
**A CULTURAL APPROACH TO
HIV/AIDS PREVENTION AND CARE**

UNESCO/UNAIDS RESEARCH PROJECT

***HANDBOOK
FOR
STRATEGY AND POLICY BUILDING***

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FOREWORD

This handbook belongs to a series of four methodological documents:

- *Appropriate Information/ Education/ Communication;*
- *Cultural approach to strategy and policy building;*
- *Culturally sensitive project design and implementation;*
- *Fieldwork: building local response.*

Each specific handbook deals with two major topics:

- *On one hand, a general explanation of the cultural approach to HIV/AIDS in relation to the risk itself, vulnerability situations and the appropriate prevention, support and impact reduction actions ;*
- *On the other hand, specific sections focus on the levels of action to be considered: strategy/policy, project design and fieldwork. These are meant to assess the current situation and to propose innovative methods and tools.*

The present handbook contains two major divisions: situation analysis and appropriate strategy/policy response building. It includes cross-references to the other three documents. Numerous UNAIDS documents were consulted during the elaboration of this work. Specific footnotes give the references of those quoted directly.



EXECUTIVE SUMMARY

The Joint UNESCO/UNAIDS Project “A Cultural Approach to HIV/AIDS Prevention and Care” was launched in mid-1998, in relation to the new approach inaugurated by UNAIDS to HIV/AIDS prevention and care. The UNAIDS strategy emphasizes the necessity of giving priority to the multi-dimensional configuration of the issue and to the diversity of its environment, in order to build comprehensive and adaptable strategies and policies.

In this sense, “A Cultural Approach to HIV/AIDS Prevention and Care”, represents a new contribution towards finding solutions to this apparently insuperable challenge. Its major methodological output aims at tailoring the action's content and pace to people's mentalities, beliefs, value systems, capacity to mobilize and, as a consequence, to accordingly modify international and national strategies and policies, project design and fieldwork.

In this respect, this initiative clearly meets the principles and orientations of the Declaration of commitment on HIV/AIDS adopted by the Special Session of the United Nations General Assembly on HIV/AIDS (June 2001), that states the importance of *“emphasizing the role of cultural, family, ethical and religious factors in the prevention of the epidemic and in treatment, care and support, taking into account the particularities of each country as well as the importance of respecting all human rights and fundamental freedoms (para n° 20).*

This Handbook is specifically devoted to presenting methods for building culturally appropriate strategies and policies. After presenting a reminder on the key assumptions, objectives and methodological implications of the cultural approach, it defines the overall terms of reference for assessment/review of the current programmes and projects in relation to field realities.

Moreover, it describes the methodological tools necessary for building a culturally appropriate response to the major challenges as identified by UNAIDS: risk, vulnerability, prevention, care, support and impact reduction. It also points to the key action priorities in this respect, with special emphasis on renewed preventive education and training/sensitizing/capacity building.





1- THE CULTURAL APPROACH: A REMINDER

1.1- ASSUMPTIONS

In the light of experience, it is more and more widely recognized that the HIV/AIDS epidemic is not a problem which concerns only the medical sector. It is a multifaceted issue, which requires a multidimensional response strategy. If this strategy is limited to medical considerations or to purely cognitive information, modern-type information, education and communication for safe practices, namely in the promotion of condom use, will not achieve the expected results. The epidemic is, indeed, a complex socio-economic, societal and cultural phenomenon, to be considered in the perspective of sustainable human development. Thus, a cultural approach is necessary for the prevention and treatment of the epidemic in order to deal with all the aspects of the problem.

Generally speaking, a cultural approach to development should meet two conditions, derived from the UNESCO Mexico definition of culture, and which can be summarized as follows:

- **Grounding development** on mentalities, traditions, beliefs and value systems, for practical and ethical reasons, in so far as they may enhance needed changes, or hamper them, if they are not correctly identified, and will necessarily interfere in the action taken;
- **Mobilizing the cultural resources** of the given populations, in order to benefit from their support, when bringing about, through the joint identification of needs and action, the necessary changes in thinking and behaviour for endogenous sustainable human development.

These cultural references and resources are sometimes misunderstood as monolithic systems, which cannot be modified, since they are supposed to represent an intangible asset, to be protected unconditionally. Observing real situations clearly shows that there is not necessarily a contradiction between culture and change, since all societies and cultures evolve over time:

- First, because of their intrinsic dynamic aspects;
- Secondly, because they interact with all kinds of external economic, social and cultural transformation processes.

These evolutions may result in destabilizing situations if these processes are not monitored and mastered.

HIV/AIDS prevention and care policies and methods will be improved and made more efficient by making them culturally-appropriate (acceptable and relevant), fully understood and highly valued (culturally integrated) among given groups and persons, according to their priorities. This will enhance a new awareness of responsibility and motivate a subsequent willingness for mobilization against the expansion of the epidemic.



Over the last 15 years, many different approaches have been adopted in an attempt to slow the expansion of HIV and minimize its negative effects on individuals, families, and society. It is now clear that there is no simple formula that works for all countries. The most effective national responses are those designed to meet the specific needs of the country. They address the specific situations that make people vulnerable to HIV and its effects, and make use of the particular strengths of the country's people and institutions. These practices are outlined in the UNAIDS *Guide to the Strategic Planning Process for a National Response to HIV/AIDS* (1998-1999) and the *UNAIDS Methodological Review* (1999).

The cultural approach is fully consistent with the policy and planning principles advocated in these documents. Its specific input consists of a detailed analysis of the particular and changing aspects of a given situation and population, and in proposing working methods derived from this appraisal.

1.2- OBJECTIVES AND IMPLICATIONS

This Handbook is meant to facilitate the design of more efficient and relevant strategies and policies aimed at HIV/AIDS prevention and care, through improving the understanding of cultural references and resources and integrating them into building relevant responses at the national level.

In view of these goals, this Handbook proposes concepts, criteria and methodological tools designed to adopt a cultural approach in building, implementing and evaluating HIV/AIDS prevention and care strategies and policies. These strategies and policies will thus be better equipped to face risk and vulnerability situations and thus reduce the impact of the epidemic through building more efficient prevention and support systems, including the appropriate preventive education.

These proposals are derived from the analysis of the current conditions, the assessment of institutional action taken to date at all levels and an in-depth investigation of field situations. This analysis is meant to show the breach between the current approach and the scope of prevention and care systems in relation to the complexity of concrete situations. More detailed evaluation of these interactions is presented at length in the other three methodological handbooks. The present handbook focuses on proposing methods for identifying major orientations and priorities, ways and means, co-operation and partnerships in order to build a response through culturally-appropriate strategies and policies.

Taking a cultural approach to HIV/AIDS prevention and care

In terms of HIV/AIDS prevention and care, adopting a cultural approach means that any population's cultural references and resources (ways of life, value systems, traditions and beliefs, and the fundamental human rights) will be considered as key references in building a framework for strategies and project planning. These key references will also serve as resources and basis for building a relevant response and sustainable action in prevention and care, as well as in impact reduction. This is an indispensable condition in order to achieve in-depth and long-term changes in people's behaviour to give full consistency to medical and sanitary strategies and projects.

2- FOUR MAJOR CHALLENGES

As emphasized by UNAIDS, building a response to HIV/AIDS at all levels requires a preliminary diagnosis in clear terms. Risk in itself, and vulnerability as its environment, are two major challenges to be faced in all their facets before proposing reliable solutions. Developing relevant prevention and support systems in order to alleviate the impact of the epidemic represent key issues in strategy-building, policy-making, project design and fieldwork. For this reason these different questions are identified as the four major challenges of HIV/AIDS.

These issues have to be analyzed in detail, separately and in their context, with due consideration to their socio-economic and societal/cultural determinants and effects at all levels. They are reflected in the evaluation of the present situation concerning policies and the appropriate response to building, in terms of national strategies, regional initiatives and local response.

2.1- RISK

High-risk behaviour is directly associated with physical proximity between infected and non-infected persons. This fact is true for all situations and regions. Nevertheless this behaviour differs significantly according to the various contexts.

- The main cause of infection is **sexual relations**, whether heterosexual, as in Africa and in other regions, and/or bi-sexual or homosexual, as recognized in the Caribbean, Latin America and South East Asia. The risk is aggravated by certain sexual practices such as having multiple sexual partners, casual sexual relations, violent sexual intercourse and prostitution. It is also related to other STDs, past, co-existing or confused with HIV/AIDS;
- **Mother-to-child transmission** of HIV/AIDS appears as another major cause, either during pregnancy, at birth, or during breastfeeding. The latter represents half of this type of infection, especially for women who have numerous children and breast-feed. This practice is often maintained because safer alternatives, such as hygienically safe milk for babies, are not available to them;
- The growing use of **intra-venous drugs** with infected needles and the simultaneous consumption of drugs and alcohol are also causes of infection, more specifically in Eastern Europe and Central Asia;
- The transfusion of **contaminated blood** is estimated to be the cause of 10% of the HIV/AIDS infections in sub-Saharan Africa. Contamination can also occur during sexual intercourse when the reproductive organs of one partner are bleeding. It can also occur through rituals of blood exchange in certain initiation ceremonies involving young men, unhygienic excision or circumcision, tattooing and skin piercing. However, recent research in certain African countries tends to show that male circumcision may entail a lower sexual contamination risk. Other factual evidence shows that violent fighting can also result in contamination through bleeding wounds.



Despite this factual evidence, identifying these various high risk situations raises two questions that go beyond the epidemiological approach, and are of an obviously more societal and cultural nature:

- Personal, family and community awareness of the risk and its consequences in matters of infection and, in optimal situations, the subsequent choice of protected contact or abstinence;
- Public acceptance and formal acknowledgement of the risk and its implication and/or the disclosure of the infection by the group, community, society or public authorities as opposed to silence and denial.

This in itself leads to issues of prevention and care at the individual and collective level.

2.2- VULNERABILITY

Epidemiological research has made important contributions to the identification of the direct determinants of HIV infection. However, it tells little or nothing about the social, economic and cultural factors, which influence people's behaviour in relation to the risk of infection. Social and economic conditions and societal/cultural features have to be analyzed in turn, first at the various levels, then as interwoven groups of causes and effects.

The first AIDS cases in sub-Saharan Africa were reported in the scientific literature in 1983. These patients did not share the main risk factors associated with the disease in Europe and North America, i.e. principally homosexual intercourse and intravenous drug use. It soon emerged that the epidemiology of HIV/AIDS in Africa was quite different from that of high-income countries: heterosexual intercourse, blood transfusion and mother-to-child transmission being the predominant modes of transmission. While common risk behaviour such as intravenous drug use and unprotected homosexual intercourse can be targeted with interventions aimed at reducing the risk, it is much harder to design interventions for larger populations engaging in heterosexual intercourse.

Source: CARAEL (Michel), "The Dynamic of HIV Epidemic in sub-Saharan Africa: what are the determinants?" *Proceedings of the Nairobi International Conference*, UNESCO, 2001.

2.2.1- SOCIO-ECONOMIC CONDITIONS

The analysis of these conditions should be carried out at two levels:

- Macro-level: economic crisis, globalization (and its impact on communication and transportation, internationalization of markets – including drugs and prostitution), environmental degradation, wars, population displacements, international migrations, mass tourism;
- Micro-level: poverty, unemployment, housing conditions, lack of access to health-care services and education, rural exodus, urban violence.



2.2.2- SOCIETAL AND CULTURAL REFERENCES AND THEIR EVOLUTION

Considering the multifaceted character of most cultural features certain aspects of local cultures are conducive to risk behaviour while others induce direct or indirect protective attitudes with respect to spiritual and ethical rules. Here are some examples of such societal and cultural references :

- Representations of health and disease, life and death, fate and human responsibility;
- Strong control on the part/benefit of society and the family;
- Prescription of attitudes and sexual norms through certain rituals, traditions and religious beliefs;
- Disruption or collapse of traditional norms and value systems;
- Inequitable gender relations and underestimation of women's potential in daily life continuity or change;
- Young people's status in society;
- Linguistic and semantic habits adopted for discussing sexuality.

2.2.3- SOCIAL /POLITICAL ENVIRONMENT : HISTORICAL AND PRESENT DIMENSION

Even if not directly linked to the material and medical aspects of risk, the overall social and political conditions at national level have a strong impact on the scope and feasibility of prevention and care policies. More specific issues can be mentioned in this respect, for instance:

- Institutional weaknesses, including the chronic instability of public authorities and subsequent fragility of administrative structures;
- Lack of communication between public authorities and population;
- Imbalance in internal/external decision-making ;
- Weight of external debt and structural adjustment policies;
- Non-respect of fundamental human rights.

2.2.4- IDENTIFICATION OF VULNERABLE GROUPS

In general, the categorization of vulnerable groups should fully take into account people's situation in the context of overall development: poverty, insecurity and fundamental human rights. In this respect, the poor, women, and youth, and more specifically refugees and minorities, are at maximum risk exposure. However, specialized target audiences have to be defined.

Underprivileged populations :	Culturally-destabilized groups:	Specific risk groups:
<ul style="list-style-type: none"> • The poor • Young people • Women and girls • Uneducated people (out-of school children and the illiterate) 	<ul style="list-style-type: none"> • Disintegrated families • Unemployed persons • Refugees and displaced people • Domestic and international migrants • Mobile workers 	<ul style="list-style-type: none"> • Segregated groups and communities • Homosexuals • Prostitutes

2.3- PREVENTION AND SUPPORT

In response to the high risk and vulnerability situations described above, national strategies and policies have to be elaborated and implemented in the following fields:

- National health-care policy;
- Preventive education and communication care and support within relevant national policies;
- Medical, social and psychological follow-up for infected people;
- In the context of social welfare policies, specific action in order to alleviate the social impact of the infection.

The range of these policies and the number of people being educated and assisted require a coordinated action, not only between national public authorities, but also among all stakeholders involved. More specifically:

- International co-operation institutions;
- International and national NGOs.

However in this context, no public or institutional policy will reach a significant stage if it is not complemented by the participation of civil society in all of its aspects facets. The various categories of economic, social and cultural actors (sports and cultural movements, business associations, trade unions, political parties, religious communities, traditional community leaders, traditional healers, midwives) are important stakeholders in the mobilization against the epidemic.

Needless to say, medical and sanitary personnel at all levels are partners in the overall effort to provide testing facilities and care to infected people, especially pregnant women intending to breastfeed their infants.

Another category of professionals actively involved in preventive education can be found, not only among youth and out-of-school educators, but also in the media (both audio-visual and the written press).

2.4- IMPACT REDUCTION

2.4.1- ECONOMIC IMPACT

The high mortality rate due to AIDS among the most active sector of the adult population can be expected to have a radical effect on virtually every aspect of social and economic life. This is due to the fact that this sector of the population is typically at an age when they have already started to form their own families and have become economically productive. While it is difficult to measure the precise impact of HIV at national level in most hard-hit countries, a great deal of information exists on the disastrous impact, direct or indirect, of the epidemic on households as well as on the public and private sectors of the economy¹.

¹ UNAIDS, *Report on the global HIV/AIDS epidemic*, June 2000.



However impact reduction policies, should not focus exclusively on the economic disruptions entailed by the epidemic, such as manpower shortage and production decrease. The education sector is also hard hit by the disease: teachers already insufficient in number to face overcrowded school classes, and new generations of trained specialists in other sectors of national development are also decimated by the virus.

2.4.2- SOCIAL IMPACT

Reducing the social impact of the disease is another **major challenge for national social development** and welfare policies. Giving support to abandoned and widowed women, unable to provide the minimum care for their children, or developing solidarity systems for HIV/AIDS orphans, abandoned street children and youngsters places an additional burden on an already fragile national public budget.

2.4.3- SOCIETAL AND CULTURAL IMPACT

The societal and cultural impact of the infection and disease can result in a general collapse of energy and hope for fighting the virus. The taboo, as such, and the widely spread rule of silence are just a few of the disastrous cultural effects of the revelation of the infection by the concerned person or his/her family. Stigmatization and rejection have been observed in many instances, especially in rural zones and among the poorest populations. In some countries, in the first phase of the epidemic at least, numerous cases of hesitation or denial were noticed with respect to the recognition of the scope of the disease and the seriousness of the challenge it posed for the country.

The pressing character of this situation clearly requires urgent action, but with adapted approaches. If people must speak out, this has to be done with the necessary respect for their societal cultural norms and for their basic human rights. Moreover, there may be significant misunderstanding stemming from semantics and language in the matter of sexuality. This may lead external prevention and care agents to erroneously consider that women are frequently ignorant of their physiological functions.

HIV/AIDS and the private sector

The impact of the HIV/AIDS epidemic on the private business sector has been growing steadily over the last years, and has become quite visible in some places. Still many business leaders need to be persuaded that AIDS prevention programmes for their employees are in their own rational self-interest. In economic terms, such prevention programmes can be marketed as "minimizing cost" or "profit-loss prevention" and protection of valuable fixed investment in "human capital". The advantage of developing new partnerships with private business is that they have substantial resources available. At the same time, workplaces provide an excellent opportunity to reach the labour force in large numbers and with high impact.

Source: UNAIDS, *Guide to the strategic planning process for a national response to HIV/AIDS*, resource mobilization. (<http://www.unaids.org/aidspub/list.asp>)



**DOMINICAN REPUBLIC:
Linguistic hiatus, silence and disclosure regarding HIV/AIDS**

In most cases, couples with HIV inform friends, families and neighbours of their condition when one member of the couple has the disease. When the husband is ill, men tend to hide the infection from the families of their wives and the majority of their neighbours. The family and friends of the wife will only be notified of the infection when the husband is tested positive. In other cases, the mothers of positive patients have revealed the condition of their sons to their friends and neighbours, and subsequently received the solidarity and support of many of them, in spite of the general poverty. Women do the housework and attend to the ill, while the men work and help to move the ill from one place to another.

Men and women tend to react differently when they discover their diagnosis: resignation among men, panic and depression in the case of women. There is evidence of apathy, family rejection and stigmatization, among other reactions, which seem to secrecy.

The economic difficulties of many of those infected, together with the loss of employment that occurs as soon as the symptoms appear, makes the purchase of food and essential medicine very difficult. Only a very small minority of those concerned has access to anti-viral drugs. There is class and generation discrimination has the labels of class and generation. Patients with a low academic level are more discriminated against within their family and community, and the less young by the health services. Only one in five persons does not belong to PWA (People with AIDS).

Source: A cultural approach to HIV/AIDS prevention and care: Dominican Republic's experience, UNESCO, 1999.



3- CURRENT INSTITUTIONAL STRATEGIES AND FIELD REALITIES

3.1- STRATEGIES AND POLICIES

It is clear that the sector mandates of institutions involved in HIV/AIDS prevention and care do not fully integrate a holistic culturally-based approach. Their actions include preventive care and support to the infected and sick people, as well as reducing the direct and indirect impact of the disease.

As a result of their specific mandates, the various institutions actually involved have narrowly defined fields of competence. For instance, UNICEF and UNFPA target women and children, mainly because of their relationship to reproductive health issues. UNDP and the World Bank focus on funding clear-cut development projects: WHO periodically re-emphasizes the prominent health and medical dimensions of the issue, while UNDCP works mostly on drug abuse and its direct effects on infection.

This situation in itself makes it difficult for these institutions to respond to the major challenges described above through an integrated strategy and policy. Actually these issues are intrinsically trans-sectoral and, in fact, require an inter-agency response, in the short, medium and long-term perspective, as repeatedly advocated by UNAIDS.

Moreover, certain institutions operate under the pressure of budgetary or technical constraints, in other words, short-term and direct cost-effective analysis. Thus, little room is left for the consideration of human, social and cultural aspects, which could be analyzed in terms of indirect cost-effective evaluations, given the appropriate research-development programmes. As a consequence, the importance of these aspects in fighting the epidemic is frequently under-estimated and misunderstood. An illustration of the effect of this approach in action programmes is given by the still prevailing prominence of the medical cognitive and sexological approach to prevention and care.

Thus, efficient, appropriate and sustainable strategies and policies, not only for prevention and support, but also for reducing the impact of the epidemic, have not resulted in relevant action and significant results to-date.

It is increasingly evident that HIV/AIDS impacts on the long-term plans and the economic development agenda of many countries. In this respect, it is obvious that, regardless of their expertise, outsiders should not impose their own priorities on national planners – not to mention the societal and cultural aspects of the issue.

Therefore it is critical and crucial that governments, who are responsible for establishing such agendas, assume the leadership role. The viability and sustainability of programmes will depend on the extent to which the response to HIV/AIDS is built into the national development framework. This is a task that only national authorities can accomplish, as emphasized by Dr Peter Piot, UNAIDS Executive Director.

In addition, specific mention must be made of the first recommendation adopted by the International Conference held in Nairobi, Kenya (October 2000), which highlighted that “HIV/AIDS should be incorporated into national development planning initiatives and related poverty alleviation measures. Such HIV/AIDS policies, strategies and programmes must be designed through using a cultural approach²”.

3.2- INSTITUTIONAL ASSESSMENT AND STRATEGY/POLICY REVIEW

This section of the handbook briefly reviews the main categories of activities currently implemented by the institutions involved.

3.2.1- PREVENTION

In its first phase, the battle against HIV/AIDS focused mainly on epidemiological research and subsequent medical measures concerning the disease alone. Later on, more in-depth scientific analysis revealed that a long period (from 5 to 10 years) could elapse between the initial infection and the development of the disease in its final stage. Therefore, greater attention was paid to prevention, more specifically to the elaboration and implementation of information/education/communication (IEC), aimed at behaviour change and, to some extent, medical support to those living with HIV/AIDS.

In this respect, preventive education in school was expected to be the key instrument in checking the pandemic. However, the mainly cognitive and factual information propagated through the school system gradually appeared to have little effect because of its content and modalities. For example, the emotional and empathic attitudes related to the problem are more frequently found in non-school counselling activities. Moreover, this information is not available to children and young people who do not have access to schools, and therefore, by definition, is not addressed to the illiterate.

In another respect, preventive information broadcast by the media reaches very different proportions of the expected audience. Information is thus limited to the number of TV and radio receivers of a given country and social group. Moreover, this information is frequently too general or sensationalized. Due to its technical modalities, it is neither targeted to specific audiences nor broadcast on a long-term basis as a continuous activity.

Whether it uses the school education channel or mass media, preventive education is far from reaching all rural areas (70% of the Indian population for instance). In urban areas, it does not reach the poorest and segregated groups, including disadvantaged young people, especially girls and women.

Moreover, preventive education frequently **advocates condom use**. In theory, this represents the best protection against the virus. However, its acceptability varies greatly, depending on societal and cultural environment. In many countries its use requires easy, private and anonymous access through distributors or wide distribution campaigns. Flat refusal to use condoms can be motivated

² UNESCO/UNAIDS Research Project A Cultural Approach to HIV/AIDS Prevention and Care, *Proceedings of the Nairobi International Conference* (2-4 October 2000), UNESCO, 2001.

by various and sometimes contradictory reasons. Thus, using condoms cannot be proposed without contextualizing the proposal within the confines of general health education and daily life conditions.

ANGOLA: resistance to condom use

According to a survey on young people's attitudes towards condom use in Angola, it appears that, at the most basic level, there is a fundamental lack of understanding of the risk and need for change in sexual behaviour. Some remarks deserve quotation: "Some people say that AIDS does not exist; others say it was invented to break the passion of lovers".

Despite their knowledge of the effectiveness of condoms in HIV/AIDS prevention, condoms are rarely used. Boys and girls assert that they "only use them in occasional sexual relations that they consider risky" and "when they want to avoid pregnancy". The criteria which define an occasional sexual relation as risky or not are often subjective. Therefore, young people may be exposing themselves to infection as a result of bad judgement. Male participants reject condom use, because they believe that condoms are painful and reduce sexual pleasure. Female participants reported that even when they suggest the use of a condom to their partner, he often argues the following:

"They say they like to feel flesh to flesh"

"Going to the bathroom to take a shower and going outside (dressed) when it is raining are two different things."

"When emotion hits there is no room for condoms."

On the other hand, some girls justify its limited use because of "the fear that the condom could remain in the vagina", so that, according to them, "it would be necessary to have surgery to take it out." This fear is mentioned by some of the secondary school female students.

Others assert that the prices of condoms make them unaffordable to the majority of them. In addition, there is no information on the places where condoms are sold.

Some young people, mostly boys and men, believe that promoting the use of condoms among the youth would indirectly motivate "irresponsible" sexual practices.

Taking into account the age and level of education of the young people involved, the use of condoms should be more effective and accepted. However, their reaction clearly demonstrates the gap between knowledge and daily experience, as well as the effect of societal and cultural pressure on individual behaviour.

Source: *A cultural approach to HIV/AIDS prevention and care: Angola's experience*, UNESCO, 1999



In many societies and cultures, advocating sexual abstinence, its acceptability, the use of different modes of sexual relief and, above all, the concern for safe sexual relations raise fundamental issues, far beyond the medical/sanitary approach, cognitive information and even more moralistic attitudes. Moreover, such direct and intimidating prescriptions do not take sufficient account of people's real life conditions. These may include: the massive emigration of men as workers to large cities and rich countries, impoverished and dehumanizing life conditions, the absence of entertainment possibilities - leading to various forms of diversion involving alcohol or drug abuse and unprotected sexual relations. To some extent, this may also explain the widespread instability of couple relations, despite the fact that stability is repeatedly advocated. However, it should be emphasized that strict adherence to religious rules may facilitate the acceptance of sexual abstinence, as part of spiritual progress.

Another serious difficulty is due to the lack of education and exclusive trust in local and traditional beliefs and representations. People do not believe the information they receive from external information sources and subsequently they are not convinced of the risks involved in their behaviour. Once they are infected, they will neither be aware nor informed of the illness. As a result, they will not feel responsible for the transmission of the virus .

3.2.2- INFECTION TESTING AND CARE SYSTEM

In many cases, periodical testing does not cover the entire population in a given area, due to inconsistencies and insufficient budgeting in national HIV/AIDS prevention and care policies. Thus, infected people may not be informed of their HIV status and subsequently are not treated by the available sanitary and health facilities. Moreover, they may keep the same risk behaviour, which caused the initial infection, thereby infecting other people and aggravating their own infection.

Care is an essential and growing component of response. As more people become infected with HIV and/or develop AIDS together with opportunistic infections, care will become an ever-increasing part of efforts to limit the spread of the epidemic³.

Beyond the increased risk caused by the behaviour of infected people themselves, the conditions for regular medical treatment are far from regulated, especially at the local level, in countries where health-care centres are not available in all areas within the country.

Another difficulty is caused by the excessive cost of medication for poor populations. In this respect, the recent development and production of generic drugs may open new avenues for medical treatment of infected people at all levels of society, at low cost or even as a free service. In addition, the medical treatment needs to be taken regularly, under safe conditions and over a long period of time. This constraint in itself necessitates a well-structured national health-care and medical system, as well as empathic and close counselling. External support is still largely lacking in this respect.

The lack of accessibility to modern medicine is not only limited to its physical availability. Very often, while medical personnel work in a permanent rush due to staffing shortages and thus cannot

³ UNAIDS *Guide to the strategic planning process for a national response to HIV/AIDS : response analysis*.

take the time to ensure a humane welcome to infected and sick people, these in turn do not trust the ability of modern medicine to cure them. This is why, in many countries, and in all social strata, people prefer to consult traditional healers, even in the case of a serious disease like HIV/AIDS. Contacts between modern doctors and traditional healers are sporadic and most frequently superficial.

3.2.3- SUPPORT

Part of the necessary overall support is the epidemiological action. This requires the screening for HIV/AIDS and sanitary monitoring of infected people. The current system, however, does not provide economic, social, psychological and moral assistance to infected people and even less to those in the final stages of the disease. More specifically, the present situation is often characterized by an almost complete absence of relevant measures, strategies and policies. NGOs, charity groups and local self-support systems are the only existing initiatives in this respect. This only highlights the lack of initiative on the part of public authorities in the recognition of this issue as a public concern, hence not fulfilling their responsibility towards the public.

3.2.4- IMPACT REDUCTION AND MITIGATION

It has been widely acknowledged that the impact of the epidemic on the most seriously hit countries has been very dramatic, whether in the economic, social, societal or cultural fields. Nevertheless, public policies acknowledge or address the consequences of the crisis linked to economic growth and manpower shortages.

DOMINICAN REPUBLIC: popular self-support and understanding

Self-support groups and mutual assistance are crucial for basic education on AIDS. In spite of economic difficulties, they provide a minimum of emotional support, as well as some supervision, essential medical attention and access to medication.

Shamans ("medicine men") know they cannot cure the disease, nor do they lead their patients to believe that they can. They feel that their task is to "level" people emotionally, giving them support, advice, tranquility and peace of mind. They recommend plants, such as cat claw, good luck water, natural products, beverages and tea.

Funeral home employees use uniforms, gloves and masks as bio-security measures. They do not believe that preparing the corpse of a person who has died of AIDS is different from their normal routine. On the other hand, the superstitious beliefs surrounding the infection seem to prevail among many of them. They refuse to carry the coffins of persons who have died of AIDS and insist these coffins be specially covered.

Source: *A cultural approach to HIV/AIDS prevention and care: Dominican Republic's experience UNESCO, 2000.*



4- WAYS AND MEANS FOR BUILDING CULTURALLY-APPROPRIATE RESPONSE

4.1- SYNOPSIS

Having reviewed the current institutional strategies and policies in relation to field realities, this section presents the methodological tools for building a culturally-appropriate response to the major challenges as identified by UNAIDS: risk, vulnerability, prevention, care, support and impact reduction. More specifically, it describes the major orientations for strategies and policies, the general policy rules to be followed and the key principles to be observed. Furthermore it presents a summary of UNAIDS best practice criteria, the technical tools based on these criteria for culturally-based strategies, and the subsequent renewal of the institutions' role and modes of action.

In the second section, this booklet outlines the main action priorities necessary to meet major challenges. It first emphasizes the need for culturally appropriate communication for behaviour change, and the necessary instruments for renewed HIV/AIDS preventive education regarding risk and solidarity. Then, it lists the prerequisites for the joint mobilization of institutional networks and civil society, bearing in mind the community-based response, the specific tasks of the institutions and the interaction between the two. Finally, it proposes ways and means for training/sensitizing/capacity building at all levels, for appropriate prevention, care and support action.

4.2- STRATEGY AND POLICY BUILDING

4.2.1- MAJOR ORIENTATIONS

As shown in the analytical part of the present document, building a coherent response to the challenges of risk and vulnerability requires broad strategies and political choices. These must be considered not only in medical and cognitive terms, but also in economic, social and cultural terms. These major challenges must be addressed through key strategic and political orientations linked to:

- Prevention of the infection, medical and emotional support to the infected and sick persons;
- Reduction of the overall impact of the infection and disease.

4.2.2- GENERAL POLICY RULES⁴

National responses will be successful if they are built on the following policy guidelines:

- Political will and leadership: from community leadership up to the countries' higher political level; along with the necessary human and financial resources;
- Social openness and determination to fight stigmatization.;
- Strategic response involving a wide range of actors: government, society, the private sector and, where appropriate, donors;
- Social policy reforms to reduce vulnerability;

⁴ UNAIDS, *Report on the global HIV/AIDS epidemic*, June 2000.



- Adequate resources.

PHILIPPINES National HIV/AIDS Strategy: Guiding Principles

- Multi-sector involvement is essential to national and local response to HIV infection.
- Individual rights and responsibilities of people affected by HIV/AIDS should be upheld.
- People should be empowered to prevent further HIV transmission.
- Care and support for persons with HIV should be integrated into existing health and social services.
- Universal precautions and utmost safety should be used to minimize the risk of HIV transmission through health procedures.
- All HIV antibody tests should be voluntary with guaranteed confidentiality and adequate pre and post test counseling.
- The formulation of socio-economic development policies and programmes should take into account the impact of HIV/AIDS.
- The unique vulnerabilities of various populations affected by the HIV infection and the impact of AIDS have to be taken into consideration for the allocation of resources.
- Continued efforts should be made to constantly improve HIV-related programmes.

Source: UNAIDS, *Guide to the strategic planning process for a national response to HIV/AIDS*.

4.2.3- KEY PRINCIPLES

Five basic principles must be articulated in order to build sustainable HIV/AIDS strategies and policies that will encourage the development of prevention, care, support and impact reduction. These principles are the following:

A COMPREHENSIVE APPROACH

A holistic and comprehensive approach to HIV/AIDS prevention and care means considering the complex interactions of the epidemic within the context of culture⁵ and development. This approach must be adopted in order to develop integrated and coordinated prevention and care strategies:

- In fact, HIV/AIDS is but one aspect of the many inconsistencies and failures in human sustainable development. It can be fought efficiently only through the appropriate **co-ordination** of directly involved institutions, the close co-operation of all agents and institutions working for development in other sectors (rural/urban development, income-generating activities, housing, education, etc.) and with due consideration for the societal/cultural dimensions of these problems. Co-ordination and co-operation in the actions of these various fields coincides with the fundamental mandate of UNAIDS;

⁵ See definition provided in section 1.1



- Thus, co-ordination must be based on an **trans-institutional** and **inter-agency** perspective. Clear knowledge of the interactions between health, education, economic and social progress, the respect for fundamental human rights and culturally-appropriate prevention and care, must also be considered in the co-ordination effort. Clear evidence of the necessity for trans-institutional strategy is given by the fact that the joint United Nations Programme on HIV/AIDS is currently co-sponsored by UNICEF, UNDP, UNFPA, UNDCP, WHO, the World Bank and UNESCO;
- The appropriate response to the epidemic also requires an **interdisciplinary** effort and, as a consequence, the participation of **pluri-disciplinary teams**, covering the various fields concerned, including the medical, social and human sciences, with special attention to cultural anthropology.

LONG-TERM PERSPECTIVE AND SUSTAINABILITY

Even though the urgent aspect of the HIV/AIDS crisis requires immediate and highly focused action, prevention has to be considered as a long-term and sustainable process.

The long-term perspective is an essential dimension of strategies elaborated within a general cultural approach. These strategies should allow for a continued action in accordance with the pace of societal evolutions. This perspective is particularly relevant given the enduring character of the HIV/AIDS epidemic, and the period of time needed to achieve the expected efficiency and sustainability in preventive action. The necessity of this perspective is outlined as follows:

- The specific time dimension of the disease. Very frequently, several years will pass between the first infection, the development of opportunistic diseases and the final stage of AIDS, making human and medical follow-up indispensable during the entire period;
- The time needed to develop and implement coherent policies and achieve significant and sustainable results in prevention and care;
- Significant change in culturally determined behaviour will occur only in the long term, because it involves an in-depth transformation in ways of thinking and practices, as well as an enduring commitment on the part of populations.

ACKNOWLEDGEMENT OF UNITY/DIVERSITY/CHANGE

Various situations demonstrate both common trends and specific characteristics. Planning strategies need to combine unity, for securing the coherence of the general orientations of the action to take, and diversity, stemming from the need to adapt policies and projects to specific situations at the regional, national and local levels.

This will allow specific conditions to be taken into account, so that concrete prevention and care strategies and policies are tailored to mobilize people's response capacity.

Similarities

The most obvious common trend is the general expansion of the epidemic in the context of the globalization process. It necessitates world-wide response and mobilization, as advocated by the



UNAIDS Strategy and recent appeals of the twenty-sixth special session of the UN General Assembly on AIDS (June 2001).

As seen above, the motivations and behaviour leading to the spread of the infection, and hence of the epidemic, are globally the same, even if they vary from region to region. The indirect causes, which have a significant impact on the epidemic, are an integral part of major development issues.

Differences

At the regional level for instance, major societal and cultural differences will have to be taken into account:

- Economic, institutional and cultural instability in large parts of sub-Saharan Africa;
- Destabilizing impact of the rapid economic development and social transformation on Southeast Asian populations and their cultural values, especially women and the poor in the various communities;
- In Latin America and the Caribbean, the high external debt and low national production of basic goods in many countries result in devastating effects: the disintegration of families, the abandonment and destitution of women, and the continuously growing number of street children;
- In Eastern Europe, the rapid increase of drug consumption, linked to the crisis of value systems and social structures, and associated with the significant economic and political transition issues;
- Significant economic, social and cultural differences are also observed at the national and community levels and should consequently determine appropriate policies.

Continuity and change

Cultures change⁶. They are not static. Cultures change because human beings have the capacity, as individuals and as a collectivity, to pool their resources, to think about nature, to reflect on themselves and their social institutions. These changes of ideas are translated into new ways of living and contact with other cultures provides input opening new horizons on different patterns and ways of social organization. Communities can then reach given goals or establish new ones. This is what modernization is all about.

HIV/AIDS and Change

HIV/AIDS evolves in an environment that can change dramatically over a very short period of time: a drastic change in legislation or migration of affected population groups can make entire plans obsolete. The ability to adapt quickly to changing situations and to re-plan and support successful newly emerging initiatives is a pre-condition for effectiveness. Building flexibility into a plan and subsequently monitoring situations and responses are essential aspects of strategic planning.

Source: UNAIDS, *Guide to the strategic planning process for a national response to HIV/AIDS: introduction*.

⁶ *Toward identification of social-cultural determinants of the spread of HIV/AIDS and their incorporation in strategic plans for the control of the HIV/AIDS epidemic.* (Research document for UNAIDS by E.P.Y Muhondwa, 1999).



All cultures borrow from other cultures. They may borrow ideas (intangible culture) or artifacts (tangible culture). This selection is subject to a wide range of considerations. Consequently, it is not simply a matter of conservatism that prevents people from the adoption of new attitudes.

Due to constraints and the changing life conditions (i.e. environmental changes, lack of access to resources), people, in particularly those socially marginalized, may innovate, rebel and change their behaviours rather than keeping themselves to their cultural norms.

MOBILIZING PEOPLE AND SOCIETY

Mobilizing people is an indispensable condition for the success of culturally-appropriate preventive action. It has to be closely linked to people's cultures, value systems, and ways of thinking. This is why views on gender, health and disease, sexuality, life and death, beliefs, needs and expectations should be duly understood, assessed and reflected upon in the design of strategies and policies. These will have to be articulated so as to allow for response building at the regional and local levels accordingly.

INSTITUTIONAL/CULTURAL RATIONALITY AND HIV/AIDS

- International and national institutions generally act and react according to a rational approach, and to their professional work habits. These are based on epidemiological and medical efficiency, resulting in a purely cognitive approach of the disease;
- Societal and cultural systems operate in terms of their own rationality, combining motivations, beliefs, behaviour norms, interests and their own views of the future.

4.2.4- UNAIDS BEST PRACTICE CRITERIA

The review of UNAIDS⁷ supported projects, which involved the collaboration of traditional healers in sub-Saharan African countries, defined criteria for best practices in HIV/AIDS prevention and care. These criteria are very similar to the three basic conditions defined for developing a cultural approach in prevention and care. These criteria are as follows:

- **Effectiveness**

Effectiveness is an activity's overall success in producing desired outcomes and reaching overall objectives. Thus, to identify the effectiveness of a project, strategy or policy, one needs to define objectives and outcomes, as well as what changed

HIV/AIDS and human rights

Respect for human rights and non-discrimination are the fundamental elements of any legal and policy environment working to implement a national AIDS strategy. Experience in a variety of settings suggests that coercive and punitive measures, such as mandatory testing, detection and lack of confidentiality are counter-productive and impede efforts to prevent HIV infection and provide care.

Source: UNAIDS, *Guide to the strategic planning process for a national response to HIV/AIDS*.

⁷ UNAIDS, *Collaboration with traditional healers in HIV/AIDS prevention and care in sub-Saharan Africa*, September 2000.

while the activity was being implemented and why the change occurred.

- **Ethical soundness**

Ethical soundness is measured according to principles of appropriate and acceptable social and professional conduct. Important concepts to be considered regarding ethical soundness include: confidentiality, mutual respect, informed consent and population, community / government dialogue.

- **Efficiency**

Interest in efficiency has grown in recent years with the realization that resources are scarce and need to be used in the most cost-effective manner. The basic definition of efficiency is the ability to produce the desired results with the minimum expenditure of energy, time, financial and human resources. It is difficult to describe measures of efficiency with respect to the costs of various activities or clear measures of effectiveness at the level of strategies and policies. Moreover, their indirect costs and benefits are almost never evaluated.

- **Sustainability**

Sustainability can be described as the ability of a programme to be effective and to carry on with some degree of autonomy over the medium to long term. It is one of the most challenging issues facing HIV prevention efforts in general. One major problem is the definition and importance given to sustainability by different funding bodies. This is why a systematic approach to sustainability is needed in order to design long-term projects and measure their impact over time.

- **Relevance**

Relevance is the extent to which a project is focused on the HIV/AIDS response within a given societal context. Issues such as cultural and political factors are usually taken into account hence, measures of relevance vary widely in different contexts. Therefore, it is essential that the objectives and the approach used in the design and implementation of policies and projects are appropriate to a given context.

The definition of these criteria involves methodological choices including the motivations and conditions of behaviour change, consideration for human, social, societal and cultural aspects and the adoption of a long-term strategic perspective.

4.2.5- TOOLS AND METHODS FOR CULTURALLY-BASED STRATEGIES

CURRENT NATIONAL AND INTERNATIONAL STRATEGIES

Despite the limited availability of medical treatment and the still frequent underestimation of the non-medical aspects of the disease significant progress has been made in prevention and care in current international and national strategies (see 3.2.1 and 3.2.4),.

However, the most serious shortcoming of institutional strategies and policies is the lack of consistent consideration of the societal and cultural aspects of HIV/AIDS prevention and care. These aspects are often considered only as obstacles to the current health care and information/education/communication methods. In addition, co-ordination between institutions is



still too insufficient to ensure a wider strategy. Nevertheless, some signs of positive change can be noticed:

- Some UNAIDS co-sponsoring agencies have begun to take into account certain cultural traits in their programming and planning methods (for instance UNFPA);
- Similar evolution can be seen in some bilateral co-operation agencies and in major development NGOs.

Moreover, efforts are being undertaken to produce more comprehensive long-term policies through inter-agency projects and by strengthening the coordinating function of UNAIDS.

In this respect a particularly encouraging step was made by the Special Session of the United Nations General Assembly on HIV/AIDS (June 2001), which adopted a Declaration of commitment on HIV/AIDS *“emphasizing the important role of cultural, family, ethical and religious factors in the prevention of the epidemic and in treatment, care and support, taking into account the particularities of each country as well as the importance of respecting all human rights and fundamental freedoms (para: n° 20).*

In the same spirit UNESCO’s new HIV/AIDS Prevention Strategy is stressing the importance of “changing behaviour by providing knowledge, fostering attitudes, conferring skills through *culturally sensitive and effective communication.*”

Yet serious methodological problems still exist among UNAIDS co-sponsors and non-cosponsoring institutions of the United Nations system. The reasons for this situation are the following:

- Sector and bureaucratic divisions and rivalries persist within and between institutions, hindering the adoption of a holistic approach, resulting in overlap and considerable deficiencies in the action taken;
- There is a breach between the need for long-term strategies and the medium and short-term planning systems currently used by most institutions;
- Institutions fail to integrate cultural and societal diversities in their planning techniques, focused on quantitative objectives and “visible” and short-term results.

In order to overcome this situation, the overall aim of the current UNAIDS Strategy is to open new avenues for the development of coordinated policies by incorporating socio-cultural elements, in order to:

- Provide the major protagonists of HIV/AIDS prevention and care activities with a global, long-term representation of the process in which they are involved;
- Co-ordinate and integrate prevention and care policies at the international and national, governmental and non-governmental, public and private levels.

MALAWI: a culturally-based institutional assessment

Recognition of the importance of culture

There are many organizations involved in activities geared towards minimizing the spread and effect of HIV/AIDS in Malawi. All the institutions identified in this study are in one way or another involved in the battle against HIV/AIDS.

Most of the institutions surveyed recognize, in principle, that culture is an important aspect of the war against HIV/AIDS. Hence cultural aspects are, to a limited extent, taken into account when implementing HIV/AIDS programs.

Insufficient consideration of research on the subject

A number of research studies have already been undertaken and have proposed some strategies for combating the epidemic. However, most of the results of research are not used by organizations and institutions working on HIV/AIDS because of the lack of accessibility to these studies.

About 90% of the institutions surveyed indicated that they are not aware of any other research being carried out. Lecturers at the Demographic Department in Chancellor College of the University of Malawi actually said they did not have access to research from other institutions. Yet the Center for Social Research which carried out quite a lot of research is part of the University of Malawi.

While some cultural factors concerning HIV/AIDS vary depending on the tribe or ethnic grouping, a good number of them are similar. Unfortunately, in the current state of affairs, the fruit of this research is wasted for researchers and even more for decision makers

Lack of proper networking

There seems to be a notable lack of networking among institutions working on HIV/AIDS. Most institutions are involved in the same type of activities, related to HIV/AIDS and culture, inevitably targeting the same population groups. This also explains why most of the activities undertaken by the institutions, even though they address cultural aspects, are not based on research findings in this area, as there is no link between research work and institutional activities. This lack of networking could also be explained by the fact that most NGOs working on HIV/AIDS target the same donors. The Officer of the coordinating body of NGOs in Malawi (CONGOMA) says as much when he notes that one of the problems faced by NGOs in Malawi is that they tend to hide or withhold information. For example, most of these NGOs indicate that they have heard of some research through seminars, workshops, or have come across it when reading a newspaper or listening to the radio. The institutions, which originally carried out the research are not cited as a direct source of information.

Duplication of efforts

Due to the lack of networking most institutions are involved in the similar activities related to HIV/AIDS and culture. This could be advantageous if carried out in different parts of the country, because of the similarity of some cultural factors. Duplicating efforts is a waste of resources, since the curbing of HIV/AIDS depends on the efficient use of available resources, specially countries, where rampant poverty, is the hardest.

Since the epidemic has struck in developing countries where rampant poverty is widespread.

Lack of flexibility

For some institutions, implementation requirements/procedures and policies are not flexible enough to allow cultural features to be taken into account, particularly positive ones (e.g. abstinence), which they think would have a negative impact on their primary objective. Population Services International (PSI) is suspicious when people question them on cultural issues in relation with HIV/AIDS. This is probably because, in their view, if people heed the gospel of abstinence, this would greatly reduce condom sales. On the other hand, condom use is sometimes considered indecent. For example if a widow is supposed to sleep with someone so as to cleanse herself of her dead husband's spirit, the risk of HIV/AIDS contamination would be reduced by using a condom but this may be unacceptable according to traditional behaviour rules.

Community involvement in NGOs projects

One strategy most institutions use in dealing with the cultural aspects of HIV/AIDS is total involvement of the community at the grassroots level. The Salvation Army HIV/AIDS Programme task forces, for example, include community leaders (e.g. traditional chiefs). This enables people to be brought together more easily and facilitates the acceptance of external messages. Other NGOs, such as Action Aid and the National Family Planning Council, frequently work with community based groups, on voluntary basis, addressing issues of HIV/AIDS and culture.

Integrating positive aspects of culture

The National Youth Council of Malawi has the important task of promoting positive cultural practices like abstinence. They are also planning to find suitable substitutes for drug and alcohol abuse, as these have a lot to do with the spread of HIV/AIDS among the youth. The Council believes that fireside stories, which have virtually disappeared, are one cultural tradition that could be used to instill good behavior principles among youth.

In its campaign against HIV/AIDS in rural areas, the Media and IDAs Society of Malawi (MASO) observed that there were big problems in rural areas linked to limited access to radio and newspapers. They have consequently integrated their message into traditional dances, songs and other forms of cultural expression.

Source: *A cultural approach to HIV/AIDS prevention and care: Malawi's Experience, UNESCO, 1999.*



CULTURALLY-APPROPRIATE PREVENTION AND CARE PLANNING PROCEDURES

Incorporating a cultural approach to prevention and care strategies and planning systems requires the following changes:

- Acknowledgement and review of the cultural interface between the industrial and pre-industrial development model, defining cultural criteria for relevant prevention and care strategies for developing and developed countries;
- Defining major common objectives, as well as regional and national cultural components in international strategies: integrating similarities and opening space for the specific rationality of different cultures when targeting more limited action areas;
- Improving co-ordination between strategies and actions of the various institutions involved and stimulating inter-institutional initiatives between UNAIDS co-sponsors programmes and administrative structures;
- Adopting a bottom-up approach in collecting information from case studies and using feedback for building future strategies and improving strategic frameworks;
- Adapting chronological time frames to the pace at which societies evolve towards collective behavioural change.

INDISPENSABLE REASEARCH TO BE CARRIED OUT

- Analysis of functional triangular interactions between culture, development and HIV/AIDS as an overall process;
- A more in-depth study of the concept and contents of an “enabling environment”, including cultural confidence and trust, and more efficient prevention and care;
- Drawing up comprehensive plans of action for prevention, support and impact reduction, defining role distribution, priority areas and types of action to be carried out, adapting information and evaluation tools, establish new partnerships, etc;
In order to take diversity fully into account, defining key policy variables per region, country and sub-national entities.

EXISTING INSTRUMENTS TO BE MORE WIDELY USED OR ADAPTED

In order to achieve culturally-appropriate institutional strategies and policies, it is indispensable to use relevant methodological instruments. Some of them already exist; others have to be adapted or even developed through specialized research.

Improved use of existing information in order to:

- Systematize the flow of information on the interactions between cultures, development and HIV/AIDS. General and specific interrelations should be considered. This can be achieved through:



- Improving collection and processing of primary data (with special emphasis on regions where the available cultural, anthropological, sociological, ethnographical, historical, geographical information is still insufficient or non-existent, for example in Africa, certain areas of Asia and the Pacific, Latin America, etc.);
 - Developing secondary information analysis and literature review;
 - Strengthening or networking specialized data banks.
- Enhance informal or formal networks of fieldworkers, resource persons, and people experienced in collecting information. In the field, these are indispensable partners for assessing and investigating current situations regarding HIV/AIDS.

Promote planning systems compatible with a cultural approach:

To some extent, new planning systems already in use in certain institutions tend to integrate the concern for a cultural approach in response to HIV/AIDS issues. Nevertheless, they tend to focus on cultural factors as obstacles and pay less attention to cultural resources and the interactions between the disease, development and cultures. Wider use could be made of the new planning systems in prevention and care strategies and policies. Attention in this respect should focus on the assessment of their efficiency and sustainability.

NEW INSTRUMENTS TO BE DEVELOPED

The development of new instruments should take into account behaviour change or continuity and the deeply embedded motivations of populations to participate in given HIV/AIDS prevention and care policies, programmes or projects.

Relevant methodological tools to develop in this respect should make it possible for the following activities to be carried out:

- Modeling (cultural interface between industrial and pre-industrial societies);
- Dynamic system analysis of actors, factors, levels and fields of action;
- Prospective and forecast studies/scenarios, long-term appraisal of strategies;
- Geographical representation of cultural diversities and similarities (cultural areas);
- Participatory observation and research/action at field level;
- Evaluation of **unconfirmed forecasts** in prevention and care strategies and policies and **unforeseen continuities or changes** in the populations value systems and behavior norms in relation to HIV/AIDS, when faced with socio-economic and macro-cultural upheavals (risks of armed conflicts, etc.) entailing project failure.

CULTURAL INDICATORS OF BEHAVIOUR CHANGE

Formulating a coherent and exhaustive set of cultural indicators in behaviour change is a highly complex methodological problem. At the present stage of research, it is impossible to establish a general conceptual framework and to define valid cultural variables for different situations. The search for a generalized global reference system, the multiple dimensions of the issue and the disparities and cleavages observed within each society at the international level must be considered.



However, it is already possible to identify the cultural indicators which should be taken into consideration in order to appreciate significant changes in sexual and non-sexual behaviour linked to HIV/AIDS:

- Testing the acceptability of present methods in HIV/AIDS prevention and care (medical and technical rationality limits);
- Cultural mobilization of populations and their capacity to fight the epidemic;
- Similarities and differences between indicators of cultural development, qualitative and human development, as initiated and used by UNDP.

It remains that institutions and populations will not regard signs of change from the same point of view. Thus, their indicators will show important discrepancies and their convergence will raise difficult methodological problems.

Institutional indicators

Cultural indicators are considered objective by institutions, when they reflect the technical and administrative perception of issues and changes subsequent to their actions. The definition of these indicators was first formulated in order to appraise the cultural dimension of population problems, an area where numerous studies, analyses and data already exist.

For example, the analysis of nuptial models made by the Economic Commission for Asia and the Pacific (ESCAP) cross-tabulates data concerning women at the age they first marry with direct or indirect socio-cultural characteristics: place of residence, ethnicity, religion, education, employment.

Population indicators

Alongside institutional indicators, it would be worthwhile to study the possibility of establishing indicators which reflect the perceptions of the populations. In other terms, this should help to build measurement tools formulated by a given group as a way of expressing its perception of its economic, social, political, cultural, environmental and spiritual welfare in relation to prevention, care and its capacity to cope with the epidemic. These indicators may, in certain cases, coincide with indicators usually employed by institutions' specialists. In other cases, they may be completely different.

4.2.6- INSTITUTIONS' RENEWED ROLE AND MODES OF ACTION

Designing new strategies and policies for modelling prevention and care within a cultural context necessitates new proposals concerning the role of institutions and their modes of action.

These proposals require a review of:

- The communication procedures within and between institutions and the field on the epidemic's evolution and the action taken;
- The collection of information concerning socio-economic, societal and cultural aspects with respect to prevention and care;
- The prevailing criteria of direct and short-term efficiency, mostly expressed through quantitative results, in view of progressing towards long-term sustainability and qualitative changes.

Regarding the information-communication procedures within and between institutions, coordinated action and information flow are supposed to be current practice. In fact, many obstacles and shortcomings have to be tackled in day-to-day activities in spite of the various coordinating mechanisms established at national and inter-agency levels.

The communication process within institutions should be remodelled, with special emphasis on the following points:

- Consultation/decision making interaction;
- Levelling budgetary/administrative/“human development” discussions;
- Plurality in planning hypotheses;
- More direct and wider consideration of feedback in finalizing top-down decisions.

It is indispensable to pay particular attention to developing qualitative information data from the field in order to define and “contextualize” quantitative data concerning the epidemic (e.g. infection, mortality, mother-child transmission of the virus, etc.) and cultural habits (e.g. the case of midwives and traditional medicine).

Another useful instrument could be a cultural self-evaluation questionnaire, such as the one elaborated by WHO and presented below:

WHO: Proposed questionnaire for cultural self-evaluation

1. Policy-makers and decision-makers

Do cultural considerations play a sufficient part in analysis by policy- and decision-makers in the health sector generally and at WHO?

Why is more attention given to the culture/development interactions among fieldworkers than among policy-makers?

What are the connections between WHO in general and field activities in this sector?

How can WHO's various echelons be reminded of the importance of cultural considerations in developing field actions in the health sector (balance between the administrative logic of the internal bureaucracy and cultural considerations)?

Do cultural concerns permeate the thinking and analysis of decision-makers and policy-makers and the design of strategies and programmes? How are cultural considerations reflected in the allocation of resources and the approval of projects and programmes?

What are examples of situations in WHO's work where cultural aspects are (or are not) of prime importance?

2. Economic feasibility

Does integrating the cultural dimension into programme and project planning represent an additional budgetary burden or does it result in budgetary savings or greater efficiency in the use of funds?

Have the socio-cultural costs and benefits of projects in the health sector, or related to health, been estimated (socio-cultural consequences, consequences for the environment or for sustainable development)?

When and how is the cultural dimension integrated into the design of a health reform policy or plan in a developing country subject to economic reforms and structural adjustment measures?

Are cultural considerations taken into account in evaluating the economic feasibility of a given health technology, and how?

3. Programme planning and management

Do work plans for health programs and budgets include specific indications relating to cultural considerations?

What is WHO's position or recommendation in situations where the national government is not sensitive to the interactions between decisions or policies on health action and cultural habits (for example, the case of midwives or traditional medicine)?

Are cultural considerations more important in some programs than in others?

Do certain WHO programs have no need to take the cultural dimension of health or health activities into account?

How is WHO's work integrated into cultural concerns, and vice versa, in sectors involved in health strategies and policy, sustainable and human development?

Does decentralized management of health care systems, as recommended by WHO, provide support for focusing more attention on cultural considerations and culture as a point of entry and a lever for health and health promotion work?

4. Managing cultural cleavages

How does WHO deal with cleavages between the cultural aspects of scientific knowledge and traditional cultures and customs?

For example:

Various forms of perception tied to culture: perceptions of the future (the need to plan, to understand the importance of prevention); of time (interpersonal relations and the time dimension of development and the processes of change); and of the need to maintain equipment and complex technologies; cultural perceptions and values relating to health and social welfare.

Does WHO take into consideration its role as a vector of institutional and administrative culture, of private sector and market economy culture, of management, and the connections between the compatibility of these cultural inputs and local cultures?

How is the transition managed if the imported culture is considered to be advantageous in terms of health objectives, <when faced with cultural cleavages or incompatibility?

Is an effort made to evaluate the undesirable but foreseeable effects of this incompatibility with the local context before adopting policies and strategies, which are considered to be culturally incompatible?

5. Health research

How is cultural research translated into tools and methodologies and into the policies and strategies that the Organization undertakes?

Are the results of this work used in preparing new manuals, guides, directives and other tools?

How does WHO use these results for decision-making at the central level?

Does WHO analyze the reasons for accepting or rejecting the cultural aspects identified by this research?

Does WHO use results achieved by other institutions in research on the cultural aspects of health issues?

6. Health professionals

How could cultural sensitivity be developed among health professionals (systems for monitoring, encouraging, training, etc.)?

Source: WHO, *Internal Document provided by the Inter-Agency Relations Division, 1994.*

A more structured response could be elaborated in terms of:

- Centralization/decentralization of decision-making and services;
- Enhancement of bottom-up demand.

Inter-institutional communication processes should be intensified at all levels in order to design joint strategies, projects and fieldwork in particular, through theme groups and internet information sites.

At the national level, designing policies for HIV/AIDS prevention and care might also require **National Cultural Assessments (NCA)**. These should consist of collecting and analyzing



information and resources on the cultural specificities of the countries in order to design policies based on a culturally-sensitive approach to prevention and care. The conclusions drawn from NCAs may later be used to draft concise documents at the sub-regional and regional levels.

4.3- MAIN ACTION PRIORITIES

As a follow-up to building appropriate new strategies and policies for prevention, support and the reduction of the social, economic and cultural impact of the epidemic, priorities have to be defined. These priorities are urgent key action programmes designed to achieve significant changes at all levels (national to local) and developing joint action between institutions and society.

More specifically these priorities are:

- developing culturally-appropriate communication for behaviour change (including education and media information);
- renewing subsequently preventive education concerning the risk of infection and developing solidarity towards infected and sick people;
- enhancing joint mobilization of the institutional network and the civil society;
- building community-based response as the cornerstone of this joint action;
- redefining the specific responsibilities of institutions;
- developing training/sensitizing/capacity-building for all stakeholders.

4.3.1- CULTURALLY-APPROPRIATE COMMUNICATION FOR BEHAVIOUR CHANGE⁸

Elaborating culturally appropriate behaviour change communication is a crucial instrument for building a sustainable and appropriate response to the challenges of risk and vulnerability to HIV/AIDS.

Fostering a better understanding of the HIV/AIDS related challenges facing populations should result in HIV/AIDS becoming a high priority for the populations themselves. This will result in the development of a sense of responsibility and a focusing of energy towards mobilization on the part of the population.

This requires that the following activities be carried out:

- **Methodological research to:**
 - Evaluate the cultural relevance of the current Information/Education/Communication (IEC) practices;
 - Understand people's cultural references and resources;
 - Identify the societal/cultural conditions for people's sensitization and mobilization.
- **Identify the specific demands and needs of the target audiences,** in respect to their relation to HIV/AIDS, their socio-economic situation, specific risk behaviour and relation to society at large;

⁸ A detailed description of methods for culturally appropriate communication for behaviour change is given in the handbook specifically devoted to this question.



- **Developing proposals for a cultural approach to appropriate IEC materials and processes for prevention and care** based on a combined elaboration and the delivery of relevant messages.

4.3.2- RENEWED PREVENTIVE EDUCATION: AN URGENCY (RISK AND SOLIDARITY)

After a first phase of action focused on health and medical care, within the limits of the epidemiological approach, education (and to some extent media information) has become the second major instrument used to spread the prevention of the risk itself and the practical protection measures it implies.

However, its limited results have raised growing concerns as to the real efficiency of preventive education campaigns. It becomes more and more patent that in fact, even when preventive education messages are well received and intellectually assimilated, very frequently their content is not appropriated in practice by populations, especially children and adolescents, and does not entail behavioural changes and solidarity towards the infected and sick people.

The reasons for these insufficient results are probably linked to the lack of distinction between preventive education and school instruction. In addition, school instruction is too often limited to the one-way transmission of purely cognitive information. Thus, in spite of the unique and indispensable capacities of the school system, it remains that by definition, it does not reach children and adolescents who cannot attend school (up to 80% in certain countries). Moreover, illiteracy rates among young people and adults above fifteen, especially girls and women, are still very high in numerous countries (above 75% in some cases).

For these reasons and fundamental considerations, preventive education has to be envisaged through all possible channels, including non-school educators such as social workers, NGOs, business people and entrepreneurs, associations and movements, sports groups, ethical, religious and traditional community educators.

From another point of view, educational material should not be “pre-cooked”, but emerge gradually from the educational process itself, from an empathic dialogue and on the basis of people’s societal and cultural values, behaviour norms and understanding capacities.

To this effect, preventive education has to be remodeled in depth, in order to adapt it to the actual diversity in people’s representations and styles of life, language and sexual habits, and also to their daily life conditions. Only through this approach will people accept to question their practices and motivations, thus giving genuine attention to new ways of considering their personal and collective priorities for the future, and begin to change their behaviour accordingly.

4.3.4- BUILDING COMMUNITY-BASED RESPONSE⁹

Involving people in the battle against the epidemic is of prime importance. In other words, building an appropriate and sustainable response to HIV/AIDS means that people have to be involved personally: at home, in their neighbourhood and at their work place. Each individual, family and

⁹ Barrière Constantin (Luc) UNAIDS *Key concepts of the local responses agenda. Presentation of the local responses team during the regional workshop on « Cultural Approach to HIV/AIDS Prevention and Care. »*

community can become “AIDS-competent” by assessing how AIDS affects various aspects of their lives and by taking concrete measures to minimize its impact at the local level.

In order to change their behaviour, people need a supportive environment. Developing partnerships at a local level can improve the effectiveness of their response. Thus, a well-supported mobilization process should result in numerous local initiatives. Sustained behavioural change comes as a result of a shared social reaction and a clear understanding that disease and death are the direct consequences of HIV/AIDS for ones self and one’s family.

As a consequence, it should be emphasized that interventions proposed by experts and planners have to be appropriated and implemented by people and communities. In this process, socio-cultural determinants may greatly influence the assessment and reaction of the community on HIV/AIDS issues. Thus, it is indispensable to learn and understand, at the local level, how the various actors have handled the assessment and response process. Experts and planners must, therefore, change their action modalities from a “control” perspective to an “influencing” perspective.

4.3.4- JOINT MOBILIZATION OF THE INSTITUTIONAL NETWORK AND THE CIVIL SOCIETY.

Community-based prevention and care projects can only be designed, carried out and evaluated successfully through a continuous exchange process with the target populations, whether non-infected, HIV-positive or sick. This is necessary in order to fully understand their concerns, priorities, and make full use of their own cultural resources and power of mobilization. Effective partnerships can, thus, be built between the institutions, networks and society.

4.3.5- SPECIFIC RESPONSIBILITY OF INSTITUTIONS

Regarding government strategy and policy, key elements for mitigating the impact of the disease on infected and affected people include the following measures:

Mitigating the impact on people infected by HIV/AIDS

- • Credit programs to mitigate the effects of HIV/AIDS on households through credits geared at maintaining levels of household expenditure, school attendance, etc.;
- Benefit packages to mitigate the impact of HIV/AIDS on families and children, targeting them, including the provision of food (at school), school vouchers, and school uniforms;
- Legal reforms or aid for vulnerable groups, such as the widows and children of those who have died from HIV/AIDS, who often risk loss of property or autonomy due to existing inheritance laws or traditions;
- Workplace interventions to maximize continued labour force participation;
- Home based care in households in order to enhance the quality of life of people living with HIV/AIDS;
- Community-based self-help groups for individual and family support, to ensure the continued participation of children in school, to maintain household expenditure patterns, and to promote savings.

Key interventions in reducing vulnerability of specific population groups

- Legal review and reforms aimed at changing laws and government policies, which make it difficult for vulnerable groups to protect themselves. For instance, laws which make sex work illegal, especially if applied aggressively, may discourage sex workers from seeking help;
- HIV/AIDS education campaigns in schools and in the workplace;
- Better accessibility to education for youth, especially girls;
- Military programs undertaken by the armed forces, specifically targeting their personnel, who are both highly vulnerable and receptive to HIV/AIDS prevention and education campaigns;
- Programs targeting persons in jail.

4.3.6-TRAINING/SENSITIZING/CAPACITY BUILDING

Training/sensitizing decision-makers in culturally-appropriate HIV/AIDS prevention and care strategies and policies means not only developing techniques, skills and know-how, but also changing attitudes and understanding capacities. Self-evaluation sessions on the compatibilities and discrepancies between institutional cultures and local people's cultural habits and ways of thinking as well as defining convergence modes between institutional and people's rationality is then possible.

This requires the elaboration, in a research-development perspective, of training programmes aimed at helping decision-makers, project planners and managers to integrate cultural references into strategies, programmes and project design and implementation. As a general rule, this should be a two-way learning process, an exchange of experience between decision-makers and practitioners.

WHO SHOULD BE TRAINED/SENSITIZED?

High and medium level decision-makers

Planners, scientific and technical specialists, medical and health programme leaders, in national and international institutions:

- Theme Groups;
- National health and HIV/AIDS planning and administrative committees;
- Educational and media specialists (see above).

Field-level actors

- Fieldworkers: local stakeholders: religious, spiritual, political (traditional chiefs)

Capacity-Building

Like many other externally driven actions, the strategic planning approach has no chance of surviving in the long term unless national and local planners have internalized this method. Hence, the capacity-building of local staff is critical in order for the process to gain the necessary momentum to affect the national, regional and global response to HIV/AIDS. As stated above, the regional networks of technical support will be used for that purpose, but the best way of learning is active involvement in the real life exercise.

Source: *UNAIDS Guide to the strategic planning process for a national response to HIV/AIDS.*



CULTURALLY-APPROPRIATE TRAINING METHODS

Category 1: senior officers

- Pre-service Training

Understanding and using the cultural approach should be part of the various training programmes at the post-graduate level. It should include academic material from the social and human sciences, supplemented by field sessions, for instance in the curricula of high-level medical schools and universities; public administration institutes and specialized economic and social management training institutions. Another possibility would be to have senior officers go through a twofold training system: medicine and anthropology.

- Sensitization and updating seminars and retreats

As most high-level and medium-level decision-makers have had specialized university and post-graduate education, short sensitizing and updating sessions could be envisaged for them. These could be organized as specialized in-service seminars and retreats and/or brief and intensive courses.

Category 2: Medium-level professionals

- Teachers, school-masters, social and welfare workers;
- Medical and nursing staff when needed;
- Press or media journalists.

Category 3: Field workers¹⁰

¹⁰ The training of fieldworkers is described in detail in the Handbook *Fieldwork and Building Local Response*.

4.4- SUMMARY

The ways and means for building culturally-appropriate response to risk, vulnerability, prevention, care, support and impact reduction can be summarized in the following methodological check-list:

- These challenges cannot be addressed only in medical and cognitive terms, but within the framework of integrated economic, social and cultural strategies and policies;
- General rules for building relevant policies are the following: political will and leadership, social openness, involvement of a wide range of actors, social policy reforms (health, education, reduction of inequities), adequate financial and human resources.
- Key Principles:
 - Adopting a comprehensive approach, planning in a long-term perspective, with emphasis on the sustainability of measures and their enduring effects;
 - Acknowledgement of need for at the various levels of strategies and policies, continuity and change in situations and institutional response;
 - Mobilization of people and society through identification of converging views in institutional and cultural rationalities and motivations regarding HIV/AIDS.
- Best Practice criteria as defined by UNAIDS:
 - Effectiveness;
 - Ethical soundness;
 - Efficiency;
 - Sustainability;
 - Relevance.
- Tools and Methods for culturally based strategies and policies:
 - Provide the major stakeholders of HIV/AIDS prevention and care with a global and long term representation of the process in which they are involved, in order to better coordinate and integrate policies at all levels.
 - New instruments for planning procedures:
 - reviewing and mapping at the macro level;
 - defining the interface between the pre-industrial and the industrial model in relation to HIV/AIDS global crisis and international response;
 - research and development of common and alternative policy scenarios reflecting diversity in situations;
 - better integration of institutional strategies and stimulation e of inter-institutional initiatives;
 - adoption of a bottom-up approach and an adapted chronological time frame in planning and implementing strategies and policies.
 - Ill-identified and crucial issues remain to be researched:
 - mutual interactions between culture, development and HIV/AIDS;
 - concept and contents of an “enabling environment”;
 - comprehensive plans of action, role distribution, information and evaluation tools, key policy variables.

- Some already existing instruments have to be more widely used or adapted:
 - Systematizing data collection;
 - processing and circulation of available information;
 - promotion of new planning procedures which account for a cultural approach.
- New instruments have to be developed regarding the global dimension of the HIV/AIDS crisis and its time and geo-cultural aspects; theoretical and practical criteria for facilitating joint action/ research/ training experimental policies; developing cultural indicators of behaviour change for institutions and populations.
- In this context, the roles, modes of action and mechanisms currently in use within and between institutions have to be reviewed and remodelled;
- Main action priorities for strategies and policies can be listed in specific terms:
 - Methods and contents of culturally-appropriate communication for change in behaviour ;
 - More specifically, renewed preventive information and education (risk and solidarity);
 - Involvement of local stakeholders and populations, in order to build community-based response;
 - Consequently joint mobilization of the institutional network and the civil society and redefinition of institutions;
 - Training/sensitizing/capacity building as a key instrument in this respect.

5- GENERAL CONCLUSIONS

From the outset (1996), the establishment of the Joint United Nations Program on HIV/AIDS (UNAIDS) inaugurated a new approach to the disease's prevention and care. The first expressed requirement was the need for inter-institutional and inter-partner co-ordination in fighting the epidemic. This necessity itself opened new avenues for building a trans-institutional strategy, making it indispensable to take a comprehensive approach to prevention and care.

For the same reasons, UNAIDS emphasized the need to pay full attention to the multidimensional configuration of the issue and subsequently to take an overall view of strategies and policies, in order to build and "contextualize" the crisis in its environment.

With a view to meet this concern and along the same lines, the UNESCO/UNAIDS Joint Project, launched in 1998 under the title "A Cultural Approach to HIV/AIDS Prevention and Care", represents a new effort towards finding solutions to this apparently insuperable challenge, on the basis of a double assumption, which points at requirements similar to those of UNAIDS strategy: the need to tailor action's content and pace to people's mentalities, beliefs, value systems and mobilization capacity and the subsequent task to modify accordingly international and national strategies and policies.

In the present booklet, three major issues have been considered in this respect:

- Preliminary in-depth rethinking of current policies and strategies in relation to prevailing direct and indirect risk practices and field situations;
- Issuing new proposals for more efficient, relevant and sustainable prevention, care, support and impact reduction strategies and policies;
- More specifically, identification and implementation of the following action priorities:
 - Joint mobilization of the institutional network and the civil society;
 - Building of community based response prior to defining the specific responsibility of institutions;
 - Renewed preventive education concerning risk and solidarity, as a key aspect of culturally-appropriate communication for behaviour change;
 - Training/sensitizing/capacity building at all levels: beyond technical, scientific and administrative skills, opening a broader view of the societal and cultural environment of prevention and care among professionals involved in implementing strategies and policies.

N.B: As mentioned in the foreword of this booklet three other practical handbooks will be devoted respectively to: project design, fieldwork and appropriate-communication for behaviour change.

