehensive framework of one's basic beliefs about things, and what this means for the question whether modernization requires westernization. I illustrate the clash of worldviews with the fight against HIV/Aids and describe why the involvement of worldview is necessary. After that, I come back to the question to what extent modernization implies westernization. I respond to that question by stating that the North should heal itself first, before it takes care of the South.

³ I refer to the title of the following article. Lal, Deepak (2000) 'Does modernization require westernization?'. In: The Independent Review, (vol. 5), pp. 5-25.

Modernity as a break with the common human pattern

The time before modernity has been characterised by the Dutch historian Jan Romein (1893-1962) as the Common Human Pattern. That pattern can be described as follows. Life, mainly agricultural, was based on a cosmic rhythm. People were subject to that rhythm; they were part of a life cycle and tradition played an important role. The authority of the elderly people and the tradition was not really debatable.⁴ Modernity broke that view, it wanted to investigate and see what goes on in the world in order to control it. The cosmic rhythm became subject of critical investigation. The strive for control and freedom replaced the subjection to life. People started to check the value and truth of traditions. Rationality became the highest authority. A new view of mankind, the world and truth emerged. Mankind became master of reality. Giovanni Pico della Mirandola (1463-1494) wrote already a characteristic essay about it. In his *Oration on the dignity of man* he wrote that God said to Adam:

I have placed thee at the center of the world, that from there thou mayest more conveniently look around and see whatsoever is in the world. Neither heavenly nor earthly, neither mortal nor immortal have We made thee. Thou, like a judge appointed for being honourable, art the molder and maker of thyself; thou mayest sculpt thyself into whatever shape thou dost prefer. Thou canst grow downward into the lower natures which are brutes. Thou canst again grow upward from thy soul's reason into the higher natures which are divine.⁵

Before Descartes a new way of facing reality was already there, but Descartes gave it an absolute anchorage in human reason.

Descartes' methodological doubt

It is very much debated when modernity started. Some would say that Gutenberg's adoption of moveable type or Luther's rebellion against the church authority signalled the beginning of modernity. Others would say that the end of the Thirty Years' War, the French or the American revolutions are the origin of modernity. I would plead for a starting point beginning with Descartes. Stephen Toulmin writes that many courses at British and American universities begin their courses on modern philosophy with Descartes and their courses on the history of science with

⁴Romein, Jan (1954). *Area van Europa. De Europese geschiedenis als afwijking van het algemeen menselijk patroon*. Leiden: Brill, p. x.

⁵Pico della Mirandola, Giovanni (1998). *On the dignity of man*. United States: The Bobbs-Merrill Company, pp. 4, 5.

Galileo Galilei (1564-1642). What Descartes and Galilei share is a commitment to a new rational method of inquiry.⁶

In the case of Descartes his commitment to the rational method was the result of his methodological doubt. He wrote about it in 1641 in his book *Meditations on first philosophy*.⁷ The book is made up of six meditations in which Descartes first discards all belief in things which are not absolutely certain and then tries to establish what can be known for sure. His first meditation starts with noting the large numbers of false beliefs that he holds for sure since his childhood. If he wants to establish something which is firm and likely to last, he should suspect all his former beliefs. The next step is that he acknowledges that his senses have deceived him before. A demon might have put the information in his head or maybe he was dreaming. All sensory information could be imagination. As a consequence Descartes's own existence could be an illusion, but the fact that he could convince himself of that illusion proves his existence. The fact that he is thinking, makes it necessary that he exists. Descartes makes the thinking I the ultimate foundation of all trustworthy knowledge. That means that we only can know the external world, e.g. the body, through our reason. All knowledge could be unreliable, except knowledge that meets the rational criteria. The rational and mathematical method becomes the only way to acquire knowledge.

According to Geertsema this leads to at least two problems in the Cartesian thinking: the problem of knowledge and the problem of meaning. The first problem results from the assumption that reality exists as an objective reality without intrinsic meaning. The subject has to give meaning to reality and this easily leads to the projecting of meaning. The second problem is a consequence of the first. If reality does not have intrinsic meaning, we do not know which norms should be applied. In the end the subject is both the origin of meaning and normativity. It could lead to an unbalance between private interests and normative appeals and facts over values.⁸ Before I start to explain how the Cartesian worldview has influenced Western Europe, I would like to remove the suggestion that modernity should be seen as rational and the Middle Ages as irrational. The Middle Ages were rational too, but Descartes made a shift with respect to Augustine, which is understandable given the historical

⁶ Toulmin, Stephen (1990). *Kosmopolis. The hidden agenda of modernity*. New York: The Free Press, p. 8.

⁷ Descartes, René (1993). *Meditations on first philosophy*. United States, 3th edition: Hackett Publishing Company.

⁸ Geertsema, H.G. (2008). 'Knowing within the context of creation'. In: Faith and philosophy (vol. 25), No. 3, pp. 237-260. and Taylor, Charles (1989). *Sources of the self. The making of the modern identity*. Cambridge: Harvard University Press, pp. 143-158.

background of Descartes. He lived during the Thirty Years' War (1618-1648) that began as a religious war and spread throughout Europe. Descartes searched for certainty in order to prevent life from uncertainty. He differed from Aurelius Augustine (354-430), whose ideas were very influential during the Middle Ages. Augustine searched for absolute certainty and found it when he said: 'My heart is restless until it rests in You, O God.' Descartes did the same but he ultimately found rest in the fact that the thinking I existed. Both Descartes and Augustine were believers, but they took a different starting point.⁹ Charles Taylor (1931-) writes that Descartes's new conception of inwardness (compared with the inwardness of Augustine), his idea of self-sufficiency and autonomy by reason, prepared the ground for modern unbelief. He also suggests that it could be an explanation of the fact that modern western civilization exhibits widespread unbelief.¹⁰ That conclusion corresponds with the way economist and sociologist Max Weber (1864-1920) sees it. The existential threshold of modernity for Weber is the 'ethical postulate that the world is a God-ordained, and hence somehow meaningfully and ethically oriented cosmos.'¹¹ The threshold of modernity may be marked precisely at the moment when the unquestioned legitimacy of a divinely preordained social order began its decline. Modernity emerges, or more accurately, a range of possible modernities emerge- only when what had been seen as an unchanging cosmos ceases to be taken for granted.¹²

As a result of the preceding part, I define modernity as the following: the period of history associated with the replacement of the belief that the world is God-ordained by the belief in the ability of reasoned thought (and especially science) to achieve breakthroughs leading to human (material) progress.¹³

The impact of Descartes on modern culture

Taylor describes in what way Descartes has shaped Western culture. For him the words disengagement and rational control are central. The

⁹ Charles Taylor has described the continuity and the transformation between Augustine and Descartes in more detail. He states that the transformation in the doctrine of moral resources from Augustine to Descartes is no less momentous than that which Augustine wrought relative to Plato. Taylor, *Sources of the self*, p. 142.

¹⁰ Taylor, *Sources of the self*, p. 158.

¹¹ Eisenstadt refers here to Weber, Max, *Religious rejections of the world and their directions*. In: Gerth, H. H. and C. Wright Mills (ed.) (1946). *From Max Weber: Essays in sociology*. New York: Oxford University Press, p. 351

¹² Eisenstadt, S. N. (2000). 'Multiple modernities'. In: *Daedalus*, Winter 2000, (Vol. 129), No. 1.

¹³ Steans, Jill and Lloyd Pettiford, *Introduction to international relations. Perspectives and themes*. London: Pearson Longman, 2nd edition, p. 251.

mechanization of the scientific world picture, was also an objectification, in the sense that it deprived the world of its normative factor. Descartes's turn to reason, situating the moral sources within us, was a shift from the senses to reason. He freed (disengaged) himself from the confusion between the soul and the material. For Plato humankind realizes his true nature as supersensible soul when he turns towards supersensible, eternal, immutable things. This turning includes his seeing and understanding of the things that surrounds him. Descartes made a distinction between the material world, which should be objectified, and the immaterial. This dualism leads to an instrumental vision of the world in which control seems central. Descartes postulated God as the divine fiat of the axioms of mathematics.¹⁴ The existence of God was necessary in order to secure the truth of reason.

These ideas have worked out differently in the following centuries. Weber has described how rationalization influenced all domains of life: economy, religion, art and politics. In politics this process revealed itself in bureaucratization.¹⁵ Later on the American sociologist George Ritzer (1940-) applied this to the present-day situation; he called it McDonaldization.¹⁶ During the Enlightenment modernity became conscious of itself. A typical expression of the mood of these times is the text of Kant about Enlightenment. For Kant Enlightenment is man's release from self-incurred tutelage: 'dare to know!' ('sapere aude').¹⁷ Laziness and cowardice are the reason that many people without external directives nevertheless remain under tutelage.¹⁸

Prior to the modern period, religion played an important role in understanding and explaining nature. Human society was thought to be ordained by God and organized according to His will. One characteristic of modernity is that secular thoughts, founded on rationality and scientific evidence, challenged the role of religion in political life. The Enlightenment rested on the belief that science could be applied to human problems and that it would improve the well-being of society. The new faith in rationality and science made this possible.¹⁹

¹⁴ Taylor, *Sources of the self*, p. 161.

¹⁵ Weber, Max, *Bureaucracy* and Weber, Max, *Religious rejections of the world and their directions*. In: Gerth, H. H. and C. Wright Mills (ed.) (1946). *From Max Weber: Essays in sociology*. New York: Oxford University Press, chapters VIII, XIII.

¹⁶ Ritzer, George (1993). *The MacDonalization of society*. California: Pine Forge Press.

¹⁷ Goudzwaard, Bob (1997). *Capitalism and progress. A diagnosis of Western society*. Grand Rapids: Paternoster Print, p. 36.

¹⁸ Kant, Immanuel, *An answer to the question: what is Enlightenment*. In: Reis, H.S. (ed.) (1991). *Kant. Political writings*. Cambridge: Cambridge University Press, pp. 54-60.

¹⁹ Pettiford, *Introduction to international relations*, p. 210.

Weber has stated that rationality is not the way for fulfilment. It can help with the decision making process, but it provides the means not the goals. That leads to a strict distinction between the world of the facts, science and reason and the world of meaning and values. According to Weber we have lost the sense of meaning and direction.²⁰ Max Horkheimer (1895-1973) and Theodor Adorno (1903-1969) called this the “Dialektik der Aufklärung”. Society became locked in an ‘iron cage’. Science and technology tried to colonize the world of meaning, but instead of controlling, human beings became controlled. They lost their freedom and meaning. Weber was rather pessimistic about this development, and the Neo-Marxists Adorno and Horkheimers were even more so.

Modernity and the relation between North and South

Western culture has been influenced by this way of thinking, the dominant cultural pattern as described above. We can trace the impact of it in politics and science. It becomes especially visible when the West comes into touch with non-Western cultures; cultures that are not familiar with Descartes and the Enlightenment. A specific field in which this plays a role is development cooperation. In a serious and well-meant attempt to help developing (southern) countries, the North often fails, because of the discrepancy between their ‘modern’ view and the ‘traditional’ view of such societies. Below, I use three notions: progress, rationality and religion to illustrate how the North has been influenced by modernity and in what way it impacts the misunderstandings between Northern countries and Southern countries.

Progress

Bob Goudzwaard describes the idea of progress in his book *Capitalism and Progress*. He states that the belief in progress became part of western culture during the Enlightenment. The natural sciences made impressive achievements, the economy expanded and new continents became accessible to all. The English historian Peter Gay (1923-) said that progress was the experience before it became a program. The idea of progress had the characteristics of a faith. It was like the letter to the Hebrews says: ‘the substance of things hoped for, the evidence of things

²⁰ Weber, Max. *Science as a vocation*. In: Gerth, H. H. and C. Wright Mills (ed.) (1946). *From Max Weber: Essays in sociology*. New York: Oxford University Press, chapter V.

not seen.²¹ They believed that reason, which had proved to be a reliable and successful guide in the past, would bring more progress on all domains of life. A typical expression of this way of thinking is expressed the French philosopher de Condorcet (1743-1794). He saw that with the idea of human perfection the final barrier to the lost paradise was removed.²² What happened in fact was the replacement of God by the self-realization of mankind. The idea of progress became a program. The notion of progress has three characteristics: it was anti-Christian, it had paradise expectations and was directed at the improvement of society.²³

Peter Gay gave the first volume of his book about Enlightenment the subtitle: 'the rise of modern paganism'.²⁴ Although French philosophers saw deism as a temporary ally in their opposition to the church, they would not call themselves deists. Carl Becker (1873-1945) has given a description of the assumptions of the Enlightenment in his book *The heavenly city of the eighteenth-century philosophers*, which are the opposite of the church's confession. (1) Humankind is good by nature. (2) The goal of life is life itself. (3) Humankind is able to fulfil the good life on earth. (4) The first and necessary precondition of the human spirit is to become freed from ignorance and superstition and the body has to be freed from arbitrary constitutional and social authorities. The German and British philosophers were not as radical as the French were. In Germany and England the deistic tradition was much more influential. But Peter Gay doubts if they were better off: 'the philosophers paid a price for fraternizing with the Christian enemy. But the Christians paid a far heavier price.'²⁵

As stated by de Condorcet, the attempt to regain the lost paradise, was a very influential motive in the Enlightenment thinking about progress. Kant's essay *Perpetual Peace* is also an example of that motive. The expectations of the Enlightenment had certain similarities with the Stoic image of paradise. The Stoic referred to a golden age in which there was no particular property. Everybody could enjoy and reap the fruits of their own labour. There was no state and everybody was equal. It came to an end, because some people misused the common property. As a result of this, classes and the state arose. The same motives returned in the Enlightenment, but it differed from the Stoic view because it was

²¹ Hebrews 11: 1 (King James Version). In; Goudzwaard, *Capitalism and progress. A diagnosis of Western society*, p. 37.

²² Goudzwaard, *Capitalism and progress*, pp. 39, 40.

²³ Ibid., pp. 42-49.

²⁴ Gay, Peter (1967). *The Enlightenment, an interpretation. The rise of modern paganism. Vol. I*. London: W.W. Norton.

²⁵ Goudzwaard, *Capitalism and progress*, p. 44.

regarded as possible with the Enlightenment to realize such a paradise again.²⁶

The foregoing development led to innovations to improve life on earth. Science was used for the sake of practical social benefit and technical improvement. Philosophers developed new social structures in order to increase the welfare and the happiness of the people. The two pillars for a better future were the growth of prosperity and technology.²⁷ The whole program was aimed at a radical restructuring of society. The French Revolutions is often seen as an accumulation of all these developments.²⁸

The ideas about progress are still present in Western society and its policies. The anthropologist Peter Kloos has written how the notion of development became influenced by the Enlightenment idea. Since the eighteenth and nineteenth century the word development did not only mean unfolding, but also implied progress.²⁹ In the twentieth century this word became the foundation for colonial policies of England, the so-called 'dual mandate'. The English government felt itself not only responsible for the well being of the people, but also for their development. The word development acquired a magic meaning. It seemed that development became a good thing in itself. The founder of modern ecology Ernst Haeckel (1834-1919) once said: 'development is the magical word with which we can solve all mysteries around us.' [Author's own translation]³⁰ President Truman (1884-1972) of the United States spoke at his inauguration in 1949 about: 'a bold new program for making the benefits of our scientific advances and industrial progress available for the improvement and growth of underdeveloped areas.'³¹ At that moment he declared that two billion people were living in underdeveloped areas. The United Nations adopted this strategy. The necessity to develop became the basis for development aid, later on called development cooperation. Many development programs and projects used development as their starting point. In this way it became, according to Kloos, the basis of the meddlesomeness and arrogance of the West and the basis of the dependency on self-pity of the South. The word development has been used as a myth that sets its believer at rest and

²⁶ Ibid., pp. 45-47.

²⁷ For more about the interlacement between science and technology. Thijs, Gerard D. 'De andere wereld van wetenschap en technologie'. In: Thijs, Gerard D., (ed.) (1995). *Cultuur, identiteit en ontwikkeling*. Amsterdam: Vrije Universiteit, 1995, pp. 62-79.

²⁸ Thijs, 'De andere wereld van wetenschap en technologie', pp. 48-51.

²⁹ Kloos, Peter. (1995). 'Cultuur in ontwikkeling'. In: Thijs, Gerard D., (ed.) (1995). *Cultuur, identiteit en ontwikkeling*. Amsterdam: Vrije Universiteit, p. 27.

³⁰ Kloos, Peter, 'Cultuur in ontwikkeling', p. 29.

³¹ Ibid., p. 30.

legitimizes his activities. In the meantime it did not help the South in fighting poverty: 'the idea of development stands like a ruin in the intellectual landscape. Delusion and disappointment, failures and crimes have been steady companions of development.'³²

When the West comes into contact with the South this typical Enlightenment thinking appears to be less universal than it suggests. El Mously from Egypt gave the following picture of western science in a report for United Nations Educational, Scientific and Cultural Organization (UNESCO):

[M]odern science didn't touch the soul of the layman in our society. Those who blame the layman for not believing in science should not forget that western science, in general, does not have legitimacy in our culture. This science has withdrawn its legitimacy in the West basically through its effective role to technological transformations associated with the strive of the western man to hegemony and his desire to be the master of other cultures, as well as of nature. (...) Scientific activity in our cultural context far from being technology-driven or power-oriented, is considered as an act of worship and is intimately associated with ethics. If the Renaissance carried along the mission of the secularisation of life meaning in the final analysis the worship of human reason and its hegemony over all other forms of life, including human life (...) An alternative approach to science is thus urgently needed.'³³

Rationality and religion

The mechanistic world picture that emerged in the seventeenth century implied a certain reductionism. The book of nature was still seen as written by God, but the preferred language was mathematics. Mechanics functioned as a model for the development of other sciences. The metaphor that portrayed this in the seventeenth and eighteenth century was the clock, in the nineteenth century the steam-engine and after the Second World War the computer. As a result of this the *how* question replaced the *why* question. Knowledge got an instrumental meaning yet at the same time lost meaning. Science was not used to discover the richness of God's creation anymore, but a way to move away from that traditional

³² Ibid., p. 31.

³³ Hoek van den, A.W. (1988) *Cultural diversity and the ideology of development. UNESCO's role in the international debate on the cultural dimension of development*. Leiden: Lidesco, 1988, p. 36.

world picture towards an autonomous world. Science disenchanting the world. The idea was that the more science progressed, the more religion would disappear. This so-called secularization thesis became very dominant in Western thinking and it influenced Western policies towards countries where religion is still very important.

Taylor has described this as a shift from the 'porous' self to the 'buffered' self. The porous self is open, and vulnerable to a world of spirits and powers. The buffered self has drawn boundaries between meanings that are only in the mind and the physical world outside. It has confidence in our own powers of moral ordering.³⁴ That means two things. Firstly, the porous self is vulnerable to spirits, demons and cosmic forces. Along with this go certain fears, which can grip the porous self in certain circumstances, while the buffered self has been removed from the world of such fears.. Secondly, the buffered self can form the ambition of disengaging. The absence of fear cannot just be enjoyed, but seen as an opportunity for self-control or self-direction. In the enchanted world the boundary between agents and forces and between mind and world is fuzzy, not only in a moral sense but also in a spiritual sense. The porousness of the boundary emerges here in the various kinds of 'possession', from taking over the person fully, as with a medium, to various kinds of domination by, or partial fusion with, a spirit of God.³⁵ Non-belief is hard in the enchanted world. That is because God is seen as the dominant spirit in this world, as the only thing that guarantees that in this awe-inspiring and frightening field of forces, good will triumph.³⁶

The example from the missionaries in northern Nigeria that I used in the introduction shows how the interaction between the buffered self and the porous self leads to misunderstandings. Their beliefs in invisible agents mean that most Africans cannot fully accept those scientific theories in the West that are inconsistent with their traditions. For Appiah this is not a reason for shame or embarrassment: 'If modernization is conceived as the acceptance of science, we have to think whether the evidence obliges us to give up the invisible ontology.' It can easily lead to the accommodation between science and religion that has occurred in the industrialized world. This has involved a considerable limitation of the domains in which it is permissible for intellectuals to invoke spiritual agency. The important question, according to Appiah, is to what extent the individualistic cognitive styles can be adopted and the communitarian

³⁴ Taylor, Charles (2007). *A secular age*. Cambridge: Harvard University Press, p. 27.

³⁵ Taylor, *A secular age*, pp. 38, 39.

³⁶ Taylor, *A secular age*, p. 41.

morals kept, because cultures and peoples have often not been capable of maintaining such double standards.³⁷

A clash of worldviews

The difficulty that El Mously describes is the experience in many part of the world. The Western worldview influences the way development programs and projects are executed. Education programs in natural science are ineffective, because they often imply a conception of knowledge which is very much instrumental and without any meaning. That is exactly the way in which the North differs from the South. In the South, rational explanations do not push aside a supernatural explanation. A student in the South, who has been told that a bolt of lightning was caused by electro-magnetic fields, does not find it a satisfactory answer to the question of why a certain person at a certain moment died as a result of it.³⁸ According to scientism the natural sciences are meant to eliminate traditional thinking. As a result of this misunderstandings appear and development programs are less effective.

These misunderstandings can be understood as a clash between worldviews: the worldview of the South against the modern Northern view: the Cartesian worldview. A worldview is a pre-scientific comprehensive framework of one's basic beliefs about things.³⁹ A worldview is the most basic view that human beings have of reality. It organizes, highlights, allows or legitimizes some experiences, while it suppresses and ignores other experiences.⁴⁰ Although a worldview has religious elements, is not the same as religion. It is the underlying driving force of people's life orientation, while religion is often an institutional manifestation of a worldview. The Cartesian worldview believes in rationality as the only reliable way to know reality. That is a pre-scientific standpoint, because there are no scientific reasons that have proven that rationality should be the only basis of all sure knowledge. Secondly it is a belief. Belief is necessary in order to explain rationality as the ultimate basis for knowledge. Thirdly it is comprehensive, because it comprehends the whole of reality. It also tries to say something about realities we cannot see. It often states that God does not exist, when we can give a

³⁷ Appiah, *In my father's house*, pp. 134-136.

³⁸ Thijs, Gerard D. 'De andere wereld van wetenschap en technologie', pp. 76, 77.

³⁹ Wolters, Albert M (2005). *Creation regained. Biblical basics for a reformational worldview*. Grand Rapids, 2th edition: William B. Eerdmans Publishers, p. 2.

⁴⁰ Buijs, Govert J., (2008). 'Religion, secularism and development: Shortcircuits about HIV/Aids'. In: Steve de Gruchy, Nico Koopman, Sytse Strijbos (eds.)(2008). *From our side. Emerging perspectives on development and ethics*. Amsterdam: Rozenberg/Pretoria: UNISA Press, p. 231.

scientific explanation for certain phenomena. It does not only give an epistemological view, but it also holds an ontological view. The worldview, which is common in many southern countries, consists of pre-scientific elements, such as the belief that God exists and that His presence can be experienced everywhere and always.

Because of the secularization process of the North, the worldviews as described above clash. In this context, secularization does not mean that societies or people are becoming less religious, but that their religious orientation is changing or being replaced. In the case of the West it is no longer the Christian religion that gives direction, but an alternative religion.⁴¹ An expression of that religion, as described by Goudzwaard, is faith in progress. A second element of this non-Christian worldview is the conviction that the relation between science and religion comes to a zero sum game, meaning that the increase of science leads automatically to a decrease of religion. Science is seen as a purely rational activity that excludes the involvement of religion. A third characteristic is the idea that the existence of God is irrelevant: God's laws are not applicable to our lives.⁴² Many people forget that the practice of science displays many similarities with the practice of religion. Appiah describes how religion and science use the same kind of arguments in order to support their theory or beliefs. He denies that religion should be seen as irrational and science as rational. Appiah quotes from the book of Evans-Pritchard *Witchcraft, oracles and magic among the Azande* that errors or failures become explained within the system. In science it works often in the same way:

it may be asked why Azande do not perceive the futility of their magic. It would be easy to write at great length in answer to this question, but I will content myself with suggesting as shortly as possible a number of reasons.' To mention one of them: 'magic is very largely employed against mystical powers...its actions transcends experience' and thus 'cannot easily be contradicted by experience (...) its main purpose is to combat other mystical powers rather than produce changes favourable to man in the objective world.

When scientific procedures fail, they offer explanations as to how the failure could have occurred consistently with the theory. Biochemists regularly ignore negative results, assuming that test tubes are dirty, or that

⁴¹ Walt, van der, B. J., (2007). *Transforming power. Challenging contemporary secular society* (Pochefstroom, Institute for contemporary Christianity in Africa, p. 229.

⁴² Walt, *Transforming power*, p. 234.

the samples are contaminated.⁴³ The conclusion of this all is that the clash between the North and the South cannot simply be framed as a clash of secularity versus religion, but should be understood as a clash between religion and religion.

Response to HIV/AIDS reveals a clash of worldviews

In the fight against HIV/AIDS we can distinguish three different worldviews.⁴⁴ The worldviews that are used are ideal types and are not representative of everyone that will count themselves as Northern, African, Catholic or Evangelical. The first worldview is the Catholic and Evangelical Worldview. In this worldview sexual intercourse is strictly confined to a legal marriage between a man and a woman. Sexuality is closely tied to fertility and the producing of offspring. Marriage is the best institution to assure the upbringing of children. Outside this boundary, sex has become a sin. This explains why Christian people who have intercourse out of wedlock feel ashamed. This is one of the great psychological and social problems that come with AIDS. The second worldview is the African indigenous one. From that perspective sexuality is seen as a sacred matter and tied to the divine. Sexuality is closely tied to the cycle of life. It is not only a kind of participation in the larger community, but also a fulfilment and duty towards the ancestors and the gods of the community. For that reason, human or male identity is largely based on the power to reproduce life. The loss of self-respect and the loss of pride are the result of people that are unable to be sexually active. When the community breaks down, people might still long for respect and identity. Sexual activity might become one of the means to achieve this. The breakdown of the community is narrowly related to the rise of promiscuity. The third worldview is the Northern quasi-secular worldview. Here the emphasis is on the absolute freedom of the individual which can be made possible by controlling the world by technical means. The individual choice to have sex has become an inviolable, holy right. Marriage is a free choice based on love and marriages that are arranged or pressured by the community are violating the freedom of the individual. Marriage is just one of the sexual options. The only limitation of individual freedom is the freedom of the other. In the Northern view rape is the ultimate crime.

Each worldview has its own approach to the spread of HIV/Aids. The Catholic and Evangelical worldview with its attention on the sin of

⁴³ Appiah, *In my father's house*, pp. 118, 119.

⁴⁴ I use the distinction that is used in Buijs, 'Religion, secularism and development: Shortcircuits about HIV/Aids', pp. 232-234.

sexual intercourse makes it also possible for people to start a new life. Through confession, repentance, forgiveness and love, people are freed from the shame and guilt. In short, this worldview makes it possible to develop an policy for people that are already affected. The African view on sexuality is very much related to life. This core value can be used as a resource to be open about HIV/Aids infection. If the taboo on, and the spread of HIV/Aids violates the sanctity of life, it will force people to be open and speak about sex and the regulation of it in situations of social break down. From the Northern perspective the dominant response to HIV/Aids is control. How can people have the freedom to live their sexual life, but still be protected from negative consequences. Technical means like anti-conception are their solutions. The condom has become a symbol of such a policy.⁴⁵ The three approaches to the fight of HIV/Aids is often narrowed down to the question of whether condoms can be a means to stop HIV/Aids or not. But, this does not justice to the fact that different worldviews are at the roots of the debate.

Why focus on worldview?

Why should we pay attention to the worldview element? Firstly, because it clarifies that the relation between the North and the South is not secularity versus religion or objectivity versus subjectivity or rationality versus irrationality. Both parties start their policy making from a pre-scientific comprehensive framework of one's basic beliefs about things. Secondly, the poverty of many developing countries and the spread of HIV/Aids require a common and shared approach, because no party can overcome this deep crisis alone. Thirdly, worldviews can change over time. In confrontation with new development and experiences, worldviews often accommodate peoples' basic belief about things. The awareness of the worldview element in development cooperation can help people to be self-critical and to debate the legitimacy of their worldview. Instead of convincing and overruling the other they start to heal themselves first. Finally, the involvement of the worldview of the people, affected by HIV/Aids, could be an opportunity to use the moral resources that can empower them.⁴⁶

⁴⁵ Buijs, Govert, J., (2008). 'Religion, secularism and development: Shortcircuits about HIV/Aids', pp. 232-234.

⁴⁶ Buijs, 'Religion, secularism and development: Shortcircuits about HIV/Aids', pp. 234-236.

Conclusion

In this paper I have described how many misunderstandings in development cooperation between the North and the South can be understood by looking at the modernization process in the North. I took the Middle Ages and the rise of modernity as a framework to illustrate the differences between North and South. As may have become clear, I do not equate the Middle Ages with the South. I just pointed out how modernity is confronted with the worldview that it left behind after Descartes. Although modernity thought that this was the way to lost paradise, it turned out to be a reduction of reality based on rationality and control. In dealings with the South, the North should be aware of the fact that they should heal themselves first, before they start to 'help' others. Is the Northern worldview still adequate when the Uganda case shows that abstinence works better and scientists confirm that condoms are not *the* means to eliminate HIV/Aids?⁴⁷

In this paper I choose the Cartesian worldview as a starting point of modernity. It appears that Descartes's methodological doubt had bigger consequences than he could have expected. Descartes's ideas gave rise to the scientific world picture that dominates the North until today. Northern countries become aware of this picture in dealings with southern cultures. I have used three specific topics to illustrate this: rationality, religion and development. The fundamental misunderstandings and sometimes disagreements hinder real cooperation between the North and the South. In that case it easily becomes a relation based on power instead of partnership. I have suggested that this ambiguous relation can best be understood from a worldview perspective. That means that the North and the South have different worldviews. Although the conflict seems to be a political, a social or an economic issue; it is influenced by a certain worldview. As mentioned, the advantages of the focus on the worldview element are several.

In this paper I have presented the process of modernization originating from Descartes, by making critical remarks about it. The worldview that has emerged in the North, as a result of it, is not superior to the worldview of the South beforehand. Although it has brought the North many advantages it also has many defects. These deficiencies become especially visible in development cooperation. That means that the North has to accept that their way of living, their economic and

⁴⁷ I refer to the article of Bonneux, Lux (2008) 'Bij gezonde seksuele levensstijl minder AIDS. In Afrika risicovol gedrag mede oorzaak HIV/AIDS-epidemie.' In: Demos, (vol. 24), No. 10, pp. 7, 8. and Green, Edward, C., e.a., (2006). 'Uganda's HIV prevention success: the role of sexual behavior change and the national response'. In: AIDS and behavior, (vol. 10), No. 4, pp. 335-346.

scientific thinking has certain shortcomings. Something has gone wrong in the development of the North. The result of this is that the answer to the question – does modernization require westernization – cannot be answered with ‘yes’.

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The involvement of religious institutions in promoting sexual reproductive health and rights in education

Martijn Marijnis, Machteld Ooijens

An estimated 33.2 million people live with HIV/AIDS. This not only has a serious impact in the lives of those infected, but also on development in general and on various sectors of society in particular. Education is one of those sectors. In our work with Dutch NGOs – partnering in a network called Educaids¹ – it became clear that our African educational partner organisations increasingly face difficulties in reaching common educational goals as a result of the impact of HIV and Aids. Consequently, the need to mitigate the impact of HIV on the education sector became obvious, as well as the intrinsic value of education in preventing the further spread of HIV. Although agreement exists on the importance of addressing HIV in education, the way to do it varies among organisations. While some organisations tend to speak openly about sexuality, including contraceptives for example, others seem to be afraid that such discussion leads to promiscuity. This is particularly evident in church-based settings where values and morals have a large influence in the way in which sex and sexuality is discussed. As a result HIV education currently seems to be influenced by two different approaches: one that we could name ‘value based’ or driven by morals as stated in the Bible and an evidence based approach driven by scientific research, proven facts and a rights-based mode of working. The two are often perceived as opposed to each other. An evidence based approach would

¹ Martijn Marijnis works as coordinator of Educaids and Machteld Ooijens works voor ICCO/ Kerk in Actie, an Educaids partner in The Netherlands. Educaids is a network of Southern and Northern NGO’s. All partners involved target the link between education and HIV/Aids. Although co-operation is not limited to organisations with a Christian background, many of the organisations working in the Educaids network share a Christian background. Educaids believes that the spread of HIV can only be stopped when strong and qualitatively sound education systems and school environments are in place that are able to contribute to the prevention of HIV/AIDS and that are capable of coping with the negative impact of the epidemic.

perceive a condom as a possible tool to prevent the spread of STI, while a value based approach might see a condom as culturally inappropriate. The existence of the two approaches leads to serious difficulties at various levels. At community level children and youth are confronted with messages that might be confusing and conflicting (condoms are safe/condoms are inappropriate). At organisational level organisations have to deal with different wishes, e.g. from back donors that give financial support (you should talk about condoms/you are not allowed to talk about condoms).

The existence of the two approaches means that we are working in a challenging environment. The Dutch organisations involved in the Educaids network all have a Protestant Christian background. Historically, a number of partner organisations also have a religious background in which the above mentioned approach based on values is the most common. In the development of our policies with regards to HIV, sexual reproductive health and education the importance of working from an evidence based perspective increasingly came up in the discussions. These discussions resulted in an agreement that final beneficiaries from educational interventions should have access to complete information with regards to sexuality. Although these policies are clear and straightforward, the co-existence of the two above mentioned approaches in reality puts us in a difficult position and forces us to ask ourselves new questions. As a result we would like to deal the following main question in this article:

How does the role of Religious Institutions in Promoting Sexual Reproductive Health and Rights in the Education Sector relate to that of evidence based interventions and is it possible to build bridges between those two approaches?

In the paragraphs below we will try to find some first clues in answering this question. First, a general overview will be given of the worldwide situation with regards to HIV. From there we will shortly explain the link between HIV and education and why this link matters. The next paragraph deals with the role and influence of the AIDS industry in the education sector in general, including the role of FBOs. This is followed by an introduction to the concept of evidence based and value based policies. This section includes, both, criticisms that FBOs have faced, and arguments in favour of their involvement. Finally, our own experience will be shared through a case study that describes the process of starting up t dialogue with partners on the possibilities of establishing evidence-based ways of working.

HIV/AIDS – situation worldwide

An estimated 33 million people were living with HIV in 2007. In that year alone there were 2.7 million new HIV infections and 2 million AIDS-related deaths. Although the rate of new HIV infections has fallen in several countries, these favourable trends globally, are at least partially offset by increases in new infections in specific countries. Women account for half of all HIV infections — this percentage has remained stable for the past several years. There are positive signs of improvement in all 18 of the most heavily affected countries where there is data on changes in key behaviours: sex before 15, multiple partnerships and condom use. Only 2 countries (Cameroon and Zambia) show improving trends in all three behaviours.

HIV has a big impact on young people. Young people between the age of 15 to 24 account for almost half (45%) of all new HIV infections. 5.5 million living with HIV today.² Few of them knew they are HIV positive; the latest data collected from 64 countries indicate that fewer than 40% of young people have basic information about HIV.³ Many infections among youth are caused by unsafe sexual intercourse. HIV is intrinsically linked with the broader theme of gender and sexual reproductive health rights. Various sources (UNFPA, WHO, Guttmacher and UNAIDS) show that many of the world's people face severe difficulties in living a healthy sexual life. This is particularly evident for countries in Africa. Figures with regards to HIV prevalence and other sexually transmitted infections (STI) for example, show that young women from 15-19 years and 20-24 years are more than twice as likely to be infected with HIV as males in the same age group in Kenya. In Ethiopia, girls aged 15-19 are 7 times more likely to be HIV positive than boys of the same age. In Uganda, 20% of sexually experienced adolescent women have contracted an STI. In addition, figures on first sexual experience and abortion indicate serious problems. In Uganda one in six pregnancies ends in abortion, while 55% of all women aged 15-19 who have ever had sex have become pregnant. Harmful Traditional Practices, abduction, early marriage and polygamy all are issues that have an impact on the sexual reproductive health (SRH) of young people.⁴

² UNAIDS (2008), Report on the Global Aids Epidemic.

³ UNAIDS (2008),

http://data.unaids.org/pub/GlobalReport/2008/20080715_fs_global_en.pdf, accessed on 2 January 2009.

⁴ Federal Democratic Republic of Ethiopia and the Ministry of Health and Adolescent Reproductive Health Extension Package (2003), *National Adolescent and Youth Reproductive Health Strategy 2007-2015*

There is general agreement that a comprehensive approach is needed in stopping the further spread of HIV. Such a comprehensive approach should generally consist of the following components: (1) prevention, (2) treatment, care and support, impact mitigation, (3) reducing stigma & discrimination, and (4) achieving gender equity.

Education is intrinsically linked to all these components. The education sector is seriously affected by the epidemic, for example by the loss of teachers and school directors who are affected by HIV. Treatment, care and support are crucial in enabling them to continue their work. Lack of access to knowledge and skills are major drawbacks; the spread of the epidemic is often fuelled – next to malnutrition, violence, armed conflicts and absence of compliance with human rights – by the lack of education for all. At the same time education can be a very effective tool in preventing HIV/AIDS. Studies indicate that young people with little or no education may be 2.2 times more likely to contract HIV as those who have completed primary education.⁵ In addition, the Global Campaign for Education has calculated that around 700,000 annual cases of HIV in young adults could be prevented if all children received a complete primary education and that the economic impact of HIV and AIDS could also be greatly reduced.⁶ Through schools vast amounts of children can be reached. Let us therefore gain insight into the issues that make education so influential in preventing the further spread of HIV.

Why does education matter?

Good quality education makes people less vulnerable to HIV. It enables them to get information and to understand this information. Moreover, education passes attitudes, skills and behaviours on to children, to enable them to protect themselves against HIV-transmission. Finally, it is also recognised that education can strengthen capacities to live healthily with HIV for those affected by the virus.

The possibility to actually influence behavioural change through education is especially important here. Not only because millions of children and adults receive information on HIV/AIDS, but because people are also equipped with the skills, necessary to make healthy decisions. While people may have an understanding of what HIV and AIDS means and how it is transmitted, they still may take the risk to

⁵ Boler, T. and A. Jellema (2005). *Deadly Inertia. A cross-country study of educational responses to HIV*. Global Campaign for Education, pp. 12.

⁶ Rispel, L., L. Letlape and C. Metcalf. (2006). *Education sector responses to HIV and AIDS: Learning from good practices in Africa*. Commonwealth Secretariat, ADEA and HSRC.

engage in unsafe sexual relationships. In other words, knowledge does not necessarily affect behaviour. A diverse approach is needed to achieve behaviour change and education can play a crucial role in this regard – it is seen as the most powerful ‘social vaccine’ against HIV/AIDS.⁷

When focusing on education, four areas of interest can be defined. Firstly, education should - besides giving information on HIV and AIDS - deal with skills that enable youth and children to lead a healthy sexual life. During childhood and adolescence the gendered sexual identity of the human being largely develops. At this stage, education can play an important role in offering guidance to this group. Peer pressure, for example - the pressure on whether one is a virgin or not, requires skills by youth to be able to negotiate with their partner about their sexual relationships. Learners equipped with life skills are more able to make healthy choices. Hargreaves and Boler⁸ prove that better educated girls delay sexual activity longer and are more likely to require their partners to use condoms, lower their HIV vulnerability, and reduce sexual risk behaviour.

Secondly, education has the opportunity to challenge existing cultural norms and values. For example, in various sub-Saharan countries men are working outside the household, meaning they earn, and thus manage, the family income. Women are more likely to feel financially dependent on their husbands, and accept more easily the sexual desires of their partners. Polygamy is another widely accepted cultural norm that results in the spread of HIV. This norm makes it difficult for women to negotiate safe sex or monogamy. Schools can challenge these existing traditions that are impeding HIV prevention and adapt norms and values that are in favour of safe sexual relationships. Thirdly, education can have a major impact on social relationships, which are strongly interlinked with cultural norms. Research has shown, for example, that the need to display masculinity can lead to forced sexual relationships. Education on social relationships and gender equality, gives young people a better opportunity to have consensual sexual intercourse.

Finally, education can decrease stigma and discrimination that is too often inherent to HIV and Aids. A safe and healthy school environment - wherein open dialogue is stimulated on HIV and Aids and where learners and teachers affected by HIV and Aids receive equal treatment - helps to remove taboos on HIV and Aids. There are a range of actors that have identified the importance of the link between HIV and

⁷ See Boler, T. and A. Jellema, (2005). *Deadly Inertia. A cross-country study of educational responses to HIV*. Global Campaign for Education, pp.: 10.

⁸ Hargreaves, J. and T. Boler (2006). *Girl power: the impact of girls' education on HIV and sexual behaviour*. Action Aid International.

education. These actors may use different approaches and interventions. In the next paragraph we will have a closer look at the actors involved.

The AIDS industry: a stakeholder analysis

The importance of focusing on skills, on challenging cultural norms and values, reviewing existing social relationships and decreasing stigma is recognized by various stakeholders. Their interpretations and related interventions, however, differ. Below a short summary is given of a number of actors involved in the AIDS industry. At the multilateral level UNAIDS brings together the efforts and resources of ten UN system organizations, in the AIDS response, to help the world prevent new HIV infections, to care for people living with HIV, and to mitigate the impact of the epidemic. UNAIDS identifies that “the education sector is critical to HIV prevention for young people, and can also play a vital role in support for children orphaned or made vulnerable by HIV.”⁹ On its website the organisation clearly states that the organisation is in favour of sexuality education, since it encourages responsibility. However, UNAIDS does not clearly prescribe the content of the messages that should be included.

Bilateral donors

The role of bilateral donors differs. The most notable example has been the US. In 2003, President Bush launched the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) to combat global HIV/AIDS. It was identified as the largest commitment ever by any nation to combat a single disease in.¹⁰ The initiative was intended to prevent 7 million new infections, treat 2 million people living with AIDS related illnesses, and provide care and support for 10 million persons affected by AIDS.¹¹ The program has been criticized from within and outside the U.S., especially with regards to restrictions on funding for prevention activities and on organizations working with commercial sex workers.¹²

⁹ www.unaids.org

¹⁰ The United States President's Emergency Plan for Aids Relief. About Pefpar, <http://www.pepfar.gov/about/index.htm>, accessed on January 10, 2009.

¹¹ Pefpar watch (2006). What is Pefpar?

http://www.pepfarwatch.org/index.php?option=com_content&task=view&id=12&Itemid=26, accessed on 10 January 2009.

¹² See again for example

http://www.pepfarwatch.org/index.php?option=com_content&task=view&id=12&Itemid=26.

Many of the European bilateral donors have a stronger focus on evidence and stress the importance of openness. E.g. the Dutch Ministry of Foreign Affairs in a recent policy document on SRHR states that the Dutch policy is characterised by pragmatism and evidence-based modes of working, by focusing on what is effective instead of focusing on moral value. The Minister for Development Cooperation states that positive results in our country could have a positive impact on the credibility of the Dutch government in sharing its vision on SRHR in the international arena. Gender equality, stigma and discrimination of vulnerable groups, and inclusiveness are important issues that are at the forefront. The Dutch government wants to play a negotiating role and to bring parties with different views together around the same table, giving them encouragement and contribute to building their capacity and expertise. In the policy document the Minister explicitly states that the taboo to talk about sexuality should be addressed among employees in the education sector.¹³

The policies of the US government and the Dutch government in the last eight years appear to be two extremes on a continuum. Organisations, however, have to deal with the policies of both governments. That specific and varying requirements of various donors sometimes put organisations in a difficult position is illustrated in an example of a Kenyan partner of Educaids. In a series of workshops on evidence-based working, it became clear that the partner saw the added value of the evidence-based approach. At the same time it was acknowledged that such a different mode of working would cut PEPFAR funding, as it was structured under the Bush administration,

(I)NGOs

There is a broad range of international and national organisations that focus on HIV and Aids. Sometimes these organisations operate on a rather individual level, in other cases they tend to build co-operations (the Stop Aids NOW network and Educaids are Dutch examples). A variety of approaches can be distinguished among NGOs, although many of the international organisations have adopted a rights based approach.

¹³ Dutch Ministry of Foreign Affairs (2008): Beleidsnotitie HIV/aids en seksuele en reproductieve gezondheid en rechten in het buitenlands beleid Keuzes en Kansen (paragraph translated from Dutch). Den Haag: MinBUZA.

Faith-based organizations (FBOs)¹⁴

70% of the world's people identify themselves as members of a faith community. That communities of faith play a very significant role in influencing people's behaviour and attitudes, and in providing care and support for AIDS has been identified by various sources. UNAIDS, for example, clearly states that FBOs have been involved in the AIDS response since the earliest days of the epidemic and often have been among the first to respond, providing services, education and care.¹⁵ It is recognised that FBOs are involved at all levels of the response. This includes for example prevention education in and outside schools, care for Orphans and Vulnerable Children, hospital and clinical care including the provision of antiretroviral treatment for HIV and voluntary testing, theological reflection and advocacy to influence political decisions on AIDS. Also initiatives such as an established network of religious leaders living with and affected by HIV (called INERELA+) – to speak out and provide support have been established.

Indeed, many traditions with origins in Asia, especially Islam, Hinduism, Buddhism and a variety of traditional religions (in Africa) cannot imagine or accept a system of rights that excludes religious dimensions because religion is part of the totality of life.¹⁶ In general, FBOs take into account this religious dimension and they are among the ones that are most trusted by a majority of community members.

Interventions of FBOs often take into account religious and moral perspectives, or as one of our partners stated: “Key messages promoting

¹⁴ A distinction is made between FBOs and RNGOs. A faith-based organisation (FBO) has one or more of the following characteristics: (1) affiliation with a religious body, (2) a mission statement with explicit reference to religious values, (3) financial support from religious sources, (4) and/or a governance structure where selection of board members or staff is based on religious beliefs or affiliation and/or decision-making processes are based on religious values. This definition also includes churches, temples and mosques. The term religious non-governmental organisation (RNGO) is more specific and can be defined as ‘a formal independent societal organisation whose primary aim is to promote general developmental goals at the national or the international level’ and ‘whose identity and mission are self-consciously derived from the teachings of one or more religious or spiritual traditions’: Verbeek, G. (2008). Religion and Education. Synthesis of findings of four case studies on the role of Christian organisations in basic education. Commissioned by the joint working group Religion and Education of Edukans, ICCO, Kerkinactie and Prisma. Synergo advice, training and research.

¹⁵ UNAIDS (2009). Religion and Aids, <http://www.unaids.org/en/Partnerships/Civil+society/religionAndAids.asp>, accessed on 12 January 2009.

¹⁶ APRODEV (2008). Human Rights, HIV/AIDS Prevention and Gender Equality. An impossible cocktail for faith based organisations? Position Paper APRODEV.

positive behaviour among young people should be based on moral well being and responsibility”. Thus, these organizations look for possibilities to ‘combine spiritual well being and self development to deal with HIV/AIDS’. They see their leaders as crucial actors in breaking the unchangeable environment: ‘The church is the people, in the church the reality of daily life is present. Its leaders should work in partnership, so that silence on HIV/AIDS is broken’.¹⁷

The challenges that FBOs face in combining values and evidence based approaches also mean that the involvement of FBOs is not without difficulties. Policymaking organisations, international donors and other stakeholders often lack sufficient knowledge and understanding of religious dynamics and the role of religious institutions and therefore often look at this role in a simplistic and reductionist manner.¹⁸ Government and large international organizations commonly categorize all their activities under the FBO label and often fail to recognize the different strategies needed in working with religious leaders, the service delivery organizations and the grassroots communities based around a local mosque, church or temple.

Policies and approaches used

Multi-lateral and bilateral donors, international and local NGOs and FBOs are all involved in financing and implementing strategies in the field of HIV and education. These strategies are based on what we have been referring to as two distinct types of approaches: (1) evidence-based approaches (often used by big international NGOs and specialised agencies), (2) value-based approaches (more common among religious organisations and FBOs). Let us explain further what we mean by this:

Evidence-based approaches

Over the past decade the popularity of evidence based approaches has increased significantly. Evidence based policy (EBP) can be defined as the following: a discourse or set of methods which informs the policy process, rather than aiming to directly affect the eventual goals of the policy. It advocates a more rational, rigorous and systematic approach. The pursuit of EBP is based on the premise that policy decisions should be better informed by available evidence and should include rational analysis. This is because policy which is based on systematic evidence is

¹⁷ Educaids (2007). Vision document.

¹⁸ Kennisforum Religie en Ontwikkeling (2008). “Religion and HIV/AIDS. The defining issue of our time”. In: Handout religion and development. pp. 28.

seen to produce better outcomes. The approach has also come to incorporate evidence-based practices.¹⁹

Various scholars have identified the importance of evidence based approaches in addressing HIV in the education sector. Boler and Archer²⁰ state:

“HIV prevention programmes in schools can succeed. There are some common threads that run through HIV prevention programmes that have been successful. Good programmes are based on frank and scientifically accurate information about sex and HIV. They make HIV a personal and real issue, going beyond an intellectual understanding to something which young people can realise – and does – and can affect their lives . Good prevention programmes explain that HIV is just a virus, rather than something that marks out a good person from a bad person. But at the same time, they deal with relationships and power dynamics – the human dimensions that are so crucial to preventing the spread of the virus. Good prevention programmes encourage open discussions about sex without moralising, letting people choose for themselves how they want to lead their sexual lives. They recognise that different people come with different experiences even if they are in the same age group and gender. Rather than dealing with how people should behave, they start from recognition of how people do behave. Good programmes give people a range of options from which to choose rather than dictating just one solution or path. They do not impose certain ideas on people; rather they involve opening up and respecting people to make their own choices. Thus our perspective on evidence based approaches is that it is a truly comprehensive or holistic approach and this is what works.”

Research has shown that sexual health and HIV education, including related life-skills education does not hasten sexual debut and does not increase the number of sexual partners. Hence sex and HIV education does not promote promiscuity amongst young people. It has also been proven that, if sexual health programmes for children are to have maximum impact, they should begin before the sexual activity begins and

¹⁹ Sutcliffe, S. and J. Court (2005). Evidence-based policymaking: What is it? How does it work? What relevance for developing countries? UK: Overseas Development Institute.

²⁰ Boler, T. and D. Archer (2008). The politics of prevention: a global crisis in AIDS and education. Pluto Press. pp. 135.

sexual behaviour patterns start to form. Moreover, it is identified that good quality sexual health and HIV education reduces levels of pregnancy and STIs, reduces stigma and discrimination against people living with HIV and AIDS. Also condoms are effective in preventing HIV infection among young people who are sexually active when used correctly and consistently. There does not seem to be much academic evidence to conclude that abstinence-only programs are beneficial in delaying sexual debut²¹, although scholars such as Edward Green have tried²².

In summary, organisations that base their activities on evidence: (1) use evidence information from research studies, opinions, and experiences²³, (2) demonstrate the links between this evidence and the local communities they work with, (3) influence sexual behaviour of young people, by providing them with information, skills, changing attitudes and risk perception, and empowering them to take their own decisions, and (4) use interventions (programmes/ projects) that are based on theory that take into account what is already known about changing behaviours and environmental factors.

Value-based approaches

FBOs are inspired and motivated by religious values and principles. The interaction between religion and development has become a topic of interest and dialogue between development and faith-based organisations. It is generally recognised that both religion and development interventions influence cultures and the behaviour of individuals. When both forces work in the same direction, religion can play a positive role in processes of change.

The role of Christian education is multifaceted. It can be relational, linking people with shared beliefs to each other and the organisation; motivational, inspiring managers, staff and teachers through Christian values and principles (that are sometimes only visible in internal practices and communication); or organisational, bringing people together who

²¹ Christian Aid (2003). Dying to learn. Young people, HIV and the churches, http://www.christianaid.org.uk/images/dying_to_learn.pdf, accessed 10 January 2009.

²² See for example http://www.firstthings.com/article.php3?id_article=6172

²³ Based on: StopAidsNow, WPF and Maastricht University (2006). Evidence based planning and support tollstools for SRHR/ HIV Prevention Intervention for Young People. Stop Aids Now, in collaboration with WPF & Maastricht University, 2006; and Sutcliffe, S. and J. Court (2005). Evidence-based policymaking: What is it? How does it work? What relevance for developing countries? UK: Overseas Development Institute.

organise themselves to pursue goals derived from Christian ideals and visions. These facets also stimulate the performance of rituals that contribute to feelings of belonging and to processes of healing and reconciliation.²⁴

That religious leaders are in the unique position of being able to alter the course of the epidemic is recognised by a broad range of actors. UNICEF for example mentions the ability of religious leaders to shape social values, promote responsible behaviour, to support enlightened attitudes, opinions, policies and laws and to promote action from the grass roots up to the national level.²⁵

In addition, various churches and faith-based organisations have been working hard on their 'theology in times of AIDS'. The most perceptible outcome of these theology-oriented activities is a growing understanding among academic theologians and church leaders of the relationship between scriptural messages about compassion, forgiveness and acceptance, and the presence and impact of HIV/AIDS in church communities. For example, this understanding is affecting the way church leaders and their congregations perceive and care for community members who are infected or affected by HIV and AIDS. It is also impacting the way that people living with HIV/AIDS view themselves as accepted and supported by the community. Furthermore, church leaders are beginning to realise that they themselves are powerful role models in fighting stigma, discrimination and denial.²⁶

It is clear that the churches are in a powerful position because of their extensive networks and influence at all levels of society. But Christian organisations do increasingly recognise that talking about sex is hard, yet critical. Christian Aid for example states that an acceptance of two realities is required: that, according to all available data, in the majority of countries, the majority of young people are sexually active from a very young age and therefore at risk of being infected with HIV. Moreover, the organizations realize that good quality sexual health and HIV education will not increase promiscuity; on the contrary, it will promote safer behaviour, and reduce HIV, other STIs and teenage pregnancy.

Christian Aid identifies that in order to address these realities, there needs to be active support of and advocacy for sexual health and HIV

²⁴ Kennisforum Religie en Ontwikkeling (2008). "Religion and HIV/AIDS. The defining issue of our time". In: *Handout religion and development*. pp. 32.

²⁵ UNICEF, World Conference of Religions for Peace, UNAIDS (2003). *What religious leaders can do about HIV/AIDS. Action for children and young people*. US: New York. p. 9.

²⁶ Kennisforum Religie en Ontwikkeling (2008). "Religion and HIV/AIDS. The defining issue of our time". In: *Handout religion and development*. p. 32.

education that is open, frank and supportive, promoting abstinence, faithfulness and safer sex and that utilises church networks to reach to out-of-school young people, child-headed households and other vulnerable children, and educate them about sexual health and HIV.²⁷

The need for understanding African religion and culture

Traditional notions about male sexuality and gender relations determine sexual behaviour to a great degree. These have to do with the concepts of vital force and fear of impotence, fertility, the cycle of birth, life and death, and becoming an ancestor. Many Africans see the body as a system of tubes; flow indicates that the body is functioning well, a blockage of tubes means disorder/disease that might badly influence other tubes. The hypothesis is that the use of a condom is perceived as blocking a tube (the penis with the ejaculation of vital fluids) and makes men impotent. Breetvelt quotes the African philosopher Kä Mana as saying: "...the message of A (abstinence), B (be faithful) and C (use condoms) in HIV/AIDS prevention cannot lead to behavioural change when the traditional African concepts of masculinity are taken into account. Faithfulness is seen as diminishing his power (vital force), abstinence as an attack on his virility, and using a condom is like taking away his masculinity.'²⁸

HIV/AIDS Christian theologies emphasise that God is love and Christ is the compassionate healer. For many African Christians, these notions are not compatible with their deep conviction that God is a distant God and that in the case of disease for which no cure is available, other powers are at work. This leaves room for all sorts of extreme healing practices. In the HIV/AIDS theologies, personal sin as the cause (or non-cause) of HIV/AIDS and liberation from sin have been mentioned as important issues for theological reflection²⁹

However, approaches of FBOs sometimes differ from the perspective given by Christian Aid. Boler and Archer in their book the "Politics of Prevention" dedicate a whole chapter on the role of religion entitled Religion vs. Science. The chapter takes the situation in the US as a starting point, building up to the export of abstinence-only programs to

²⁷ Christian Aid (2003). Dying to learn. Young people, HIV and the churches, http://www.christianaid.org.uk/images/dying_to_learn.pdf, accessed January 10, 2009.

²⁸ Kennisforum Religie en Ontwikkeling (2008). "Religion and HIV/AIDS. The defining issue of our time". In: Handout religion and development. pp. 34-35.

²⁹ Kennisforum Religie en Ontwikkeling (2008). "Religion and HIV/AIDS. The defining issue of our time". In: Handout religion and development. p. 35.

Africa. The Uganda is perhaps the most-striking, where a relatively successful open policy has been re-shaped into a policy focused on abstinence only.

Elizabeth Pisani has pointed at the fact that a third of the US prevention budget has to be allocated to FBOs, which refuse to distribute condoms and will promote only abstinence before marriage. The failure rate of "virginity pledge" programmes among young Americans in the US is about 75%; condoms' failure rate is roughly 2%. Research conducted by Guttmacher proves the opposite. Yet Pefpar, Pisani argues, "claims that its policy decisions are evidence based".³⁰ It is fair to state that the role of FBOs is not always uncontested with respect to the transfer of (religious) beliefs and values. Religion can be a conservative factor and can also become, especially in a multi-religious context, a factor of tension, exclusion and even conflict. As with the positive examples, no easy generalisations can be made. The relationship between religion and education cannot be described in uniform characteristics. The role of religion in the various realms of personal behaviour and societal influence is highly dependent on its context.³¹

Tiendrebeongo and Buyckx give a similar, yet more nuanced view on faith based approaches. They argue that "the response from the religious community has been uneven. On one hand, the primary prevention methods espoused by the major religions are in themselves valid means to prevent HIV infection spreading. The care and support provided by FBOs had alleviated the suffering of many PLWHA both physically and spiritually. However, religious leaders often reach a deadlock with other stakeholders over condom use and mandatory testing before marriage. Tiendrebeongo and Buyckx argue that they may also have contributed to self-stigmatisation, which is common among followers who find themselves HIV positive."³² In their conclusions they make clear that there is a lack of in-depth review studies on the scope and effects of FBOs work. On top of that these authors have argued that many projects of FBOs are still designed on the basis of perceived needs or driven by values and moral duty, which ensure ownership, but fail to

³⁰ Pisani, E. (2008). "Aids? There's big money at stake", in: Times, June 16, http://www.timesonline.co.uk/tol/comment/columnists/guest_contributors/article4143943.ece, accessed on January 12, 2009. And Wesselink, K. (2008). "Interview met Elizabeth Pisani", In: Internationale Samenwerking, No. 05, http://www.isonline.nl/?node_id=63744, accessed on January 15, 2009.

³¹ Kennisforum Religie en Ontwikkeling (2008). "Religion and HIV/AIDS. The defining issue of our time". In: Handout religion and development. p. 32.

³² Tiendrebeongo, G. & M. Buyckx (2004). Faith based organisations and HIV/AIDS prevention and impact mitigation in Africa. Development Policy & Practice, Bulletin 361. Amsterdam: Royal Tropical Institute. p. 8.

meet the needs of some part of the population. Thus projects remain local or are insufficiently backed-up by in-depth needs assessments and subsequent capacity building, monitoring and evaluation.³³

In summary, it is clear that faith communities are ideally placed to respond in the broadest way to the epidemic's challenges, not just as service providers, but also (and perhaps most importantly) as networks and movements that reach right to the heart of community and family life. This makes them key players in a holistic, multifaceted, integrated response to HIV/AIDS. At the same time many FBOs lack the skills and capacity to redesign programmes in such a way that value and evidence based approaches are in line. Ideally, the possibilities and influence of the church would be combined with in-depth needs assessments and interventions based on evidence. One example of an on-going process that tries to bridge the two worlds is the Shareframe process initiated by EDUCAIDS.

Case study: Shareframe

In 2007 Educaids started collaborating with World Population Foundation: the Sexual development, HIV/Aids and Reproductive health Education Framework (Shareframe). It was initially started in Kenya (end 2007) and Uganda (early 2008), where partner organisations are supported in redefining their existing policy or developing a new policy on how to deal with issues related to sexuality including HIV/AIDS. In the dialogue sessions organized early in the process it was argued that policies should be based on evidence, rather than (moral) presumptions. The objective of the process is – in the longer term – to enable the partner organisations to set up comprehensive sexuality education programmes that are consistent with the actual situation in which young people find themselves. It might also lead to the development of joint lobby or advocacy strategies and activities.

In Kenya twelve partner organisations are involved in the Shareframe process; in Uganda nine organizations. The background of the organisations vary; some are clearly faith-based (e.g. the educational departments of the Protestant and Catholic churches), others have a Christian history (e.g. Undugu Society, set up by a priest in the 70's) or are operating from a secular point of view (e.g. Nairobi's). The participating organisations are linked up to a local resource organisation – the Centre for Study of Adolescence in Kenya and Schoolnet in Uganda –

³³ Tiendrebeogo, G. & M. Buyckx (2004). Faith based organisations and HIV/AIDS prevention and impact mitigation in Africa. *Development Policy & Practice*, Bulletin 361. Amsterdam: Royal Tropical Institute. p. 8.

that provides input in terms of research and openly talking about sexuality on the basis of among others the implementation of local versions of a sexuality education programme that is called “The World starts with me”.

So far, awareness of the importance to plan interventions on the basis of evidence has clearly increased among partner organisations. They realise that they can only serve their target group effectively if they are not only well aware of the contextual situation of this group, but also if they develop interventions in accordance with that reality and not necessarily on the basis of morality or assumptions. In practice this means that partner organisations – through literature review, focus group discussions and discussing existing research reports - have come to realise that comprehensive sexuality education, including HIV/AIDS prevention, does not lead to promiscuity. In fact, evidence shows the contrary: young people, who have access to comprehensive sexuality education, opt for delay of sexual onset, are more faithful and/or more consistently use condoms than their peers who did not have access to comprehensive sexuality education.

Nonetheless, it should be recognized that the FBOs – although they acknowledge the fact that it is a human right for youngsters to receive complete and objective information - until now have the tendency to stick to their values based approach. Observations show that participants tend to avoid discussions on sensitive issues like sexual behaviour, condom use and sexual orientation and/or are judgemental or have a tendency to correct or advise in their interactions with young people. Being non judgemental, starting in a neutral way, asking relevant questions (also sensitive ones) is a challenge for many of the participants – this includes participants from FBOs, but also secular organisations. It must be admitted that during the workshops some FBOs tend to leave the discussion of sensitive issues to other NGOs. However, organisations did agree to conduct a situation analysis and needs assessment in the communities they work with in 2009. This might further stimulate discussions within organisations, including FBOs.

To complicate things further we have observed a tendency towards subjective selection of sources in the situation analysis/literature review (i.e. selection of those – sometimes unscientific - sources that suit the opinion of an organization). However, this cannot automatically be attributed to religious backgrounds, since organizational staff tends to have a lack in research experience. It is therefore not unlikely that organizations tend to argue on the basis of a specific mindset (which in the view of organizations might be evidence-based) more than on the basis of research. It is essential to continue to focus on 1) strengthening of the ability to apply research skills and 2) being able to openly discuss issues related to sexuality and being able to be non-judgemental.

In addition, the question arises to what extent the involved staff members of partner organisations will be able to make a real change to the policy of their organisation. It should be noted that the involvement of key actors in the process is of a crucial value. Many organizations do not operate in a vacuum and have direct ties with (church) institutions at national, regional or international level. To ensure commitments at all levels (director, board) advisory boards have been established to guide the Shareframe process. In conclusion, the Shareframe process enables individual partner organisations to set up sexuality education programmes that are consistent with the actual situation in which young people find themselves. The abovementioned issues make clear that success cannot yet be guaranteed.

Conclusions

In this article we have tried to answer the following question: How does the role of religious institutions in promoting sexual reproductive health and rights in the education sector relates to evidence-based interventions, and is it possible to build bridges between those two approaches?

We have tried to answer this question by looking at our own experience in working with a number of partner organisations in Eastern Africa. These organisations have a broad expertise in setting up educational interventions. Their backgrounds vary from secular to church-based. In the past decade it has become clear that many educational interventions will not have a lasting impact if the impact of HIV is not mitigated. At the same time, it was identified that education can play a key role in stopping the further spread of HIV. We have tried to make clear that the organisations we work with have to operate in rather complex contexts. This is partly due to a yet existing “Aids industry” in which bilateral donors, NGOs and FBOs are key actors. These actors do not only fight HIV; but also try to put their own beliefs (and related approaches) high on the agenda. These approaches might be divided in two lines of thinking: value-based and evidence based.

In analysing the context in which partner organisations are operating we came to the following conclusions: (1) evidence-based approaches have a clear added value in addressing HIV and sexual reproductive health; (2) organisations that use a value-based approach are among the ones that are most trusted by the groups we target. This leads to the question, whether those organisations that are using a value-based approach might be willing and able to use an approach that is based on evidence. A case study of a process – called Shareframe – is described that tries to combine the best of both worlds: sexual development,

HIV/Aids and reproductive health education. The lessons learned so far show that there is an increasing awareness of the importance to plan interventions on the basis of evidence, but that there is also a tendency to avoid discussions on sensitive issues and to use selective sources. Opening up the discussion between faith-based and secular organisations around evidence might open up new forms of collaboration between those two – formerly rather divided – worlds.

Shifting Perspectives: analyzing discourses on faith-based development organisations in the fight against HIV/AIDS

Brenda E. Bartelink

It is the end of November 2008 and I am in a conference centre in a rural part of the Netherlands holding up a small sheet of paper that says ‘masturbation on your self’. I am a bit embarrassed and hope that my red cheeks will go by unnoticed. While attending an expert meeting organized by two Dutch *faith based organisations* (FBO), I took part in a workshop in which Dutch FBO employees are introduced to a methodology to engage religious leaders, like imams or priests, in dialogues on sexuality, sexual education and HIV/AIDS. What had I expected from a workshop for and by religious leaders? At least not that sexuality would be discussed so openly. Obviously I was wrong here!

What were we doing, you may wonder? We were discussing sex and safety. By holding up sheets of paper with the names of different sexual acts, we illustrated a continuum of sexual activities, moving from ‘safe’ to ‘unsafe’. In the next round we made a similar continuum, now moving from ‘lawful’ to ‘unlawful’ in a Christian, or biblical sense. Obviously, such an exercise creates a lot of discussion on what is accepted in a Christian perspective and what isn’t. And that is exactly what it should do, illustrate that theology and public health messages can be contradictive, and argue that religious leaders should work on an integration of both into a comprehensive approach to HIV/AIDS.

This example brings us to the topic of this paper which aims to analyze discourses of FBOs on HIV/AIDS. The main question I will try to answer in this paper is how discourses of FBOs on HIV/AIDS are constructed and how the contradictions that FBOs experience, between religious values and practical challenges such as evidence based and rights based approaches of HIV/AIDS are dealt with. In order to do so I will first introduce a set of concepts and tools enabling me to analyze these discourses. In the second paragraph I will then consider the

different audiences that FBOs address when discussing HIV/AIDS. In paragraph 3, I will focus on two examples of a specific discourse, the religious discourse on HIV/AIDS that is constructed by FBOs. Religious discourses often remain a 'black box' to other actors in the fight against HIV/AIDS. The unfamiliarity with religious language and discourses may lead to a neglect of this discourse by outsiders, or even as a reason to regard FBOs as 'strangers' in the fight against HIV/AIDS. However, I argue that such discourses contain valuable information on how FBOs develop their visions and policies on HIV/AIDS. Moreover analysis of different discourses may illustrate that religious positions are by no means clear cut, and that faith based actors develop their perspectives and approaches based on multiple identifications.

Concepts and analytical tools

In this paper I make use of concepts and analytical tools that need some introduction. First I will make a distinction between insider and outsider perspectives on religion, FBOs and HIV/AIDS. FBOs have a religious identity and therefore have an insider perspective on the religious discourse on HIV/AIDS. At the same time FBOs are also development organisations, engaging in discourses with other development actors that have an outsider perspective on the religion and HIV/AIDS. A Dutch FBO for example will use different language to advocate for recognition of partner FBOs when talking to the Dutch Ministry of Foreign affairs, than they use when discussing issues of faith and HIV/AIDS with their partner organisations in Africa. In this paper I will focus on *insider* perspectives, or the perspectives of FBOs. However, I am interested in how these perspectives vary, especially when they are conveyed in messages towards specific actors and audiences, including *outsiders* to the religious discourse.

In the following, I will look at two characteristics of these discourses that I refer to as *instrumentalist* and *intrinsic*. With *instrumentalist* I mean those discourses that are focused on the practical role of FBOs. It asks what FBOs do, or what religion does in the fight against HIV/AIDS. As I will show in this paper, *instrumentalist* discourses are often focused on clarifying the added value of FBOs in the fight against HIV/AIDS. In contrast but not necessarily opposed to *instrumentalist* arguments, I will discuss *intrinsic* arguments in discourses on HIV/AIDS. *Intrinsic* arguments are those that refer to special religious frameworks of meaning. Instead of asking what religion does, it asks what a religious perspective on HIV/AIDS is. Thus, *intrinsic* arguments are often built on transcendental or theological knowledge and

perspectives. Yet, *intrinsic* discourses often remain a ‘black box’ to outsiders, especially because of the theological or biblical language used. I will analyze two examples of *intrinsic* discourses, while stepping out of the biblical and theological paradigm. In doing so, I will make use of an analytical tool developed by anthropologist Gerd Baumann to gain insight into how (religious) identities are constructed.¹

Claims to identity and inclusion are always linked with exclusion. The construction of a collective identity, or an ‘us’, always coincides with the construction of an ‘other’ or ‘them’. For example, if I identify as a Muslim, it is also clear to me who is not a Muslim. That can be the people who do not obey the five pillars of Islam, or those who identify as Christians. This process is also referred to as ‘selfing’ and ‘othering’. A way to understand discourses on religious identity is to look at the way they order the relationships between self and other. Baumann and Gingrich point at three grammatical structures that shape identity through specific forms of selfing and othering: the grammar of orientalisation, the grammar of segmentation and the grammar of encompassment.

The grammar of orientalisation creates ‘a self’ through a process of negative mirror imaging; what is good in us lacks in them or vice versa. This grammar includes the possibility of both rejection and desire of the other.² An example of *orientalist* grammar can be found in discourses of development workers on their *selves* and the Tanzanian or African *other* in a book written by Erikson-Baaz.³ While the self of the development workers is characterised by punctuality, the Tanzanian other is associated with laziness. If Tanzanians are hard working and punctual, this is because they are ‘westernised. In such a way the negative mirror image is continued, sometime even by people that are on the negative side of the mirror.⁴

The use of *segmentary* grammar excludes people on a lower level, while including them on a higher level. An example can be found in the segmentary structure of the European Union. On one level, one is Dutch, German or English, while on another level the same person is a European. As I will not refer to this grammar in this paper, I will move onto the third grammar: the grammar of *encompassment*. Encompassment is done

¹ Baumann, Gerd (2004). *Grammars of Identity/Alterity. A Structural Approach*. Oxford: Berghahn.

² While the grammar is based on Edward Said’s famous work on orientalism, it is important to note that Bauman uses the concept of orientalism in a broader sense than Said did. The grammar of *orientalism* is applicable to every case in which identities are constructed in reference to another that symbolizes everything that is opposed to the self.

³ Eriksson Baaz, Maria (2005) *The Paternalism of Partnership*, New York

⁴ Baumann, Gerd. *Grammars*, 21

through assuming the ‘other’, while a certain degree of otherness is accepted. The other is subsumed through emphasizing universal sameness. This grammar can be seen in arguments stating that differences between man and woman are not important, since both man and woman are human. However, as there are still many examples of gender inequality, the *encompassing* grammar can also be used to deny that a degree of otherness still exists. The *grammars* are used as analytical tools in paragraph three in which I focus on *intrinsic* discourses, but first I will discuss discourses of FBOs on HIV/AIDS in relation to their different audiences.

Actors, audiences and messages

FBOs reflect on the role of FBOs in the fight against HIV/AIDS from an insider’s perspective. However FBOs also engage in dialogue with different actors and design messages on the role of FBOs in the fight against HIV/AIDS addressing various audiences. In this paragraph I distinguish between these various audiences and analyze the *instrumental* and *intrinsic* discourses that are used in addressing these audiences. As I will show, the use of *instrumental* and *intrinsic* discourses relates to the insider or outsider perspective of the various audiences. My argument is based on an analysis of a selection of professional literature, research and policy reports, published recently by several FBOs. These publications allow me to distinguish between different actors that are addressed by FBOs, such as multilateral organisations and donors. Then I will move on to discussing some occasional and long term alliances in which FBOs are engaged. I will close this paragraph with some examples of how FBOs address their own religious communities, with messages on HIV/AIDS. While this contribution is by no means exhaustive, it does provide some insight into how discourses on FBOs and HIV/AIDS are structured and different messages address different audiences.

Actors

The most famous example of dialogue between FBOs and donor organisations is the World Faiths Development Dialogue, initiated by World Bank president James Wolfensohn and the Bishop of Canterbury James Carey. While this initiative hasn’t focused on HIV/AIDS specifically, The World Bank has been an influential actor in creating an agenda that emphasizes the importance of FBOs as ‘agents of

transformation'.⁵ Examples of actors that have been actively addressed by FBOs concerning FBOs and HIV/AIDS are the United Nations Aids Organisation and the World Health Organisation.

First the collaboration between UNAIDS and The Ecumenical Advocacy Alliance (EAA) an umbrella organisation of the World Council of Churches is examined. The EAA brings together churches and FBOs from all over the world to campaign for common concerns.⁶ HIV/AIDS is a priority theme. The EAA has cooperated with UNAIDS on involving FBOs and religious leaders in the fight against HIV/AIDS. Reports focus on exploring the role of FBOs in fighting HIV/AIDS and define strategies for cooperation with organisations and leaders.⁷ Thus, the cooperation between the EAA and UNAIDS is characterized by an *instrumental* approach of FBOs and their involvement in the fight against HIV/AIDS. However, UNAIDS has also facilitated EAA's activities with a more *intrinsic* approach. This was done in a workshop that brought religious leaders and FBOs together to develop theologies that counter the stigma attached to HIV/AIDS.⁸ Thus the cooperation between EAA and UNAIDS has mainly been focused on practical, policy oriented approaches to FBOs, but UNAIDS has also recognized the importance of reflection on the content of religious perspectives. While an *instrumental* approach to FBOs has been central, UNAIDS has also stimulated an *intrinsic* approach.

Another example of intensive cooperation between various faith based and non faith based actors on religion and HIV/AIDS is the WHO-initiated African Religious Health Assets Programme (ARHAP). This programme combines an *instrumentalist* and *intrinsic* approach. ARHAP promotes a broader approach to understanding the capacity of people to healthy behaviour.⁹ The programme sets out to gain an insight into the (potential) roles of FBOs and religious groups in 'the response to global

⁵ The expression is taken from Clarke, Gerard (2007) 'Agents of Transformation? Donors, faith based organisations and international development'. In: *Third World Quarterly*, vol. 28, 1, pp 77-96.

⁶ Ecumenical Advocacy Alliance (2009): <http://www.e-alliance.ch/en/s/about-us>, accessed on April 29th

⁷ UNAIDS (2009). <http://www.unaids.org/en/Partnerships/Civil+society/unaidsStrategicApproach.asp>,.An example of a report with an instrumental approach is: Lux, Steven *Scaling up effective partnerships: A guide to working with faith-based organisations in the response to HIV and AIDS*. UNAIDS.

⁸ UNAIDS (2005) *A report of a workshop focussing on HIV and AIDS related stigma*. Windhoek, Namibia.

⁹ Religious assets are understood to represent more than only the formal organised FBOs, for further reading Cochrane, James (2006) 'Conceptualising Religious Health Assets Redemptively' in *Religion and Theology*, vol. 13, 1., Leiden, pp107-120.

health challenges' such as HIV/AIDS.¹⁰ Instead of discussing HIV/AIDS and other health problems in negative terms, the focus is on assets. Religion as an asset is seen as something that 'may be leveraged for greater value' in the fight against HIV/AIDS.¹¹ Thus, while the language of 'assets' suggests primarily, an *instrumentalist* approach focused on the functions of religion, this approach also aims to include *intrinsic* discourses on HIV/AIDS .

Lobby and advocacy

Many FBOs have been active in focusing the attention of government and multilateral donors on the work of FBOs. The British FBO Tear Fund is an example of an organisation that has published several reports and documents on FBOs and churches, and their role in the fight against HIV/AIDS.¹² Fitting well with the lobby and advocacy aims one would expect from every non governmental organisation, many of these publications set out to emphasize the importance of recognizing the roles churches and FBOs play, or can play in the fight against HIV/AIDS. Tear Fund voices its partner's experiences and concerns in relation to donors and funds. A report on the Global Fund for Malaria, Aids and TB states that:

Tear Fund partners have been surprisingly consistent in voicing areas of concern about the international funding instruments. Overall they feel that local faith-based initiatives have something significant to contribute in the response to HIV and AIDS, but the funding instruments are not geared at supporting them.¹³

This quote illustrates that Tear Fund's position as an *insider* enables them to relate to the experiences of partner FBOs in developing countries. At the same time Tear Fund is a Western, development organisation and therefore in a position to engage in dialogue with Western donor governments and multilateral organisations. This audience of *outsiders*

¹⁰ Ibid, p. 108.

¹¹ Cochrane, James R. (April 2006), 'Religion, Public Health and a Church for the 21st Century', In *International Review of Mission*, (vol. 95), nr. 376/377 59-72:60.

¹² Taylor, Nigel, (2005), *Many clouds, little rain? The Global Fund and local faith-based response to HIV and Aids* Tear Fund: and Taylor, Nigel (2006), *Faith Untapped. Why Churches can play a crucial role in tackling HIV/AIDS in Africa*. Tear Fund. Tear Fund: <http://tilz.tearfund.org/Research/HIV+AIDS+reports>, accessed on April 28th 2009.

¹³ Taylor *Many Clouds*, p. 12.

obviously influences the way their perspectives are shaped and carried out. In doing so Tear Fund uses only *instrumental* arguments, emphasizing the ‘significant contribution’ FBOs can make to the fight against HIV/AIDS.

Alliances

An example of an occasional alliance is the position paper *Human Rights, HIV/AIDS prevention and Gender Equality* that was written for the International Aids Conference held in Mexico in September 2008. This paper, written by a number of northern European FBOs, among others the Dutch Protestant development organisations ICCO and KerkinActie, Finn Church Aid, Norwegian Church Aid, Church of Sweden, Dan Church Aid, Christian Council of Norway, Bread for the World and Christian Aid.

The document seems to be written with two purposes: to disseminate the message that FBOs have a unique value in the fight against HIV/AIDS, and to call upon FBOs themselves to take leadership in the fight against HIV/AIDS. The document emphasizes the unique possibilities that FBOs create in the fight against HIV/AIDS because they provide extensive, already existing community structures. However, the document also speaks in terms of responsibility and what FBOs should do; pointing at the challenges FBOs face in addressing issues of gender and sexuality. Well known examples are the sensitivities around sexual education and condom use as a prevention of HIV/AIDS, because this is often associated with promiscuous lifestyles. The document challenges FBOs to combine a value based approach with an evidence based approach, a discussion that will be illustrated in the contribution of Marijn in this volume. The position paper argues that FBOs must take leadership in fighting HIV/AIDS, take issues of gender equality seriously and challenge norms of gender inequalities. Furthermore FBOs should promote evidence based prevention including condom use and promote basic sexual and reproductive health and rights. Finally, it is argued that they should recognize that empowering women is essential to a holistic HIV and AIDS strategy and that involving men both as right holders and as important duty-bearers to change unequal relationships is crucial.

The position paper, thus not only serves the aim of bringing the important role of FBOs to the attention of the powerful actors present at the Mexico conference, it also gives specific directions as to how FBOs should be involved. The position paper is thus both directed to outsiders and insiders. A closer look at insider discourses of FBOs shows that there is debate on what the role of FBOs is, or should be. Moreover, certain alliances are created to pursue a specific agenda.

While the position paper is the result of an occasional alliance, an example of a long term alliance is the fore mentioned Ecumenical Advocacy Alliance on HIV/AIDS, amongst others responsible for organising an ecumenical pre-conference to the AIDS conference in Mexico. Among their strategies and activities are advocating for more just policies on HIV/AIDS, reminding donors on their commitments towards HIV/AIDS funding, reducing stigma on HIV/AIDS within religious communities and stimulating participation of FBOs in the International AIDS conferences. The text of a paper introducing the theme of the pre-conference illustrates the dual role of alliances such as the Ecumenical Advocacy Alliance on HIV/AIDS:

Now! more than ever, is the time for churches to hold world leaders accountable to their promised commitments towards universal access by 2010—universal access to prevention, care and treatment services—and the Millennium Development Goals.

Now! more than ever, is the time for churches to continue to lead the way—restoring hope and health in the face of HIV and AIDS. The sick, the hurting, the hungry, the marginalized, the destitute, the orphan, the widow and the dying, find hope through the services offered by churches.¹⁴

Similar to the position paper discussed above, this paper also emphasizes the role of FBOs in fighting HIV/AIDS as well as in their role in the religious communities themselves. In the previous paragraph on UNAIDS we already discussed the dialogue of the EAA with UNAIDS, an outsider to the faith perspective on HIV/AIDS. In the quote we are also introduced to the insider discourse in which the EAA calls upon churches and faith communities to become active in the fight against HIV/AIDS. While their main argument is *instrumentalist* and emphasizes the role of churches in service delivery, the language also has *intrinsic* aspects. Words like ‘the sick, the hurting, the orphan, the widow’ are related to an *intrinsic* biblical and theological discourse in which Jesus tells a parable on a King who explains that to take care of the hungry, the sick and the prisoner is like taking care of him.¹⁵

¹⁴ Ecumenical Advocacy Alliance on HIV/AIDS, (august 2008), *Faith in Action Now. Theme paper*. <http://www.e-alliance.ch/en/s/hivaids/international-aids-conference-2008/ecumenical-pre-conference/>.

¹⁵ New International Version, Matthew 25:34-41.

Addressing religious communities

In June and August 2008, readers of two Christian newspapers in the Netherlands could read two articles written by employees of the Dutch network of Christian organisations.¹⁶ Both articles affirmed that FBOs have an important role in the fight against HIV/AIDS, but also recognizes that religious groups can also play an obstructive role. The first article closes with a firm message to the readers: ‘As Christian organisations we want to contribute to a world in which love and justice are central’ and ‘let us continue to pray for people who live with HIV’. In these articles *instrumentalist* and *intrinsic* discourses are combined. *Instrumentalist* arguments are used to appeal to the readers of the newspapers who are potential individual donors to Dutch FBOs. *Intrinsic* arguments serve the mission of these organisations to fight stigmas associated with HIV/AIDS by Christians in The Netherlands, trying to change the still persistent association of HIV/AIDS with sin into an attitude of compassion. These articles illustrate that the importance of FBOs lies not only in their added value in the fight against HIV/AIDS, but in their ability to access religious communities and groups with their informed positions on HIV/AIDS. In Tanzania, for example, religious leaders call on believers to go to a clinic for voluntary counselling and testing. In the Netherlands, FBOs set out to involve Dutch Christians in their work in developing countries. Such efforts are focused on an insider perspective and *intrinsic* discourses can be founding or legitimatising more *instrumentalist* goals. I will illustrate this in two cases in the next paragraph.

To summarise: FBOs continue to bring the importance of their work in the fight against HIV/AIDS to the attention of different actors and audiences. In dialogue and cooperation with outsiders like government donors and multilateral organisations, FBOs are more likely to use an *instrumentalist* discourse in which the important role of FBOs in the fight against HIV/AIDS is emphasized. In dialogue and cooperation with insiders both *instrumentalist* and *intrinsic* discourse is used. In the example of alliances of FBOs, I have tried to show that there are diverse positions among FBOs on HIV/AIDS. Insider perspectives on HIV/AIDS are by no means clear cut, but can be made understandable to an audience of outsiders, as I hope to illustrate in the last paragraph.

¹⁶ Kupers-Oving, Darije (2008) “Bestrijd Aids met uitstap en afkickprogramma’s” In Reformatorisch Dagblad, issue August 7, p. 9, Kupers-Oving, Darije (2008) “Samen met Kerken in de strijd tegen Aids” In Nederlands Dagblad, issue August 6, Kupers-Oving, Darije (2008) “Dreiging van HIV/AIDS niet voorbij” in Reformatorisch Dagblad, issue June 13th.

The role of FBOs in religious communities

In this paragraph I will explore two cases in which FBOs develop an *intrinsic* discourse on HIV/AIDS. In the paragraph 3.1 I analyze a report published by Christian Aid in which a theology on HIV/AIDS is proposed. Paragraph 3.2 is based on ethnographic material I have collected on the Evangelical Lutheran Church of Tanzania, combined with the analysis of their AIDS policy.¹⁷ I will use the grammars of identity/alterity as an analytical tool. My overall argument in this paragraph will be that *intrinsic* approaches to HIV/AIDS contribute to the construction of religious identities with HIV/AIDS as a special frame of reference. The case of ELCT will allow me to argue that *intrinsic* discourses can lead to *functionalist* discourses from which policies can be designed and put into practice.

Selfing and othering in a Christian Aid Report on HIV/AIDS

The paper, *Theology and the HIV/AIDS epidemic* by Christian Aid, provides an interesting example on how FBOs engage in substantive discourses on religion and HIV/AIDS.¹⁸ *Theology and the HIV/AIDS epidemic* is a response to ‘a spectacular theological error of the church in the epidemic’s early days’ and sets out to prove that the view of AIDS as a punishment of God is fallible in a theological and pastoral sense. Christian Aid introduces a theological approach to HIV/AIDS that draws upon notions of ‘the fidelity of Gods love’ and the ‘goodness of creation, love and life’. Following the work of the 20th Century theologian Karl Barth, it is argued that in the story of creation a covenant of grace is central to the relationship between God, his creation and his people. The personal stories of individuals derive their meaning from the creation and because of that, all personal stories ‘whether in health sickness or suffering, are somehow related to the fuller narrative of God’s purposes for the world’.¹⁹

Unlike the previous publications we have discussed, Christian Aid has not published this report to advocate for recognition of FBOs by donors and multilateral organisations, nor is it directed at developing new

¹⁷ In March and April 2008, I have visited 11 organisations in two cities; Mwanza and Arusha. Four of these organisations were Muslim; others belonged to different denominations of the Christian faith. In addition I interviewed two missionaries with long-standing experience in the Archdiocese of Mwanza. This case is based on several interviews with ELCT employees, on narrative accounts from conversations and observations and on organisational materials such as policy documents.

¹⁸ Clifford, Paula (2006). *Theology and the HIV/AIDS epidemic* Christian Aid.

¹⁹ Clifford, *Theology and the HIV/AIDS epidemic*, p.5.

policies on HIV/AIDS as such. The language of the report very clearly shows that the report is written for people who share the Christian faith with the organisation and are familiar with this language and its underlying frameworks of meaning. At the same time the report is aimed at changing a particular theological understanding of HIV/AIDS that excludes people living with HIV condemning them as immoral and sinful. It is argued that this view is not in line with the active involvement of churches, FBOs and individual believers in the fight against HIV/AIDS.

In light of the grammars of identity/ alterity, what first stands out in the Christian Aid report is that the 'fuller narrative of God's purposes for the world' exceeds the variations in personal stories whether they are characterized by sickness or health.²⁰ Thus, people living with HIV are no longer excluded on the bases of the sinful life that is associated with HIV, but included by looking at them and all people in general, through the narrative of creation. This is an excellent example of a shift from an *orientalist* grammar to an *encompassing* grammar approach. The black and white approach of the *orientalist* grammar divided the world into sinners and faithful. The association of HIV/AIDS with promiscuity provided believers with a narrative to structure the world into a faithful, healthy us opposed to a sinful, HIV-positive them. In the grammar of encompassment, differences between people are subsumed under a larger narrative of universal sameness through God's creation. Of course this argument is not exclusive for HIV/AIDS, but applicable to many other elements in personal life stories that make one human being different from the other (i.e. gender, ethnicity etc.).

To give another example, concerning the problem of stigmatization of people with HIV/AIDS:

The stigmatization of individuals is a sin against the Creator God, in whose all human beings are made. (Because) To stigmatize an individual is to reject the image of God in the other, and to deny him or her life in al its fullness.²¹

In this quote the use of the grammar of encompassment enables the authors to change the concept of sin to apply it to those who contribute to stigmatising people infected or affected by HIV/AIDS. Thus, while HIV/AIDS is no longer an acceptable mode of *othering*, sin remains a means to separate between us and them. Within an *encompassing* grammar however, everyone is included without looking at their HIV

²⁰ Ibid.

²¹ Ibid.

status, the 'sins' they have committed or the hierarchical position they occupy.

The use of the grammars enables us to understand an *intrinsic* religious discourse. The shift from an *orientalist* to an *encompassing* grammar proves that *intrinsic* discourses are not static and capable of change. Christian Aid is an example of an FBO that argues in favour of changing dominant discourses in such a way that they are more inclusive of people infected and affected by HIV/AIDS. This supports amongst other things, their *instrumentalist* aim of removing stigma and taboos on HIV/AIDS in religious communities. We will see this shift again in the following paragraph where I will discuss the Aids policy of the Evangelical Lutheran Church in Tanzania.

Discourses in policy and practice: The ELCT in Tanzania

The Evangelical Lutheran Church (ELCT) was founded in the 19th century, by Lutheran missionaries. Reflecting the heritage of the missionaries; pastoral tasks, social service and development efforts are still intertwined. While the head of the Health department of ELCT describes the role of the Church in development and social services as historical and therefore natural, others also mention that the Church fills a gap left behind by the government in the development of the country. In fact ELCT is one of the largest providers of health services in the country today.²² The HIV/AIDS programme is part of the Health services section of the Department for Social Services and Women's Work. The church employs a professional staff working on different projects and programmes, each having its own funding and partner networks. In addition, some lay missionaries from sister churches in Europe and the USA work for the church, investing their professional qualities as a doctor or a nurse in the church programmes.

The ELCT published an HIV/AIDS policy in 2002, but was active in fighting HIV/AIDS before. The AIDS policy recalls that the first programme on HIV/AIDS was launched in 1987, however according to an interviewee the first programmes were developed in the 1990s. Initially ELCT focused on HIV/AIDS as a medical issue, for example by giving traditional birth attendants and circumcisers in the Masai community clean blades to prevent infections and reduce HIV transmission. During the 1990s it became increasingly accepted that HIV/AIDS was a social and spiritual issue as well as a health issue. HIV

²² Minha, Amos (2007), *Religions and Development in Tanzania, A Preliminary Literature Review Working Paper 11*, Religions and Development Research Programme University of Birmingham: <http://rad.bham.ac.uk/index.php?section=40>.

activities combined voluntary counselling and testing services, with home based and pastoral care. After the Millennium the ELCT also started prevention activities, including some successful foreign funded programmes.

The ELCT AIDS policy departs from the divine calling ‘to serve humanity spiritually, physically, mentally and socially’ and ‘recognize the humanity and love of God in and among people with HIV/AIDS’. The policy document thus departs from an *encompassing grammar* from which it derives the mission to ‘minister the people with HIV/AIDS with love and compassion’. The document continues with the recognition that previous responses to HIV/AIDS have been sinful. Here we see a shift similar to that in the Christian Aid report discussed before. A difference is however that ELCT itself is an insider and not an observer to this shift in discourse, and therefore the confession of sin is more personal.²³ Let me illustrate this with a quote:

We, the ELCT, confess before God and our fellow human beings that we have not loved our neighbour with HIV/AIDS as ourselves. We have throughout the course of the epidemic fallen short of God’s plan for us in relating to one another. Regarding the HIV/AIDS epidemic we have been biased, discriminatory, lacking in love, superior, and lacked the love and care that is deserved.²⁴

The encompassing approach thus is presented as a better alternative, than the previous *orientalist* approach in which people living with HIV and AIDS were ill-treated. The confession of sin is a religiously powerful way to underline the equality and unity that belongs to the *encompassing grammar*. Because of this, sin is no longer a basis for *othering*, but the love of God is for people infected and affected by HIV/AIDS as well as for the church that has ‘fallen short of God’s plan’. The act of confessing sin also removes hierarchical boundaries between church leaders, believers and the people at large at least symbolically.

In practical terms, the policy document serves as a way to make a new commitment to a more effective approach to HIV/AIDS. Nine goals are formulated, of which the first concerns the promotion of education and prevention activities to reduce the prevalence of HIV/AIDS in

²³ It must be noted that the report is not clear about if Christian Aid itself has ever embraced an orientalist approach of HIV/AIDS, or an observer of this orientalist perspective on HIV/AIDS tries to influence a shift towards an encompassing grammar.

²⁴ Evangelical Lutheran Church of Tanzania (2002) HIV/AIDS Policy – issued in July, a copy was obtained in an interview with an ELCT Health advisor in April 2008.

Tanzania. One of the activities following from this policy goal is the Local Competence Building and HIV/AIDS Prevention project that was designed in cooperation with Dan Church Aid and funded by the European Union. ELCT is one of the organisations I have researched that places much emphasis on professionalism. One is even tempted to forget that they are in fact, primarily a church and not a development organisation. What characterizes their approach to HIV/AIDS is, that it is both functional as one of the largest health providers in the country, and substantial in constructing a particular religious perspective on HIV/AIDS. The *encompassing* approach of HIV/AIDS following the confession of sin seems, at least in the policy of the organisation, to be a positive influence on the involvement of ELCT in HIV prevention.²⁵

An analysis of the ELCT AIDS policy points at a shift in discourse from an *orientalist* to an *encompassing* grammar, similar to the shift in the theology of Christian Aid. A difference however is that the ELCT is an *insider* to both discourses and confesses that their *orientalist* approach of people with HIV/AIDS has led to stigma and discrimination. That the AIDS policy starts out with a confession of sin legitimates the shift to *encompassment*. The Aids policy of the ELCT shows that *intrinsic* arguments can be the foundation of an *instrumental* approach that is focused on the design and implementation of the policy. In this case both discourses were necessary to achieve a comprehensive perspective on HIV/AIDS in which religious values and practical challenges in the fight against HIV/AIDS come together.

In the two cases discussed in this paragraph we see a shift from an *orientalist* grammar approach to an *encompassing* one. Christian Aid uses this to argue for such a shift in theological discourses of religious leaders, communities and FBOs and engage them in the fight against HIV/AIDS. The ECLT has made this shift. As a church and health care provider they admit to have contributed to the stigmatising and discrimination of people infected with and affected by HIV/AIDS. The recognition of this *orientalist* approach as a sin, makes possible a *encompassing* discourse on HIV/AIDS. Based on this *intrinsic* argument, the ELCT Aids policy then moves to an *instrumental* approach to HIV/AIDS in the design and implementation of policy. The policy document thus seems both a reflection of, and an attempt to a more inclusive and comprehensive approach to HIV/AIDS. The fact that ELCT has started successful prevention programmes as a result of this policy may be a coincidence. However the *encompassing* grammar seems almost necessary to embrace

²⁵ The careful formulation of this conclusion is based on my limited perspective, since I have only interviewed policy workers at head quarters and have not evaluated the programs in the field.

in order to be able to deal with the dilemma's FBOs encounter when they engage in prevention programmes, especially when it comes to sex education.

Conclusion

This paper started with the example of the continuum in which sexual acts were discussed in terms of their safety and in terms of their 'lawfulness' from a Christian perspective. What is interesting in this example is that the exercise raises questions on how religious values can be combined with evidence and rights based approaches. The tensions and negotiation between these two aims are practical challenges that FBOs face in their fight against HIV/AIDS. In this paper I have aimed to show how FBOs deal with this tension and seek a more comprehensive approach. In order to do so, I distinguished between insider and outsider perspectives of FBOs and HIV/AIDS. Furthermore I have pointed at *instrumentalist* and *intrinsic* characteristics of discourses of FBOs on HIV/AIDS. Because *intrinsic* arguments or discourses contribute to the construction of specific religious identities, I have proposed to analyze such discourses using the grammars of identity/ alterity.

Discourses constructed by FBOs in dialogue and cooperation with outsiders such as UNAIDS or the Global Fund are characterized by an *instrumentalist* approach, in which the importance of recognition of FBOs in the fight against HIV/AIDS is emphasized. While, outsiders such as UNAIDS and WHO have stimulated a more *intrinsic* discourse of FBOs on HIV/AIDS, these discourses are only constructed from an insiders perspective on religion, thus by FBOs themselves. In dialogue with insiders, as we have seen in the example of the news paper articles by Dutch FBOs, FBOs use both *instrumentalist* and *intrinsic* arguments.

In paragraph three I analyzed two examples of insider's discourses. The grammars of identity/ alterity enabled an analysis of *intrinsic* discourses that often remain a "black box" to outsiders because of the theological arguments used. The Christian Aid report argued that theology has often served to legitimize the stigmatizing and discrimination by Christians, towards people infected with and affected by HIV/AIDS. With the shift from an *orientalist* to an *encompassing* grammar a theological base for inclusion of people infected with and affected by HIV/AIDS has been proposed. In the Aids policy of ELCT we see a similar shift, but with the difference that ELCT confesses that it has been contributing to stigma and discrimination because they previously embraced an *orientalist* approach to HIV/AIDS. The ELCT

has experienced this shift itself and root their *instrumentalist* policies in the *encompassing* grammar of their *intrinsic* discourse.

Obviously the question of whether the use of an *encompassing* grammar still involves a certain degree of *othering* and inequality is still very much up for research and discussion. This paper, however, did not set out to answer the question whether discourses and practices of FBOs such as ELCT and Christian aid still contain a degree of inequality. I have aimed at illustrating that religious discourses are not the ‘black box’ they are thought to be. Moreover, I have showed that religious thinking is not static and fixed but up for change. In the examples of Christian Aid and ELCT I have shown that FBOs can have an important role in the process of changing religious discourses on HIV/AIDS.

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