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# Politics behind Aids Policies Case Studies from India, Russia and South Africa

edited by

**Rolf Rosenbrock** 

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#### **Abstract**

Im Kampf gegen die Aids-Pandemie und ihre zahlreichen Sub-Epidemien wird auch für die absehbare Zukunft die Verhütung neuer HIV-Infektionen, also die Primärprävention die wichtigste Rolle spielen. Gestützt auf theoretische Modelle aus der Sozialpsychologie, der Sexualwissenschaft und des sozialen Lernens hat sich in den letzten fünfzehn Jahren weltweit ein Konsens über Methoden herausgebildet, mit denen die dazu notwendigen Änderungen des Verhaltens im Bereich der Sexualität und des i.v. Drogengebrauchs unterstützt und bewirkt werden können. Solche Interventionen folgen dem Ansatz der Ottawa Charta der WHO zur Gesundheitsförderung (1986). Sie sind weltweit in unterschiedlichen Kulturen, Schichten und Zielgruppen erfolgreich.

Größere Schwierigkeiten als der Entwurf geeigneter Maßnahmen, Anreize und Infrastrukturen für primäre HIV-Infektion (policies) bereitet die Überwindung von politischen, kulturellen, ökonomischen und organisatorischen Hindernissen (politics), die diesem Ansatz entgegenstehen.

Die vorliegende Veröffentlichung vereinigt Fallstudien zu Aids politics aus Indien, Rußland und der Republik Südafrika. In Südafrika wird die Implementation einer bereits formulierten policy v.a. durch die gleichzeitig stattfindende Ablösung vom Apartheidregime und die dadurch ausgelösten Transitionen im Institutionengefüge behindert. Nachdem die Aids-Epidemie nicht mehr einfach geleugnet wird, liegen die wichtigsten Hemmnisse in Indien in der Tabuisierung der Kommunikation über Sexualität sowie der umfassenden Unterdrückung der Frauen. In Rußland schließlich verhindert derzeit eine politisch außerordentlich heterogene Koalition die Schaffung elementarer Voraussetzungen von Aids-Prävention, wie z.B. die Einführung von Sexualaufklärung. Alle drei Fallstudien enthalten neben der Analyse von Hindernissen auch Hinweise zur Überwindung derzeitiger Defizite sowie auf weiteren Forschungsbedarf.

Die hier veröffentlichten Beiträge wurden zuerst am 29. Juni 1998 in Genf auf der 12. Welt Aids Konferenz "Bridging the Gap", Grand Round Session "Politics behind Aids Policies" (D 15) vorgetragen.

#### **Abstract**

In the fight against the AIDS pandemic and its numerous sub-epidemics, the prevention of new of HIV infections, i.e. primary prevention, will play the most important role in the fore-seeable future. Based on by theoretical models from the fields of social psychology, sexology and social learning, a consensus on methods has developed over the last fifteen years which can effect and reinforce the necessary behavioural changes in the areas of sexuality and iv drug use. Such interventions follow the approach of the WHO's Ottawa Charter on Health Promotion of health (1986). They have proven successful all over the world, among different cultures, classes and target populations.

The overcoming of political, cultural, economic and organizational obstacles to this approach (politics) presents greater difficulties than the designing of appropriate measures, incentives and infrastructures for primary HIV infection (policies).

The present publication brings together case studies of AIDS politics in India, Russia and the Republic of South Africa. In South Africa, the implementation of a previously formulated policy is being hampered, above all by the simultaneous dissolution of the Apartheid regime and the resultant changes in the institutional framework. In India, the most important impediments -- now that the AIDS epidemic is no longer simply being denied -- are taboos on discussing sexuality and the extensive oppression of women. Finally, in Russia, an politically extraordinarily heterogeneous coalition is currently hindering the establishment of the basic preconditions for AIDS prevention, such as the introduction of sex education. In addition to analyzing the obstacles, all three case studies also suggest means of overcoming the current deficiencies as well as areas where further research is needed.

The contributions published here were first presented in Geneva at the 12th World AIDS Conference, "Bridging the Gap", Grand Round Session, "Politics behind AIDS Policies" (D 15) on June 29, 1998.

#### Tribute to Jonathan Mann and Mary-Lou Clements-Mann

This Publication "Politics behind Aids Policies" is dedicated to the memory of Dr. Jonathan Mann, Professor of Public Health, and Dr. Mary-Lou Clements-Mann, Professor of International Health, who died in a plane crash, on Sept. 2nd, 1998.

Statement by Dr. Peter Piot, Executive Director of the Joint United Nations Programme on HIV/Aids (UNAIDS)

It is with deep shock that we have learned today that Jonathan Mann and his wife, Mary-Lou Clements-Mann, were both passengers on the flight that crashed off the coast of Nova Scotia late last night. They were on their way to attend a series of WHO and UNAIDS meetings on Aids. Jonathan was a brilliant and committed colleague who, during the last fifteen years, was a visionary global leader in the fight against Aids and tirelessly promoted a response to the epidemic based on respect for human rights and human dignity. He was an exceptionally gifted human being, a charismatic and courageous leader, and an understanding and loyal friend.

His international career started in 1984 when he founded Projet SIDA in Zaire, the most comprehensive Aids research effort in Africa at the time. In 1986, he joined the World Health Organisation to lead the global response against HIV/Aids, and became the first Director of the WHO Global Programme on Aids (WHO/GPA). He was instrumental in bringing global and political attention to the seriousness of the epidemic. He developed the first Global Aids Strategy and organised an historic World Summit on Aids prevention in 1988 in London, UK. In his address to the meeting he said: 'We live in a world threatened by unlimited destructive force, yet we share a vision of creative potential ..., Aids shows us once again that silence, exclusion, and isolation - of individuals, groups, or nations - creates a danger for us all.'

Today, over 30 million people are living with HIV/Aids, the vast majority in the developing world. His conviction that health was inextricably linked to the respect of human rights led him to join the Harvard School of Public Health where he subsequently became the Francois-Xavier Bagnoud Professor of Health and Human Rights. In January of this year he was nominated Dean of the Allegheny University School of Public Health in Philadelphia.

In 1996, he married Mary-Lou Clements. A professor in the Department of International Health, at Johns Hopkins University in Baltimore, she was a distinguished expert in vaccine development and former director of the Johns Hopkins Center for Immunisation Research. Mary-Lou was involved in the conduct of numerous trials of candidate vaccines against Aids in the United States. In 1992, she spent a sabbatical year assisting WHO/GPA in the development of its international HIV vaccine activities. She was a member of the UNAIDS Vaccine Advisory Committee and was travelling to attend an HIV vaccine meeting in Geneva.

Our thoughts are with Jonathan's former wife, Marie-Paule, his children Naomi, Lydia and Aaron, the family of Mary-Lou, and their many friends and colleagues all over the world.

Geneva, Sept. 3rd, 1998

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## Politics behind Aids Policies: Appropriate Approaches, Fostering and Impeding Factors

There is world-wide consensus¹ to the effect that in the battle against infectious diseases clear priority must be given to primary prevention, or protection from infection. Nor is it disputed that the earlier a preventive policy is implemented, the greater the chances are it will be effective. Time counts. Delays cost lives.

It is also clear and undisputed that successful, primary prevention of HIV infections has to aim at reducing the number of risk situations.

Since the virus is transmitted via penetrating sexual contact and the use of contaminated syringes in the vast majority of cases, safer sex and safe use are the pragmatic aim of HIV prevention.

Sexuality and drug use are intimate spheres of life that are often linked to fears, shame, taboos, prejudices and police persecution. Handed-down balances of power often play a role in this connection as well, e.g. between men and women, between the family and the individual, between rich and poor, between various ethnically defined groups.

Behaviour in these spheres of life cannot be efficiently influenced by repression and persecution, or by simple information and appeals.

At the beginning of the epidemic there was great scepticism as to whether it would be possible to influence such risky, HIV-related behaviour in any way at all.

In the last 15 years, however, numerous experiments and innovations show – as constantly confirmed by large numbers of evaluations – that it is possible to bring about and stabilise large-scale changes in behaviour that would prevent infection with HIV. As is the case with most health risks, 100% prevention cannot be achieved; but well-organised prevention can be effective enough to stop the further spread of a respective sub-epidemic. It thus provides the scaffolding for an effective and efficient HIV prevention policy, the policy-of-learning strategy.

This paper is based on the author's plenary lecture "The Role of Policy in Effective Prevention and Education" at the IXth International Conference on Aids and the IVth World STD Conference in June 1993 in Berlin/ Germany. Published in: D. Friedrich/W. Heckmann (eds.): Aids in Europe - The Behavioral Aspect, Vol 5., Berlin 1995, pp 17-26, German versions: Rolf Rosenbrock: Ein Grundriß wirksamer Aids-Prävention, in: Zeitschrift für Gesundheitswissenschaften - Journal of Public Health, Vol. 2, No. 3/1994, pp 233-244, and: Rolf Rosenbrock: Strategie und Politik für wirksame Aids-Prävention, in: Aids-Forschung (AIFO), Vol. 9, No. 2/1994, pp 85-90

An effective learning strategy regularly operates at three levels

- 1. Population-wide messages focusing on the issues of:
  - how can I not be infected?
  - what are risk situations?
  - what is effective protection?
  - cohesion and solidarity:
- 2. Group-specific campaigns to suit the relevant social and regional settings and cultures, and which are best organised by the groups and/or communities affected.
- 3. Empathetic individual counselling and support, done either by professionals or by those in the same situation.

At the core of an Aids policy aimed at modification of behaviour is the following model<sup>2</sup> which can also be formulated in the following Ten Commandments:

- Start and maintain persistent communication of risks and possibilities of protection.
- Make intensive use of person-to-person contacts and counselling.
- Develop, establish and maintain community-based stimuli for the avoidance of risks and encouragement of health-promoting behaviour.
- Take into account the material and cultural conditions that can foster or impede risk-avoidance and health-promoting behaviour.
- Strengthen and propagate social norms that encourage people to avoid risks and shoulder a fair share of responsibility for preventive behaviour.
- Strengthen and propagate social cohesion within the communities affected.
- Advocate tolerance and respect for life styles within target groups.
- Support community building and community organising of, and within, the target groups.
- Organise Aids prevention in the form of predominantly non-medical intervention.
- Avoid coercive measures whenever possible.

There are numerous successful examples of how these relatively abstract sounding criteria can be adapted culturally and contextually to the concrete values, norms, histories and life situations of the various target groups. The resulting specific policies are successful with target groups and communities consisting of heterosexuals, homosexuals and iv drug users, with rich and poor. They are successful in rural communities and in large cities, among illiterates and university graduates, among women, men and the young. They are successful in Africa, North and South America, Asia, Australia and Europe.

So why isn't this policy model taken as a basis everywhere? Why does so little happen so often, so late or not at all? What are the factors that hinder and often enough prevent the worldwide application and generalisation of successful HIV prevention?

see Rolf Rosenbrock: Some Social and Health Policy Requirements for the Prevention of Aids, in: Health Promotion. An International Journal, Vol. 2, No 2/1987, pp 161-168

The following must first be noted: shortcomings and bottlenecks are not to be found primarily in a lack of knowledge or resources. The model's essence and core statements are just as well known as the methods employed for its cultural adaptation, implementation and assurance in practice. And even in very poor countries and communities it would be possible to mobilise the requisite material and human resources, alone or with the help of international donors.

So where's the problem?

The answer is not to be found in the policy itself. The answer only becomes apparent when we stop and remember that successful Aids policies do not arise in a vacuum or on their own. Rather, a whole number of actors and groups have to come to the following conclusions for them to arise:

that Aids is an important problem deserving priority attention,

that Aids prevention should be handled on the basis of the model outlined here,

that every important actor has to make a contribution based on his or her competence,

that obstacles to its implementation have to be eliminated,

that positive incentives have to be provided for its realisation and assurance.

Such processes involving perception, negotiation and the reaching of agreement take place in the political structures of governments, religious institutions, parties, interest groups, the private sector and NGOs. They thus take place between the interests and disinterests of political decision-makers and are shaped by the way in which the same perceive the subject of Aids and treat it as a political problem<sup>3</sup>. The answer is therefore to be found in the field of politics, and thus at a level behind the level of policies.

What is the difference between policies and politics in respect to Aids prevention?

Policy designates how Aids prevention is concretely organised, i.e. who transmits what information via what channels, who uses what tools to assume what tasks in community organising, fund raising, the distribution of condoms, counselling, etc.

Politics designates the process in which the relevant actors reach agreement on what is to be done about Aids and how that is to be organised.

Policies are the result of politics.

If we want to understand the politics level and – more importantly – want to nudge it in the direction of an efficient Aids policy, we must first ask ourselves who the actors are on whom it depends whether the preconditions for efficient Aids prevention can be created. Roughly speaking – though, after corresponding modification, this is true of every country in the world – we are concerned with ten groups:

1. The government. As a rule, heads of government have to publicly declare and actually assume active and responsible commitment. They must not shape the process only from the top down but must also permit bottom-up processes.

see Rolf Rosenbrock: Aids: Questions and Lessons for Public Health, in: Aids & Public Policy Journal, Vol. 8, No. 1/1993, pp 5-19

- 2. What is absolutely central and indispensable is the role the affected communities and/or peers and representatives of target populations and corresponding NGOs play in regard not only to the development of the model, i.e. its cultural adaptation, but also to its activation and mobilisation within the scope of bottom-up processes.
- 3. The importance of the health care system in prevention is, in contrast, modest; it is largely reduced to counselling individuals, providing voluntary HIV tests on request<sup>4</sup> and safeguarding blood and blood products.
- 4. More important is the role of the public health system, which is technically responsible not for primarily individual intervention but for population- and group-related intervention of the kind required in the case of Aids prevention.
- 5. The courts, police, military and other coercive powers have virtually no productive role to play in the prevention of Aids and must often quite contrary to their wont take a back seat and refrain from using their tools of repression, especially when that could jeopardise the trust and cohesion of the target populations.
- 6. Scientists and researchers have to play an often uncustomary role in which they react sensitively to problems from the communities and tackle them in close cooperation with the same. In this respect they should be partners and servants of practical efforts and the communities affected.<sup>5</sup>
- 7. The contribution of the education system is also indispensable, because that is where large parts of the population groups at risk can be reached directly and, moreover, where intellectual and human resources can be mobilised for campaigns and multiplier effects.
- 8. The mass media have to mobilise the affected communities without resorting to sensationalism or prejudices; they have to fairly and accurately educate people about risks and report on the possibilities of avoiding them, the organisation of solidarity with afflicted persons and groups as well as the success and failures encountered in the process.
- 9. In the light of Aids and the groups affected by Aids, churches as well as religious and ideological organisations have to follow the humanitarian precept that it is first and foremost important to protect life and keep the epidemic from spreading. We cannot reshape those to be protected according to our own moral values; we must accept and respect them as they are.
- 10. The private sector, finally, has the task of demonstrating solidarity with people who are infected with HIV or ill with Aids and of providing resources for community-borne prevention.

This short list should make it clear that successful Aids policy does not depend on one factor but on many. Successful Aids policy takes place in an actors' network that extends far beyond

see Rolf Rosenbrock: Screening for Human Immunodeficiency Virus, in: International Journal of Technology Assessment in Health Care, Cambridge University Press, 7:3 (1991); S. 263-274

see: Rolf Rosenbrock: Social Sciences and HIV/AIDS policies: Experiences and perspectives, in: D. Friedrich/W. Heckmann (eds.): AIDS in Europe, Vol. 1, Berlin: edition sigma, pp259-269

the customary responsibilities and limits of health policy. Each of these actors has to abandon his customary role and become receptive to a new perception of the problem as well as to new responsibilities and cooperations<sup>6</sup>. In this connection, the customary ways in which people pursue their own interests must take a backseat to the higher-ranking interests of Aids prevention.

I would like to use the example of governments to briefly explain the difficulties this faces: for governments Aids is always only one of various urgent problems; Aids competes with these other issues for priority on the agenda. Often, governments also seem to find it hard to stop taking their orientation from the economic and power interests of their clientele. Governments sometimes refuse to depart from their customary parochial routines and the verbal defence of ostensibly moral, and thus highly respected, positions. Due to their roots or social ties, they often shy away from recognising and making a public issue of inequalities in health opportunities, e.g. in social classes or in gender relations. Governments can also find it hard to dispense with a style of governing based on commands and obedience and create the preconditions for democratic participation "from below", to permit bottom-up processes and support them morally and materially. It can be difficult to persuade coercive forces to refrain, in the interest of efficient prevention, from using their tools of power. Also, it is often tempting to leave the organisation of Aids prevention to lower levels, e.g. to ministries of health or regional administrations, or to the health system, without creating the preconditions required there for successful implementation. And, last but not least, it can also be hard for governments to turn down resources from international aid in favour of NGOs.

For all the other nine actors, acceptance of the role to be played for efficient Aids prevention can also run up against strong obstacles, resistance and habits similar to the ones confronting governments.

The world of politics does not, of course, consist only of obstacles. Impeding conditions also face fostering conditions in the case of all ten actors.

But even if everyone understood and accepted what is important for Aids prevention and why, the necessary processes of negotiation and policy formulation as well as assurance and co-ordination would remain difficult, because they are uncustomary and susceptible to interference.

So we see: behind Aids policies is Aids politics. Success at the level of politics therefore improves, on the one hand, the preconditions for a good Aids policy, i.e. efficient Aids prevention, while, on the other, requiring a large number of preconditions for its part.

Any community worker, NGO representative, public health officer, government official or physician who wants to create the preconditions for better Aids policy, and thus for more ef-

see Rolf Rosenbrock, Doris Schaeffer, Martin Moers, Francoise Dubois-Arber, Patrice Pinell, Michel Setbon: The Normalization of Aids in Western European Countries, Publication Series of the Research Unit Public Health Policy, Wissenschaftszentrum für Sozialforschung/Social Science Research Center (WZB), P98-207, Berlin 1998

fective Aids prevention, will need an analysis of the actors involved in the decision-making process, i.e. the politics, their interests and possibilities of action.

That is why the international Aids community has to deal with the politics of Aids, as well. In view of its importance and complexity, the scientific treatment of these problems is extraordinarily low-key<sup>7</sup>. That is particularly true of societies in transition, poor countries and those with strong traditions and religious underpinnings.

The present publication includes case studies from India, Russia and South Africa<sup>8</sup>. Any reader is invited to compare the findings and conclusions from these countries with the problems they face in their own countries. They will find similarities. Whenever they see differences, that too can hone analyses of the situation in their own field of work: every analysis begins with the perception of difference. What is intended is the beginning of a process in which the international Aids community reaches agreement on strategies to influence Aids politics like we all did in the 80s on the principles of successful Aids policy, thus achieving success everywhere politics did not thwart our plans. Further research and action is requested.

Norman Hearst and Jeffrey S. Mandel ('A Research Agenda for Aids Prevention in the Developing World', in: AIDS, Vol 11, Supplement 1, 1997, pp S1-S4) propose three main components for Aids prevention research in the developing world: epidemiologic and behavioral surveillance, enhancing local understanding of HIV and risk behavior, and testing interventions. Obviously, the recognition of the importance of politics would imply a broader research agenda.

There are, of course, case studies which follow a similar approach (e.g. Héctor Carillo: Another Crack in the Mirror: The Politics of Aids Prevention in Mexico, in: David Buchanan/George Cernada (eds.): Progress in Preventing Aids? Dogma, Dissent and Innovation, Amityville/New York 1997, pp155-177). But with respect to countries in transition or the developing world, there is no comparative research done as is for the industrialized countries (see the landmark study: David Kirp/Ronald Bayer (eds): Aids in Industrialized Democracies: Passions, Politics and Policies, New Brunswick 1992); German edition: David Kirp/Ronald Bayer (Hg.): Strategien gegen Aids. Ein internationaler Politikvergleich. Berlin: edition sigma 1994

#### The Politics behind Aids: The Case of South Africa

#### Introduction

"There are times when I need to remind myself why and how I got involved with HIV/Aids. These moments are stimulated by the political quagmire around Aids, and always leave me wondering at the gap between intentions and results...."

Anonymous, Aids Analysis Africa, Southern Africa Edition, June/July 1998

Few would argue that politics and Aids are deeply inter-twined. No other disease in the 20th century has been associated with so much overt conflict and contestation, whether in attributing origins and causes or in proposing solutions and allocation of resources. The fact that we have "Aids activists" and not "TB" or "measles" activists is symbolic of the special political status of HIV. However, many people feel at a loss in the face of politics. They have no explanations for the "political quagmire" surrounding Aids, and do not recognise themselves as political actors.

In South Africa, politics has always loomed large, and Aids is no exception. South Africa is in a transitional period with restructuring of just about every aspect of the state. It also has a serious HIV epidemic. The environment offers clear opportunities but also many constraints for Aids prevention. In describing the politics of Aids, in other words, the different actors, institutions and interests that have influenced Aids policy implementation in South Africa, I hope to show that a political or policy analysis can promote successful prevention by identifying realistic options, and accepting limits, for moving from "intentions to results".

#### The South African context

South Africa is a middle income country with a population of 39 million people and a percapita GNP of about US \$2,500 (SA Health Review 1996). With the exception of Botswana, South Africa has an income level far above its African neighbours and is similar in this respect to certain Latin American and Asian countries (Table 1).

South Africa is not dependent on donor aid to fund its health and social services, although a considerable amount of foreign aid has flowed into the National AIDS Programme. The country has the financial resource potential to provide a universally accessible "package" of HIV prevention activities including mass and targeted educational programmes, a safe blood supply, good STD care, free condoms and short course anti-retroviral therapy to HIV positive pregnant women.

<sup>1</sup> The issues relating to Aids prevention are relevant to Aids policy generally and the terms are used interchangeably in this presentation.

Despite South Africa's relative wealth, however, it has fared poorly on every indicator of social access and outcome that one cares to examine (Table 1). For example, its infant mortality rate is considerably higher than Malaysia, Argentina and Mexico, and exceeds that of Zimbabwe with a level of income quarter that of South Africa. These differences reflect the enormously unequal distribution of wealth and resources in the society. They are a legacy of the white, minority "apartheid" government, which ruled the country until 1994.

Table 1: South African in international context (1990/91)

Country	GNP per	Human devel-	Infant mortality	TB incidence (per
	capita	opment index	(per 1000 live	100 000 popula-
	(US\$)	1993	births)	tion)
South Africa	2560	0.649	54	250
Other Africa				
Botswana	2530	0.741	36	-
Malawi	230	0.321	143	345
Zimbabwe	650	0.534	48	207
Other				
Malaysia	2520	0.826	15	67
Argentina	2790	0.885	25	50
Mexico	3030	0.845	36	110

Source: McIntyre and Kirigia 1997

This government, however, did not go uncontested. The 1980s were characterised by internal mobilisation in every facet of life, from worker, to youth, civic, religious and professional sectors, and established a culture of participatory democracy within the country. The "mass democratic movement" as it was known, identified strongly with the African National Congress (ANC) in exile. The ANC, in turn, spear-headed the apartheid regime's political and economic isolation from the rest of the world. In 1990, as a consequence of massive internal and external pressures, the apartheid government un-banned the national liberation movements and began discussions leading to a negotiated settlement and the first democratic elections. In 1994, a new government with the ANC in the majority and Nelson Mandela as its head, was elected.

The implementation of social policy post 1994 has been significantly shaped by two conditions agreed to in the negotiations preceding the hand-over of power. The first was that jobs of civil servants would be protected in the first five years after 1994, and the second was the establishment of a quasi-federal political system to satisfy minority political interests.

The new government thus inherited the apartheid administration intact. This administration was geared towards divide and rule, concerned much less with social delivery than with maintaining a political system. It was chaotic, organised along racial and ethnic lines into 18

different bureaucracies. Financial and information systems were poor<sup>2</sup> and many managers in responsible positions lacked basic skills such as planning, budgeting and evaluation. It was an expensive, inefficient and authoritarian system that encouraged corruption, rather than delivery (Human and Strachan 1997). This ethos also permeated service provision. For example, in surveys of community opinion, harsh and unsympathetic attitudes of front-line health professionals repeatedly emerge as a key complaint (Rispel et al. 1996; Jewkes and Mvo 1997; Oskowitz et al. 1997). While a whole new layer of progressive cadres entered government in 1994, they had to impose new policy frameworks on an old administration that lacked capacity, in the broadest sense of the term, for implementation. The new cadres were mostly drawn from the NGO environment and they had skills in project planning but not in policy implementation through large bureaucracies.

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South Africa's quasi-federal system now consists of one national and nine provincial governments. Responsibility for implementation of most public functions, including Aids prevention, lies at provincial level. Apart from certain strategic functions (military, prisons, tertiary education) the role of national government is to collect and distribute revenue in an equitable way between provinces, to set broad policy frameworks, and to define norms and standards for service provision. In 1997, fiscal federalism was introduced and provinces received global budgets rather than defined allocations per sector. National government does not directly control health and even less Aids spending. As a consequence, Aids budgets vary enormously between provinces, ranging from R2.5 million (US\$ 0.5 million) to R55 million (US\$ 10.1 million) for the 1998/9 financial year (Schneider 1997).

The health sector is itself undergoing a further step of decentralisation to the district level, with attempts to marry it to a third and local sphere of government. By May this year, cadres responsible for implementing Aids prevention and care had been appointed to more than half of these most decentralised structures in all nine provinces (Ibid).

An additional feature of the South African context is that the transition period coincides with an era of increasing globalisation and free trade agreements. There is little room for manoeuvre in the economy. Macro-economic policy is emphasising fiscal discipline, limits on public sector expenditure and a reduction in the budget deficit. Social spending in South Africa since 1994 has not increased in real terms and the backlog in equity has to be financed through gains in efficiency.

#### HIV in South Africa

HIV was first seen in South Africa in the early 1980s. It was the start of an epidemic linked biologically to those in Western Europe and North America and was joined in the late 1980s by a second wave of HIV that descended from East and Central Africa to Southern Africa. In 1990, the first of a series of annual national surveys in antenatal clinic attenders found an HIV

One of the first exercises undertaken by the new government was a national census. As a consequence of this census, the total population of South Africa "dropped" from 42 million to 39 million, an indicator of the lack of information under the old regime.

prevalence of 0.8%. By 1991, this figure had doubled, to 1.5%, and it became abundantly clear that South Africa was in the early stages of a rapidly growing HIV epidemic. Already in 1991, reliable projections and modelling work from within the country had mapped the likely course of the epidemic if left unchecked, and more importantly, the potential impact of immediate preventive measures (Doyle 1991).

In October 1992, the ANC, with the then Department of Health convened a conference to discuss Aids in South Africa. It was an unusual show of national unity at a time of complex and sensitive political negotiations, well before an election date for the new government had been decided. The conference was attended by nearly 450 people, representing a wide range of actors across sectors. It led to the launching of NACOSA (the National Aids Committee of South Africa), an umbrella body whose purpose was to co-ordinate the Aids response in the country. A creative period of policy development through NACOSA followed, characterised by broad mobilisation (typical of the general political processes at the time), consensus on the need for a non-discriminatory approach to Aids, and the formulation of an Aids Plan for South Africa.

The task team that wrote the Aids Plan was armed with knowledge and experiences in Aids prevention, care and support during the 1980s and early 1990s from both industrialised and other African countries. It was drawn up during a time when the National Bill of Rights was being formulated and debates on human rights in the new South Africa were at their maximum. The Plan thus combined the technical with the political and was comprehensive, practical and carefully costed. It was explicit in rejecting what Kirp and Bayer (1992) refer to as a "containment-and-control" in favour of "co-operation-and-inclusion". It went further than the generation of WHO-inspired Medium Term AIDS Plans of the time to embrace the sexual rights of women as a cross cutting theme and to accord people living with Aids a key role in Aids policy development and implementation. The Plan recommended that final authority rest with the President's office nationally, and the Prime Ministers' offices at provincial levels. (NACOSA 1994)

In 1994, the new government immediately adopted the Plan and set about mobilising resources and establishing an Aids programme. Along with 20 other social priorities, Aids was declared a "Presidential Lead Project". This gave the Aids programme special status and early access to resources set aside for reconstruction and development.

We are now four years later. HIV prevalence rates are continuing to rise in South Africa. At the end of 1997, 16% of pregnant women attending public antenatal clinics were HIV positive, and in the worst hit province, Kwazulu-Natal, prevalence rates were as high as 27%. This state of affairs has led many to conclude that we have lost the battle to prevent HIV in South Africa. However, others point to the apparent stabilisation of the epidemic in certain provinces, large increases in the distribution of condoms and improvement in the quality of STD management, as evidence that the situation could be much worse. All are in agreement that the National AIDS Plan was not implemented as expected, and has turned out to be not much more than "a neat book on the shelf". This is not due to insufficient funds. Between 1994 and 1997 the Aids programme consistently under-spent on its allocated budget (Schneider and Stein 1997).

The last few years have taught us a number of important lessons about trying to actualise Aids policy, particularly in the context of a society in transition. In brief, it is very difficult to introduce an urgent, new programme through government when it is grappling with change on so many fronts and is faced with a multitude of more visible priorities. Another expectation of the AIDS Plan, notably the ability of the state to lead and co-ordinate the broader social response to Aids outside of government, has not materialised. However, the presence of a civil society willing to challenge and provide a critical mirror to government on an ongoing basis, is key to the medium and long term success of Aids prevention. The rest of this paper examines the difficulties of implementing an Aids programme through a state in transition, and the roles of political commitment and of civil society with regards to Aids policy in the South African context.

#### Implementing Aids programmes through a state in transition

The AIDS Plan assigned a central role to government, as leader, funder and implementor of a comprehensive response to Aids. It envisaged a co-ordinated network of technically competent and progressive cadres at national level and the nine new provinces, who together would form the core infrastructure of the government Aids programme.

A National AIDS Programme Director was appointed in December 1994. Significantly, this director was placed within the Department of Health, rather than in an inter-sectoral capacity as recommended by the NACOSA Plan. With hindsight, this was not necessarily an inappropriate decision. The experience of the short-lived Reconstruction and Development Programme and the presidential lead projects suggest that projects based within line departments have been more successful than those placed in a co-ordinating unit or at presidential level.<sup>3</sup> In practice, cross-sectoral projects have had difficulty persuading line departments to realign their objectives and resources to an issue perceived as additional to their usual mandate (Friedman 1998).

Provincial governments followed the lead of the national department in placing responsibility for Aids within health. In contrast to the national department, however, most provincial Aids co-ordinators were only appointed from 1996 onwards, after the initial phase of consolidating provincial bureaucracies had occurred. Most are in mid-level managerial positions and generally associated with communicable disease control. With notable exceptions, these provincial Aids managers were reassigned from positions in the old structures (rather than recruited from the network of Aids activists), and appointed at relatively low levels of power and influence. They relate to an emerging network of communicable disease officers in district structures.

Placed within a biomedical framework, staffed mostly from the old civil service, and having little power or connection with policy processes and networks prior to 1994, it is not hard to imagine the obstacles to launching comprehensive Aids prevention programmes from within provinces. In a period where Aids was not as yet visible, provincial policy makers chose to

Some see this as symbolising the lack of an overarching social development framework within government. (Marais 1997)

gradually institutionalise the response through the evolving health system, rather than make a special case of Aids by creating a separate vertical programme. Urgency, quality and scope were traded for universal accessibility. Although an attitude of "exceptionalism" (Kirp and Bayer 1992) was expressed towards Aids prior to 1994, and to some degree at national level, it rapidly became incorporated into mainstream restructuring at the crucial implementation level, in provinces, after 1994.

An added difficulty has been in defining responsibilities and co-ordinating actions between spheres of government in a quasi-federal and decentralised system. On paper the positions may be clear, but in practice the needs are mixed and relationships complex. Stronger provinces resent national interference and the weaker provinces would like to abdicate responsibility to the national level. Provincial co-ordinators have the task of implementing a programme through district staff over whom they have no line authority.

Aids policy implementation in South Africa is thus now characterised by multiple parallel and unconnected spheres of activity in which coherence and continuity— over time and between levels of government - is missing (Rosenbrock 1995). Essential tenets of the Aids Plan, in particular the non-discriminatory aspects, have become diluted or lost. Calls for the re-introduction of traditional public health measures such as notification and removal of confidentiality have become increasingly common, especially from front-line providers, and have found support amongst senior policy makers in the Department of Health (van der Linder 1997).

It took a rigorous national evaluation in 1997 for the limited capacity within government to be understood and accepted. As a consequence, the National AIDS Programme has revised its priorities. It has shifted from an implementation function to drawing up guidelines, developing capacity and co-ordination. However, a disjuncture still exists between national planning/expectations and implementation realities within provinces and districts. Although an infrastructure now exists for Aids policy implementation, this infrastructure is far from being able to actualise the ambitious aims of the National AIDS Plan. The next step is to define what can realistically be achieved at each level, to focus on co-ordinating actions, and to respect the maxim – do a simple thing well, rather than a complex thing badly.

One of the successes of the national Aids programme has been its ability to work through multiple role players to increase access to and quality of STD care in the public sector. A combination of limited targets, training, engaging with the individual needs of provinces and providing opportunities for sharing of strategies between provinces are given as reasons for this. Ensuring good STD care is simpler than organising peer education or doing outreach with marginalised groupings, and points to the kinds of prevention tasks that are within the capacity of the system to implement at present. If simple tasks are successfully managed, they will contribute to building an environment which will make more challenging interventions through government possible at a later stage.

## Calling for greater political commitment does not necessarily solve the problem of implementation

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One of the most common reasons given for the difficulties in implementing Aids policy in South Africa is "lack of political commitment". Political commitment is taken to mean a number of things, including personal and public identification with the Aids cause by high-level politicians, and willingness on their part to mobilise adequate resources and "fast-track" implementation. President Museveni of Uganda is often cited as an example of a national figure willing to make Aids a central issue of government. In South Africa, groups such as NACOSA recently successfully lobbied for presidential leadership and the creation of an inter-ministerial committee on Aids, forcing all national ministries and government departments to formulate policy on Aids. Similar developments are taking place within some provinces. This may herald a new phase of cross-sectoral state involvement in Aids.

However, greater political commitment will not necessarily remove implementation difficulties experienced by government. The view of Grindle and Thomas (1991), writers on public policy in developing countries, is that lack of political will is too readily blamed for failures of implementation. "... the usual remedy is to call for greater efforts to strengthen institutional capacity or to blame failure on lack of political will, an explanation often propounded by external analysts and donors who see countries not carrying out the reforms they consider desirable. In the absence of detailed knowledge about what goes on within another government and a capacity to analyse the decision-making process, lack of political will becomes a catch-all culprit, even though the term has little analytic content and its very vagueness expresses the lack of knowledge of specific detail." (Ibid:pp122)

Calling for more involvement by politicians can also be a double-edged sword. Politicians have their own imperatives and objectives, and could be caricatured as not seeing beyond the next election. The "political commitment" which led to the National AIDS Plan, ensured that sufficient resources were mobilised, funded the National Association of People with Aids, and more recently initiated an inter-sectoral response, has also had a negative side. Aids "scandals" have broken out at regular intervals in South Africa and have dominated media coverage of Aids. These scandals have been precipitated by the actions of politicians suggesting that, in fact, they are already under pressure to act on Aids, and are searching for short-term solutions.

The first controversy started in 1995, when a decision was made at ministerial level to commission Sarafina II, a musical about Aids which would build on the popular imagery of Sarafina I, and which would be launched to coincide with World AIDS Day in December 1995. A contract of R14 million (US\$ 3 million) was signed with the South African playwright of Sarafina I in August 1995. When knowledge of the size of the contract became public 6 months later there was an outcry from several quarters - from the range of stakeholders outside government, the government's own AIDS Advisory Committee and the emerging provincial Aids programmes who had not been consulted on the decision, and from the European Union whose funds were used to finance the contract. The issue was taken up vigorously by both the media and the parliamentary opposition and eventually became the subject of an investigation by the office of the Public Protector of the new government. Extensive irregulari-

ties in the tendering procedures were uncovered and there was little clarity as to how such a large sum of money had been approved for a play (Public Protector 1996). As a consequence of the Public Protector's report, the contract was terminated and the play withdrawn. For months, Sarafina represented the public face not only of the Aids programme, but also of the Health Department generally. President Mandela, in a review of 1996, cited it as one of the ANC's key mistakes of the year (*Cape Argus*, 20 January 1997).

The second controversy erupted soon thereafter in February 1997, when a Cabinet press release announced the development of a South African treatment for Aids. A group of researchers from a local university had approached the Minister of Health for funding of their "break through" and were given an audience with Cabinet. The drug, known as Virodene, (an organic solvent) had been tried in the form of skin patches on a few volunteers with Aids, apparently with some success. However, subsequent investigation into Virodene by an independent panel of experts, revealed that it had not passed the most elementary biological and animal experimentation ("19th century science" (Crewe 1998) as one observer labelled it). Both the university ethics committee and the Medicines Control Council turned down applications for further testing on humans. Once again, a polemic through the media ensued. There was massive clamour for the drug from people with Aids, and the medical profession was accused by both the Minister of Health and the Deputy President of retarding access to life saving therapies.<sup>4</sup>

In August 1997, at a large conference to discuss the findings of a National AIDS Review, the Minister of Health unexpectedly announced that Aids was to be made notifiable. The Review report (SA National HIV/AIDS/STD Review 1997), the Medical Research Council, and the government's Law Commission were strongly opposed to notification and had proposed more efficient and less problematic methods of tracking the epidemic in South Africa. Representation to the Minister was subsequently made through the government's Aids Advisory Committee (AAC) in late 1997 and early 1998, but while awaiting a response from the Ministry, members of the AAC were informed that the committee had been disbanded.

These events represent the responses of politicians to a serious and increasingly visible problem, affecting the elite as well as the poor. Although well intentioned, these "quick fix" initiatives have precipitated individual and institutional fall-out<sup>5</sup> while doing little to further Aids prevention or care in the country. They have diverted energies from facing the real challenges of implementation. Aids in South Africa has come to symbolise the need to extract public accountability from senior government officials, allowing the society to externalise the problem as belonging to bumbling politicians rather than to the nation as a whole.

The experiences with trying to tackle Aids, and with transformation in South Africa generally, have highlighted the extent to which "individuals in strategic locations" (Grindle and Thomas 1991: pp125) can significantly shape, positively or negatively, the policy process. The real

<sup>&</sup>lt;sup>4</sup> There appear to be parallels between circumstances surrounding Kemron, the Kenyan anti-Aids drug, and Virodene. (Hyden and Lanegran 1993)

The departure from office of the first AIDS Programme Director, and more recently the Director-General, the replacement of the Chair of the Medicines Control Council, and the closure of AIDS Advisory Committee have all been directly or indirectly linked to the events described above.

problem underlying Aids implementation failure in South Africa appears to be less in the *degree* of political concern but rather in the *quality* of this concern. Lack of political commitment is perhaps better understood as a failure of leadership. This is most evident in the inability of government to mobilise a broader social response to HIV.

In 1996, a national Aids database listed a total of 661 organisations with an interest in Aids (Griesel and Wege 1996). They included a number of prominent Aids-specific NGO's, a network of government supported AIDS Training Information and Counselling Centres as well as numerous workplace, community based, clinical, religious, academic and other groups. If overall, the government bureaucracy is a weak player, it should be possible for credible political leaders to harness the considerable energies available outside of the formal government Aids programme. This leadership function is very different to the bureaucratic notion of leadership as control. The ability to mobilise a range of actors around a common vision, and engaging and communicating across the many divides are the key aspects of this function.

This type of leadership has been aptly described as "managing meaning" (Smircich and Morgan 1982). Managing meaning involves three tasks - firstly, paying attention to the perspectives ("interpretive schemes") of the range of actors; secondly, bringing these perspectives together and defining reality in manner that all these actors can identify with; and thirdly, pointing to the practical actions required of actors. The management of meaning is by nature a process negotiated through interaction, of defining reality in a manner "that is sensible to the led". It is both active and facilitatory.

Sarafina, Virodene and Aids notification have been centralised actions with little consultation or regard for the views of other players in the Aids world. They have polarised those who should have been allies, and turned valuable "social" capital into "sour" capital (Bulder et al 1996). Alternative and more appropriate leadership styles from within and outside government, which could shape a new public agenda on Aids, have been overshadowed by these events.

A more enabling style of leadership, however, requires taking short-term risks for longer term gains. It means admitting that there are no immediate answers to Aids, that the impacts will be great and that the situation will get worse before it gets better.

#### Productive conflict is essential to successful implementation

The positive side of scandal is that there is scandal at all! While I may have presented a somewhat negative picture of Aids policy implementation in South Africa, the society has a major strength in a culture of criticism and debate, stemming from the democratic and trade union movements of the 1980s. The actions of leaders do not go uncontested, within or outside government (Ncayiyana 1998; Public Protector 1996).

The human rights lobby within Aids is very active and has successfully used the law to protect people with HIV from unfair discrimination. It has links with an assertive and organised gay rights movement, which ensured that South Africa is the only country with a constitution that prohibits discrimination on the basis of sexual orientation. The National Association of People

with Aids (NAPWA) has built on this tradition while bridging the numerous social divides within South Africa – between white and black, middle class and poor, rural and urban, heterosexual and gay – around a common agenda of access and non-discrimination. Emerging networks of support and solidarity between people with Aids probably represent the most powerful force for action at the local level. If this is to be harnessed for Aids prevention, however, care and support must be seen as an inseparable part of prevention.

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To its credit, government has been a strong supporter of NAPWA, and has provided it with the funding to establish an infrastructure and appoint full-time staff, while allowing it to remain independent. This reflects another, perhaps less public side of the Aids programme – an ability to be self-critical and the presence of institutional mechanisms for feedback and reflection within government. In 1997, in partnership with Aids NGO's it conducted a review of the response to Aids in South Africa that involved tens of people in all provinces of the country. It had the very important effect of creating a shared understanding of the strengths and weaknesses of the Aids response in South Africa. The recommendations fed into processes of reprioritisation and planning at national level (Department of Health, 1997), although less so at provincial level.

The NGO environment also offers models of prevention programmes that set a standard for government. One example of this is Soul City. Soul City is a multi-media "edutainment" strategy that has been running since 1994. It uses five media - television, radio, newspapers, public relations/advertising and education packages - to convey health and social messages through the basic format of a soap opera. Soul City is hip, funny and thoroughly modern while powerfully conveying pro-social messages such as the empowerment of women and community action for health and development. HIV messages have appeared in each of the three series. The initiative has enjoyed phenomenal success – it has penetrated the most rural parts of South Africa, consistently outstripped other soap operas in viewership and listenership, and won numerous awards. Before-after evaluations have also shown significant changes in self-reported behaviour such as usage of condoms (Soul City 1997).

The presence of individuals and groups, both inside and outside government willing to challenge and provide a critical mirror to government and the society, is the key to the medium and long term success of Aids policy implementation. This could be described as a monitoring and evaluation function, although in a difficult implementation environment such as South Africa, the less neutral term "productive conflict" better encapsulates the process. Conflict does not need to imply violence. Rather, it provides the possibility for progress by highlighting the gap between what is and what should be.

#### **Conclusion**

In the absence of an effective vaccine, preventing Aids is a complex task in any context. The formulation of Aids policy in industrialised societies has been described as highly political, but once decided, implementation appears to be an administrative activity (Ballard 1992). In contrast, initial policy-making and mobilisation of resources in South Africa were relatively

straightforward. The real politics has been in the implementation, and has left many workers in the field wondering whether rationality and predictability can indeed be part of the policy process.

Aids prevention in a society undergoing changes on many fronts (and I would add most low income countries) is especially difficult. Universal prescriptions on the content of Aids prevention, inter-sectoral action and political commitment have to be reinterpreted within the possibilities and constraints of the situation. The gap between what is possible and what is ideal thus makes implementation a highly strategic, not an administrative, task. While sharing lessons across countries helps one to think about one's own situation, blue prints for Aids prevention developed out of context are inappropriate and unhelpful.

Finally, policies and plans are starting points, a means to an end, not ends in themselves. As long as role players in complex implementation environments, such as South Africa, retain a willingness to be self-critical, to improve on the past and the present, and to constantly learn while doing, successful Aids prevention will be possible.

#### References

"A.I.D.S. Dementia" 1998. The wonder-filled world of AIDS (Opinion). AIDS Analysis Africa, Southern Africa Edition, 9:1 (June/July 1998).

Ballard J 1992. Australia: Participation and Innovation in a Federal System. Chapter 4 in: Kirp DL and Bayer R (eds.) *AIDS in the Industrialized Democracies: Passion, Politics, and Policies.* New Brunswick, New Jersey: Rutgers University Press.

Bulder B, Leeuw F, Flap H 1996. Networks and Evaluating Public-sector Reforms. *Evaluation* 2(3):261-276.

Cape Argus 20 January 1997. ANC has made serious mistakes, admits Mandela.

Crewe M 1998. The tangled webs of Virodene. *AIDS Bulletin* 7(1):29-30.

Department of Health 1997. Minutes of the National HIV/AIDS Meeting, 6-7 October 1997. Pretoria.

Doyle PR 1991. The Impact of AIDS on the South African Population. Part 1. In: *AIDS in South Africa: The Demographic and Economic Implications*. Johannesburg: Centre for Health Policy, University of Witwatersrand.

Friedman S 1998. Interview with Dr Steven Friedman, Director, Centre for Policy Studies, 28 May 1998.

Griesel RD and Wege JW 1996. South African AIDS Network: A Directory of the National AIDS Database. Pretoria: Department of Health.

Grindle MS and Thomas JW 1991. Public Choices and Policy Change: The Political Economy of Reform in Developing Countries. Baltimore and London: Johns Hopkins University Press.

Hyden G and Lanegran K 1993. Aids, Policy and Politics: East Africa in Comparative Perspective. *Policy Studies Review* 12(1):47-65.

Human P and Strachan B 1996. *Transformation of the Public Sector: An Assessment of Managerial Capacity and the Implications for Management Development*. Report produced for the Oliver Tambo Fellowship Programme, Diploma in Health Management. Cape Town: Department of Community Health, University of Cape Town.

Jewkes R and Mvo Z 1997. Study of health-care seeking practices of pregnant women in Cape Town. Report two: Women's perceptions of Kayelitsha Midwife Obstetric Unit. Pretoria: CERSA-Women's Health, Medical Research Council.

Kirp DL and Bayer R 1992. The Second Decade of AIDS: The End of Exceptionalism? (Conclusion) In: Kirp DL and Bayer R (eds.) *AIDS in the Industrialized Democracies: Passion, Politics, and Policies.* New Brunswick, New Jersey: Rutgers University Press.

Marais H 1997. The RDP: is there life after GEAR? Development Update Quarterly Journal of the South African National NGO Coalition and INTERFUND 1(1):10.

McIntyre D, Bloom G, Doherty J, Brijlal P 1995. *Health Expenditure and Finance in South Africa*. Durban, South Africa: Health Systems Trust/World Bank.

McIntyre D and Kirigia J 1997. Input paper on the health sector. Prepared for the 20/20 report on public expenditure. Cape Town: Health Economics Unit.

NACOSA 1994. A National AIDS Plan for South Africa 1994-5. Pretoria: National Secretariat, National AIDS Committee of South Africa.

Ncayiyana DJ 1998. Policy making by stealth is not on. (Editorial) S Afr Med J; 88(4):-

Oskowitz B, Schneider H, Hlatshwayo Z 1997. Taking care of quality: perspectives of the patients and providers at an STD clinic. Johannesburg: Centre for Health Policy, Department of Community Health, University of Witwatersrand.

Public Protector 1996. Investigation of the play Sarafina II. Report in terms of Section 8(2) of the Public Protector Act 23 of 1994. Pretoria: Republic of South Africa.

Rispel L, Price M, Cabral J 1996. Confronting Need and Affordability: Guidelines for Primary Health Care Services in South Africa. Johannesburg: Centre for Health Policy, University of Witwatersrand.

Rosenbrock R 1995. The role of policy in effective prevention and education", in: Friedrich D/Heckmann W (eds): *Aids in Europe - The Behavioural Aspect*. Vol 5, Berlin: edition sigma, pp17-26

Schneider H 1998. Results of a questionnaire distributed to provincial HIV/AIDS and STD programme co-ordinators, May 1998.

Schneider H and Stein J 1997. From policy on paper to action on the ground: contextual issues affecting implementation of the National AIDS Plan in South Africa. In: The South African National STD/HIV/AIDS Review 4-18 July 1997: Comprehensive Report. Pretoria: Medical Research Council.

Smircich L and Morgan G 1982. Leadership: The Management of Meaning. The *Journal of Applied Behavioural Science* 18(3):257-73.

Soul City 1997. Evaluation Report: Series Two. Johannesburg: Soul City.

South African Health Review 1996. Durban, South Africa. Health Systems Trust/Henry J Kaiser Family Foundation.

The South African National STD/HIV/AIDS Review 4-18 July 1997: Comprehensive Report. Pretoria: Medical Research Council.

van der Linde I 1997. Drop secrecy around HIV/AIDS (Izindaba - News and Information). *S Afr Med J* 87(1):12-13.

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#### HIV/Aids in India: Gulf between Rhetoric and Reality

#### **Background**

India is the second most populous country in the world after China (around 900 million). The majority of the population (around 75 per cent) live in the rural areas and practice agriculture and allied occupations. India also has a large and well developed industrial sector. Although the urban concentration is relatively small, the rate of growth of big cities and small towns and, therefore, of the urban population has been rapid over the last few decades, both due to rural stagnation and industrial growth, and the problems of urban development have already begun to assume considerable significance in economic, environmental, social and political terms.

Income and social inequalities continue to remain high and the incidence of absolute poverty is widespread. Economic status determines life expectancy at birth, access to food, education, career opportunities, healthcare, housing and even basic amenities such as drinking water and sanitation. There is no state provision for social security. The economic disparities, evident everywhere, are most glaring in the cities, where between 40 and 60 per cent of the population are forced to live in overcrowded and unhygienic slum settlements with poor access to infrastructural facilities such as water and sanitation. The quest for livelihood propels considerable migration from the rural to the urban areas. While earlier, migration was directly to the metropolitan centres, the rapid growth of smaller towns and cities in recent years reveals a step-by-step pattern of migration, as individuals and households seek to improve their lifetime earnings. While some cultural/regional groups or totally propertyless groups may migrate with their families or acquire families once they come to live in the city, several large regions of the country have a tradition of male only migration, where the urban networks are used to further income earning opportunities in order to repatriate money home to the village.

The Indian State is committed to providing free access to health and educational facilities for the vast majority of the population which does not earn enough to purchase good quality education or health care. However, in quantity, quality, and gender sensitivity, these public facilities fall short of real needs. Huge social inequalities, based on caste and gender relations, exacerbate the role of economic disparities in making for unequal access to these important human development inputs. Just in terms of literacy alone, India has the largest number of illiterates in the world, with no lessening in the numbers in sight. The overall literacy rate for the country as a whole is around 52 per cent, with around 64 per cent for males and 39 per cent for females. These rates are higher for the urban areas, but the gender disparities remain strong. Although the public sector for health care is large, it is surrounded by a thriving private sector, which is the preferred option even for the very poor who see it as more efficacious than the overcrowded, politicised, bureaucratised, and inefficient government sector. In effect,

therefore, private expenditure on health and education is estimated to be around three times the public expenditure (World Bank, 1995).

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India is a country of continental proportions. It is divided into 26 self governing linguistically organised states, and 6 union territories that are directly administered by the federal (central) government. The states vary hugely on all major human development and economic indicators, depending on their social, political and developmental history It is a complex society, which is multi-lingual (over 16 languages and several hundred dialects), multi-religious (Hindus constituting over 80 per cent, Muslims (12 per cent), Christians (2.5 per cent) and Sikhs, Jains, Buddhists, Jews, and Parsis being the other important religious groups), with a multitude of castes, ethnic groups and cultures. But irrespective of these differences, every Indian citizen enjoys equal status in the eyes of the law. The country is a sovereign, democratic and secular republic, governed by a constitution which guarantees significant fundamental rights to every citizen, regardless of caste, religion, race, language, sex, or place of birth. It is in the access to and exercise of the law that the social and economic disabilities outlined above act as constraints.

#### Introduction

The Aids epidemic in India is referred to in official Indian documents as being in its "early stages" (NACO, 1996). This, I believe, is a euphemistic description of an epidemic whose real epidemiological and social dimensions are even now inadequately understood, twelve years after the first case of Aids was isolated in a woman commercial sex worker in Chennai (originally Madras), the capital city of the southern Indian state of Tamil Nadu. It would be more accurate to describe India as being at an early stage of social learning and policy formulation with respect to Aids, even as the epidemic itself threatens to get out of hand.

According to WHO estimates, today India reportedly has the largest number of HIV positive individuals among the countries of the WHO south and south east Asian region (along with Thailand, India accounts for an estimated 95 per cent of the reported cases of Aids in the region) (WHO, 1992). There are an estimated 3 million HIV positive cases in India. Given the size of its population, India is expected to have the largest concentration of Aids affected individuals in the world, if the present rate of transmission continues unchecked.

During the 1980s when Africa was the negative centre of attention with respect to Aids, India took refuge in postures of denial, on the grounds that Aids was a foreign disease. It was believed that the traditional socio-cultural norms of monogamy, universal marriage and, therefore, heterosexual relations and virtual non-existence of homosexual behaviour, mother goddess worship, and societal proscriptions against an explicit focus on sex and sexuality in public social interactions and discourse, provided the necessary shelter from a predominantly sexually transmitted disease. The fact that STDs were the third most important group of diseases in the country, next only to malaria and T.B. was glossed over (Ramasubban, 1990). And the international scientific evidence to support the link between pre-existing STD infection and vulnerability to Aids had not yet been firmly established.

The first Aids case was isolated in 1986 in a commercial sex worker, and the official response was one of treating Aids as a problem of vigilance by law and order agencies - suspicion of foreign visitors, incarceration by some state governments of individuals (e.g. blood donors, sex workers) found to be HIV positive to prevent them from infecting the rest of society and, in some other states, deportation of commercial sex workers by the government of their state of domicile to their state of origin, in an attempt to transfer the problem.

By the early 1990s, denial had given way to an attempt to contain "Aids control" within the medical establishment. The viewing of Aids as an exclusively medical problem was prompted as much by ignorance of the changing socio-cultural context of sexual behaviour, as by the fact that it came naturally to a medical establishment that had a long experience of running national (i.e., top-down, federally administered) curative-oriented disease control programmes.

Of the several national disease control programmes initiated since the early 1950s (including a national STD control programme), none had a clear strategy for disease prevention or an understanding of health behaviour. Disease prevention calls for predominantly non-medical, i.e., social, political, public health and administrative solutions, all requiring complex, sensitive and politically controversial interventions, such as localised and differentiated social education strategies, public participation, policy planning to effect structural changes in the socioeconomic linkages of communicable diseases, and integration into primary health care. With the exception of small pox (for which a vaccine existed) and malaria (where the DDT technology was available), all others such as T.B., leprosy, etc., control programmes have been curative in approach. Failure in co-ordination between the federal and state governments and the low priority accorded to public health by the state governments have combined with poor attention to public participation in disease prevention, to wind down the effectiveness of these programmes (Ramasubban, 1984). Today among these diseases, malaria has resurged, leprosy eradication still remains a major challenge, and the high rates of T.B. and STDs have become the greatest ally of the Aids epidemic.

The positive aspect of this medical definition of Aids was the concern for the mode of transmission through blood and blood products and organ transplants, a real concern in a country where resort to blood transfusions is high and where quality control of blood banking is poor.

But the negative aspect was the neglect of the socio-cultural, behavioural and economic dimensions of HIV transmission in favour of moral condemnation and victimising of high risk groups and, therefore, failure to develop the necessary technical and administrative skills in the direction of raising awareness about the disease, high risk behaviours and primary prevention among these groups and in the larger society or, to develop support structures for those suffering from the disease.

In the ensuing chaos, Aids funding became a politically contested issue, as both the Government of India and all manner of NGOs attempted to jump on the Aids bandwagon, resulting in ineffective and counter-productive use of international donor funds. Studies in selected areas of the country among certain groups now reveal that the epidemic has developed as rapidly in India as was observed in some African countries in the mid-1980s.

For India, Aids has been and continues to be a social learning experience (as it has been for all the countries of the world with respect to Aids, in lesser or greater ways). The Indian Aids policy has taken a long while to come to terms with the challenges required of it and is, today, still at an incipient stage. Much of its evolution has been a process (albeit a slow and contradictory one) of responding to pressures both from outside the country and from within, to move in a more coherent and integrated (Rosenbrock 1995) direction. The former have been mainly international donors, who have been an important impetus for policy change, and who have also been bringing in new scientific knowledge and technical skills, and methodologies for research in both the medical and social and behavioural sciences. The latter, i.e., forces within the country, have been health and legal NGOs who have been pressing for more space and funding for NGO participation, more enlightened legislation with respect to Aids, and more evidence of political will to tackle the disease.

Starting from an exclusionist stance, Aids policy is now very slowly incorporating a more inclusive and co-operative element into its structure, making a space for involvement from sections of civil society. These sections as of now, are only a few isolated NGOs working with specific target groups (and even these NGOs have to struggle consistently for the security and expansion of this space). They do not include people affected by the disease or other marginalised groups at high risk such as sex workers or drug users. Such a wide-ranging partnership with civil society does not come easily to a traditionally top down system of governance, and to a society where topics such as sexuality and substance abuse have tended to be pushed underground, and where stigmatising of any degree of deviance from dominant social norms is widely practised, among rich and poor, high and low caste alike.

It is only since 1992 that here has been a serious effort to put into place an infrastructure at Central and State levels for tackling the problem of Aids. In 1992 the National Aids Control Organisation (NACO) was set up and the Control Programme expanded into a National Aids Prevention and Control Programme, acknowledging that all sections of society had to be addressed rather than the "high risk" groups alone. 1994-96 witnessed a more systematic move in the direction of epidemiological surveillance, although the dearth of credible surveillance data continues to be a major constraint to policy planning and programme formation. In one state alone, Tamil Nadu, policies and programmes for sentinel surveillance, risk behaviour assessment, primary prevention and organisational and managerial reforms involving partnership with NGOs and people affected with Aids (PWA) began to be put into place in 1994, and today Tamil Nadu provides a model for other states to emulate. In 1996, judicial activism made for a landmark Supreme Court directive making HIV screening mandatory in all blood banks. Several organisational reforms in the matter of collection, testing and handling of blood have since been set into motion. Since 1997, a further process of overhauling of NACO, to enable it to consolidate some of the reforms mentioned above, and to spearhead changes at the level of the individual states, have been initiated. Today, in mid-1998, a draft National Aids Prevention and Control Policy is under consideration. A beginning, therefore, has been made.

#### The Aids situation

As of 31 May, 1997, the seropositivity rate per thousand screened was 18.6 or around 1.9 per cent (NACO, 1997). Seropositivity increased from 2.5 per 1000 in 1986 to 11.2 per 1000 by 1992, to 16.3 per 1000 by end-1996. A cumulative total of 3551 Aids cases have been reported to NACO. This is estimated to be barely 1-2 per cent of the actual cases and it is believed that at least 150,000 Aids cases and around 2.5 to 3 million infections must have occurred.

The reason for this huge discrepancy is that disease surveillance is among the weakest links in the health infrastructure and planning chain. It is only in the context of Aids that this weakness has come to be squarely confronted. Until 1994, surveillance was based on data from 62 surveillance centres situated in different parts of the country. Data from different target groups were pooled and was cumulative in nature and, therefore, did not lend itself to monitoring trends of infection in the country. Again, HIV infected individuals were found in whichever states testing facilities were available for surveillance, blood testing or research The more urbanised states, with their greater concentration of facilities and technical skills, therefore, showed higher rates, such as Maharashtra, Tamil Nadu, Karnataka, and Gujarat. In 1993-94 the sentinel surveillance system was adopted. But epidemiological data remains a major weakness affecting policy planning and even today tell us virtually nothing about what is happening in the rural areas.

The deficiencies in data notwithstanding, some major trends may be discerned. The major concentration of Aids cases is in Maharashtra (in western India) and Tamil Nadu (in southern India), with Maharashtra alone accounting for almost half the number of cases. Along with Manipur (in north-eastern India), these three states count for 77 per cent of total cases in the country. Despite this concentration, HIV is present in all the states of the country with the exception of one.

The 55 sentinel sites established in 1994 to monitor trends in specific "high risk groups" (CSWs and STD clinic attenders) and in "low risk groups" (women attending ante-natal clinics), and the rounds done so far have been reflecting rapid increases in seropositivity among all three groups (NACO, 1996). STD clinic attendees are almost all married, or are adolescents who will go on to marry, given the cultural norm of universal marriage. Therefore, the spread to the general population is very likely. About 1 per cent of HIV cases according to current estimates are antenatal mothers, who are considered a low risk group. But these figures do not tell anything about women even in the urban areas who are not married, pregnant or who are sterilised and who would not be attending ante-natal clinics, not to mention the fact that ante-natal clinic attendance is not universal given the low awareness of hazards to reproductive health and women's poor financial, logistic and social access to health facilities. Recent studies of sex workers reveal an increasingly complex picture of this group (Voluntary Health Services, 1996). While these are overwhelmingly women driven into the profession due to destitution, and are without stable marital family ties as in the brothels of the big cities, in the small towns and major truck halts along inter-state routes, there is growing trend for married women living in marital unions to take to this activity as a means of coping with poverty.

There are clearly several ongoing HIV epidemics in India. The epidemic among sex workers has been the most alarming, with seropositivity climbing steadily and exponentially among them. Patients attending STD clinics come next with rising rates among them, too, and recipients of blood/blood products come third. These trends are all India in character, although the rates are highest in two states – Tamil Nadu and Maharashtra - followed by Gujarat and Karnataka. Other discernible epidemics are among injecting drug users (this is localised in one state at present, Manipur where 54 per cent of IVDUs are estimated to be HIV positive) (NACO, 1996, 1997 (b)).

This suggests that the majority of infections are contracted through the sexual route (around 75 per cent), followed by unmonitored blood transfusions (8 per cent) and unsterilised needle sharing by drug users (around 8 per cent). Almost 90 per cent of the cases are between 18 and 40 years of age. Higher HIV prevalence is being found along major truck routes. Migrant workers and rapid transport facilities have increased the chances of spread of HIV from urban to rural areas and from one state to another. (NACO, 1996; 1997 (b)).

The reported male to female ratio is 3:1 as discerned from the reported Aids cases. The credibility of this figure, too, suffers from the same disability as described above, since women are even less likely than men to access a medical facility. While within the sexual mode of transmission heterosexual unions are the norm, and a culturally sanctioned definition of homosexual identity is conspicuous by its absence, bisexuality tends to be commonly practised by men who may or may not be in marital unions. Considerable numbers of HIV positive men, particularly, report to be practising bisexual preferences (Dr. J.K. Maniar, pers. comm.). Hijras (or third sex members) have generally been known to provide such avenues in the form of receptive anal sex, but there is growing evidence that homosexuality may be a commoner practice than is acknowledged. This may be particularly true of situational homosexuality in unequal (i.e., exploitative or potentially exploitative) relationships, defined by age (older men with adolescent boys, particularly restaurant/hotel workers), occupation (truck drivers with boy cleaners), or power (jail inmates). The sexual abuses meted out to the millions of street children in cities has yet to be tackled in the context of Aids. A 65 city sexual behaviour study initiated by NACO in the early 1990s revealed that men who have sex with men were among the hardest to reach groups (along with intra-venous drug users).

In sum it may be said that since Aids is not a notifiable disease (for obvious reasons of confidentiality), and since the official figures reflect only cases reported to public hospitals with testing facilities, and since these hospitals may be expected to be accessed by barely 10-20 per cent of the population, the reported figures do not convey the full magnitude of HIV/Aids infection.

We know even less about the actual morbidity due to HIV, since the majority of patients are believed to be succumbing to opportunistic infections such as TB long before they reach the stage of full blown Aids, given general conditions of poverty, ignorance on the part of sufferers and providers alike, and rapid depletion of immunity. Indian studies have yet to tell us whether the incubation period of immune suppression attributable to HIV is the accepted average of ten years. A number of cases go underground, both private and public hospitals generally refuse to accept HIV positive patients with some notable exceptions, there is a tendency

on the part of patients generally to go treatment shopping, and the tendency for practitioners to offer widely different drug regimens even in the cases of those diseases for which standard multiple drug regimens exist (such as TB, leprosy), and there is no reason to believe that this might be different in the case of HIV.

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#### Impeding and fostering factors

Aids, as no other disease before it, holds up a mirror to Indian society, compelling both policy makers and members of civil society to bring on centre-stage policies, social processes, social groups and behaviours that had hitherto been relegated to the margins.

These are, on the one hand:

- a) sexuality (a taboo topic about which no clear, unambiguous information exists in the public domain and which, therefore spawns a host of misconceptions);
- b) promiscuity (differential sexual freedom norms for men and for women, permitting degrees of freedom for men without knowledge of how to prevent disease, but enforcing through severe moral and religious strictures pre- and post-marital chastity for women, leaving women powerless to negotiate safe sex with their husbands or partners);
- c) prostitution (grinding poverty which forces huge numbers of women into commercial sex, where they are again powerless to negotiate safe sex or ensure early treatment);
- d) intra-venous drug use (which is a legal offence and therefore inhibits the possibilities of needle exchange programmes, counselling and care; a high proportion of such persons in the state of Manipur are in jail);
- e) homosexuality (again, a morally proscribed behaviour, forcing men underground); and;
- f) the private domain of the patriarchal family, which is based on the subordination of women, leaving them in a poor state of reproductive health, silent victims of a range of reproductive tract infections, and with little autonomy to seek and purchase timely and effective health care for themselves (Ramasubban, 1995).

How these marginalised social spaces are confronted would determine the successful mounting of an enlightened and timely response for prevention and management of the disease.

On the other hand are the long-standing disabilities and anomalies arising from the current stage in the country's socio-economic developmental history, disabilities that have serious implications for the sustained success of management of the epidemic. These are:

- a) the low priority accorded to health generally in national planning and resource allocation;
- b) the relative neglect of primary health care, and the resultant weak health infrastructure in the states and people's alienation from it, encircled by a huge and variegated private sector which is accessed by over 80 per cent of the population and is not easily amenable to reform and control;
- c) failures in co-ordination between the federal and state governments in the funding and management of the disease control programmes, mainly the inability/unwillingness on the

- part of the states to sustain commitment of financial and manpower resources for the programmes once the federal and international donor sponsorship has run out;
- d) inefficiencies and bureaucratic inertia in the administration of the programmes at the level of the states, resulting in failure to maintain consistent drug supplies, failure to integrate the programmes with the primary health care system;
- e) lack of support preventive work at the level of local communities, and patient counselling work by health outreach workers;
- f) the history of neglect of elementary education, resulting in continuing high rates of illiteracy, and low levels of school education, and the lack of sensitivity to the need for health education and sex education, both through the educational system and the mass media;
- g) the high incidence of STDs in the country (40 million new infections a year, and an estimated incidence rate of 5 per cent), and historical neglect of both prevention and facilities for diagnosis and treatment, due both to ideological barriers, low status accorded to the scientific speciality and bureaucratic apathy;
- h) widespread poverty and the survival strategies of the poor which forces whole sections of women into prostitution and ignorant migrant workers into unsafe sex;
- i) the exclusive focus in the national family planning programme on women's sterilisation and failure to focus on men and on counselling/educating them in the direction of behavioural change such as condom use and more equal sexual and contraception negotiation;
- j) patriarchal structures and taboos on the open discussion of sex and sexuality which make for gross ignorance and impede public acceptance of such a disease; and
- k) the late arrival of the sexual revolution in India in the context of such widespread ignorance and the threat of Aids.

In this sense, Aids has been a major political challenge to ongoing health and educational policies, and to state-society dialogue. Inability to come up with a coherent response to this challenge has led to the relegation of Aids to the recesses of the National Aids Control Organisation (NACO) in the Ministry of Health and Family Welfare, rather than bring it into the public arena for debate and social policy.

The very low levels of literacy and education, and low levels of health awareness generally, mean that HIV awareness raising interventions will take longer to have effect, will require more innovative instruments for conceptualisation and dissemination, and would have to ensure that women, who are the most disadvantaged with regard to education and who cannot be easily reached in any institutional context, get access to HIV related information. There is strong evidence to suggest that direct health related information can be more effectively absorbed and retained when there is a pre-existing basis of general education. This could well become the crucial marker of how consistently HIV prevention awareness will actually be practised.

The emphasis so far on surveillance of marginalised high risk groups such as sex workers, STD clinic attenders and drug users is, admittedly, one of the necessary attempts to under-

stand the dimensions and behaviour of the disease, and to establish Aids related infrastructure – primarily for surveillance and testing – in the states in the country. However, this preoccupation has tended to overshadow the development of policy thrusts in the direction of legislative and ethical issues to do with testing, freedom of movement, right to livelihood, messages for condom use, and access to treatment and care. The Aids epidemic has come in the wake of a dawning sexual revolution and rapid economic and social change. And neither the state nor civil society have as yet been able to overcome the ideological barriers, to be able to come up with wide-ranging interventionist tools to deal with this sensitive area of behavioural change. What is required is a whole new paradigm for public discourse.

From the foregoing discussion it would seem to suggest that the only progressive way ahead for Aids policy is to forge close working partnerships between the state and civil society. Given the ideological barriers, this is bound to be a slow process. But it could be a sure one if planned sensitively and holistically.

Among the major societal factors present in the Indian context that could foster such partnerships are:

- a) The open nature of the polity, theoretically leaving space for debate, and for pressure groups safeguarding human rights.
- b) An active judiciary which in recent years has taken the initiative to set off political and administrative reforms in the public interest to circumvent a stonewalling executive.
- c) With a long history of governmental interventions in the social sectors, the state can play an active role in Aids prevention, if there is political and administrative will.
- d) There is a growing sector of NGO-led developmental activism in the country, particularly in the states which, coincidentally, are also among the most affected by the epidemic, e.g., Tamil Nadu, Maharashtra, Gujarat and Karnataka. Although few NGOs are engaged in exclusively Aids related work, with more active state involvement these numbers may be expected to grow.
- e) In the last five years, there have been considerable social and behavioural science inputs into understanding prevailing patterns of sexual behaviour. Given the neglect of this area of research in the traditional academic preoccupations in the country, much of the impetus for this has come from international donors who have been instrumental in bringing together research and advocacy NGO groups into the Aids and reproductive health domain.
- f) Today, a growing body of evidence exists to show that notwithstanding traditional prescriptions and proscriptions, there is considerable sexual mobility within the sub-continent. Apart from visiting commercial sex workers who are far the most ubiquitous avenue for pre- and extra-marital sexual gratification particularly among the poor of all ages and among adolescent youth, there is much partner change that is not paid for among relatives, neighbours, friends and acquaintances. The fact that this takes place within the context of universal marriage, and within a framework of gross ignorance regarding sexually transmitted diseases and how these may be prevented, suggests the plethora of channels of HIV transmission into the general population. Genital ulcer disease is very high in the country,

women have lower knowledge about methods for STD prevention than men and this cuts across educational differences, and male students who will go on to marry count for the highest proportion of non-treatment seekers for STDs (as compared with even commercial sex workers and truck drivers) (Ramasubban, 1990; Voluntary Health Services, 1996).

g) The Indian government's positive response to deliberations at the Cairo conference on population and development, has culminated in the recasting of the national family planning programme into a reproductive and child health programme, incorporating STD and reproductive tract infections (RTI) diagnosis, prevention and treatment, safe hospital practices and safety of blood and blood products (World Bank, 1997).

#### Case studies

1. State led interventions – the case of Tamil Nadu (southern India)

The first initiative that the Government of India has taken, in the light of the new draft Aids policy, is to assume leadership for the fight against Aids and in this, its first steps have been to overhaul the NACO structure. Simultaneously, the effort is on to communicate this philosophy to the states in the country, and to encourage them to set up and strengthen state level Aids cells. The technical and financial assistance for Aids related work is entirely from the federal government at this point in time, which is in turn aided by several bilateral and multilateral donors (mainly World Bank, USAID, DFID).

How the states will generate the necessary political and administrative will to overcome their historical inertia in the area of public health, and indifference to participation from the civil society in government sponsored programmes, is the moot question. This would also determine the prospects for the integration of Aids prevention into primary health care.

Tamil Nadu in southern India has been the first state to show the way since 1994. It is the state with the second highest incidence of HIV after Maharashtra, where the first HIV positive case was isolated in the country, one of the most urbanised states with an acknowledgedly large population of commercial sex workers in big cities and small towns, with a large concentration of medical research groups and a tradition of NGO activism.

The main thrust of the Government of Tamil Nadu's initiative is in three directions: organisational reform, media involvement, and state-NGO partnership.

The Tamil Nadu State Aids Control Society (TNSACS) uses an organisational paradigm (which has also proved to be effective in other government-led social sector interventions in the country), whereby a state government sponsored body sets itself up as an NGO structure for the purposes of effective non-bureaucratic functioning in order to achieve time-bound results. The main features of this model are: self governance, ease of receipt of foreign assistance, experimentation with organisational innovations, co-ordination with other crucial government departments (such as finance), and establishing partnerships with other NGOs.

The TNSACS, with financial and technical backing of NACO and international donors, has shown in its three years of functioning that governments can take the initiative in controversial and morally charged areas like Aids prevention. The TNSACS's agenda has been: blood safety, STD control through better equipped (including counselling services) government clinics, high visibility campaigns through the mass media and film celebrities for Aids prevention awareness, skill formation among government health sector personnel in the care of Aids patients, plans to start such training for private medical and paramedical personnel, financial support to NGOs, and care for people with Aids.

Of these, the government funded media campaign – which involved training of English and regional language print journalists in Aids coverage, and deployment of private advertising agencies - is what brought Aids into the public arena. Aimed at reaching beyond "high risk" groups of sex workers and STD patients, the open advertising of and regular newspaper coverage to a sexually related theme was an unprecedented government led initiative, and created shock waves and generated protest and controversies. But the result was that people's knowledge of the disease underwent a major change.

In 1994, e.g., a survey among married women had found that only 23 per cent had heard of Aids, around 27 per cent thought it was transmitted through heterosexual relations, and only 9 per cent felt that it was transmitted through blood. A Family Health Survey conducted in the state in 1996, three years after the launch of the campaign, found that awareness had gone up. 46.5 per cent of married women had by now heard of Aids, 60 per cent knew of the heterosexual mode of transmission and 29 per cent had become aware of the blood transfusion route. Tamil Nadu claims that it is the only state which, while continuing to witness steadily rising rates of HIV among commercial sex workers and STD clinic attenders as in the other states of the country, has been able to bring down HIV incidence among the general population (using women attending ante-natal clinics as a proxy), from one per cent to 0.5 per cent (Ramasundaram, 1997).

Notwithstanding the political legitimacy given to Aids prevention, which is the most important contribution of this initiative, the experiment admittedly raises several questions. Even now, what we know from the above data regarding awareness levels pertains only to urban areas. We know nothing as yet about the impact upon rural populations. While there is reason to believe that the mass media campaigns must have impacted on the educated middle class and better-off in the cities – going by the private clinics for treatment and care that now exist in the capital city of the state where at least 22 per cent of the patients are reportedly married women who are in what they believe to be monogamous relationships -, the urban poor have no recourse to high quality counselling and care (Business India, 1997/98).

Another question pertains to the impact of media campaigns upon illiterate or poorly educated populations, who are bereft of a tradition of reasoned enquiry or the back-up of counselling/face to face information communication channels. There is reason to believe that the poor may be becoming the victims of irrational fears spread by the fear of Aids, leaving "Aids patients" with heightened prospects of being discriminated against through witch hunts and violence against them as messengers of death and destruction of local communities. There have been recent media reports from Tamil Nadu of known HIV positive patients being driven out of

their villages/localities and beaten or burnt to death by fear driven mobs afraid of contagion (Natarajan, 1998). The government's media campaign may be stressing morality over, more importantly, consistent practice of protected sex whatever the circumstances (the more critical message for Aids prevention), since governments might be reluctant to be seen condoning promiscuity. In a culture where stigmatisation – on the basis of colour, gender, disability, caste, widowhood, divorce/desertion, pale skin patch – is deeply ingrained (applicable to large parts of the country and not to Tamil Nadu alone), an HIV positive identity may be full of dangers. Indigenous health beliefs which stress acceptance of particular states of the body as being "in one's nature", and which associate presence of disease only with a calamitous or life-threatening consequences, may also serve to bolster resistance to behavioural change in the ordinary course, while setting off panic reactions in the face of suspected or confirmed HIV presence.

That the rich are not free from the fear of stigma attaching to their image is also evident from the fact that large private hospitals in Chennai still do not accept HIV positive patients. Public admission of a personal problem, particularly one with possible moral overtones, may open a person, family or institution to all manner of speculations, and may evolve into degrees of neglect, rejection or even ostracism. Tamil Nadu has made a bold attempt to involve celebrities in Aids awareness media campaigns, as part of the effort to legitimise the problem of Aids. However, at this point in time, celebrities endorsing Aids campaigns may still be a culturally dissonant import of the western model, at least in relation to poor audiences. The openness that one witnesses in the west in the matter of personal lives even among celebrities, is missing among elites in predominantly tradition-bound societies, where the latter's legitimacy and mystique depends upon their distance from ordinary people's lives. This leaves the poor unable to identify with celebrities in non-fantasy roles, and may thus reduce Aids endorsements into condescending gestures. India has yet to witness a member of the elite social groups publicly admit to have contracted Aids and willing to talk about it. Until this begins to happen, celebrity endorsements notwithstanding, counselling and face-to-face support as a back-up to media messages is inescapable. This is particularly true of resource poor environments, where low levels of education make absorption and retention of complex information through impersonal communication channels difficult. The strengthening of the health and education infrastructure, with the important component of counselling – a hitherto neglected area of social skills and provisioning – is an inescapable adjunct of efforts to induce and sustain behavioural change. In the long run, Tamil Nadu's ability to sustain the gains made in direct Aids control, will depend on reforms in these allied areas of social policy.

# 2. NGO- led interventions – the case of the STD/HIV Intervention Project, Sonagachi, Calcutta

This sexual health project was initiated in 1992 by NACO through the All India Institute of Hygiene and Public Health, with assistance from international donors. Begun in order to tackle the Aids issue among commercial sex workers, the project has grown from its initial view of Aids as a public health and medicine problem, into one that recognises the complex

sociological and environmental ramifications of sex work and the inevitability of confronting these for a sustainable sexual health programme.

Sex work in Calcutta is predominantly brothel based. There are an estimated 6000 sex workers who live in the Sonagachi area, and an estimated 20,000 men who visit them, the women thus averaging around 4 customers a day. The women are drawn from India, Nepal and Bangladesh, and over 90 per cent of them come to this trade as victims of destitution, desertion/divorce or other lack of family support. The women are powerless, controlled by the madams who run the brothels with the active assistance of pimps, and who are broadly supported by a network of policemen, politicians, landlords and other underworld elements.

At the start of the project in 1992, less than 3 per cent of the women used condoms. STDs were found to be high amongst them – over 80 per cent were found to be infected with one or more STD causative agents, and HIV positivity rate was 1.1 per cent. The main thrust of the project, therefore, was condom use promotion and Aids awareness-raising through the agency of peer educators. For the purpose of STD control, a clinic was set up in the heart of the area.

By 1995, condom use had gone up to 82 per cent, of which 50 per cent was habitual condom use and 32 per cent was frequent condom use. Whereas knowledge of STDs and Aids, respectively, had been 70 per cent and 31 per cent in 1992, by 1995 it had gone up to around 97 per cent in the case of both. Prevalence of genital ulcer disease, which had been around 6 per cent in 1992 had come down to 3 per cent in 1995; syphilis alone had witnessed a decline from around 25 per cent in 1992 to 14 per cent in 1995.

While the positive response to the intervention project is testimony to the will of the women to safeguard their own health, the project has begun to encounter limits to further improvements, both in condom use and STD prevalence. These limits were found to arise mainly out of the power structures within which the women have to practise their occupation, complemented by the infrastructural constraints within which the women operate, and the continuous influx of new sex workers into the area. The women are bonded to the madams, who are unwilling to permit insistence on condoms, and brothel rules and client insistence on sex without condoms are upheld through the violence meted out by the pimps, police and local mafia. The competitive nature of the trade and resulting insecurity among the women was also found to act as a constraint on adopting behavioural changes. The infrastructural constraints such as lack of space and the shared natured of the space available, further impeded condom use negotiation with clients. The easy availability of all manner of private practitioners for treatment of STDs, the widely differing drug treatments practised by them, and the resistance of clients, particularly of the habitual partners of the women, to use condoms even while they indulge in multiple partners, have kept the STD rate reasonably high (AIIHPH, 1997).

The community mobilisation process, however, has had unexpected effects of a wider nature. The sex workers have begun to undergo an increase in self esteem and have begun a search for an professional identity and better work environment, and towards this end they have begun a process of self organisation. Among the ingredients of this new self awareness is the knowledge about and ability to protest against uninformed blood testing and unethical vaccine trials,

and demand for repeal of the Prevention of Immoral Traffic Act which, they argue, actually strengthens the police and further victimises the sex workers.

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In keeping with these demands from the sex workers themselves, what began as an Aids intervention project has begun undergoing the following changes:

- a) the collaborative base is now a broad one, comprising both governmental and non-governmental organisations;
- b) the Sonagachi sex workers forum has begun networking with other sex workers forums within the state and outside to feel part of the larger democratic process;
- c) there is a demand for the legalisation of the sex trade in order to ensure health, hygiene and safety of the women and to prevent children and adolescents from being brought into it;
- d) advocacy at the policy level is underway for change and modifications in oppressive legislations;
- e) STD management has changed from laboratory based diagnosis to syndrome-based management;
- f) follow-up of cases is through peers.

#### Lessons learnt

- 1. The early stages of the evolution of Indian Aids policy denial, precedence accorded to medical solutions over behavioural ones have parallels with responses in other parts of the world. While faith in the traditional socio-cultural norms prescribing private behaviour provided the basis for denial in the early stages of the epidemic, the open nature of the polity facilitated the flow of foreign assistance and the stimulus for critical investigation of actual patterns of sexual behaviour. The result has been the growing evidence that sexual behaviour is not in keeping with the traditional stereotypes.
- 2. One of the major factors impeding the assertion of an "effective, efficient and equitable" Aids policy has been the lack of political commitment, first, to collect and disseminate information and foster a public debate on HIV prevalence, risk behaviour, effectiveness of alternative programmes, their costs, etc., and second, to work constructively with those at greatest risk of contracting and spreading HIV. There would seem to be fear of formulating policies that might be seen as facilitating socially deviant or immoral behaviour, such as teaching people how to use condoms irrespective of the nature of the sexual union. Both the case studies presented earlier have attempted to do this in limited ways, i.e., created space for discussion about HIV and sexual behaviour, and shown that it is possible to do so in the Indian socio-cultural context.
- 3. The above-mentioned case studies notwithstanding, a major obstacle to a coherent Aids policy has been the lack of frank and public discussion of sources of risk. Public discourse about sexuality is lacking in Indian society, although emerging studies show considerable partner change beneath the veneer of monogamy. The absence of frank public discussion means that open and validated sources of knowledge about sex and about sources of infec-

tion are unavailable. Personal behaviour, doubts and agonies have no "safe" spaces to be aired in. A recently set up hotline in the capital city of Delhi – safe space for knowledge about safe sex – by an NGO reveal the exponential growth of demands for accurate knowledge. Even now, these demands are made only by men, as women are not supposed to evince public interest (a hotline is a public space) in sexual matters.

- 4. One of the greatest challenges is how to formulate an Aids policy that is integrated into more general public health and primary health care programmes. One of the obstacles to mounting an adequate policy response to Aids in India has been lack of knowledge and skills in public health management, born largely out of the historicallack of political will to generate such skills in what has been a low status, residual area of social policy. In a country where the majority are poorly educated and live in poor physical and socio-economic conditions, there is need for interventions to take the form of multi-faceted programmes in which mutually amplifying public health and social policies play as integral a role as possible. Success in the Aids sphere will depend upon complementary reforms in the larger spheres of health and education policy, since a sustainable Aids policy must aim at integration, especially in the area of treatment and care of those affected, and must base its preventionstrategies on education and awareness raising for consistent behaviour change.
- 5. One of the major cultural and political challenges posed by Aids is that men's behaviour is being called into question for the first time. Indian population control/family planning programmes have consistently targeted women and have left men well alone. Aids is showing up men's attendance at STD clinics, men engaging in pre and extra marital sex with multiple partners without thought for the health consequences of their actions, and adolescent youth engaging in casual sex in a state of gross ignorance. Women are emerging as powerless whether as sex workers or as unmarried adolescents or as wives with little or no knowledge of sex or of STDs or of reproductive tract infections (RTIs), nor in a position to negotiate condom use. It is becoming clear that women's powerlessness and vulnerability arising out of the prevailing gender inequalities, are among the most deep-rooted and resilient of the factors impeding effective implementation of Aids policies. Reaching into the private domain of men in order to effect far-reaching behavioural change, is the major challenge of any Aids policy. Media campaigns (as in Tamil Nadu) will have to be bolstered by direct mobilisational strategies to reach men in an effective way.

In conclusion it may be said that what is happening in India is that there are a growing number of projects, mainly with high risk groups, which are doing some very useful work. However, HIV/Aids prevention and care is not yet part of the mainstream social process. The main factors inhibiting this have been the resilient socio-cultural norms and stereotypes. These have combined with organisational inefficiencies and weaknesses, and the lack of political will, particularly at the level of the states, to undertake major public health and educational reforms or tackle the intractable problem of poverty. This is the stage at which we are today, despite the presence of several fostering factors such as an open political system, an active judiciary, the role of international funding and scientific collaboration bridging the gap between scientific developments world-wide and the situation in the country, and the drafting of a national aids control and prevention policy. The Tamil Nadu case is one illustration where HIV/Aids

has been mainstreamed and where things are beginning to work, largely due to certain inherent advantages that the state enjoys. However, even that experience suggests that with all the good intentions and resources, it is still uncharted territory. The constraints upon open discussion of sex and sexuality inhibit the emergence of safe spaces wherein enough information may be obtained. We still do not have the methodology to formulate messages that can be correctly interpreted by ordinary people, so that they may protect themselves. Underlying these are the patriarchal structures and gender relations that constitute the most enduring obstacles. Bridging the gap between women's powerlessness and the uncharted terrain of men's private behaviour is one of the major cultural and political challenges posed by the Aids epidemic. Bridging the gap between Aids control measures and primary health care strategies is an area requiring immediate attention. The challenge of Aids prevention and control should act as a stimulus to other bridging processes as well: such as between the federal government and the governments in the states with regard to health policy formulation and programme implementation; between socio-cultural stereotypes and the real world within which sexual behaviour actually takes place, through a more concerted process of knowledge generation; between telling people what they should do and listening to what they say are their needs, through skill formation in the area of counselling; and, between what is happening in people's bodies and people's own understanding of and ability to cope with it, through the tool of both education and counselling.

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# References

All India Institute of Hygiene and Public Health. 1997. Five Years Stint of STD/HIV Intervention Programme at Sonagachi 1992-1997, Calcutta: November.

Business India, December 29, 1997-January 11, 1998).

National Aids Control Organisation, Ministry of Health and Family Welfare, Government of India. 1997 (a). HIV/Aids in India, A Status Report, June (mimeo).

National Aids Control Organisation, Ministry of Health and Family Welfare, Government of India. 1997 (b). Draft National Aids Control and Prevention Policy (mimeo).

National Aids Control Organisation, Ministry of Health and Family Welfare, Government of India. 1996. National Aids Control Programme, India: Country Scenario and Update, New Delhi (June).

Ramasubban, R. 1984. "The development of health policy in India", in T. Dyson and N. Crook (eds.), India's Demography: Essays on the Contemporary Population, New Delhi: South Asian Publishers.

Ramasubban, R. 1990. "Sexual behaviour and conditions of health care: potential risks for HIV transmission in India", in T. Dyson (ed.), Sexual Behaviour and Networking: Anthropological and Socio-cultural Studies on the Transmission of HIV, Liege: International Union for the Scientific Study of Population.

Ramasubban, R. 1995. "Patriarchy and the risks of HIV transmission to women." In M. Dasgupta, T.N. Krishnan and L.C. Chen (eds.), Women's Health in India: Risk and Vulnerability, Bombay: Oxford University Press.

Ramasundaram, S. 1997. "Tamil Nadu: blazing a trail," Nexus, March-May.

Rosenbrock, R. 1995. "The role of policy in effective prevention and education", in: Friedrich, D./Heckmann, W. (eds.): Aids in Europe - The Behavioural Aspect. Vol. 5. Berlin: edition sigma, pp17-26

Shyamala Nataraj. 1998. "Testing positive for ignorance on HIV," Times of India, June 9.

Voluntary Health Services. 1996. Aids Prevention and Control Project: HIV Risk Behaviour in Tamil Nadu: sentinel surveillance survey, Report on Baseline Wave –1996, Chennai.

World Bank. 1995. India: Policy and Finance Strategies for Strengthening Primary Health Care Services, Washington.

World Bank. 1997. Appraisal Document, India: Reproductive and Child Health Project, April.

World Health Organisation. 1992. Aids in South East Asia: no time for complacency, Who Regional Office for South East Asia, New Delhi.

Select Cor	untry Profile India	
Total population <sup>1</sup> (in millions)		850
Proportion of population in sexually acti	50.0%	
Proportion of adolescent population <sup>3</sup>		20.0%
Urban population <sup>1</sup>	26.0%	
Rural population <sup>1</sup>		74.0%
Population below poverty line <sup>4</sup>	Combined	29.2%
Rural		
Crude death rate <sup>5</sup>	All India	9.8%
Urban		
Rural	7.1%	
Literacy rate <sup>1</sup>	All India	52,2%
Female	39.3%	
Male	64.1%	
Literacy rate (urban) <sup>1</sup>	Female	64.0%
Male	81.0%	
Literacy rate (rural) <sup>1</sup>	Female	30.6%
Male		

#### Sources:

- 1. Census of India, Series 1, Paper No. 2 of 1992, Final Population Total, Brief Analysis of Primary Census Abstract.
- 2. Office of the Registrar General, India (Vital Statistics Division), Ministry of Home Affairs, New Delhi, "Sample Registration System 1988"
- 3. Office of the Registrar General, India 1993 (Fertility and Mortality Survey Division), Ministry of Home Affairs, New Delhi. "Sample Registration System: Fertility and Mortality Indicators, 1992, IIPS, National FHS, 1992-93"
- 4. Government of India, "Family Welfare Programme in India, Year Book, 1989-90"
- 5. Office of the Registrar General, India (Vital Statistics Division), Ministry of Home Affairs, New Delhi, "Sample Registration System: selected demographic indicators 1991".

Aids	Profile India				
Seropositivity rate per thousand screened (May 1997 <sup>1</sup> )					
Cumulative total of Aids patients <sup>1</sup>					
(May 1997 as reported to NACO)		3551			
HIV present in all states except one, princip	pal <sup>2</sup>				
concentration in Maharashtra, Tamil Nadu,		77%			
Trend in Seropositivity rate <sup>3:</sup>	Sept. 1993	6.89			
March	1994 7.32				
March	1995 7.25				
July	1996 15.97				
May	1997 18.60				
Main routes of transmission:	Sexual	75%			
Blood transfusion	8%				
iv drug users	8%				
Main affected groups :	Commercial sex workers				
STD clinic attendees					
Clients of CSWs					
iv drug users					

## Sources:

- 1. National Aids Control Organisation, Government of India. 1997. HIV/AIDS in India: A Status Report (June).
- 2. National Aids Control Organisation, Government of India. 1997. Draft National Aids Prevention and Control Policy.
- 3. National Aids Control Organisation, Government of India. Reports for relevant years

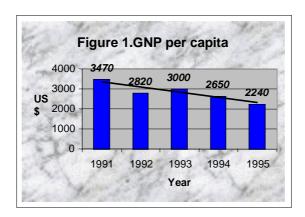
Valeriy Chervyakov, Igor Kon

## **Sex Education and HIV Prevention in the Context of Russian Politics**

#### Russia in Transition

With a land area of 17,075,000 km<sup>2</sup> and a population of 148 million, the Russian Federation is one of the largest countries in the world. In this context, the extraordinary economic and political conditions of the 1990s have pushed millions of its citizens into poverty and resulted in major changes in social life.

GNP per capita has declined from \$ 3470 to \$ 2240, i.e. by one-third (see Figure 1). The proportion of people living in poverty has increased from about 10% (according to official statistics) to 15% (estimated) of the population in the Soviet era to an official figure of about 25% in 1995, based on a national poverty level of \$ 50 per month. Independent estimates based on a higher poverty level have placed this figure at around 90% of the population. \(^1\).



The decline in living standards and especially the psychological impact of the political and economic changes have led to an unprecedented drop in life expectancy. Male life expectancy has decreased from circa 65 years in 1987 to circa 58 years in 1995. At 14 years, the differential between male and female life expectancy in the Russian Federation is now the largest in the world (see Table 1).

Human Development under Transition: Europe & CIS. UNDP Regional Bureau for Europe and the CIS, May 1997, p.181.

Table 1: Life Expectancy in Russia, Eastern Europe (EE), European Community (EC), and in the USA

Year	Males				Females			
	Russia	EE	EC	USA	Russia	EE	EC	USA
1970	63.0	66.3	68.6	67.1	73.5	71.9	74.9	74.7
1980	61.4	66.8	70.7	70.0	73.0	73.6	77.5	77.4
1984	61.7	67.1	71.8	71.2	73.0	74.1	78.6	78.2
1987	64.9	67.2	72.6	71.5	74.3	74.0	79.3	78.4
1991	63.6	66.8	73.2	72.0	74.4	74.9	80.0	78.9
1992	62.0	66.9	73.5	72.3	73.8	75.1	80.3	79.1
1993	59.0	67.2	73.6	72.2	71.9	75.3	80.3	78.8
1994	57.5	67.2	74.0	72.4	71.1	75.4	80.6	79.0
1995	58.2	67.3	74.0	-	71.7	75.6	80.7	-

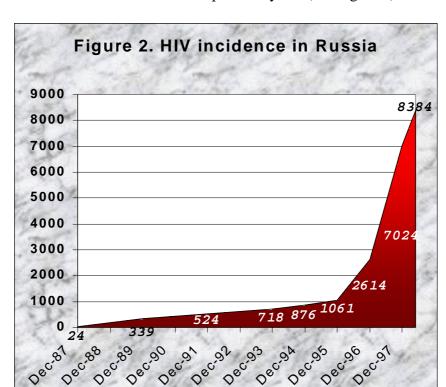
**Source:** Shkolnikov V. et al. Causes of the Russian Mortality Crisis: Evidence and Interpretations. *World Development*. Special Issue, 1998. (Forthcoming).

The country's social and economical difficulties are furthermore aggravated by severe Communist opposition to all the initiatives of the Yeltsin administration.

## HIV/Aids in Russia

Due to the USSR's self-imposed isolation from the rest of the world, Aids entered the country relatively late. At the very beginning of the epidemic in the United States, articles appeared in the Soviet press declaring that the HI-virus had been invented by the Pentagon for military purposes. At the same time, Soviet epidemiologists argued that Aids posed no threat to Russians, as it only affected homosexuals and drug users.<sup>2</sup> Due to a sad irony, the first large population group to be infected with HIV was new-born babies, the innocent victims of the negligence of medical personnel and of the absence of disposable syringes.

On general trends and history of the Russian sexual culture see: Kon I.S. Sexualnaya kultura v Rossii: klubnichka na beryozke. Moscow, O.G.I., 1997, earlier version of this book - Sexual Revolution in Russia. From the Age of the Czars to Today. New York, The Free Press, 1995; I.S. Kon. Russia. In: The International Encyclopedia of Sexuality. NY: Continuum Press, 1997, vol. 2, pp. 1045-1079; Russia. In: Sociolegal Control of Homosexuality: A Multi-Nation Comparison. Edited by Richard Green and Donald West. NY: Plenum Press, 1997, pp. 221-242; I.S. Kon. Sexuality and politics in Russia (1700-2000), in: Sexual cultures in Europe. Manchester University Press (in press).



Exponential Growth in HIV Incidence in the past two years (see Figure 2).

Some international experts, particularly from UNAIDS, have cast doubt on the official statistics, estimating the number of those infected with HIV in the country at 40.000. Approximately half of them are thought to be intravenous drug users. Yet the figures concerning sources of infection are not reliable.

From the very beginning, the main emphasis of Aids-prevention work in Russia has been on testing. The number of HIV tests performed in Russia exceeds that of any other country in the world: 24 million in 1993, 20 million in 1994. Meanwhile, sex education and propaganda on safe sex have remained negligible.

### Aids Vulnerability Factors in Post-communist Russia

Under communist rule, Russia seemed almost immune to the threat of Aids due to the totalitarian methods then in place to control human behaviour, including sexual behaviour. But during the period of transition, the situation has changed dramatically. The most significant changes have been:

• The commencement of sexual activity at an earlier age. According to our survey data, in 1993 only one-quarter of sixteen-year-old girls had had sexual experiences, while this figure had risen to one-third by 1995. For boys of the same age, the corresponding figure rose from just over one-third in 1993 to one-half in 1995. The 1995 survey revealed that 22.5%

of sixteen-year-old female respondents were sexually active, while only 11% of the respondents then aged 19 had had sexual encounters by the age of 16 (see Figure 3). In other words, changes in sexual behaviour that had taken place over 20 years in most Western countries had in Russia been compressed into only 2 years. Thus, the society had very little time to get used to these changes.<sup>3</sup>

• Sexual morality in Russian society has also changed significantly. According to survey data, people have become much more tolerant towards premarital sex for both men and women; many more people are in favour of erotica on TV; and there is less hostility towards sexual minorities, commercial sex, etc. In a representative opinion poll conducted in Russia in 1992, 37.2 % of respondents considered premarital sexual relations to be "normal" and "acceptable" behaviour; by 1994, this figure had risen to 51.7 %. Our own data indicate a similar development (see Table 2).

Table 2: Agreement/Disagreement with the Statement: "A girl should not have sex before marriage" (1997 survey, %)

	Students		Their pare	nts
	Male	Female	Male	Female
Absolutely disagree	40.6	26.9	14.1	13.6
Rather disagree than agree	20.1	25.6	25.0	26.8
Rather agree than disagree	12.4	17.0	29.3	24.2
Agree in full	13.9	17.2	21.1	21.8
Not sure	13.0	13.3	10.5	13.6

• Numerous sex-workers have appeared in all the major cities, many of whom are involved in sex tourism and contribute to the spread of STDs and Aids over national borders. Public opinion demonstrates a growing tolerance towards prostitutes. During the national public opinion poll conducted in 1989, 27 % of those responding to the question "What must be done with prostitutes in our society?" indicated that they should be "liquidated", 33 % that they should be "isolated", 8 % that "they should be helped" and 17 % that they should be "left to themselves". The results of a 1994 poll in which the same question was posed were as follows: 18, 23, 12 and 30 %, respectively. In the 1997 national poll, 47.4 % supported

For more details see: Chervyakov V. Early Sex and Risk Taking Behaviour of Teenagers. Abstracts. The 4th Biennial of the European Association for Research on Adolescence. May 28-June 1, 1994. Stockholm Sweden. Chervyakov V. Survey Supports Arguments to Start Sexuality Education in Russia. *SIECUS Report*, December 1996. Chervyakov V., Kon I. Adolescent sexuality in Russia. In: Aids in Europe. New Challenges for Social and Behavioural Sciences. 2<sup>nd</sup> European Conference on the Methods of Social and Behavioural Research on Aids. Working papers for synthesis sessions. January 12-15, 1998, Paris, France.

Levada Y.A. "Homo soveticus" five years later: 1989-1994 (Preliminary results of comparative research). *Informational bulletin of monitoring*. January-February, 1995, p. 10.

the legalisation of prostitution. In our 1997 survey, in which both high school students of 14-16 years of age and their parents were questioned, the proportion of male teenagers who stated that "sex for money should not be condemned in contemporary society" exceeded the corresponding figure for parents by 400 %; the proportion of female students who said so exceeded the corresponding figure for parents by 200 %. Meanwhile, prostitution is one of the main channels of dissemination of STDs.

- Control over STDs has become less effective. In 1987, free medicine in connection with coactive treatment of sexually transmitted diseases resulted in an incidence of only 5.6 cases of syphilis per 100,000 people in the USSR, a figure 2.2 times lower than in the United States. The incidence of gonorrhoea in 1987 was 86 cases per 100,000 6 times lower than in the U.S. In the period from 1990 to 1996, the incidence of syphilis increased by 48 times in general population and by 68 times among children. In 1996, 265 new cases of syphilis per 100,000 people were diagnosed. Now it is possible for people infected with the disease to avoid treatment for years while remaining sexually active; earlier this was impossible.
- Social and economic differentiation has resulted in reduced access to health care among low-income segments of population.
- A rise in the number of intravenous drug users has increased the frequency of non-coital dissemination of the HIV. However, the 5.5-fold increase in the number of those convicted of drug-related crimes between 1990 to 1995 reflects only the tendency, not the whole situation.
- The increased mobility of the Russian population, both within the country and abroad, must be also considered a contributing factor in the spread of the epidemic.

Although some of them are positive, all of these changes have made Russian society much more vulnerable to the threat of Aids.

There are some significant factors inhibiting effective Aids prevention.

The first and perhaps most significant group of factors could be called cultural: the absence of a tradition of safe sex, prejudices against using condoms or openly discussing sexual problems (to the extent that in some areas, even the vocabulary for such discussions is lacking), and the Russians' characteristic love of risk, an inclination that can turn sex into Russian roulette.

The second factor might be called educational; namely, the widespread ignorance about issues relating to sexual healthcare, even among physicians.

The third group of factors might be called organisational, and include the predisposition to the bureaucratic-administrative approach to social problems. The most explicit examples of this approach in Aids prevention policy have been the attempts to organise population-wide Aids-

testing instead of educating people about the disease, and the legislative initiatives forbidding foreigners from entering the country if they are unable to certify that they are free of HIV.<sup>5</sup>

## Positive Tendencies and Steps

Public opinion polls as well as practical measures show that Russian society has come to understand the necessity of preventing STDs and HIV/Aids. Nevertheless, to achieve this end, it is necessary to bring about a change in the sexual culture of the Russian people. This objective can only be realised through sex education and the promotion of safe sex practices (see Table 3).

Table 3.: Agreed/Disagreed with the Statement: "It is necessary to introduce a special course on sex education in schools" (1997 survey, %)

	Group					
	Students		Parents		Teachers	
	M	F	M	F	M	F
Absolutely disagreed	5,4	4,7	3,1	2,4	6,8	2,1
Rather disagreed than agreed	2,2	2,2	3,9	2,2	2,3	6,5
Rather agreed than disagreed	16,3	14,7	25,8	23,5	20,5	33,5
Absolutely agreed	67,1	69,3	60,2	65,6	65,9	48,1
Not sure	9,0	9,2	7,0	6,3	4,5	9,8

The three main agents of Aids prevention policy are:

- 1. Medical institutions;
- 2. Voluntary organisations, such as the Russian Family Planning Association; and
- 3. Educational institutions.

Yet there is no common strategy for these three main forces, not to mention the numerous (if not particularly powerful or influential) Egos, which include women's organisations as well as some institutions promoting sexual health.

<sup>&</sup>lt;sup>5</sup> (Editors footnote) see Pokrovsky, V.V., "Expected changes in national Aids policy in Russia", in: D. Friedrich/W. Heckmann (eds.) Aids in Europe - The Behavioural Aspect. Vol. 5. Berlin: edition sigma 1995, S. 27-30, and

Prokrovsky, V.V., Conceptualisation and development of Aids policy in Russia, in: Aids in Europe. New Challenges for Social and Behavioural Sciences. 2<sup>nd</sup> European Conference on the Methods of Social and Behavioural Research on Aids. Working papers for synthesis sessions. January 12-15, 1998, Paris, France.

The initial steps in this direction have produced some positive results. A few more people have turned to modern contraceptive methods, including condoms, which are also effective in preventing the spread of STD. According to sociological data, approximately 50 % of women aged 15-25 used some form of contraception the first time they had intercourse, 17-30% having used condoms. The same figures characterised teenage sexual behaviour in the United States 15 years ago. Statistics show some reduction in abortion rates, even among teenagers (in 1996, for the first time). But the main achievements have been the launching of a network of family planning centres throughout the country and the founding of a project, supported by UNFPA and UNESCO, aimed at developing sex education programs for secondary schools.

#### Sexual Counter-revolution

Unfortunately all of these initiatives have faced extremely active opposition from Russian ProLife organisations, the Communist majority in the Duma (Russian Parliament) and the Russian Orthodox church. There has been a well-organised attack on different fronts, aimed at destroying the whole system for improving sexual culture.

First of all, the law on reproductive rights was voted down in the Duma.

Then, the same forces pushed through a reduction in the state financing of family-planning programs. As a result of a huge public scandal, the so-called UNESCO project on sex education for Russian schools was cancelled. The anti-Aids propaganda campaign in Moscow organised by *Médecins sans frontiers* was also blocked. The words "safe sex" became virtually taboo.

At first glance, such an alliance seems rather unlikely. The ProLife movement used to be one of the most vociferously anti-Communist organisations in the country, while the Communist Party has always been militantly atheistic. Furthermore, the Russian Orthodox Church is afraid of foreign competition. However, these three forces also have many things in common. The official Soviet "communist morality" was as afraid of and hostile to sex as any form of Christian fundamentalism, including Russian Orthodoxy. Moreover, ProLife is an alien movement in Russia: the sin of interrupting a pregnancy cannot be taken seriously in a country where human life is still not considered an absolute value and where people are tired of state intervention into private life. In the national public opinion poll of April 1998, only 4.9 % responded that abortions should be forbidden under any circumstances; 65.3 % believe that abortions should be permitted as a woman's free choice and 18.3 %, that they should be performed under specific conditions.

So it was easy for Russian nationalists, Communists, the Russian Orthodox Church and Western Christian fundamentalists to unite their forces against the principles of liberalism and in defence of the restoration of censorship. Sexuality is only the tip of the iceberg.

Their arguments are:

- 1. All the new initiatives on reproductive rights, safe sex and sexual education were initiated by Western secret service agencies and pharmaceutical companies, with the deliberate aim of depopulating Russia and undermining its national security (i.e. state security reasons).
- 2. Any public discussion about sexuality is immoral and vicious, while propaganda on safe sex leads only to sexual license (i.e. moral and religious arguments).
- 3. Sexual freedom is part of dissolute lifestyle that ultimately leads to drug addiction, sexual crimes and violence, and hence to social destabilisation (i.e. public health and legal arguments).
- 4. The acceptance of sexuality contradicts Russian national traditions of chastity and family values (i.e. nationalistic arguments).
- 5. Both school sex education and sex research are initiated by pedophiles, and constitute sexual temptation and an offence against minors (i.e. child defence arguments).

This virulent anti-sexual crusade has been generally successful. ProLife activists, Communist deputies in the legislative bodies and representatives of the Russian Orthodox Church have managed to form a united front and have consolidated their forces. They efficiently use social demagogy and have successfully spread all kinds of lies (e.g. about the ineffectiveness of condoms due to intrinsic voids in the latex "which are 50 times larger than the HIV virus"). Playing on the most sensitive chords of mass consciousness, such as national pride, family values, and state security, they effectively use the mass media and public relations agencies to create a state of moral panic in the society, while the bureaucratic organisations promoting reproductive rights and sexual education have failed to mobilise their resources. Few in the Russian democratic mass media have dared to oppose this crusade, and some of the so-called "democratic" newspapers have even joined this chorus.

#### What is to be Done?

The epidemic of STDs and the real threat of Aids have turned the problem of disease control and prevention into a vital problem for Russia. So far, Russian social policy in this field has been extremely inefficient. The reason of this is not only shortage of money. An important public health issue has become a victim of personal ambitions and of indecent political game playing.

The only way to save the situation is to co-ordinate the efforts of all interested institutions and organisations and to start to influence public opinion by:

- 1. debunking of the position of the ProLife movement, Communists and the Russian Orthodox church on this question and all of their false arguments;
- 2. organising positive propaganda based on a solid, up-to-date strategy and with the support of sufficient social-psychological monitoring.

Russian governmental bodies that are potentially interested in changing the situation, especially the head of the federal HIV Centre, Dr. Vadim Pokrovsky, have demonstrated a complete intellectual and organisational inability to cope with the problem. Even while talking about the necessity of safe sex education, Dr. Pokrovsky stresses that this should be done "in the forms" and "corresponding to the national ideas of our nation and not borrowed from other cultures" (a typical anti-Western euphemism). The Russian epidemiological community is deeply divided and its contacts with other scientific organisations are inadequate.

That is why support from international organisations, and above all from WHO, UNAIDS, UNDP and UNFPA, is needed. An international conference held in Russia on the experiences of different countries in the field of sex education and safe sex promotion would be of great help.

A second factor that could improve the situation in this country are the activities of various voluntary organisations, such as *Médecins sans frontiers*, Aids-Infoshare and others.

However, Russian problems cannot be solved by international help alone. A new presidential or governmental program of STDs and Aids prevention, with clear objectives and bringing together all the institutions working in this field, is badly needed.

Pokrovskii V.V. Lozhka myoda v bochke dyogtia, ili o neobkhodimosti novoi gosudarstvennoi programmy po profilaktike SPIDa. Meditsinskaya gazeta, N 16, 1 marta 1995

# The Politics Behind Aids Policies: Comments and Perspectives

At the opening ceremony of the 12<sup>th</sup> World Aids conference on June 28, 1998, at Geneva, Dr. Peter Piot, Director of UNAIDS, stated that "Aids is out of control in many countries, yet we know what to do." While the theme of the conference, "Bridging the Gap", refers to many gaps, Dr. Piot declared that the biggest gap is that between knowledge and action.

This gap is what we are discussing today. Professor Rosenbrock's introduction provides an outline of what it is that we know to do, of our current understanding of best practice concerning Aids. The three country papers discuss the factors which have fostered and impeded action on best practice, stressing the politics of policy-making and implementation.

In discussing politics, we are engaged in a process of interpretation, one which draws on several disciplines. There are no clear rules or methodologies for political interpretation, and this tends to mean that the kinds of insights produced here are completely overlooked in the currently orthodox fields of policy analysis and policy evaluation.

I should like to suggest that Rolf Rosenbrock's catalog of appropriate approaches to prevention (most of them also appropriate for care and treatment) constitutes a model of Aids rationality -- a coherent set of principles and practices in line with the Ottawa Charter concerning public health in a healthy society. Aids rationality is developed around the creation of responsible and health citizens, communities and even policy-makers, who are capable of recognising the risks from HIV and of taking appropriate action.

A central problem for Aids rationality in relation to prevention is making explicit and open for discussion what most cultures and states have kept hidden and silent, if not forbidden: sexual relations, especially prostitution and homosexuality, gender relations and drug use. Often the only language available for public discussion is that of religion and the state in terms of rules and sanctions.

There are major differences among societies in terms of their preparation to engage in open debate on these matters. In North America, Western Europe and Australasia, the twenty years prior to the onslaught of Aids brought a cumulative series of changes. The introduction of the contraceptive pill, followed by feminism and gay and lesbian "liberation", introduced what was known at the time as a "sexual revolution". The Vietnam War brought with it an explosion of injecting drug use and sex tourism. In addition the 1970s saw the beginnings of a new set of ideas about health promotion, embodied in the Ottawa Charter of 1986. Thus when Aids arrived in the West, public policy was better equipped to conceive of greater openness concerning sex, gender and drugs than would have been possible in the 1950s. In effect there was some preparation for broader conceptions of healthy citizenship. Non-Western societies did not experience the same cultural revolution and have had to confront all these issues in the context of Aids. Aids rationality has to be set out as a pragmatic strategy for social and eco-

nomic survival to have any chance of reaching public policy agendas. Here, however, there are very powerful forces arrayed in support of existing gender and sexual codes and beliefs, which are seen as fundamental to the maintenance of valued cultures.

Turning to our three country studies, the Indian case portrays most starkly the clash of rationalities, between rival conceptions of the appropriate language and behaviour of good citizens. In Russia, despite the compressed sexual revolution of the past two years, an opportunistic alliance asserting traditional values has been able, for the moment, to forestall programs framed in terms of Aids rationality. By contrast South Africa offers the example of a society in full transition, where the fundamentalism of Afrikaner rationality has been freshly overthrown and new concepts of citizenship are welcomed.

There are, of course, other entrenched forces in all societies ready to challenge Aids rationality. These are most often medical establishments committed to the older public health rationality of containment and control, and public services threatened by the participatory mandates of Aids rationality.

Taking up a few of the specific issues arising from the country papers, and drawing to a limited extent on other comparative experience, I should like to focus first on the turning points, the moments at which Aids has succeeded in reaching the public policy agenda. These are often the moments when Aids rationality has an opportunity of being seriously considered.

A change of government clearly offers one such opportunity. South Africa's incoming political elite participated in the Aids conference of 1992 which provided the first assertion of Aids rationality, and in the same year a new government in Thailand was able to open the door to new thinking about the Thai Aids crisis.

New and startling evidence of risk can also trigger governments into Aids awareness, with epidemiology playing a significant role. In both Australia and China, evidence of substantial contamination of the blood supply forced Aids, and Aids rationality, onto government agendas.

External agencies obviously play a major role in providing occasions for taking Aids seriously. The World Bank appears to have been critical in getting the Indian government to commit resources to Aids programs. In a somewhat different vein, UNDP workshops on the social and economic impact of Aids provided a starting point for China and several other countries. Lengthy consultative exercises in strategic planning, facilitated by UNAIDS, are the latest of a series of efforts to mobilise societies in terms of Aids rationality.

Much of this discussion is focused on committing governments to Aids rationality but, given the cultural and social nature of the changes required, how much can we count on political leadership as an effective agency for change? In India such leadership seems to have counted for very little; in Russia it may have been present, but ineffective; in South Africa it is seen as a mixed blessing. Even in the widely cited example of political leadership in Uganda, President Museveni was for many years unwilling to tackle church opposition to condom distribution.

Perhaps the most important role for political leaders is to provide a protective umbrella, what Dr Schneider's paper refers to as enabling leadership, for the spread of Aids rationality through programs sponsored by government and non-government agencies, communities and international organisations. Providing support for a learning environment may be the best that we can expect of political leaders. What is required is an open society with tolerance for non-government initiatives and decentralised activities supporting all groups within a society.

Finally there is the issue of maintaining a commitment to Aids rationality once it has achieved some measure of policy status. Condoms, once available, are likely to create their own continuing market, but programs like needle exchanges and school sex education require continuing government support and can prove vulnerable. The mobilisation of alternative rationalities, whether those claiming the legitimacy of traditional values or those asserting the superior efficacy of containment and control, is a constant possibility in any society. Clear evidence of this is last week's announcement that the New York state legislature has adopted a policy of reporting names of those testing HIV-positive and of aggressive contact tracing.

Some years ago Professor Ronald Bayer raised the spectre of an end to what he termed Aids exceptionalism, suggesting that Aids rationality might be a temporary aberration from a longer tradition of policies of containment and control. In the early years of WHO's Global Programme for Aids, one of its most successful contributions to the development and promulgation of Aids rationality was its series of consultations, meetings of recognised authorities to define best practice on a wide variety of contested issues. It may be time for UNAIDS to revive this GPA model to reinforce the legitimacy of basic tenets of Aids rationality in the context of renewed challenges.

see Ronald Bayer: Public Health Policy and the Aids Epidemic. An End to HIV Exceptionalism? JAMA, Vol. 324, No. 21/1991, pp 1500.1504

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