Information and HIV/AIDS in Mexico: Towards building an appropriate system for public documentation?

Celso M. Musiño & Oscar Maya Corzo

Introduction

This paper describes the relation between mankind and diseases. HIV/AIDS is no exception; since it first appeared on the scene; many sectors within society have searched for ways to reduce its impact. Therefore, we consider that a better informed society can generate answers on this scourge and find effective alternatives to reduce and prevent the impact of the pandemic.

The paper provides a general view of the HIV/AIDS situation in Mexico and its impact over the last years, as well as discusses national, regional and worldwide proposals, and actions taken by institutions engaged in the fight to prevent and control HIV/AIDS. We also include examples of some of these initiatives such as international congresses, paper presentations, advocacy and promotion activities, and articles in the media.

Information and its social interaction involves the design of programmes and development of promotional and educative materials by representatives of national bodies responsible for national politic, and educational and research institutions, as well as NGOs and CSOs.

We conclude that due to the fast growing of HIV/AIDS, information professionals should collaborate more actively in the organisation and systematisation of documental information systems, using the Technology of Information and Communication (TIC's) as a crucial resource.

Our relation with diseases

The relation between mankind and diseases has always been painful. Characteristics such as beauty, youth, and strength are related to health, and so are values associated with dignity, honour, and forgiveness. An often repeated saying runs: *Mens sana in corpore sano:* "A healthy mind in a healthy body." For the ancient Greeks and Romans, it was vital and unimaginable to understand diseases and their explanation as part of nature. Diseases could have a number of causes - biological, physical, chemical, environmen-

tal, economic, and social - and the general reaction to them was to despise, marginalise, and forget the ill that were considered pariahs - the undesirables. While causes of diseases were analysed, the results had no relevance, and the explanations for anomalies (diseases) were philosophical, magical, and religious founded. They took promptly care of illnesses of short duration, and accidents but not of the chronic diseases.

This historic overview allows us to identify the symbolic, economic, and social relations established by people and conclude that diseases are mirroring a confrontation between life and the possibility of death. Leprosy is mentioned in the Bible as a divine disease meant to punish impious, and the plague, a common scourge during medieval times, was attributed to God's ire. During the Renaissance and the era when syphilis was discovered, diseases were considered a symbol of mundane excess and lightsome behaviour. In the 19th century, tuberculosis was associated with the tragic destiny of the great romantics, who gave us a rich literary, artistic, and musical legacy. At the beginning of the 20th century, the horrors of the influenza epidemic were related to unhealthy conditions of industrial development in spite of the cult of hygiene. Cancer in its multiple variations was associated with new products saturated of harmful substances as a consequence of the lack of control of industrial processes. The disease of diseases: Acquired Immunodeficiency Syndrome (AIDS) scared many during the last century.

The use of information related to these diseases is important. In particular when medicine and health sciences consolidated and acquired an undeniable prestige, the use of scientific systematised data determined the correct answers and the decision making processes. It is vital to state that information is a mental process that aligns different components to resolve a need or a problem. Besides data, information is composed by ideas, symbols or a set of symbols with a potential meaning, "*information reduce uncertainty and help to make decisions*" (Faibisoff 1976:3), this is one of the basic principles of science and its methods. Specialised information generated by medical centres, research groups, academic circles, and professional practices is produced in big volumes and has a surprising quality. As a result, the use of information, organisation mechanisms, and management of specialised health information is common practice.

Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome (HIV/AIDS)

At the end of the 1970's, the trust in technologies, economic stability, and progress was undeniable, and society's control over most diseases evident. Nevertheless, in the mist of this perception of well-being, signs of an unknown and lethal disease occurred. At first, it was called the pink cancer (it was believed to be a rare disease attacking almost only men having sexual relations with other men) and it was identified with promiscuity among drug addicts (and promiscuity in general) as well as with donors or recipients of blood. As it rarely happens, the scare of this new mortal disease spread around the globe, having its epicentre in the prosperous North America. In the first years, negative values were associated with the disease now known as AIDS caused by HIV (Human Immunodeficiency Virus). Those values decisively impacted the ill (social and family status, sexual

orientation, and racial identification), and his immediate environment. This formed a complex picture where information played an important factor against terror, fear, anguish, uncertainty and other feelings generated by the geographic spread of the epidemic.

By the end of 2004, UNAIDS estimated that 39.4 million people in the world live with HIV: 37.2 million are adults of which 17.6 million are women, and 2.2 million are minors of 15 years and under. Each day, 14,000 people around the world are infected with HIV; thus 4.9 million people were infected in 2004, and approximately 50% of the new cases were found in young people between 10 and 24 years old. To compare with "only" 3.1 million died of AIDS in 2004. Even though Latin America and the Caribbean experienced a more recent epidemic, the number of HIV infections went beyond 2 million (1.7 million in Latin America and 440,000 in the Caribbean). The concern is that the Caribbean has become the second most AIDS infected region in the world after Africa, with a prevalence of 2.3% among the adult population (CENSIDA 2006). The patterns among vulnerable groups are relatively stable but, there are new actors on the scene: heterosexual women and children. This makes it difficult for poor countries to provide the services needed.

HIV/AIDS in Mexico

Due to Mexico's close location to the United States, the country already in 1982 received the first reports of an unknown epidemic attacking certain groups of the population. Since that very moment, the public health system and some NGO's showed an interest in this health problem that threatened to reach an alarming level as documented by European and American doctors. The first measures taken were preventive; however, the development of AIDS was increasing over the years. This was documented at an acceptable level of precision in medical information, current epidemic statistics, and in papers on the advances and newest discoveries. Probably resulting from the worldwide tendencies to label HIV/AIDS as a priority issue for public health authorities, Mexico supported the creation of an information system dedicated to one of the most well-known and puzzling epidemic in history. In this context, the situation in Mexico is parallel to that of the rest of the continent, and in the world.

From the start of the epidemic and until November 15, 2005, the National Registry of Cases of AIDS has listed 98,933 cases with a distribution of 83.3% males and 16.7% females; that is five: one. The higest number of registered cases (78.9%) is found in the group of 15 to 44 years old. Sexual transmission is the cause of 92.2% of the registered AIDS cases in Mexico: 47.7% are males having sex with other males, and 44.5% are heterosexuals. A total of 5.3% of the cases were originated via contact with blood - of which 3.6% were infected via blood transfusion - another 0.7% derives from drugs consumption with hypodermic needles, 0.6% from blood donors, 0.4% from haemophiliacs, and less than 0.1% from infections caught at work. The prenatal transmission represents 2.2% of the total cases; and a combined category of males having sex with other males, and drug users infected via hypodermic needles, represents 0.3%. The risk factor for one of each three cases (37.8%) is not known (CENSIDA 2006). Global statistics state:

"Considering the total number of reported cases,

> Mexico is in the third place within the American continent, after the United States and Brazil. However, according to HIV prevalence, Mexico is in the 23rd place in America and the Caribbean, and it is the 77th worldwide." (CENSIDA 2006)

Beyond documentation and specialized data publicly available, the popular perception of causes and consequences of the disease is generally determined by the mass media, rumours, prejudices, and disinformation. Moral lynching and social stigma are frequent; and so are negative press coverage - ranging from exclusion and violation of human rights to hate crimes. However, sensibility and tolerance campaigns supporting those infected and their families started in the 1980's with the establishment of CONASIDA (National Committee to Prevent AIDS), and NGO initiatives that focused on a better informed public, particularly in the cities. Slowly, the effects of the many campaigns taken place in the federal capital are seen. They have inspired authorities of state capitals and cities - even municipal administrations. The rural areas present a high degree of marginality in this context, and information about HIV/AIDS is rare and of bad quality.

Institutional actions to prevent and control HIV/AIDS

Since the first HIV/AIDS cases were detected, health institutions have taken measures towards the fast and dangerous transmission of the disease. Their actions are founded in three rationales: *"a) fast and invasive start among social stigmatized groups to avoid the fatal affects of the disease b) its transformation into a fast growing scourge within the area, and c) the research results of number of disciplines."* (Benitez 1990; 52)

To answer the call of the World Health Organisation (WHO), Mexican institutions formed the National Committee to Prevent AIDS in 1986, from 1988 known as the National Council to Prevent and Control the Acquired Immunodeficiency Syndrome (CONASIDA) a body of the Health Secretariat. CONASIDA had more autonomy and institutional pull and worked with noticeably efficiency. However, Mexico like other Latin American countries has a tendency to create and rename public bodies depending on the government in power. The order to modify CONASIDA was executed on July 6, 2001, voiding the 1988 order to recognise it as a government institution. After this change, CONASIDA became the National Centre to Prevent and Control HIV/AIDS (CENSIDA). As established by the Official Diary of the Federation on July 5, 2001, the new role of CENSIDA is exclusively coordinating: to strengthen actions to promote; and to support prevention and control of HIV/AIDS and other sexually transmitted infections. Before 2001, the following institutions participated in the work of CONASIDA: the Secretary of Health and Public Education, Director General of the Mexican Institute of Social Security (IMSS), the Institute of Social Security and Services for State Workers (ISSSTE), and the National Institute of Nutrition and Medical Sciences "*Zalvador Zubiran*" - one of the pioneer institutions that runs high quality programmes to control and follow up HIV/AIDS.

Since 1988, economic support from the government and the WHO (via the *Pan-American Health Organisation*) had been assigned to national programmes trying to prevent AIDS in Mexico. The country's national health system is responsible for the execution of actions regarding HIV/AIDS as well as for the

provision of specialized information and guidelines to support the work of CENSIDA. The Health Secretariat (SSA), IMSS and ISSSTE maintain and manage federal health services integrated with state services via a net of clinics, hospitals and institutes that serve (with varying degrees of effectiveness) HIV/AIDS patients. The national health system also generates the largest part of official data and public statistics on HIV/AIDS; and includes information on most research, and programmes that monitor and follow up on HIV/AIDS projects. However, the national health system is not part of the strategic programmes; its work only concerns general data, reports, and information on other infections and chronic diseases.

Human rights and HIV/AIDS

Over the last years, autonomous state institutions such as the National Commission on Human Rights (CNDH) - established in 1990 and a governmental agency from 1992 - and the National Council to Prevent Discrimination (CONAPRED) - established in 2003 - have participated in campaigns to foster scientifically based knowledge, answers and actions to help diminish intolerance. The classification of HIV/AIDS as a social disease that has personal impact and a dramatic outcome for those affected (exclusion, discrimination, violence, degradation, and violation of civil and human rights.) is a fundamentally important result. Future results will depend on cooperation with and the function of institutions regulating social and civic relations in Mexico, and of the fulfilment of requests for protection and legal petitions expressed by HIV/AIDS patients, their families, and NGOs. Some of these requests are already carried to fruition.

In its programme on "*HIV/AIDS and Human Rights*", the National Human Rights Commission (CNDH) declared:

> "Besides being a serious public health problem, HIV/AIDS is also a Human Rights problem; since the beginning of the epidemic, prejudices and false ideas has contributed to discrimination and the violation of the right to protect the health of those infected."
>
> "Due to mistaken conceptions about the disease, Mexicans living with HIV or AIDS face discrimination in multiple ways; from discrimination subtle and difficult to detect like that expressed by using language or inoffensive and discriminatory jokes to cruel and clear discrimination such as exclusion or restrictions of rights. Such discrimination adds up to other abuses as negation of health services or denegation of access to medicines needed to stay healthy."
>
> "With the conviction that people's health condition should not motivate stigma, and that the right to health protection without discrimination is essential for mankind to live with dignity and develop own skills, the National Human Rights Commission created a programme especially dedicated to promote and defend the human rights of people with HIV and AIDS:
> The objective of this programme is to protect, supervise, inform and promote respect of the fundamental rights of the population through 1) Design and establish courses and workshops about HIV/AIDS, 2) Establish links with human rights organisations working with people with HIV or AIDS, 3) Research and development of programmes on

> stigma, discrimination and HIV/AIDS, 4) Develop informative campaigns to prevent discrimination and to promote a culture of respect, dignity, and rights of people with HIV or AIDS in Mexico." (CNDH 2006)

The National Council for the Prevention of Discrimination (CONAPRED) emphasized that *"The surface of HIV/AIDS added up to the stigmatization and mistreatment associated to people with different sexual preferences."* (CONAPRED 2006)

Information about HIV/AIDS

Efforts to advance cooperation between organisations that work to prevent HIV/AIDS have resulted in the establishment of information systems. These systems aim to support health authorities, the medical community, researchers, and civil society in locating knowledge and research, and developing public policies to prevent and control HIV/AIDS.

To support the exchange of knowledge, the *Regional Centre of Exchange, Documentation and Information on AIDS* (CRIDIS), was established. Supported by the WHO and the Pan-American Health Organisation, CRIDIS became part of CONASIDA in 1988 with the following objectives:

> "encourage regional exchange of experiences and strategies of programmes and projects, prevent and educate about AIDS, publicise scientific and journalistic information related to HIV/AIDS, and support researchers, health educators, students, institutions, and people interested in the topic" (Ayala 1992:154)

In 1990, CRIDIS had three departments that compiled and analyzed scientific, journalistic, and educative materials managed by an institutional library. During that year, CRIDIS edited three publications: "*Boletín Bibliohemerográfico, Gaceta CONASIDA*", and "*Bibliografía Comentada*". Furthermore, a special department for the exchange of experiences and information among Central American countries, the Caribbean (Dominican Republic and Cuba), and the 32 federal states of the Mexican Republic was established.

The "Mexican Research and Intervention AIDS Registry" (RIIMSIDA) is a database created in 1997 by the research unit of CONASIDA. Currently, it is considered a vital programme of the National Centre to Prevent and Control HIV/AIDS. The purpose of RIIMSIDA is to systematically register all works on HIV/AIDS by Mexican researchers and activists including books, scientific magazines, and national and international congresses. In February 2006, RIIMSIDA became the repository of the Mexican Virtual Library of HIV/AIDS making available for the public more than 4,200 research and intervention works on HIV/AIDS developed in Mexico as well as completing/full text (PDF format) of most published articles on the topic (Virtual Library of HIV/AIDS 2006):

> "The Virtual Library of HIV/AIDS is seen as the base of health, scientific and technical knowledge registered, organized and stored in electronic format in the countries of the region. It is accessible through the Internet thus placing it on the level of international databases. The Virtual Library of HIV/AIDS operates within a virtual space composed by a net of regional health information resources. Users from different levels of education

and locations will be able of interact and search a number of information resources, independently of their physical location. Information resources are generated, updated, stored and managed on the Internet by producers and intermediaries in a decentralised way and in compliance with current methodologies. Basic information resources will be enriched, and/or transformed into new valuable information products and services to effectively meet the information needs of users from specific communities." (Virtual Library of HIV/AIDS 2006)

At the time HIV/AIDS burst into our lives, information systems and documentary techniques were going through a critical and decisive transition from physical to electronic formats. However, databases that could maximize information resources dedicated to the study and control of the disease were eventually created; so what in past decades would have been a catastrophe in terms of documentary controls, has worked well for the organisation of data about HIV/AIDS. Twenty-five years after the first break of HIV/AIDS, documents on the disease can generally be classified as follows:

Specialised instructional materials:
- Formats: primary and secondary information resources
- Publications: manuals, guides, and other instructional material (leaflets, flyers, brochures, posters)
- Media: printed, audiovisual, and electronic (including online documents)

Specialised literature:
- Formats: primary and secondary information resources:
- Publications: Articles - published in periodicals, series, monographs, flyers, reports, manuals, guidelines, statistics, bibliographies, and directories
- Medium: printed, audiovisual, and electronic (including online documents)

Expectations were that,

"Prevention campaigns are a collective work where society should participate, specifically those sectors identified with a higher risk. A number of studies concerning the effect of promotional and educative campaigns to prevent HIV have demonstrated that campaigns help to increase awareness about the disease and the perception of risk. They also help to foster solidarity and empathy towards those infected." (Pagan 2006)

Considering the fact that one of the most concerning characteristics of HIV/AIDS is its epidemiologic behaviour and fast growth, the use of information becomes vital. International organizations such as the Pan-American Health Organization (OPS) have identified the value of access to information through their "*GenSalud*" Information System:

"Information is an important tool available to help us fight this disease from the perspective of gender and health. The objective of the GenSalud Information System is to provide precise, relevant, and useful information about the effect of gender in the health of men and women of the Americas. The mandate of the Gender and Health Unit of integrating gender into projects, programmes, and health policies of the OPS and participating countries, requires a clear understanding of the effects of the relations between men and women and

their health. GenSalud is motivated by a) efforts to generate and collect enough evidence of the effect of gender on health to call for action; and b) the fact that there are no web sites, databases, or information systems dedicated to gender and health, although there are books on the topic".

The website of "Gensalud Information System" holds relevant information on HIV/AIDS, a legal kit, flyers, and other resources such as the UNIFEM Portal of Gender and HIV/AIDS. In contrast neither the website of the National Centre to Prevent and Control HIV/AIDS nor the Virtual Health Library's website on HIV/AIDS refer to GenSalud, and until 2006, Mexico did not participated in this initiative.

Even though decisions about HIV/AIDS initiatives must be based on public policies, weaknesses can be identified in public health policies as well as in governmental mechanisms to support such policies in many Latin American countries; Mexico is no exception in this regard. In some cases, the problem is methodological anomalies, and in others inexperience in strategic work based on public policies.

[…]. Some characteristics are:
- Documents are more casual than conceptual
- Conceptual confusion between politics and public policies on HIV/AIDS
- Actions outlined in documents are not implemented
- Public policies on HIV/AIDS are considered static when in reality, they are very dynamic
- Compared to other policy areas, development of HIV/AIDS policies are methodologically more complex due to the complexity of solving a real problem
- Refusal to interact and coordinate with other actors and sectors including the government. (Uribe 2003:249-251)

Moreover, without considering this a conclusion, the 2nd Forum on HIV/AIDS/STD in Latin America and the Caribbean (2003) identified common practices related to the documentation and study of HIV/AIDS:
- Technical cooperation between south-south countries
- Process towards social or strategic management
- Integration and decentralisation of HIV/AIDS services
- Preventive strategies and services from other countries
- Training of health personnel, civil society, and multidisciplinary teams
- Information systems to monitor the epidemic and establish a line of action
- Ethical aspects linked to HIV/AIDS research
- Community projects such as the establishment of support services to people living with HIV/AIDS
- Projects on self-esteem and identity
- The right to anti-virus medicines
- Social mobilisation and pressure on governments (Uribe 2003:247-248)

A construction was established to better manage the duties executed by the Council (formerly known as CONASIDA) and transfer its substantial operational tasks to a governmental Centre. This was done to prevent those topics, which should rather have been prioritised as national or federal actions, to be put on the agenda only for the purpose of general strategic discussion. This would also advance the development

and implementation of socio-economic parameters and indicators for the health sector, allowing the creation of concerted solutions and generating appropriate and valuable documentation.

Table 1: Selected indicators for new AIDS cases per year of diagnosis, 1983 - 2003

Year	New Cases[a]	Incidence rate[b, c]	Male rate[c]	Female percentage
1983	62	0.8	61	1.6
1990	3 719	44.4	6	13.9
1993	4 306	48.5	6	14.7
1996	5 311	56.8	5	15.5
1999[d]	7 036	NA	ND	ND
2000	5 723	NA	ND	ND
2001	3 476	NA	ND	ND
2002	2 294	NA	ND	ND
2003	324	NA	ND	ND
1983-2003	69 795	NA	ND	ND

a: In 2002 CENSIDA implemented a programme to correct registrations. The number of cases per year is different from previous years.
b: Rate per 1,000,000 residents. In 1983 the rate was calculated using standards from INEGI, and CONAPO. Projections of the Population in Mexico and the Federal States: 1980-2010. Processed by the National Centre to Prevent and Control HIV/AIDS (CENSIDA) at the end of 2002. From 1990 -1996 the rate was calculated using standards from CONAPO. Projections per population, sex, age group, and federal entities 1990-2005. Final version, August, 1999. Processed by (CENSIDA) at the end of 2002.
c: Data was presented by (CENSIDA) at the end of 2002.
d: Starting on this date, figures relate to June 30, 2003.
NA: Not applied ND: Not available

The National Institute of Public Health, the National Council on Population (Conapo), and the National Institute of Information, Geography and Statistics (INEGI) generate relevant data on citizens' development and wellbeing, and their economic and social status. However, to support public policy development on HIV/AIDS the data might be presented in separate settings as part of a problem rather than studied as a whole.

Spread of HIV/AIDS in Mexico

The National Institute of Information, Geography and Statistics (INEGI) have compiled data on the increase of the disease for a period of twenty years: See Table 1.

In its report on Mexican health in 2004, the Health Secretariat stated: Currently there has been a feminization of the epidemic: more than half of HIV infected people in the world are women who usually face more stigmatization and discrimination problems and lack of support to resolve problems associated to the disease. A number of studies have showed that, in some countries, the probability of infection in women is three times higher than in men. Equally alarming is the fact that in most cases women are infected by their husbands. This is related to social aspects difficult to modify and therefore strong actions to advocate the use of condoms are required. Up to date, and beyond any ideology or argumentation, that is the only way to prevent HIV.

The latest official figures (2003) show that 4,069 people died in Mexico of AIDS related causes in Mexico. A total of 42 were children younger than 1 year old;

and 3,061 were between 25 and 44 years old. A little over 80% of deaths caused by the disease occurred in men, although the tendency among males is descending, unlike the slow but consistent growth among females. Veracruz and Baja California had the highest mortality rate among men in 2003; and Zacatecas the lowest. The analysis is more difficult for women because few deaths can increase the mortality rate by a number of points. For example, Baja California only had three more deaths compared to the previous year, but the mortality rate was doubled. Nevertheless, the death rate of women is a critical problem in Veracruz, and Queretaro. (Salud Mexico 2004:54)

Investments in health

For the years 2003 and 2004, data concerning expenses of the general health services and the mortality rate of HIV/AIDS is available. The most recent data shows that the total expenses of the health sector represent 6.3% of the GDP. Public expenses on HIV/AIDS represent 3% of GDP, a slight increase compared to the previous year. Although less than 50% of the total expenses are public investments, the latest increases will reduce the percentage of private expenses. The GDP percentage invested by Mexico in health is still below the average of Latin America but the variations are huge; Colombia thus dedicates 6.7% of its wealth to health while Ecuador barely invests 1.7%. The differences in expenditures on a federal level are important to note: The percentage in Quintana Roo, Nuevo Leon, Queretaro, Chihuahua, and Baja California is less than 2.5%, while in Tabasco and Nayarit, public expenses in health represents more than 5% of the budget. (Salud Mexico 2004:68)

The total public expenses of Mexico are budgeted as a) earmarked and b) non-earmarked expenses. The first group concerns expenditures of government institutions and includes investments, services, and production of goods. Thus public health expenses, including treatments and care of HIV/AIDS patients, are earmarked. They explain the needs of investment in infrastructure and the epidemiologic profile of each department. The non-earmarked expenses are generally spent on legal obligations such as the payment of national debts.

In the United States and Canada, public expenses on health represent 23.1% and 15.9% of the total national budget, respectively; and in Argentina and Colombia 15.3% and 20.4%, respectively. To compare with, Mexico's percentage is on middle level. In 2004, the percentage of total public expense for health was 17.4% of the national budget although considerable differences between federal states were found. Campeche, Distrito Federal, and Durango had the lowest percentages - four times below the level of Jalisco and Nuevo Leon that invested 34.1% and 26.9% of their total public expense, respectively (Salud Mexico 2004: p.70).

Within this context, the national health system is considered a responsibility of the public sector; and therefore most information on medicine, health, and in this case HIV/AIDS is generated by this sector. The quantity of resources (and sometimes, the quality of information) is largely determined by the current structure; thus the health care of more than half of the population is the responsibility of state and federal health departments. Their duties go beyond health care to include preventive medicine, health

promotion as well as other activities geared to improve peoples' health condition. The health budget of each state is composed of its own funds as well as funds received from the federal sector, and shows how health expenditures are prioritised by both sectors, e.g. how the lack of federal funds allocated to the states impact the whole health care system. The tendency is that the states are increasing their own contributions, while federal allocations are decreasing - by 5% compared to 1999.

> [...]
> "The state with the largest percentage of health expenditures is Tabasco that spends 50% more than Jalisco, that is number two on the list, three times more than the national average, and 100 times more than Baja California which reported the lowest state expenditures." (Salud Mexico 2004: 72)

In 2002, participants in a conference entitled "Country Response to HIV/AIDS: National Health Accounts on HIV/AIDS in Brazil, Guatemala, Honduras, Mexico and Uruguay", discussed parameters to measure investments and use of funds. The methodology used for the parameters was developed by the National Health Accounts (NHA) and published in the HIV/AIDS National Report. On the basis of the investments and funds allocated for the period 1997-1999 an evaluation of the fight against HIV/AIDS was carried out - from a continental as well as a national perspective (Izazola). The National Public Health Institute reported:

> "Based on team work headed by John Stover of the international organisation Futures Group, and Stefano Bertozzi of the National Institute of Public Health of Mexico, researchers, working on the study "The global Impact of Scaling-Up HIV/AIDS Prevention Programs in Low-and-Middle-Income Countries," estimated that, during the period of 2005- 2015, each case concerning the prevention of HIV in Latin America will cost 5,000 dollars, and the cost of health care and medicines will amount 12,000 dollars per case. The potential of substantial savings would amount more than 7,000 dollars per case - almost 12 thousand million dollars saved in ten years - if prevention programmes be expanded and specific programmes coordinated according to proved efficiency strategies."

Currently, Sergio Bautista and a group of other researchers of the INSP are developing an efficiency model to measure the performance of 40 HIV/AIDS prevention programmes initiated by civil organizations in Mexico. Studying 17 organizations administering HIV screening tests and HIV counselling - a programme otherwise known for its high efficiency - the first findings show high levels of inefficiency and big gaps between allocated resources and results. While some organizations do a high number of screenings, others show poor results even though the same resources were allocated; for example, two screenings including counselling compared to ten. The screenings amount only 19% of their total capacity (INSP 2006).

These examples of how to organize preventive work and display of HIV/AIDS data in a country of median revenues such as Mexico demonstrate the seriousness of the situation and the need to resolve structural problems such as design of homogeneous policies on health and specialized documentation that - as a consequence - must be generated from public and private

sectors. Up till 2006, systems that organized information included statistics, loose notes, and reports written by NGOs supported by international foundations, obsolete data, and information not related to government sectors.

Information and social interaction

With help from the health sector, that is funded and maintained by the state, the government has attempted to address the many problems associated with HIV/AIDS. However, civil society has expressed concern over the way this is done. Since the beginning of the scourge, political and social initiatives have been implemented such as participation in international events coordinated by different social sectors. A study covering the period 1989-1998 shows that presenters and authors from Brazil and Mexico had the highest participation rate in the international HIV/AIDS conferences (Table 2). The greater part represented governmental institutions, followed by NGOs, CSOs, and local community based organisations. The topics included HIV/AIDS epidemiology, health care, promotion, communication, and education systems (Licea 2001:139). Though their circumstances are very different, this indicates a noticeable level of activity for both groups. Participants working in public health institutions - of variable quality - should partner with these bodies to make use of their facilities such as laboratories, research and follow up on activities, access to and use of scientific publications and collections on health, epidemiology, and HIV/AIDS issues. While NGOs and CSOs normally interpret and value data of the basic research of governmental institutions; these factors determine the content of works and proposals of each group: a) study of tendencies of the disease behaviour, and adjustment of hard facts; b) preventive reports; c) weight of policies over the impact of the scourge within groups and communities, and government initiatives to solve identified problems.

Table 2: Presentations at international conferences on AIDS, 1989-1998

Origin	Number of Presentations
Brazil	961
Mexico	405

Source: Table 2. Geographical distribution of presentations within international conferences (Licea 2001: 145)
Note: The total of participants by Latin American countries was 2070.

Research on the topic for the IFLA/FAIFE Theme Report 2006 showed that Current Contents Connect in a report has identified documents generated by the three countries with the highest number of HIV/AIDS cases in America: The United States, Brazil, and Mexico. The methodology used was general search, selection of the seven research areas (agriculture, biology & environmental sciences (ABES); social & behavioural sciences (SBS); clinical medicine (CM); life sciences (LS); Physical, Chemical & Earth Sciences (PCES); Engineering, Computing & Technology (ECT); and Arts & Humanities (AH). The research covered the period 1998 until May 26, 2006. Regarding languages and type of documents: “all” was selected. The results of the research on HIV/AIDS topics, by country, themes, and authors, showed that the United States generated the majority of documents, followed by Brazil and Mexico. (Table 3 and 4)

Table 3: Production of documents about HIV/ AIDS per country (topic)

Country	Number of documents
United States	532
Brazil	300
México	76
Search strategies per topic: Brasil: HIV/AIDS and Brazil or Brasil; México: HIV/AIDS and Mex* or Mejico; Estados Unidos de América: United States	

Table 4: Production of documents about HIV/AIDS per authors' address

Country	Number of documents
United States	2964
Brazil	102
México	78
Search strategies per topic for the three countries HIV/AIDS including guidelines (author affiliation: Brasil: Brazil or Brasil; México: Mexico or Mejico; Estados Unidos de América: USA or EEUA.	

Recommendations

As was earlier established, Mexico has not implemented a national mechanism that can handle a federal information system; each institution and body develops their own systems according to their individual needs and resources. The Health Secretariat (SSA) assigns most of the basic research, training, and updates of programmes to national institutes working within the national health system maintained by the state. The Mexican Institute of Social Security (IMSS) initiates programmes generated by its research sectors (in particular research projects organised by the National Medical Centre).The Institute of Social Security and Services for State Workers is organized in a similar way, identifying its medical centres and hospitals as learning units.

Noticeable efforts are made to develop a national health information system by public academic institutions such as the National Autonomous University of Mexico - and its biomedical science institutes - the National Polytechnic Institute (in particular its Centre for Research and Advanced Studies), although formally the HIV/AIDS topic has not been assigned to them as a fundamental academic duty; in many cases institutions work in conjunction with the IMSS and the SSA.

These institutions all run programmes on HIV/AIDS studies; they should, however, be attached CONASIDA - the governmental body working with the disease - to influence the actions of CENSADA. Each institution generates its own results, and distributes them to their partners in most cases external agencies such as NGOs, CSOs and IAPs (Private Assistance Institutions) that work in the field of alternative prevention and information initiatives - when they have resources to finance projects.

Other important players that manage public health information are federal institutions such as: The National Institute of Information, Statistics, and Geography (INEGI), the National Council on Population (Conapo), and the Social Development Secretariat (Sedesol) which analyses health, marginality, poverty, demography, and human development problems and

share important data on the social and economic status of the infected populations, or those at high risk. They publicize statistics that supplement information produced by the academic and health institutions already mentioned.

Besides the problems connected with the nature of HIV/AIDS, educational campaigns about the risks of the scourge and how to control it should include other problem areas in particular human rights and discrimination which are the responsibility of the National Human Rights Commission (CND) and state commissions such as the National Council to Prevent Discrimination (CONAPRED.)

Various sectors and a number of public institutions (private organizations seldom participate) create valuable and useful information that unfortunately is scattered in a badly organised and inefficient way in terms of accessibility, availability, and circulation.

The following proposal that includes a reorganization of Mexican information units derives from the question: Is it possible to develop a national health information system that will function?

- Given that the HIV/AIDS problem is not a local or national problem measures must be taken to connect with efficient global programmes.
- Institutional libraries and information services should be responsible for the organization, systematization and administration of documents (in all formats), and for enhancing their services through collaboration with other institutions.
- The administration and coordination efforts should be delegated to a body such as CENSADA in order to advance the sharing and exchange of documentary information between information units of institutions working with HIV/AIDS related issues. Officially, CONASIDA already has this objective but despite representation on State Secretaries level in the steering body; results of the last years are on minimum level compared to the advance 20 years ago.
- Given the change of formats of documentary information, efforts most be made to transfer documents into the new formats.
- Since documentary information can be presented in different formats (text, images, audio- information) professionals most implement and make available the necessary tools to offer new and better services and more efficient use of information products.
- Communication and Information Technologies (TIC's) should support management and systematization of documentary information. There exists a net of libraries that can be the backbone of this process making available information on HIV/AIDS to a large number of groups and people. This would bring information services to rural areas that have formerly been neglected and where the disease is increasing. The use of Internet portals and websites is an excellent solution for countries like Mexico because it reduces costs and maximizes the provision of information.
- Besides printed materials such as books, periodicals, and magazines; TIC's should be used to produce, edit, and publish educative materials (tutorials, presentations, posters, and leaflets etc.) and make them available and easy to access in electronic formats.
- Information services that have perfected the control and systematization of information would

be able to produce and adapt materials for communities. The use of simple and common language to communicate information on topics like HIV/AIDS is not meant to vulgarise academia but to help people survive.

Conclusion

There is no doubt that in a short time HIV/AIDS has caused a deep wound to societies, such as Mexico. Until we find a cure, all sectors of society should continue their research to develop medicines and coordinate and establish prevention programmes. Information professionals should coordinate the use of better and more advanced organization systems and information systematization to establish collaborative networks among government institutions and other bodies.

It is common knowledge that the work of multidisciplinary, interdisciplinary and transdisciplinary groups can present the best results at local as well as regional and international level. Research to develop medicines or coordinate prevention programmes on HIV/AIDS - that in some parts of the world is no longer a mortal but a chronic disease affecting marginal groups (economically , socially and in terms of religion - is needed. Information professionals should work more closely with decision making bodies with regard to national policies, advocating the principle: "information reduce uncertainty and help to make decisions" (Faibisoff, 1976:3).

Information and Communication Technologies (TCI's) have developed very fast making it possible to reduce processes, storage and retrieval of information, and the implementation of programmes directed to receive and send documentary information in large volumes faster and more efficiently. TCI's have also changed the way in which we relate to information and knowledge allowing a move from local level to national, from national to global, and vice versa. The concept of a nation as it was known until the last century is changing; TCI's make it possible to go beyond frontiers. Let us use TCI's not only to design the best possible information services but to become responsible and autonomous professionals and users.

References

Ayala Picazo, Micaela; Musiño, Celso M.; Torres Puente, Federico; Rico Galidno, Blanca (1990). CRIDIS, antecedentes, situación actual y perspectivas. En: Memorias II Congreso Nacional de Bibliotecarios en Biomedicina A.C., 26 al 28 de noviembre de 1990. México : BIBAC. pp. 149-169.

Biblioteca Virtual en Salud, México. La biblioteca virtual en Salud. URL: http://bvs.insp.mx/queeslabvs.php (Accessed 5/20/06)

Biblioteca Virtual en Salud VIH/SIDA, México. (2006). El Registro de Investigaciones e Intervenciones Mexicanas en SIDA (RIIMSIDA) URL: http://bvssida.insalud.gob.mx/riimsida.php (Accessed 5/20/06)

Comisión Nacional de los Derechos Humanos, México (2006). Programa de VIH/SIDA y derechos humanos. URL: http://www.cndh.org.mx/progate/progate.htm (Accessed 5/20/06)

CONASIDA (2000). Programa de fortalecimiento para la prevención y control del VIH/SIDA y otras enfermedades de transmisión sexual 1997-2000. México: CONASIDA. 38 p.

Faibisoff, Sylvia; Donald P. Ely (1976). Information and needs. En Information reports and bibliographies, 5(5), pp 3-16

INEGI. Mujeres y Hombres en México, 2006. México: Aguascalientes, Ags., URL: http://www.inegi.gob.mx/est/contenidos/espanol/rutinas/ept.asp?t=msal11&c=3363 (Accessed 5/23/06)

Instituto Nacional de Salud Pública (2006). Efectividad y eficiencia en la prevención del VIH/SIDA. México: INSP URL: http://www.insp.mx/Portal/Cuidados_salud/efectividad_efeciencia.html (Accessed 5/18/06)

Izazola-Licea, José-Antonio; Avila-Figueroa, Carlos; Arán, Daniel; Piola, Sergio; Perdomo, Rodulio; Hernandez, Patricia; Saavedra-Lopez, Jorge A; Valladares-Cardona, Ricardo (2002). Country response to HIV/AIDS: national health accounts on

HIV/AIDS in Brazil, Guatemala, Honduras, Mexico and Uruguay. En AIDS (London, England,) Dec, 16 Suppl 3:S66-75

Licea de Arenas, Judith; Valles, Javier; Izasola, José Antonio (2001). Agenda científica y extracientífica de VIH/SIDA. En Anales de documentación: revista de biblioteconomía y documentación, Vol. 4, pp. 139-149.

NotiS: reformas en CONASIDA (2001).En La Jornada, Supl. Letra S, 2 de agosto de 2001. URL: http://www.jornada.unam.mx/2001/08/02/ls-notiese.html (Accessed 5/27/06)

Organización Panamericana de la Salud. Sistema de información Gensalud . Disponible en http://www.paho.org/Spanish/DPM/GPP/GH/GenSalud.htm, (Accessed 4/10/06)

Pagán Santini, Rafael H. (2006). Universidad y SIDA. Puebla, México: Centro Universitario de Investigación Sobre SIDA URL: http://www.cuiss.buap.mx/universidad.htm (Accessed 5/21/06)

Secretaría de Salud (2005). Saludo México 2004: información para la rendición de cuentas. 2a ed. Secretaría de Salud, Dirección General de Evaluación del Desempeño, Dirección General de Información en Salud. México: SSA. 229p http://evaluacion.salud.gob.mx/saludmex2004/libroelectronico/index.htm

Uribe Zúñiga, Patricia Estela; González Contreras, Edgar Manuel (2003). Políticas públicas y VIH/SIDA: hacia un diseño de políticas inclusivas y efectivas. En: Situación del VIH/SIDA en América Latina y el Caribe: una revisión basada en el Foro 2003 / ed. José Antonio Izazola. México: Fundación Mexicana para la Salud: SIDALAC: ONUSIDA. p. 239-276 URL: http://www.sidalac.org.mx/spanish/publicaciones/foro2003/foro2003.pdf (Accessed 5/15/06)