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HIV / AIDS in Sri Lanka

A Profile on Policy and Practice

July 2007

The Centre for Policy Alternatives (CPA) is an independent, non-partisan organization that focuses primarily on issues of governance and conflict resolution. Formed in 1996 in the firm belief that the vital contribution of civil society to the public policy debate is in need of strengthening, CPA is committed to programmes of research and advocacy through which public policy is critiqued, alternatives identified and disseminated.

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Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral Medication
CBO	Community Based Organisation
CPA	Centre for Policy Alternatives
CSW	Commercial Sex Workers
FTZ	Free Trade Zone
GFATM	Global Fund against AIDS, TB and Malaria
HIV	Human Immunodeficiency Virus
IDH	Infectious Diseases Hospital
ILO	International Labour Organisation
I/NGO	International/ Non-Governmental Organization
IOM	International Organisation for Migration
MDG	Millennium Development Goals
MOH	Ministry of Health
NAC	National AIDS Committee
NSACP	National STD/AIDS Control Programme
NHAPP	National HIV/AIDS Prevention Project
OI	Opportunistic Infections
PEP	Post-exposure Prophylaxis
PLWHA	People Living with HIV/AIDS
STD	Sexually Transmitted Diseases
TB	Tuberculosis
UN	United Nations
UNAIDS	UN Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNGASS	UNGASS Declaration of Commitment 2001
UNICEF	United Nations Children's Fund
UP	Universal Precautions
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

Introduction

This paper discusses the status of HIV/AIDS in Sri Lanka, with a special focus on laws, policies, institutional structures and practical issues such as the prevalence of stigma and discrimination, lack of adequate resources and infrastructure. While Sri Lanka is a low prevalence country, several factors such as poverty, conflict, low awareness levels and low condom use coupled with vulnerable groups as listed in this document, could result in the possibility of an outbreak of HIV/AIDS in the future. In such a situation, it is vital that the response to HIV/AIDS is targeted, timely and effective, recognising the needs and vulnerabilities of people living with HIV/AIDS (PLWHA), their families and friends, communities and vulnerable groups. This paper also maps out the role played by civil society, religious leaders, media, the private sector, international organisations and donors and particular initiatives undertaken by these actors in their response to HIV/AIDS. Finally the paper sets out recommendations for future action combining a multisectoral approach and a rights based framework.

Overview of the socio-economic situation in Sri Lanka

Having been ravaged by a civil war for over two decades, the people of Sri Lanka saw a glimmer of hope with the signing of the Ceasefire agreement in 2002. However, peace was not forthcoming and today the violence in the North East of Sri Lanka continues as fiercely as before. In 2004, the Sri Lankan coastal line was devastated by the tsunami. This together with the continuing conflict has severely affected the development of Sri Lanka.

With low levels of development, poverty in Sri Lanka persists. While poverty in urban areas receives attention and is being addressed, it is yet to be adequately addressed in the rural and estate sectors. Basic services such as education, health, water and sanitation are scarce and inadequate in many rural areas in Sri Lanka, resulting in increased migration to urban areas and overseas.

Sri Lanka boasts of a high literacy rate 91.1% and attributes it to free education. Yet it is important to note that poverty is the main reason children drop out of school. Limited resources continue to affect those who live below the poverty line and the lack of basic services such as education, health, sanitation and water have heightened the vulnerability of various groups such as women.

Health care is financed by the Government as well as by private persons through direct out-of-pocket payments. In recent times, there has been a surge in the use of private hospitals due to overcrowding, long waits and queues at public hospitals. However, since most of the population cannot afford the high private hospital charges, they continue to rely on public hospitals for services, many of which have insufficient resources, infrastructure and staff.

The lack of good infrastructure has excluded poor communities from enjoying the benefits of economic development. Gender inequality is another barrier. In order to empower such communities and to bring about gender equality it is essential that infrastructure and basic facilities are provided to the poor and vulnerable communities. Further, adequate recognition must be given to the role women play as the heads of households and as breadwinners. For economic growth, development and social equality to be successful and impact the lives of all citizens, there must also be a framework of laws and policies that are rights based and effectively implemented.

1 HIV / AIDS situation in Sri Lanka

Although the official number of cases of Sri Lankans living with HIV is 862[1], the actual figure is much higher as a result of the stigma, discrimination and fear associated with HIV/AIDS. Furthermore, there are probably countless others who are simply unaware that they are infected. Therefore, the actual number of people living with HIV/AIDS is estimated by UNAIDS to be 5,000. UNAIDS/WHO has classified Sri Lanka as a low HIV prevalence country in the South Asia region, with an estimated adult prevalence rate of less than 0.1%.[2]

The Western Province accounts for 60% of HIV infections, with the Central and North Western Provinces each accounting for 8%, and the North East Province 7%.[3] A point to remember is that this merely reflects the reported cases and does not reflect estimated cases. While the Western Province has a substantial number of infected cases, this may also be due to the high number of HIV tests done in the area. For example, although migrant workers come from other provinces, HIV tests are generally done in the Western Province. Further, poverty results in migration to urban areas. Having better infrastructure and testing facilities in the Western Province results in a higher percentage of infections being detected. Consequently there are more cases reported from the Western Province. Nearly 90% of the reported HIV infections are within the 15-49 age group.[4]

The majority of HIV-positive people (96%) acquired HIV/AIDS through sexual transmission.[5] While the majority of them were through heterosexual/bisexual relations only a few cases of prenatal transmission or through blood transfusion were reported.

The number of women with HIV/AIDS is increasing, with 50% of these women being migrant workers who have been employed abroad.[6] The current ratio of HIV-positive men to women in Sri Lanka is reported at 1.4 to 1.

Despite the current low prevalence rate, Sri Lanka is vulnerable to an impending epidemic due to a number of risk factors: the country has large numbers of at risk groups such as sex workers, migrant workers, military personnel, Internally Displaced Persons (IDPs), refugees and drug users and a high incidence of unsafe sexual practices, which includes low condom use and escalating rates of STDs.

Poverty which has led to prostitution and trafficking has resulted in women and children who are in the sex trade and/or are trafficked being vulnerable to HIV/AIDS. Poverty is usually the primary “root cause” of prostitution and trafficking. Those from the poorest and most marginalized households are the most susceptible to prostitution and/or trafficking. Poverty alone does not lead to prostitution and/or trafficking but often places individuals in other vulnerable situations. It often forces individuals to leave their place or residence in search of work or better opportunities. Once away from the familiarity of their own community, these people are vulnerable to prostitution and/or trafficking.

Gender-based discrimination is perpetuated at both the family and community level. Women are expected to play a subservient role to that of men and not challenge their authority. This creates a social atmosphere in which men control women and of women being susceptible to the coercive and deceptive tactics wielded by predominantly male traffickers. Additionally, gender based violence and woman having minimum power to negotiate sex (as well as negotiate using condoms) further heightens women's vulnerability to STDs and HIV/AIDS.

2 Vulnerability factors and groups

A) Low Condom Use

Condom use in Sri Lanka is reported to be low, with a prevalence of only 3%.[7] Accordingly, with an estimated adult population of approximately 10 million, the condom availability is 1.2 condoms per adult per year.[8] The risk of HIV/AIDS spreading among sex workers is heightened by low condom use and the high prevalence of sexually transmitted infections (STIs), which make a person more susceptible to contracting HIV/AIDS. In one study, 45% of female sex workers experienced multiple STIs, and 70% of male patients at STI clinics reported frequenting sex workers.[9] An additional element that should be kept in mind is whether women have the power to negotiate condom use, when they have little say in negotiating sex. Though the general picture is bleak, there are various initiatives undertaken by private organizations that have encouraged the use of condoms through awareness programmes and training.[10]

B) Commercial Sex Workers and Clients

It has been estimated that there are over 45,000 commercial sex workers (CSW) in Sri Lanka.[11]This number is increasing due to the deteriorating socio economic conditions and prevailing poverty. There is also an upswing in the number of foreign sex workers in Sri Lanka.

C) Drug Use

According to the Dangerous Drug Control Board, there are 400,000 heroin users and 200,000 cannabis users on the island with 7.5% estimated to be injecting drug users.[12] Although there is only one reported case of HIV infection through intravenous drug use, this group is at high risk because of needle-sharing and can be recognized as a population vulnerable to HIV/AIDS.

D) Refugees and Internally Displaced Persons (IDPs)

Internally Displaced Persons and refugees living in camps can be considered as a group at high risk to HIV/AIDS and STIs due to the conditions they face namely a breakdown of essential services, a disruption of social structures and support and sexual violence, rape and coercion.

E) Military Forces and Police

Military forces and the police are considered a vulnerable group mainly due to risky sexual behaviour , which leaves both the military personnel and the sex worker/partner at risk.

F) Youth and Adolescents

The lack of information on HIV/AIDS among youth is another serious problem. In a study contacted by the UNICEF it was found that very few were aware of STIs and HIV/AIDS.[13] Due to cultural reasons, there is little or no sex education, which leaves school children ignorant on the matter, and hence vulnerable.

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G) Worker in Free Trade Zones

Workers in the Free Trade Zones have been identified as a vulnerable group and it has been estimated that there are approximately 96,000 workers of which a majority are women.[14] The shift from rural to urban areas results in a change in lifestyle and the lack of a social network or protection leaves female workers vulnerable.

H) Migrant Workers

Women who travel overseas as migrant workers have been identified as a high risk group as they do not have the support of their families and communities, they undergo lifestyle changes and further have no support networks.

I) Workers in Tea Plantations

Women in plantations have limited access to health care facilities and due to a dearth of employment options many have had to migrate to other areas including traveling overseas. Changes in lifestyle, lack of awareness, as well as limited access to health care have all contributed to the group being considered as a vulnerable group to HIV/AIDS.

J) Men Having Sex with Men (MSM)

Men having sex with men (MSM) are another group that has been identified as being vulnerable to HIV/AIDS. There are also a growing number of beach boys who are vulnerable to STDs and HIV/AIDS. 11% of the reported HIV infections have been due to homosexual transmission.[15]

3 Review of Laws and Policies on HIV / AIDS

3.1 Constitutional and Legal Framework[16]

The Constitution of Sri Lanka does not have a specific provision on health. Under the present Constitution, Article 12 (1) ensures that all people are equal before the law and are entitled to the equal protection of the law. Article 12 (3) states that no person shall be subject to any disability, liability, restriction or condition on the grounds of race, religion, language, caste or sex. The Government of Sri Lanka has made international commitments, which make the State responsible for providing health care to all citizens without discrimination.[17]

The 13th Amendment to the Constitution devolves health to the Provincial Councils. A criticism of the 13th Amendment, especially with regard to health, is that it introduced an additional layer of governance, expenditure and bureaucracy, without devolving power to a smaller unit that is closer to the people.

The current health structure is set up under the Health Services Act of 1953, the Provincial Councils Act of 1987 and the Provincial Councils (Consequential Provisions) Act of 1989 . Under these Acts, the Central Government is responsible for policy as well as the training and management of special and teaching hospitals. Provincial health ministries are responsible for health care in their respective areas. However there are marked disparities in the provision of health care between provinces and even between different districts within provinces. This can be attributed to a 'rural-urban' divide, as it is alleged that the concentration of resources and industrial development in the Western Province is partly due to an over-centralised system.

Financial Allocation Mechanisms within the country: The main source of financing for the Provincial Councils is through the grants made by the Central Government. In disbursing these funds, the Central Government and Treasury act on the recommendations of the Finance Commission. It must be noted however that the Finance Commission recommendations have to be within the limits indicated by the Treasury. Further, the Provincial Councils have no role to play in the finance allocations but are only passive recipients of the funds doled out. Another criticism of the system is that the funds allocated are insufficient to address the needs of the hospitals.

3.2 National Legislation with regard to HIV/AIDS

There are no laws that specifically deal with HIV/AIDS in Sri Lanka. A notable landmark in the law and policy reaction to HIV/AIDS in Sri Lanka is the Draft Health Care of Public Act (1996) which aimed at establishing an Authority to deal with the issue. The Bill emanated from the Legal and Ethical Affairs Subcommittee of the MOH. The Bill was not passed due to opposition from various quarters.

The Bill, which was never enacted, was subject to much criticism on the grounds that it typified a very narrow approach towards the issue, and made little reference to human rights and ethical concerns that form an integral part of the issue. For example, there was no reference to the dignity of persons living with HIV/AIDS or any provisions to prevent discrimination against such persons. In a manner which some would describe as being characteristic to Sri Lankan legislation, the Bill was heavily focused on establishing a National Authority for the Prevention and Control of AIDS (composed mostly of secretaries to Ministries) and delineating its powers and functions as opposed to addressing some of the more substantive issues. In fairness, it must be noted that the Bill states that one of the responsibilities of the Authority is 'to take effective measures to protect the rights of HIV and AIDS patients and prevent HIV and AIDS and related diseases', though there is no guidance given as to what such measures should be.

It must be noted that MOH officials strongly argue that this was but a preliminary draft and several officials were displeased that it was 'leaked'. However, it has been argued in response that the format of the Bill indicates that the drafting had progressed beyond the preliminary stages. Even if the Bill as was discussed was not the final draft, it portrays the attitude (at least as of that time) of certain sections of the government towards the issue of HIV/AIDS.

The debate on whether there should be a separate law dealing with HIV/AIDS and the rights of PLWHA has been going on for some time. A law with a strong emphasis on the rights of PLWHA, which binds both private and public institutions, would help to a great extent in reducing stigma and discrimination.

However, in order to protect the rights of PLWHA it is extremely important that any legislation on HIV/AIDS be introduced in a transparent and participatory manner. As indicated by several studies[18], due to misinformation and prejudice among sections of society, there is a high level of stigma and discrimination towards PLWHA. Hence if a law is formulated without taking these points into consideration, the resultant law could be discriminatory, depriving the rights of PLWHA instead of protecting them. It is also worth noting that there is no judicial review in the Sri Lankan legal system, making it extremely difficult to amend laws passed by the legislature. In such a context where there is a possibility that misinformation, prejudices and fear among law makers could result in law that is discriminatory, bureaucratic and/or weak. Furthermore, such a law without adequate protection provisions may draw more attention to people living with HIV/AIDS and lead to their further marginalisation.

Sri Lanka does not have cases decided by the national courts that support the rights of PLWHA, nor are there any that deal with issues such as consent, confidentiality, or the right to work. Therefore, we are in a situation where there are no adequate laws to protect the rights of PLWHA, nor judicial activism on the subject. As a result, the general public, health care professionals and officials are largely unaware of the basic rights of PLWHA.

There are several discriminatory laws not specific to HIV/AIDS that undermine efforts to control the spread of the virus. The Penal Code of Sri Lanka[19] continues the 'criminalisation of homosexuality, carnal intercourse against the order of nature and acts of gross indecency'. Penal sanctions against such acts when committed by consenting adults in private cannot be considered reasonable or just in a liberal society. These laws also undermine programs aimed at the prevention of HIV/AIDS and other STIs since they drive marginalized people further underground.

The Vagrants Ordinance[20], which targets "every common prostitute", defines soliciting as a criminal offence. This provision makes it difficult to reach commercial sex workers in order to educate them on HIV/AIDS and other STIs as well as on the importance of practising safe sex. Furthermore, the public and the police often harass the groups mentioned above, making it more difficult for these individuals to seek redress when necessary.

3.3 International Obligations

Sri Lanka is a signatory to many international conventions and treaties specifically related to HIV/AIDS. Most recently the Government of Sri Lanka participated in a SAARC Health Ministers conference in June 2006 in Bangladesh. At this conference a SAARC Regional Strategy was launched which focuses mainly on preparing an action plan on cooperation in medical expertise and pharmaceuticals and producing affordable medicines. It is to be seen how the regional strategy will be implemented in Sri Lanka.

UNGASS implementation

Sri Lanka has yet to follow up on many of the commitments made at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) Declaration of Commitment in 2001. The Declaration recognises the need for an urgent, coordinated and sustained response to HIV/AIDS. Currently there are initiatives by the Government, civil society, the private sector, the donor community and others to achieve UNGASS targets. However, efforts should be made for better co-ordination and sharing of information. UNGASS also recognises that stigma, silence, discrimination, denial, and lack of confidentiality can undermine prevention, care and treatment efforts, and these need to be addressed. Furthermore, there should also be initiatives made for equal access to medication and voluntary testing in all health institutions. There needs to be more work initiated by and involving communities and religious leaders.

Millennium Development Goals

As a country committed to achieving the Millennium Development Goals (MDGs), Sri Lanka must ensure that by 2015, there is a halt to the spread of HIV/AIDS and begin to reverse its spread. A MDG country group, working closely with relevant ministries, government agencies and international and national organisations, is working to ensure that all MDGs are achieved.[21] The Sri Lanka Millennium Development Goals Report 2005 states that Sri Lanka is on track with tackling HIV/AIDS by the year 2015, increasing the present level of 40% condom use among CSW to 80% and the use of condoms by clients of sex workers from 30% to 70% by the year 2015. The Report further identified risk factors such as large numbers of CSWs, large numbers of military personnel, low condom use, high incidence of STDs, external migration, presence of men who have sex with men, beach boys and commercial sex tourism, free trade zone workers and the large youth population. The Report also identifies challenges such as improving prevention programmes targeting vulnerable groups, improving infrastructure in hospitals, the need to have a multi-sectoral approach in tackling HIV/AIDS, encouraging greater participation by CBOs and civil society as well as a stronger political leadership.

3.4 Commitments made by Political Leaders

Former President Chandrika Bandaranaike Kumaranatunge in her 2004 AIDS Day message stressed the importance of working with civil society, the private sector and the international community to improve the situation in Sri Lanka[22] while former Prime Minister and current President Mahinda Rajapakse highlighted the lack of awareness on HIV/AIDS among people and the need for a multi-sectoral response to address the problem in his message on World AIDS day 2004.[23]

Furthermore, the former Prime Minister instituted the ILO code of ethics at the work place to combat HIV/AIDS in July 2004. In his "Mahinda Chinthana" proposals[24] in 2005, he also had a separate section focusing on good health called the "Suva Sevana" programme. This programme contains a component focused on immediate steps to save the "youth" and the "country" from the "serious threat" of HIV/AIDS. Cabinet spokesman and Minister for Health, Nimal Siripala de Silva, stated that more work needs to be done to address the lack of awareness on HIV/AIDS and promised that the government would

initiate programmes to address awareness and other related issues.[25] The present interest in the formulation of a National HIV/AIDS policy is directly related to the interest taken by the present Government.

3.5 National Policies on Health and HIV/AIDS

(A) Health Policy

Until the late 1980s, there was no comprehensive national health policy document, although there were guidelines issued by the Ministry of Health. In 1992, a Presidential Task Force formulated a National Health Policy for the first time. This was not taken forward however due to the change of government, which resulted in new policy documents in 1994 and 1996. A Presidential Task Force on National Health Policy was set up in 1997. The change of government in 2001 again altered the situation. The Poverty Reduction Strategy paper and Vision 2002 also commented on health policy.[26] The Ministry of Health drafted a Health Master Plan, and the first draft was released in November 2003. This was however quickly withdrawn due to criticism that stakeholder participation was minimal. The final document is to date not available to the public. However, through all these changes of government, there were principles common to all the different documents. They were mainly: cost effectiveness, multisectoral co-operation, maximisation of efficiency and quality of service, equitability and accessibility of services in remote areas, respect for the dignity of patients, and the involvement of people in the planning and implementation process.

(B) National HIV/AIDS Policy[27]

Background

Currently, there is no finalised national policy on HIV/AIDS. In October 2005, a draft policy was presented at an NAC meeting and was circulated among a select few for comments. This follows a previous draft policy (Draft 1), circulated in early 2004 among a few individuals and organisations. Though feedback was sent to the subcommittee on legal and ethical issues, there was no final document, which was widely circulated or made public. Further, the Government has not given a time frame as to when the document will be finalised. The MOH convened a meeting with stakeholders in January 2006 to discuss an updated version of the National HIV/AIDS Policy. This version of the draft policy is discussed below. It has been reported that the draft policy discussed below is presently being amended by the MOH and is to be presented to the Parliamentary Advisory Committee for approval before being presented to the Cabinet. The Parliamentary Advisory Committee meets every quarter and the next meeting will be after the ICAAP Conference, at the end of August 2007.

The Draft Policy

The draft policy places a heavy emphasis on medical-science as the primary mode to HIV/AIDS prevention. The rights framework is very weak. This is unfortunate as a rights-based approach would inform and empower individuals in accordance with human rights norms and would therefore be more successful in HIV/AIDS prevention. The policy should also place emphasis on rights of PLWHA and vulnerable groups, women's rights, adolescents' rights and the right to complete information on sex and sexuality for all individuals.

The policy looks at issues such as prevention, monitoring, testing, counselling, care, treatment and the promotion of positive behaviour. However, the policy has left out several issues that should be addressed in a comprehensive and multi-sectoral policy on HIV/AIDS. These include:

- The involvement of PLWHA in the formulation and implementation of the policy
- Confidential reporting of HIV/AIDS in medical terms and in the media
- Recognising and promoting informed consent and counselling with testing
- Promoting safe practices including Universal Precautions (UP) and Post-exposure Prophylaxis (PEP)
- Carrying out programmes on behavioural change and communication
- Including provisions on basic standards for the work place and educational institutions
- Developing care and support for PLWHA

The draft policy has been circulated among certain individuals and organisations for comments. Since the draft policy was only sent to selected persons, many people are unaware that such a policy exists. Health staff across the country must be consulted on any programs, plans and strategies that are formulated, as they are involved in day-to-day procedures and are the most knowledgeable on what is required.

3.6 National Strategic Plan[28]

The National Strategic Plan for Prevention and Control of HIV/AIDS in Sri Lanka for 2007-2011 (Strategic Plan) guides the national response. In the absence of a HIV/AIDS policy, the Strategic Plan provides the framework within which government initiatives are undertaken in the response towards HIV/AIDS.

The goals of the Plan are:

1) To maintain the low HIV prevalence amongst risk groups and the general population
2) To increase the quality of life of those already infected.

Six strategies have been identified in the Plan to achieve the above goals. They are:

1) Increase coverage and quality of prevention interventions
2) Increase coverage and quality of care, support and treatment intervention
3) Improve generation and use of information for planning and policy development
4) Increase involvement of relevant sectors and levels of government in the response
5) More supportive public policy and legal environment for HIV/AIDS control
6) Improve management and coordination of the response

The Strategic Plan has identified the following areas as needing attention-

- Prevention
- Treatment, care and support services for PLWHA and their families
- Work with civil society including NGOs, CBOs, religious groups and the private sector to complement the public sector prevention and care services
- Mainstream HIV response by relevant non health ministries
- Develop a national monitoring and evaluation framework and related activities
- Strengthen the institutional and human capacity of the NSACP
- Develop sectoral policies and laws including sensitisation, capacity building, monitoring and enforcement of such laws and decrees.

Prevention is still the primary focus, yet the present Strategic Plan has taken on board the importance of treatment and care of existing PLWHA.

The Strategic Plan also recognizes the importance in working with non-government actors, religious actors and the private sector. It also mentions working closely with UNAIDS and other UN agencies to mobilise resources and co-ordinate their use. This is evident with the UN Theme Group actively engaging various ministries and organisations in identified areas.

The Strategic Plan has several positive aspects. These are:

- It identifies vulnerable/risk groups such as CSW, Clients of CSW, MSM and drug users. When comparing the Strategic Plan and the draft policy, it seems that the Strategic Plan has a broader approach and identifies both vulnerable groups as well as groups at risk.
- It recognises the importance of a multi sectoral approach, with participation from all stakeholders including PLWHA, CSW, MSM and drug users.
- It includes a component on the respect for human rights including the respect and dignity of sexual and reproductive rights, non discrimination based on gender, disease status, sexual behaviour or sexual orientation, importance of informed consent and confidentiality.
- It has an emphasis on the involvement of communities and PLWHA in the design, implementation and evaluation of services.
- There is identification of communication strategies and media as an effective tool in prevention activities.
- It sets out greater engagement with relevant ministries and departments and local government.

While the Strategic Plan has positive aspects, there are several areas that need consideration. The Strategic Plan has a welcome shift in recognising the importance of a rights based approach but it is to be seen how such a rights framework could be practiced in Sri Lanka with the existence of discriminatory laws and high rates of stigma and discrimination. It is hoped that the government will take the lead in amending discriminatory laws, policies and regulations, working closely with other actors.

Further, while involvement of all relevant governmental actors is vital including local authorities, there needs be clarity in the levels of engagement, facilitating an effective engagement and response. It is also of concern on how such engagement, especially of local authorities, provincial AIDS committees, district AIDS committees and the Colombo Municipal AIDS committee will be funded. As noted in this document, there are several problems in capacity of local actors in the response towards HIV/AIDS. For an effective strategy, involving greater engagement of local actors and relevant ministries, the government must ensure sufficient funds and expertise is available.

National framework:

The lack of a strong HIV/AIDS policy has impeded the response to HIV/AIDS, leaving a vacuum on the policy direction. While the Strategic Plan provides an overall guidance in the response to HIV/AIDS, this is not a policy document but merely sets out goals and strategies of the government towards the response. Therefore it is vital that a policy based on a rights framework is introduced, providing guidance to an effective, targeted and sustained response.

4 Institutional structures in relation to HIV / AIDS in Sri Lanka

4.1 The National AIDS Council

The National AIDS Council is the highest government body in the response to HIV/AIDS in Sri Lanka, and is chaired by the President. The members of the Council include members of relevant ministries. The Council was established to provide the highest leadership to the response. It is perceived by many in the government sector that having the President chairing the Council provides greater space and encouragement for the involvement of non health ministers towards the response. While the Council is expected to provide leadership to the response, it is yet to be seen whether the establishment of the Council has been effective since it has only met once.

4.1 The National AIDS Committee (NAC)

The National AIDS Committee (NAC) co-ordinates activities on HIV/AIDS at the national level and is chaired by the Secretary to the MOH. The NAC is composed of several other ministries including Finance, Education, Justice, Social Services, Labour, Women's Affairs, Tourism, Youth Affairs, Defence and Sport. It also has representation from the Chamber of Commerce, UN Theme Group, Lanka + and a NGO representative. The NAC is meant to meet twice a year.

Decisions by the Council are conveyed to the NAC which is expected to follow up and implement such decisions. The Terms of Reference set out the following functions for the NAC:

- advise the Government on policy regarding the prevention and the control of HIV/AIDS;
- facilitate inter-sectoral co-ordination; monitor the implementation of activities related to the NSACP; and
- bring to the notice of the National Health Council (NHC) difficulties in the implementation of any activities as a result of changes in the prevailing situation.[29]

While the NAC is meant to play a larger role on policy related issues, in practice it has played more of an operational role. It is essential that the NAC takes the responsibility of guiding and monitoring the response to HIV/AIDS rather than getting itself bogged down by operational issues.

The composition of the NAC is also an issue. It is extremely important that the NAC and its subcommittees are representative of all sectors in society, especially PLWHA. Though Lanka+ is a member of the NAC, there needs to be a high level of representation of PLWHA as well as other vulnerable groups such as drug users, men who have sex with men, and migrant workers.

Though collaboration of line ministries and other stakeholders is meant to take place at the NAC, this is not always the case. This is because negotiations at the NAC are limited to the secretaries of the respective ministries, with limited/no involvement of the Ministers. Therefore coordination and interest on HIV/AIDS is most often limited and this needs to be rectified in order to ensure greater participation from the various ministries.

4.3 The National STD and AIDS Control Programme

In 1992, the Government initiated the National STD and AIDS Control Programme (NSACP), which is managed by the Directorate of Health Services in the MOH, and implemented in collaboration with the provincial directors of health services, STD clinics, and the National Blood Transfusion Service (NBTS). The Director of the STD Clinic reports to the Director General of Health Services through the Deputy Director General, Public Health Services. Multilateral and bilateral agencies, such as WHO, UNICEF, and JBIC have provided financial and technical assistance. The IDA has been providing about one million dollars in support annually for the STD control programme through the Health Services Project (1997-2002). This has been used to support capacity building measures at the STD clinics.

The NSACP is responsible for co-ordinating and supporting the national response for prevention and control activities in Sri Lanka. Since its inception, the NSACP has made significant progress in improving STI services by refurbishing health clinics, meeting staffing and equipment needs, and establishing outreach camps. In addition, the programme has helped to ensure blood safety through screening transfusions for HIV and upgrading blood banks. It has also raised the level of awareness and knowledge of HIV/AIDS among the general population.

At present, there are 26 STD district committees and 8 provincial committees. As stated in the Strategic Plan, initiatives are underway to decentralise prevention and control activities to the provincial and district levels.

One of the key problems facing the NSACP is that many STD clinics have inadequate infrastructure, human resources and skilled professionals to manage STDs and HIV/AIDS. For example, in Jaffna there is no doctor trained to deal with STDs and HIV/AIDS. Furthermore, there is no consultant specialising in HIV/AIDS in Kandy, and it is the general practitioners who are treating STD patients.

Even at the Infectious Diseases Hospital (IDH), the lab and X-Ray facilities are inadequate. As a PLWHA stated, "presently, only the Colombo hospital is providing ARV treatment, but it would be very easy if they could provide the medicine in at least two or three more hospitals in the country. Upgrading of the facilities is also essential. Some of the main hospitals such as the IDH do not have all the facilities needed, so we have to go to other hospitals to get our tests done which is very problematic for us"[30]. As a result of the ongoing conflict, the North and East Provinces have been severely affected in terms of health care and infrastructure. There is a dearth of trained health staff based in Jaffna and basic facilities such as adequate testing equipment are lacking with reconstruction and development efforts progressing at a slow pace.

The STD Clinics have not limited their activities to treatment but also include prevention work through raising awareness. Various actors, including the STD Clinic itself and individual health professionals, have carried out awareness programmes. For example, the STD Clinic carried out sensitisation and awareness programmes targeting religious leaders. The National HIV/AIDS Prevention Project (NHAPP) has contracted the creation of media programmes on HIV/AIDS to Young Asia Television, a private media group. These programmes are currently being aired on national television in all three languages.

4.4 Overall response

This section has set out the governmental actors involved in the national response towards HIV/AIDS namely the Council, the NAC and the NSACP. While both the Council and NAC are meant to provide leadership to the response, initiatives and interest by the relevant leaders has been slow and sporadic, resulting in the absence of a strong message by the govern-

ment. It is also noted that NAC, which is meant to be a body deciding on policy is in practice more a forum for operational issues. Such haphazard leadership in policy results in ambiguities and lack of direction. With the development of the NSACP, and interest taken by particular individuals within the MOH and NSACP, the response has improved. While there has been improvement, there is still much more improvement needed in areas including policy direction, increased resources, infrastructure and expertise.

5 Stigma and discrimination

In a study conducted by the Centre for Policy Alternatives (CPA) in 2005, it was found that there were high levels of stigma and discrimination faced by PLWHA due to the lack of knowledge and the misconceptions by people including those involved in the health care, employment and education sectors as well as family and society at large. This section captures several issues highlighting the stigma and discrimination in the specific areas, case studies demonstrating experiences of PLWHA and their family members.[31]

5.1 Health Care

With regards to health care it was found that PLWHA faced many difficulties when obtaining medical treatment. These were identified as:

- Lack of confidentiality
- Lack of informed consent
- Discrimination against the patients and their families by the hospital staff
- Lack of basic services
- Refusal to treat

"This incident occurred in a private hospital. The patient had been tested there since his brother-in-law was employed by the hospital. When the test result returned positive, prior to informing the patient, the doctor had passed the result on to the patient's brother-in-law. Furthermore, the test results had been leaked by the hospital lab, and as a result, the entire hospital staff learnt about it. The patient stated that the immediate family was only notified after everyone in the hospital had already found out. People outside the hospital, such as van drivers parked near the hospital, were told of the case. One such van driver was from the same village as the patient and spread the news of the patient's HIV+ status throughout the village. This led to various acts of discrimination – people wanted them to leave the village, making derogatory comments and informing the child's school, which in turn led to complications at school."

"At a government hospital, a patient was operated on by hospital staff without any testing or consultation with the patient's family. After the operation, the patient's mother had informed the doctor that the patient was HIV+. Though the doctor had behaved respectfully towards the patient and family, the attendants and minor staff had treated both the patient and family badly. The mother of the HIV+ person, when interviewed, stated that the health staff were ignorant of HIV/AIDS and this resulted in stigmatization and discrimination. She went on the mention that the hospital staff had even refused to touch the sheets on the patient's bed."

"A similar case of discrimination occurred at a government hospital, where the patient had given birth. The nurses on duty had refused to touch her sheets and had insisted that the patient change them herself. This was soon after she had given birth and was unable to move from her bed. After the birth, a nurse had put a sign up saying that the patient had an infectious disease. When the people from the village saw it, people made derogatory remarks about her and her family, and her mother had been sent offensive letters. The same patient experienced discrimination at the Lady Ridgeway Children's Hospital in Colombo, where her child was warded. The nurses had not allowed the child to play with other children, claiming that it put the other children at risk for HIV. They had not permitted the patient to use the common bathroom, giving her a separate bathroom and space to wash her clothes."

5.2 Education

Pertaining to stigma discrimination in the sphere of education, it was found that there were very few cases where discrimination had taken place. There was no mistreatment on the part of the educational institutions but objections and discrimination by parents of other students towards children of parents living with HIV/AIDS.

5.3 Employment

The majority of people interviewed during the study were unemployed, and a few were self-employed. It was reported that those who were employed and whose HIV/AIDS status was made known to their employers and co-workers were subject to much discrimination and had to face the lack of regard for confidentiality pertaining to their HIV/AIDS status.

"A qualified computer operator (SF) who was found to be HIV+ was sacked from his post overnight and the reason given was that they just could not employ an infected person in their establishment. He then applied to other organisations and found that every interview he went for he was rejected because his previous employer somehow was keeping track of him and informing every interview panel of his ailment."

5.4 Family Life

(a) Positive Aspects

The majority of interviewees have only shared knowledge of their HIV+ status with their close family: spouses, children, parents or siblings. It is only in a few cases that they have
revealed it to others.

(b) Negative Aspects

There were situations where things turned out more negatively. PLWHAs felt that people were not aware or had little knowledge of HIV/AIDS, and that disclosure would result in stigmatization and discrimination. There were reports of close family members stigmatising and discriminating PLWHA. Until society becomes more aware and accepting of people living with HIV/AIDS, they are unwilling to disclose their status to outsiders.

"A male school teacher, who was married with two children was detected HIV+ at a government hospital following a lengthy period of various sicknesses. Due to his ill health he couldn't continue teaching and resigned prematurely on heath grounds. His family deserted him upon the HIV+ diagnosis. His wife left him taking his children along with her. The little support he got was from his elder brother who kept him in a cow shed away from home fearing that they might contract HIV. He starved as he didn't have any income to buy food and attempts to get away from that place resulted in that he was chained to the shed. The AIDS Coalition when informed of his plight offered to bring him down to Colombo and admit him to the IDH. His relatives and he himself refused saying it will be difficult for them to visit Colombo on a regular basis. He was provided with financial assistance to purchase food items and clothing. In 2004 he died exposed to the monsoon rains in his cowshed, ravaged by opportunistic infections."

5.5 Housing

Not many PLWHAs experience stigma and discrimination with regards to housing although there have been reported instances when villagers had set fire to their houses or made living in the village impossible for them.

"In 2001, after the village found out the HIV status of the husband, the wife and the children were ridiculed and tormented to an extent that they (school going teenagers) had to stop their schooling. The wife was given poison into her hand in order to give it to her husband and put an end to his life. After this whole ordeal, the husband could not deal with the suffering that the family was going through and committed suicide. After the husband's death, while the wife and the two children were sleeping, the villagers set fire to the house. But the family managed to run to safety. Since then they have not visited their home."

5.6 Social Life

Due to ignorance and fear, people living with HIV/AIDS and their families are often treated with insensitivity and cruelty. Lack of awareness on what HIV/AIDS is and how it can be transmitted has left many people with misconceptions about the disease. Fear and ignorance can lead to various discriminatory practices, which sometimes turn violent.

6 Access to medication and treatment

There is clear recognition today that all persons infected with HIV/AIDS should receive treatment as part of programmes to control the disease, and further that preventive measure and ART cannot be separated.[32] The U.N. General Assembly has encouraged states to acknowledge that the "prevention, care, support, and treatment for those infected and affected by HIV/AIDS are mutually reinforcing elements of an effective response and must be integrated in a comprehensive approach to combat the epidemic".[33] Nevertheless, the issue is one that gives rise to debate, particularly given the cost of ARV therapy in a developing country context.

In the Sri Lankan situation, the issue of treatment was brought to the fore during discussions on World Bank funding for the Sri Lankan NHAPP in 2002. Initially, the grant focused only on prevention and outreach activities, though the appraisal document did note that prevention and treatment were not mutually exclusive but considered it more cost efficient to emphasize the former over the latter.

In response to this allocation of funds, the AIDS Coalition, headed by Dr. Kamalika Abeyaratne and assisted by three law clinics at the University of California, Berkeley prepared a memorandum[34] addressed to the World Bank and the Government of Sri Lanka requesting that the grant include financing for treatment.[35] The document also appealed to the government on moral grounds (the daily deaths attributed to lack of access to medication) and practical grounds (an AIDS epidemic would threaten not only the health of the Sri Lankan population but the country's economic health as well).[36]

The AIDS Coalition and CPA, using the memorandum successfully lobbied the World Bank to allocate funds for treatment.[37] Eventually, a compromised was reached and presently the NHAPP allocates US $ 1 million for treatment and US $ 11 million for prevention activities). Provision is made for 100 recipients to receive ARV treatment at no cost as discussed below. As noted below, there are several practical aspects that need to be considered in the provision of free ARVs. These include free ARVs only being provided in Colombo, making it difficult for many to access it and prevalence of stigma and discrimination limiting many from coming forward.[38]

7 Initiatives by Other Actors in relation to HIV/AIDS in Sri Lanka

This section looks at initiatives by civil society, private sector, media, international organisations and donors. While it captures several initiatives conducted by key actors it is not an exhaustive list and is only an indicator of some of the activities in the response towards HIV/AIDS.

7.1 The Role of Civil Society & NGOs

Many civil society organizations such as the AIDS Coalition, Companions on a Journey, Lanka +, Salvation Army, Sarvodaya, Alliance Lanka, SCDF, Migrant Services Centre and TRRO have conducted effective awareness and sensitisation programmes throughout the country.

Civil society initiatives remain largely uncoordinated. Certain key actions need to be taken in order to increase the capacities of NGOs to work with vulnerable groups and of the government to systematically contract and fund NGOs.

Organisations such as Nest, Salvation Army, Lanka +, Companions on a Journey and YMCA have programmes for care and support such as providing hospice services, counselling, assisting in obtaining medicine and dry rations, and providing financial support. People from a cross section of society and from across Sri Lanka are being cared for & supported by these organisations. However, many of the organisations providing care and support services are solely funded by private donors. It is also notable that many people in rural areas have difficulty in accessing such care. For example, there are few care and support services in the conflict-affected North and East of Sri Lanka. Many organisations could travel to areas outside Colombo to provide care and support if not for funding constraints. While the work done by these organisations are commendable, filling a vacuum that is essential in the response to HIV/AIDS, several of these organisations lack the capacity in planning and monitoring their programmes to ensure the services are sustainable and have the necessary funding. There needs to be more attention by the government and the donors in building the capacity of local NGOs and providing them necessary training and expertise in making programmes in prevention, care and support more effective, targeted and sustainable.

Civil society actors have also collaborated with leaders in others areas. For example, Sarvodaya took the initiative to sensitise religious leaders with regards to HIV/AIDS. One such programme was mobilizing Buddhist leadership towards Aids prevention at the community level and as part of it, increasing community awareness on HIV/AIDS. While such initiatives are underway, very few documents are available on the involvement of religious leaders in the response towards HIV/AIDS.

7.2 Role of the Private Sector

There has been growing activity among the private sector on HIV/AIDS related issues. Awareness and sensitisation initiatives have increased where sectors such as health care, employment, and the armed forces are being targeted. Several awareness programmes have been conducted in the workplace under the leadership of the Chamber of Commerce, John Keells Group, Unilever and other companies. However there needs to be more participation from the private sector with regard to prevention and awareness raising activities.

7.3 Role of the Media

The media needs to play a more proactive role in the response towards HIV/AIDS, namely by accurate and informed portrayal of the true facts and increased and consistent reporting. There have been instances where the media has portrayed HIV/AIDS in advertisements and pictures in a very negative light. Such actions have created fear and even traumatised PLWHA and their families. This was especially true of an advertisement for AIDS Day – it was a half page print advertisement depicting a body being prepared after death. Other advertisements have used fear-generating phrases such as 'AIDS Kills'.

A striking example of negative reporting is an article carried in the Sinhala language independent newspaper 'Ravaya' in February of 1995 which reported an operation carried out on an AIDS patient at the Colombo General Hospital. The newspaper alleged that the patient had bribed the doctors to carry out the operation, thereby creating the impression that AIDS patients had no right to medical treatment.

Confidentiality has also been an issue in media coverage. As highlighted in a CPA study,[39] an organisation working on HIV issues spoke of a newspaper article on the death of a child as a result of AIDS. The article had given details of the occupation of both parents, the part of the country they resided in, the previous death of their first child, and the subsequent death of the second child. From the information provided, people in the area where the family lived were able to identify them. It is important that articles in the media are sensitive to issues of anonymity concerning people living with HIV and their families.

Studies carried out among media personnel as recently as in 2000 indicate that there is still considerable levels of prejudice against and lack of proper awareness on HIV/AIDS[40]. According to this study, which was carried out among personnel reporting on health issues in the print and electronic media in Colombo, upon aggregation only 27% were found to have a good knowledge on HIV/AIDS. 41% of the group studied was of the opinion that HIV positive persons are a threat to society. It is also noteworthy that majority of the reporting has been in English media, with much more report and awareness raising needing to take place in the Sinhala and Tamil media. Several initiatives to raise awareness among Sri Lankan media personnel have been undertaken by organisations including UNAIDS[41] and Panos.[42]

7.4 Initiatives by International Organisations and Donors

A) Initiatives by the World Bank

The World Bank is the major donor to the HIV/AIDS Prevention and Control Programme 2002-2006, funding the NHAPP as well as the other programmes within the MOH.

The National HIV/AIDS Prevention Project (NHAPP): This project is financed by a World Bank grant and was set up to initiate a variety of prevention programmes.[43] Its responsibilities include liaising with provincial and district health authorities and setting up multi-sectoral responses by working with various actors.[44]

Awareness raising & Prevention Activities: The primary focus of the NHAPP is prevention. Several initiatives encompass this aspect of the NHAPP. These are:

a) The NHAPP supports NGOs/CBOs already working on HIV/AIDS issues with the general population and vulnerable groups, and it aims to improve information and knowledge exchange between these organisations. These projects are targeted at behavioural change such as encouraging the use of condoms. An obstacle faced by NGOs in dealing with such projects is that many lack capacity in handling large project including putting together proposals within the requirements of the NHAPP and having the adequate capacity to report, monitor and evaluate ptojects. Further, the government is responsible for the running of the NHAPP and therefore many of the local NGOs and CBOs that are doing a lot of good work may be excluded from collaboration due to various issues such as the approach taken by the NGO or personality issues.

While the World Bank funding has strengthened the response to HIV/AIDS, much more needs to be done. As noted previously, funding is through the MOH, and as a result may exclude other actors involved in HIV/AIDS work, especially entities working in rural areas. The existing bureaucracy in the government structure can also prevent the process from being efficient and inclusive.

b) Another aspect within the World Bank project is the media campaign to raise awareness on HIV/AIDS. YA TV, a private TV production house, has undertaken this component, which has conducted interviews, discussions and documentaries on HIV/AIDS in Sri Lanka, carried out in all three languages. While this is a positive step, there should also be initiatives encouraging more radio programmes and articles in newspapers and magazines.

c) The World Bank project has also revived the provincial and district committees. This has resulted in more programmes managed from the provincial and district committee level, resulting in some decentralization. Though this is a positive step, the project is still very centralized with the MOH having a large say in how project implementation takes place.

ARV Treatment Component: Under this grant, there is provision for 100 recipients to receive free ARVs.

The present guidelines followed by the STD Clinic for the provision of ARVs stem from a “Guide to Anti-Retroviral Therapy” by the MOH and World Bank issued in January 2005. According to the guidelines used by the STD Clinic, advice and counselling is provided prior to ARV treatment. At present health professionals at the STD Clinics follow these guidelines, though it remains to be seen whether they will be adhered to when the programme is expanded geographically.

One of the main problems encountered by the ARV treatment programme is that many PLWHA are reluctant to come forward to receive treatment. Stigma and discrimination against PLWHA is very high in Sri Lanka, and fears of being ostracised force affluent PLWHA to access treatment outside the country. Furthermore, since free ARVs are provided only by a few STD clinics, particularly in Colombo, Kolubowila and Kandy many have difficulty in gaining access.

The sustainability of the ARV programme also needs to be considered. The World Bank grant is for a period of 5 years and ends this year. Hence the authorities need to consider options for the future in order to ensure the continued provision of free or subsidised drugs. It is also important to ensure access to affordable short-term ARV prophylaxis for people who have experienced exposure to HIV such as health care workers and home based care providers, as well as victims of rape.

Focus on other aspects: The NHAPP contains a component to strengthen the National Tuberculosis and Respiratory Disease Control Programme (NTP). The country's vulnerability to an HIV epidemic has heightened concerns over a resurgence of Tuberculosis (TB). TB is the principal killer of HIV-infected persons worldwide. Though there is no evidence that HIV-associated TB is yet a problem in Sri Lanka, the deterioration of the national TB programme due to insufficient resources and support, together with the emergence of HIV, could effect a dramatic change in this situation. A grant from GFATM would primarily support enhanced social mobilisation and outreach functions through NGOs, which have not been involved previously in TB efforts.

Another project working closely with the NHAPP is the National Blood Transfusion Service (NBTS), which aims to improve the blood bank infrastructure and screening for HIV.

While several gaps have been listed above, a significant aspect that is lacking in the World Bank project is that it does not contain space to address the needs of the IDH. With the initiatives underway at the IDH, with special care available to patients, it is unclear as to why there were no funds allocated for improving infrastructure and training staff. Presently the IDH has limited space for PLWHA and therefore it has been recommended that it have a separate building that will solely focus on and care for the needs of PLWHA. It is also notable that ARVs are not available at the IDH. Measures should be taken to ensure that patients at the IDH need not travel to Colombo to receive ARVs but can obtain them at the IDH.

B) Efforts undertaken by the UN Theme Group pertaining to HIV/AIDS

The UN Theme Group on HIV/AIDS is active in various spheres, working with local actors to address various issues related to HIV/AIDS.

- **UN Programme on HIV/AIDS (UNAIDS)**, the lead UN agency on HIV/AIDS, has been working in Sri Lanka since 1998, partnering with UN agencies to address HIV/AIDS. Therefore, UN agency heads decide on funding and spending and the working group, consisting of technical people from all agencies draft the proposals and follow through with the work. The UN strategic plan sets out the overall framework and activities of the UN agencies in Sri Lanka.
- **United Nations High Commissioner for Refugees (UNHCR)** deals with issues related to displaced communities in the North East.
- **International Organization for Migration (IOM)** deals with issues related to tsunami-affected communities.
- **World Health Organization (WHO**) provides technical support on epidemic surveillance and estimation to the NSACP, and is also involved in the strengthening of counselling and testing and has collaborated with UNFPA in capacity building of medical practitioners.
- **United Nations Population Fund (UNFPA)** primarily focuses on providing information and services to vulnerable groups and in under-served geographic areas. It also supports women's clinics providing training and counselling. Further, it also aims at providing technical assistance for the formulation of national strategy for adolescent sexual and reproductive health.
- **United Nations Children's Fund (UNICEF)** is yet another actor in the UN Theme Group, which has done a lot of work on HIV/AIDS, issues. UNICEF has funded government projects targeting children and adolescents, working closely with the Department of Education, Youth Services Council as well as non-governmental organisations. UNICEF working with UNIFEM has initiated a program on raising awareness in relation to reproductive health and HIV/AIDS.
- **The International Labour Organisation (ILO)** has been actively involved in HIV/AIDS and related issues. The most recent work of the ILO is the signing of the National Tripartite Declaration on Prevention of HIV/AIDS at workplaces in Sri Lanka both within and outside the formal and informal sectors.

Future programmes on HIV/AIDS should be the responsibility of the Government, working closely with all other stakeholders, ensuring better coordination and information sharing. This will avoid duplication of effort and ensure maximum results. Though the UN agencies are involved in several areas related to HIV/AIDS, there are several activities that need further attention such as more targeted interventions with groups perceived to be vulnerable to HIV/AIDS as well as more work with government actors, including provincial and district officers and with local actors including NGOs and CBOs.

Further, the UN agencies should take a stronger stand on policy initiatives. For example, there needs to be more involvement of all stakeholders in the formulation of the draft HIV/AIDS policy, especially PLWHA and vulnerable groups. There should also be a coordinated effort by all line ministries, ensuring that the draft policy is multi-dimensional. In this regard, the various UN agencies can work with the respective line ministries, ensuring active participation. For example, the ILO should ensure

the active participation of the Ministry of Labour in this initiative. Similarly, since the various UN agencies already have an existing relationship with the various ministries, they should actively pursue encouraging ministries and government offices to formulate and implement action plans regarding HIV/AIDS. The same encouragement should be offered to the private sector and other entities that require action plans in their activities. Such action plans should be supported by the UN agencies, by providing financial and technical assistance, since they have been working in the respective areas and have the requisite knowledge and expertise.

C) Initiatives by Other Actors

USAID initiated a 5 year plan on prevention, focusing on several risk groups. The project is largely focused on outreach activities, working with local NGOs on topics including VCT, condom promotion, communications and providing technical assistance and capacity building

Action Aid initiated a project on HIV/AIDS in February 2005, largely focusing on capacity building and behavioural changes. Action Aid works in collaboration with local NGOs, attempting to empower PLWHA and providing assistance to NGOs working with PLWHA. For example, LANKA + have been provided with assistance for office maintenance and capacity building.

The Asia Pacific Leadership Forum (APLF) initiated leadership in HIV/AIDS activities. Several activities have been commissioned by APLF such as high-level leadership initiatives and media programmes using popular personalities.

Save the Children focuses their work on child related issues. They were in the process of initiating programmes on the risk behaviour of children and young persons, stigma and discrimination associated with HIV/AIDS, monitoring and evaluation, and surveillance systems improvement.

There are several international organizations that work through their partner organizations.

The Canadian International Development Agency (CIDA) has projects on gender issues such as gender based violence and runs programs targeting groups such as migrant workers, prisoners and commercial sex workers. Most were awareness raising programmes including training on STDs and condom use.

The European Commission in Sri Lanka is not directly involved in HIV/AIDS projects but is involved in reproductive and sexual health projects which are implemented by partner organizations

The Japan International Cooperation Agency (JICA) and **the Japan Bank for International Cooperation (JBIC)** work with the government by providing soft loans targeting mainly infrastructure projects and providing assistance in drafting the Master Plan document as well as providing assistance on improving the Blood bank.

Gaps in Interventions by International Actors:

Coordination among international actors, local actors and government actors must be strengthened to ensure an efficient response. With the increasing number of projects and actors involved in HIV/AIDS, a comprehensive mapping exercise should be undertaken to obtain a clear picture as to who is involved and what activities are underway, what is yet to commence and what has been completed. This would give a clear idea of the activities related to HIV/AIDS, the actors and the geographic areas covered, and assist in reducing duplication of work.

As pointed out previously, organizations may only concentrate on geographic areas that they are working in or had a prior presence in, and may avoid working in certain geographic areas that are in need of HIV/AIDS activities. International organizations should ensure that *interventions take place depending on need and urgency.* Lack of field presence should not be the determining factor on whether to get involved or not. Partnerships with local actors

including government officials, NGOs and CBOs should ensure that activities on the ground are undertaken by the local actors who know of local issues and already have a relationship with the community. Such measures would reduce the need to establish large field offices and at the same will build the capacity of local actors.

Funding and technical assistance should not solely target prevention activities, but should also improve treatment, care and support. Certain agencies are experiencing financial constraints or limitations resulting in shrinking projects. For example, due to UNHCR shrinking their projects and moving to more emergency work, development issues are handed over to other actors such as UNICEF. In such instances, measures must be in place ensuring that the new actor takes on all areas covered and that certain aspects are not abandoned.

The International Conference on AIDS in Asia and the Pacific (ICAAP)

Sri Lanka is hosting the ICAAP in August 2007 and as a result there is an increase in the focus on HIV/AIDS activities. Many are focusing on the ICAAP event in order to ensure that it is a success with several projects planned around the same time. While acknowledging that such an international event can be beneficial in addressing HIV/AIDS issues in Sri Lanka, attention must also be paid to the process of handling the issue and raising awareness among the public on HIV/AIDS. While many are getting involved in the event itself, there should also be attention to what will happen subsequent to the ICAAP. It is vital that all the actors who are involved in the conference are encouraged to sustain their efforts and ensure continued work in HIV/AIDS activities. All stakeholders should also keep in mind that other events may receive greater attention and thereby diverting funds year marked for HIV/AIDS work. For example, large amounts of money were spent on the relief and rehabilitation work following the tsunami disaster in December 2004, resulting in less funding and attention being given to the response towards HIV/AIDS. The interest and attention generated in August 2007, needs to be sustained by all stakeholders, keeping the response targeted and effective.

8 Conclusion

The increasing attention on HIV/AIDS in Sri Lanka has resulted in the influx of more resources towards a more targeted response. While several positive changes have taken place in the last few years, there is much more that needs to be done both at the policy level and in practice. There have been encouraging signs from the political leadership in relation to HIV/AIDS, but statements must be converted into concrete measures. Discussions and meetings need to materialise into strong policies and plans. Attention and funds generated through international conferences need to be best utilised in raising awareness and the profile of HIV/AIDS, removing myths and misconceptions and reducing stigma and discrimination. Interest generated through international conferences need to be sustained, ensuring that the response does not revolve around a particular event but is well planned, sustained, effective and targeted.

A significant issue that needs to be addressed is the treatment of HIV/AIDS as a health issue and not as a development issue having socio-economic and cultural implications. Such a perspective limits the scope of the response by excluding key actors that should be involved in the process. Consequently the response is one sided and not as effective as it could be. Sri Lanka needs to progress from previous held views, recognising the debilitating impact HIV/AIDS can have on its population; increased numbers of PLWHA having a strain on the income of their families and severely affecting livelihoods, creating problems within and among families and communities. Loss of livelihood, homes, educational opportunities, families and social network negatively affect people and adversely impact economic growth and development.

In addition very little attention is given to a rights based framework in relation to the HIV/AIDS response, raising issues including the rights and dignity of PLWHA and their families, informed consent, confidentiality, participation and inclusiveness in decision making. For an effective response, it is crucial to have a rights based approach coupled with good governance principles ensuring the decentralisation of health care and decision making in relation to the response.

Due to the low prevalence in Sri Lanka, the response has been dominated by initiatives on prevention rather than treatment, care and support. While there is a need for prevention activities and curbing the spread of HIV/AIDS, this should not result in side lining the importance of treatment, care and support. With HIV/AIDS estimated cases numbering at 5000, with vulnerability factors pointing to a possible outbreak, the government and others should take steps to strengthen treatment, care and support activities. The situation of PLWHA and their families should also be considered in the development and improvement of treatment, care and support services.

Laws and Policies

There is a limited framework of laws and policies in relation to HIV/AIDS in Sri Lanka. While laws respecting and protecting the rights of PLWHA and vulnerable communities are needed, it is questionable whether Sri Lanka with its high levels of stigma and discrimination, misconceptions and prejudices is prepared to legislate on such a sensitive subject. Being cognizant of the draft policy and the debates surrounding it (evidence demonstrating the heavy reliance on the medical science approach over a rights framework,) goes to show the thinking behind the response towards HIV/AIDS. Though the Strategic Plan strives to address certain human rights and governance issues, and is an improvement on previous Strategic Plans, policies and regulations, there is still concern regarding the process of formulation and implementation of the Strategic

Plan. Further, while the Strategic Plan incorporates several improvements in relation to human rights and governance, the overall response towards HIV/AIDS is still very much centralised and top heavy, with many still considering it a health issue rather than a development issue.

Institutional Framework

There are several structures in place in the response to HIV/AIDS, the highest having the presence of key leaders including the President of Sri Lanka. While there are prominent leaders supposedly involved in the response, it has been slow, lethargic and to some extent ineffective. It is to be questioned whether the response towards HIV/AIDS by politicians is only motivated by international attention, conferences such as ICAAP and media blitz. A good example is the role of the National AIDs Council chaired by the President of Sri Lanka and the NAC chaired by the Secretary of Health, both which are yet to play an active role in the response towards HIV/AIDS. Without strong political leadership which is sustainable beyond the ICAAP, institutional structures in the response to HIV/AIDS is plagued with bureaucracy, inefficiency and lack of direction. While this paper recognises the positive role played by particular individuals in the MOH and NSACP in the response towards HIV/AIDS, the government of Sri Lanka and its leaders need to take a strong, consistent and enduring proactive stand in the response towards HIV/AIDS.

Stigma and Discrimination

The level of stigma and discrimination and its existence in the different spheres captured in the document is only an indicator and not exhaustive of the situation in Sri Lanka. While no comprehensive documentation has been done to study the sources and levels of stigma and discrimination, the issues captured demonstrates certain trends in the society at large such as a lack of awareness of what HIV/AIDS actually is, methods of contracting, rights of PLWHA and their families, misconceptions, prejudices and fears. Issues such as the absence of rights based legislation and policies, existing discriminatory laws, policies and regulations that marginalise PLWHA and vulnerable communities, centralised planning, inadequate resources, infrastructure and trained staff and other issues all add up to exacerbate the situation, drawing a negative picture on HIV/AIDS, PLWHA and vulnerable communities. Reducing stigma and discrimination, coupled with raising awareness on HIV/AIDS and its profile, is important for an effective response. In this respect, the leadership needs to be from the government of Sri Lanka, through the National AIDS Council and NAC, working closely with the relevant government officers, I/NGOs, private sector, media and other relevant actors.

Access to Medication and Treatment

The process in which free ARVs were obtained demonstrates the increased bureaucracy within the system. The bureaucracy coupled with lack of coordination and poor information flow among relevant government actors as well as the possibility of a lack of understanding of issues related to HIV/AIDS, all add up to a system which is weighted down with too many actors, procedures and plans, and which easily forgets the human element in the response to HIV/AIDS.

Access to medication is an inherent right of people. This does not and should not change in relation to HIV/AIDS. All PLWHA should have access to free ARVs. The present system, while providing ARVs to 100 is not resourced to address the needs of all PLWHA in Sri Lanka. In addition, practical difficulties and stigma and discrimination impede many others from coming forward to access free treatment. In a country that boasts of free public health care, effort should be made to address this situation speedily, ensuring that PLWHA across the country have easy access to quality treatment. In such a context, effective decetralisation needs to take place ensuring availability of resources, infrastructure and trained staff in all STD clinics

across Sri Lanka. The provision of medication and treatment must be planned in close coordination with prevention responses including awareness raising campaigns that aim to reduce levels of stigma and discrimination.

Initiatives by Non Governmental Actors

Glancing at the initiatives underway, and the numerous actors involved, it is evident that non governmental actors play a large role in the response to HIV/AIDS in Sri Lanka. While there are several government actors listed, with leadership provided by the President of Sri Lanka, it is evident that there is a dependency on non governmental actors to step in, providing resources, infrastructure, expertise, knowledge and care. This could also be due to the bureaucracy, delays and other impediments within the government system. As highlighted in this section, while non governmental actors can play and continue to play an active and much needed role, this should not leave space for the government to shirk its duty of being the primary actor in the response towards HIV/AIDS.

It must also be noted, that non governmental actors are not free of blame. As noted above, much more needs to be done to make the response effective, targeted and timely. Leadership must be demonstrated from the specific sectoral leaders, taking the initiative to introduce and sustain activities in the response towards HIV/AIDS. Coordination and better information flow within and between the specific sectors needs to be improved, with better planning in prevention, treatment and care programmes, thereby avoiding duplication of efforts.

The various actors involved in the response can also play a pivotal role in projecting the true facts on HIV/AIDS, raising awareness levels and reducing stigma and discrimination. They can also exert pressure on the government to formulate and implement rights based legislation and policies in a transparent and participatory manner and to amend discriminatory laws and policies that infringe the rights of PLWHA and vulnerable groups. Leaders in the specific categories mentioned in this section can play a pivotal role in the response towards HIV/AIDS, actively promoting a rights based approach that recognise, respect and protect the rights of PLWHA and vulnerable groups, and through their leadership dispelling myths and misconceptions related to HIV/AIDS.

9 Recommendations

1. Formulating a National HIV/AIDS Policy

- A National HIV/AIDS Policy, which is comprehensive and multi-sectoral, needs to be formulated.
- The policy should have a strong rights framework, ensuring participation, transparency, inclusiveness in the formulation process.
- The policy should recognise, respect and protect the rights of PLWHA and vulnerable groups.
- The policy should include a component on sensitive media reporting, and provide for a monitoring body to ensure compliance.
- The policy should state the negative implications of mandatory testing and reiterate the importance of informed voluntary testing, involving pre- and post-test counselling.
- The policy should advocate behavioural change programmes and communication programmes specifically targeting people in situations of risk as well as include standards for the work place and educational institutions.
- The policy should include a component on building and strengthening family and community capacity to provide a supportive environment for PLWHA.

2. Legislation in relation to HIV/AIDS

- In the event legislation in relation to HIV/AIDS is introduced, the legislation should have a strong rights framework, formulated in consultation with all relevant stakeholders including PLWHA and vulnerable groups.
- Legislation in relation to HIV/AIDS should recognise, respect and protect the rights of PLWHA and vulnerable groups.
- Amend discriminatory laws such as the Penal Code and Vagrants Ordinance.

3. Issues associated with the Strategic Plan

- Implementation of the Strategic Plan should be multisectoral and with the involvement of PLWHA.
- The Strategic Plan should strengthen and involve regional STD Clinics and other entities.
- The Strategic Plan should ensure there is an effective media and communication strategy in place.

4. Proactive leadership

- The National AIDS Council and the NAC need to be strong and proactive in the HIV/AIDS response.
- Policy decisions and direction on the HIV/AIDS response need to be made at the Council and the NAC and communicated to the NSACP and local actors.
- There should be a coordinated and concerted effort by all political, religious, private sector, youth, women and community leaders in the response towards HIV/AIDS.

5. Strengthening of the NSACP

- All STD Clinics should have trained staff who are educated and sensitised on STDs and HIV/AIDS. Specialized staff should be available to provide information on ARV treatment, treatment for STDs and opportunistic infections.
- All STD Clinics and the IDH should have all necessary resources and infrastructure which is provided primarily by the government.

6. Prevention Activities

- There should be coordinated efforts to raise awareness on HIV/AIDS, which can reduce the stigma and discrimination.
- There should be programmes to increase awareness of precautionary steps and reduce high-risk behaviour.
- Prevention initiatives should be coordinated and led by Government bodies with the assistance of international agencies, NGOs, CBOs, the private sector and the media.
- Prevention initiatives should involve PLWHA, marginalised and vulnerable groups, ensuring inclusivity and diversity, while at the same time empowering these groups.
- Prevention initiatives should take place in all geographic areas, both urban and rural. Special consideration should be given to areas where there are high levels of high-risk behaviour/groups in situations of risk.

7. Treatment, care and support

- The Government must ensure that access to medication and health care is available to all.
- Resources and attention towards treatment, care and support should increase in both government and non government programmes.
- The Government should provide free ARTs to all PLWHA.
- Access to ARTs should extend beyond a few STD Clinic in urban areas and expand to other areas.
- Health staff working in all STD Clinics should be trained in providing ARVs.
- Treatment for opportunistic infections should also be available to all in all health institutions.
- The MOH should ensure that all health institutions practice Universal Precautions (UP) and Post-exposure Prophylaxis (PEP).

- Pre-test and post-test counselling must be made available to all taking an HIV test. The MOH should ensure that pre-test and post-test counselling is a policy that is adhered to by all health institutions.
- There should be increased assistance and resources in developing and sustaining community care and support initiatives.

8. Initiatives by Non Governmental Actors

- Leaders in the respective fields should play a proactive role in raising awareness and the profile of HIV/AIDS.
- There should be organizational capacity building, training and financial resources provided to organizations working on HIV/AIDS and related matters. Attention should be given to organizations providing hospice and community based care, as there are a limited number of such organizations.
- There should be better coordination among the various organizations as well as with the Government, international actors and the private sector should be encouraged and facilitated.
- There needs to be sensitive reporting of HIV/AIDS and related stories. All stakeholders must ensure that there is training of journalists, editors and media personnel on methods of reporting a HIV/AIDS story.

Endnotes

[1]Sexually Transmitted Diseases (STD) Clinic in Sri Lanka,

[2] Dr. Samarakoon, Current HIV/AIDS situation in Sri Lanka and its impact on the world of work, 2005

[3] Ibid.

[4] Ibid.

[5]Ibid.

[6] Ibid.

[7] Ibid.

[8] Ibid.

[9] HIV/AIDS in Sri Lanka, The World Bank, June 2005

[10] One such organization, the Community Strength Development Foundation (CSDF), has access to commercial sex workers and conducts awareness programmes on a regular basis.

[11] Sri Lanka Country Report on Follow Up to the Declaration On Commitment on HIV/AIDS (UNGASS), Ministry of Health, December 2005

[12] Ibid.

[13] National Survey on Emerging Issues Among Adolescents in Sri Lanka, UNICEF 2004

[14] National Strategic Plan for Prevention and Control of HIV/AIDS in Sri Lanka 2002-2006

[15] Ibid.

[16] For more information on laws and policies please refer to the draft paper "A Critique on Policy Interventions on HIV/AIDS in Sri Lanka" prepared by Bhavani Fonseka, CPA to be presented on 16th August 2007.

[17] Further, the draft policy includes a section under the subheading "Medical Treatment" which states that there is a right of PLWHA to have access to treatment without any discrimination (refer to Draft Policy). The Strategic Plan includes a component on care and support which deals with treatment, care, counselling and personal support (refer to Strategic Plan).

[18] A Profile of the Stigma and Discrimination faced by People Living with HIV/AIDS, CPA 2005

[19] Amendment Act No. 29 of 1998, Section 365A

[20] No. 2 of 1978, section 3(1)(b)

[21] See http://www.mdg.lk as at January 2006

[22] Daily News, 1st December 2004

[23] Daily News, 1st December 2004

[24] Proposals which were used at the Presidential elections, and which introduce the policies of the Presidential candidate. These proposals are used as guiding principles by the present government.

[25] Speech made at the National Consultation on HIV/AIDS and Human Rights, 2nd December 2004.

[26] The Poverty Reduction Strategy paper and Vision 2002 is a policy paper introduced by the then UNP government with the objective of restoring economic growth and eliminating poverty in Sri Lanka.

[27] For more information on laws and policies please refer to the draft paper "A Critique on Policy Interventions on HIV/AIDS in Sri Lanka" prepared by Bhavani Fonseka, CPA to be presented on 16th August 2007.

[28] For more information on laws and policies please refer to the draft paper "A Critique on Policy Interventions on HIV/AIDS in Sri Lanka" prepared by Bhavani Fonseka, CPA to be presented on 16th August 2007.

[29] Sri Lanka Country Report on Follow Up to the Declaration On Commitment on HIV/AIDS (UNGASS), Ministry of Health, December 2005

[30] Draft paper "A Critique on Policy Interventions on HIV/AIDS in Sri Lanka" prepared by Bhavani Fonseka, CPA to be presented on 16th August 2007.

[31] More information on Stigma and Discrimination faced by PLWHA and their families in Sri Lanka can be accessed in "A Profile of the Stigma and Discrimination faced by People Living with HIV/AIDS" CPA, 2005.

[32] www.unaids.org

[33] U.N. GAOR, Special Session on HIV/AIDS, Declaration of Commitment on HIV/AIDS: Global Crisis—Global Action, U.N. Doc. S-26/2 (2001), para. 17

[34] Memorandum addressing the need for a treatment agenda to be included in the proposed World Bank financed Sri Lanka National AIDS Prevention Project, available at www.samuelsclinic.org

[35] The memorandum suggested methods to address the lack of access to HIV medications, including negotiating with drug manufacturers for reasonable prices for AIDS drugs.

[36] Attention was drawn to the Brazilian Experience, where in 1996 a policy to provide universal free access to ARV therapy has resulted in improved and longer lives for all persons living with HIV. The report notes that since the introduction of ARV therapy, Brazil had achieved a 50% reduction in the number of AIDS deaths and a 60%-80% reduction in the incidence of opportunistic infections among HIV infected patients.

[37] The MOH declined to utilize the funds because it believed that such a program would not be sustainable once the grant period is complete. Nevertheless, the Ministry representatives indicated that they will be prepared to accept aid for the cost of ARV treatment if the MOH Budget includes a line item specific for the provision of drugs for HIV. However, this suggestion was rejected by the Treasury, Dr. Kamalika Abeyratne, Drug Access for Persons Infected with HIV, loose-leaf

[38] Please refer to page 23 for more information.

[39] A Profile of the Stigma and Discrimination faced by People Living with HIV/AIDS, CPA 2005

40 A study on HIV/AIDS among media personnel for the first time in Sri Lanka, Samarakoon S, Batuwantudawa R. Int Conf AIDS. 2002 Jul 7-12; 14: abstract no. TuPeE5099. Sri Lanka Public Health Women's Network, Colombo, Sri Lanka. Available at http://gateway.nlm.nih.gov/MeetingAbstracts/102253746.html

[41] http://www.unaids.org/en/MediaCentre/PressMaterials/FeatureStory/20060731-srilanka.asp

[42] http://www.panossouthasia.org/Left_read.asp?LeftStoryId=104&leftSectionId=1

[43] This programme has three main strategies. The first is the high–risk population strategy, which focuses on identifying vulnerable groups with the assistance of organisations working on HIV/AIDS issues. The second strategy, the general population strategy, aims to address stigma and discrimination through actors in the government sector. These include the MOH, Youth Services Ministry, SLBFE and other government ministries and District and Provincial AIDS Committees. The strategy also focuses on the promotion of blood safety through the National Blood Donation Programme. The third strategy, which deals with care and treatment, focuses on providing medical and nursing care, psychological support, socio-economic support, as well as involving positive individuals and their families, and meeting their legal needs.

[44] These include the National Child Protection Authority, the Sri Lanka Bureau of Foreign Employment, the National Institute of Education, the Ministry of Labour's Workers' Education Unit, the Department of Prisons, National Youth Services Council, the Army, Navy and Air Force, Police Department, the Vocational Training Authority and the Ministry of Fisheries, as well as liaising with provincial and district health authorities.