AIDS and Rights Alliance for Southern Africa (ARASA)

Leadership Report for the meeting held 27-30 July 2003

Airport Grand Hotel, Johannesburg

Introduction

On the 27th, 28th, 29th and 30th of July 2003 the AIDS and Rights Alliance for Southern Africa held a leadership training workshop for its interested partners in the Southern African region in Johannesburg, South Africa at The Airport Grand Hotel. Mark Heywood of the AIDS Law Project opened the workshop. Presentations were given by Sr Sue Roberts of the HIV/AIDS clinic at Helen Joseph hospital, Michaela Clayton of the AIDS Law Unit; Jonathan Berger and Marlise Richter of the AIDS Law Project.

ARASA's regional office that is situated in Windhoek, Namibia informed partner organisations that attended the workshop in October 2003 about holding this leadership training workshop in July 2003 and representatives from 12 different countries in Southern Africa responded positively to attend this workshop. The following organisations attended the workshop that were The Centre, Zimbabwe; FARAJA Trust Fund, Tanzania; ZARAN, Zambia; Rebuilding Hope Association, Mozambique; Centre Against Sexual Abuse, Mozambique; SAHRiNGON, Tanzania; Ditshwanelo, Botswana; BONELWA, Botswana; SAfAIDS, Zimbabwe; CAJ, Angola; Lironga Eparu, Namibia; National Women's Lobby and Rights Group (Lobby), Malawi; WLSA, Lesotho; AIDS Consortium, South Africa.

This training workshop is part of ARASA's workplan activities that was agreed upon by the Steering Committee Board during the first Steering Committee Meeting held Johannesburg 2003. It is ARASA's mandate to underscore the following issues:-

1. Strengthen / Build National Capacity
2. Establishing Regional / SADC Capacity
3. International Advocacy

The objective of the leadership workshop was to:

- to expose the participants to the more complex issues and debates around ARV treatment programmes in particular that dealt with treatment literacy covering the full spectrum of treatment but zooming in particularly on the issues around ARVs and the science.

- To give the participants a perspective on what are the human rights issues, how they emerged historically, and where they are going to; current key issues, etc.
- To provide participants with both the foundation for understanding the debates and issues around access to treatment, as well as taking people in detail through the key legal questions.
- The Human Rights professional has a role to play in society and needs to be disciplined and furthermore understand the evolution of the culture that the HIV/AIDS virus created and is constantly inventing its continuously place in society But most of all it demands of us learn from the experience. It also expects from the professional to articulate issues in such a manner that are acceptable to respective socio-economic societies. That we should integrate our various organisations on the same issues in order to reach a concerted effort and to redefine barriers with regard to interpreting our basic resources such IT technologies.
- It was further emphasised that historically human rights should be addressed and to look at privacy access to employment, treatment medicines, health care services and governance.
- The meeting was also encouraged to appreciate the evolution of the virus and understand the mutating virus and looking at HIV as a catalyst that causes reason of stigma and discrimination and major human rights offences.

Gender and HIV/AIDS has been integrated throughout all of the presentations and it had nevertheless been identified that an overview on Gender and HIV/AIDS be addressed during the workshop.

Following hereto are an overview of the areas that have been primarily identified that were covered during the workshop.

Gender and HIV/AIDS - Sex & Gender

Women are in general biologically more susceptible to the transmission of HIV than men. It is generally accepted that male-to-female transmission of HIV infection is

more likely to occur than female-to-male transmission. Thus, the consequences of unprotected sex can be especially serious and life threatening for women.

Sex refers to the physical or biological differences between men and women. *Gender* refers to the ideas that people have of what it is to be a boy or girl, man or woman.

Literacy and HIV/AIDS: Treatment Literacy for the professionals/ Cooperate Institutions

The purpose was in preparation to access affordable acceptable available treatment in order to create an enabling environment by providing effective practical psychosocial support services and facilities.

Treatment Literacy:

Definition: this is the knowledge needed by individuals so that they can make informed decisions pertaining type of service they require so that they can manage various life threatening illness easily such as:-

- Medication
- Counseling
- Spiritual support
- Physical support
- Nutritional and vitamin supplementation etc.

Methodology

To conduct training of trainers workshops at various levels.

Human Rights and HIV/AIDS: HIV/AIDS and Human Rights: Exploring the Connections

Introduction

"AIDS doesn't discriminate" – or does it?

Common public health messages underscore individual behaviour change: "its not who you are that puts you at risk but what you do …" They miss the point: social inequalities powerfully sculpt both the distribution of HIV as well as the health outcomes of those affected. Inequality itself has become a pathogenic force at the heart of which is gender inequality, poverty and racism

The African Epidemic

By 2001 28,5 mil with HIV/AIDS in sub-Saharan Africa. Less than 30 000 with access to ARVs 11 million orphaned by AIDS. West and Central Africa recent saw a rapid HIV spread. The scale far exceeds worst case scenarios predicted decade ago. It is important that human rights professionals understand the connections: HIV/AIDS, stigma, discrimination, racism, sexism, poverty and social inequality. Health and Human rights: historically distinct entities

Health and rights: making the connection.

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

The mission of public health: to provide conditions in which people can be healthy. Disease is a function of the basic organisation and function of society. It further illustrates the indivisibility and interdependence of rights as they relate to health – rights to autonomy, information, education, association, equality participation and non-discrimination are integral part of achievement of right to highest attainable standard of health.

Just as enjoyment of health is inseparable from other rights we need to close the gap looking at the following scenarios

- Aims of public health:
- Reduce morbidity, mortality and disability through prevention, care and support

- Promote healthy lifestyles by recognizing and acting on risks imposed by cultural or social constructs
- Develop health systems that equitably improve health
- Promote enabling development policies that contribute to advancement of health

WHAT IS THE LINK?

Health and rights are inextricably linked and we therefore need to examine the following:-

- Consider the example of the core human right of non-discrimination and the impact that the violation of this right may have on health:
- Discrimination increases vulnerability to infection: Women and other vulnerable groups are particularly at risk of infection – largely because of unequal status in society – unequal capacity to access information , to reduce risks and access prevention and care services

Patents and Intellectual Property Rights

Persons with HIV disease or AIDS are confronted with exclusion from an equitable share of health resources. You violate a person's humanity by testing him or her for HIV without consent, or by improperly divulging information about her or his health status. But the deepest violation of another person's humanity is to deprive that person of the means to remain healthy, to fight off illness and to live-or die-in reasonable comfort and dignity. Discrimination in the allocation of resources is the most debilitating discrimination of all.

Mr. Justice Edwin Cameron-Person living with HIV/AIDS

The effect of a patent shall be to grant to the patentee in the Republic of South Africa, subject to the provisions of this Act, for the duration of the patent, the right to exclude other persons from making, using, exercising, disposing or offering to dispose of, or importing the invention, so that he or she shall enjoy the whole profit and advantage accruing by reason of invention. (section 45(1) Patents Act No. 57 of 1978)

The duration of the patent shall, unless otherwise provided in this Act, be 20 years from the date of application. (section 46(1) Patents Act No. 57 of 1978)

SOME KEY DEFINITIONS

What is a patent? A patent is granted by the government to a person (individual or company) who reveals or invents a new product or process for its use in industry or trade. In relation to drugs, a patent gives a company at least a 20 year long monopoly on any new medicine. This allows that company to set the prices at artificially inflated levels.

Patent abuse by drug companies has become an obstacle to the provision of medicines to the majority of people in the world. It is the state at national level, and, the World Trade Organisation that enforces patent laws. Civil society can also use the patent laws to protect the right to health.

Compulsory licensing and parallel imports are tools that must be considered by all governments, generic manufacturers, and health activists to promote access to essential medicines. However, they are not a panacea for high prices and profiteering in the pharmaceutical industry. Medical inflation and profiteering require long-term structural transformation, consumer awareness and action.

Compulsory licensing refers to an order by a court or government body that allows any person or the government to use a patent legally without permission from the patent holder in the public interest. Most national patent laws and TRIPS allow compulsory licensing. This can be used effectively to lower health and nutrition costs.

Parallel imports refer to importing a drug or product from another country where it is sold cheaper than in the local market with the permission of the patent holder.

What are essential drugs? All medicines necessary to prevent, diagnose and treat physical and mental illnesses, (especially life-saving medicines), are essential drugs.

Conclusion

Collette will compile a report on the ARASA workshop to be made available by the 18th August 2003.

All members are to avail the contact details of HIV/AIDS and Human Rights organisations in their respective countries. Collette will remind members of the particulars required via email. The group agreed to allocate a two week period to the establishment of the database, starting from the 18th August 2003. The deadline being 1st September 2003.

The group also agreed to carry out a country analysis of the situation of or the state of Treatment and HIV Literacy, Human Rights and HIVAIDS and Patents and Intellectual Property Rights. Collette to request from Marlise her research done regionally in that field.

Members will submit their organisations' workplans and identify gaps within their plans and their organisations has to provide the ARASA network with opportunities to provide assistance where possible; benefit from projects with other countries and keep the network with knowledge of events within the regions. The deadline for submission was left to the discretion of the representatives however to be finalised within 3 months that is by October 2003.

The Treatment Action Plan was also agreed upon for development for the region. It was suggested the members contact their AIDS Coordinator within the governments who had attended to WHO meeting in Harare, Zimbabwe and inquired how far the plans are and what their organisations could do to assist its development.

Other issues raised are as follows:-

- Members requested the redefinition of ARASA taking into consideration member's considerations.
- It was also requested that ARASA work closely with TAC and the rest of the region establishing work relationships through existing relationships within countries for purposes of advocacy, capacity building and so on.

- Following a request to develop a standardised ARASA TOT Manual it was decided that training manuals would be developed within countries and therefore should be country specific that is left to each country to develop its own manual through integration and adaptation of existing documentation.