COUNTRY ANALYSIS:

ATTITUDES OF STIGMATIZATION AND DISCRIMINATION PRACTISES IN THE FIELD OF MENTAL HEALTH, HIV AND AIDS IN BULGARIA

Expert Center for Mental Health and HIV/AIDS

Blagoevgrad 2007

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Table of Contents

Acronyms

AIDS .....Acquired Immune Deficiency Syndrome
FGD .....Focus group discussions
GOB .....Government of Bulgaria
HIV .....Human Immunodeficiency Virus
HIV/AIDS .....The combined disease entity as described in policy and programs1
IDU ..... Injection Drug User
IEC .....Information, Education and Communication
MOH.....Ministry of Health
MTP .....Medium-Term Plan 1996-2000
MLSP .....Ministry of Labor and Social Policy
NAC ..... National AIDS Committee
NGO .....Nongovernmental Organization
PLHA or PLHIV .....Person living with HIV and AIDS
STD .....Sexually transmitted disease
CSW.....Commercial Sex Worker
USAID .....United States Agency for International Development
UNDP .....United Nations Development Program
WHO……..World Health Organization

Executive Summary

From August 2005 until June 2007, the HIV/AIDS Expert Centre in Blagoevgrad conducted research on Mental Health and HIV and AIDS-related stigma and discrimination in the context of the Bulgarian culture. This research set out to describe the context in which stigma occurs and to document the experiences of stigma and discrimination among people living with HIV and AIDS, people with severe mental illness and their family members. The research sought to explore the ways in which HIV-related stigma and discrimination intersect with stigmas that may adhere to injection drug users and sex workers, and to understand the ways in which age, sexual orientation and gender roles may affect these processes. Fieldwork for this qualitative research study was conducted in selected communes of the city of Blagoevgrad in the spring and early summer of 2007 by trained researchers from the Expert Centre. Structured thematic analysis of qualitative data gathered from over 50 participant transcripts and careful studies and recherché of other relevant publications in the field indicates that HIV and AIDS-related stigma in Bulgaria stems largely from two issues. First, people in the community generally understand the ways in which HIV is transmitted, but ambiguities persist, leading to fears of acquiring HIV casually through everyday contact with infected persons. This leads people to take unnecessary, often stigmatizing, actions which they perceive will prevent further transmission of the disease. A second important cause of HIV-related stigma relates to the fact that in the minds of community members, leaders and health care workers, HIV and AIDS are inextricably linked with homosexual behavior, injection drug use and sex work and the persons from these groups are regarded as belonging to "risk groups". Thus, judgments are passed against people living with HIV who are thought to have acquired the infection through behaviors that are considered to be morally, socially and economically harmful to both family and society.

The analysis has concluded that more can and must be done to confront and address the root causes of HIV and AIDS-related stigma and discrimination in society, not just their effects. Firstly, programs are needed to reduce the fear of casual transmission of HIV and AIDS by delivering specified, target oriented, factual information about HIV and AIDS, and how and why it is and is not transmitted. Secondly, sincere, deliberate efforts are needed to delink HIV from "risk groups" in programming and the public imagination. Thirdly, the media should do more to reinforce these messages through positive portrayals of people living with HIV and AIDS.

1. Introduction

The HIV/AIDS Expert Centre in Blagoevgrad have undertaken an 6-month study investigating the causes and consequences of HIV related stigma and discrimination in Bulgaria. This project was funded by GIP through the program on HIV/AIDS and mental health problems prevention. The research explored the context in which HIV-related stigma occurs, how it intersects with the stigmas associated with mental health problems and sex work and how sexual orientation interact with these processes.

The phase of the project reported here ran from January 2007 through June 2007 and the fieldwork was conducted in April, May and June 2007 in the city of Blagoevgrad.

A planned second project phase, beginning in 2008, will involve specific activities putting the findings and recommendations from this research into practice.

1.1 Context of the study

From the moment of discovering the first cases of HIV in Bulgaria in 1989 social responses of fear, anxiety, stigma and discrimination have accompanied the spreading of the infection. The new disease with its accompanied emotions and reactions found and strengthen the already present and deep attitudes towards some chronic illnesses like the serious mental disease. Discrimination has spread rapidly, fuelling anxiety and prejudice against the groups most affected, as well as those living with HIV or AIDS.

Stigmatization against PLHA and the mentally sick was and is widespread and severe in Bulgaria. It ranges from the cultural pattern of instilling in young children fear and disgust for the PLHA and the mentally sick to the enforcement of a long list of restrictions on their human rights. People known to be HIV positive or have experienced psychiatric disorders are as a rule avoided in social interaction and end up marginalized. This attitude finds its way into numerous stipulations that are parts of various regulations in domains ranging from health, through education, social welfare, vocation and labor to private life. **Advocacy** is a very recent development on the public scene of the country with a formidable task. Clarity as to the observance of human rights in general is still very scant in the community.

Stigma is a powerful tool of social control not only in Bulgaria but in most of the countries of the former socialist countries. Stigma is used often to marginalize, exclude and exercise power over individuals who show certain characteristics. While the societal rejection of certain social groups (e.g. people with homosexual behavior, people injecting drugs, commercial sex workers) may predate HIV/AIDS, the disease has, in many cases, reinforced this stigma. By blaming certain individuals or groups, the Bulgarian society excuse itself from the responsibility of caring for and looking after such populations. This is seen not only in the manner in which "risk" or "outsider" groups are often blamed for bringing HIV into a country, but also in how such groups are complicated or in more severe cases denied access to the services and treatment they need. Stigma and discrimination arise often from community-level responses to HIV and AIDS. The harassing of individuals suspected of being infected or of belonging to a particular group has been widely reported. It is often motivated by the need to blame and punish and in extreme circumstances can extend to acts of violence.

Perhaps as a response, Bulgaria have now enacted legislation to protect the rights and freedoms of people living with HIV and AIDS and to safeguard them from discrimination. Much of this legislation has sought in vain to ensure their right to employment, education, privacy and confidentiality, as well as the right to access information, treatment and support.

1.2 Objectives of this assessment

The overall objectives of this qualitative analysis were to:
- Describe and analyze experiences of people living with HIV and AIDS;
- Explore how HIV-related stigma interacts with other stigmas, specifically those associated with chronic mental illness;
- Investigate the role of sexual orientation in the causes and consequences of HIV-related stigma;
- Sensitize social organizations to stigma and its impact;
- Mobilize groups and individuals, forma and informal leaders to serve as advocates on behalf of people living with HIV and AIDS and their family members.

These objectives were explored through five key study components:
1. Participant's reactions and attitudes during the first module of the workshop "Introduction to HIV/AIDS and Mental Health", produced by Global Initiative on Psychiatry; the Social AIDS

Committee (SKA), Warsaw, Poland; and the HIV/AIDS Team, GGZ Buitenamstel, conducted in Sofia in April 2007. This workshop brought together individuals working in a range of national and local NGOs as well as key grassroots social organizations, people living with HIV and AIDS and health care providers working in HIV and AIDS in Bulgaria.
2. Field work and experience of the Informational center for mental health which is part of the GIP-Sofia 3 year project "Piloting community-based services in a Bulgarian setting". Some of the basic aims of the centre are:

- gathering and classifying information about mental health, mental health disorders and the groups at risk;
- informing of the community about the problems of the people with ling-term mental disorder and their families and friends;
- improving the coordination between the responsible institutions;
- supporting the fulfillment of different initiatives that will contribute to the realization of the reform in the field of social and mental health policy;
- organization of an informational campaign for reducing the discrimination and stigma towards people with mental health disorders and helping them to find jobs and homes.

3. The field research, conducted in June 2006 and in spring 2007.
4. Data analysis.
5. Dissemination and publication of the research results in both Bulgarian and English.

1.3 Scope and limitations of the research

The scope and focus of this research was to observe, document and attempt to describe the nature of stigma experienced by people living with HIV and AIDS, its root causes and principal manifestations in specified areas of Bulgaria. We were particularly interested in whether, and to what extent, HIV-related stigma overlapped with and was affected by other social stigmas affecting those at risk, specifically mentally ill persons. Our aim was not to quantify this stigma or to measure its impact, but to document and describe experiences and to determine underlying causes of stigma. Because so little is known about HIV-related stigma in the Bulgarian context, we felt it appropriate to focus our efforts in those geographical areas in which HIV is already present and making an impact. Although our sample was not quantitatively representative of the country as a whole, our findings do enable us to generate generalizable principles, on the basis of which meaningful interventions can be developed. It is important to note, however, that in our sampling we omitted one important group: people who inject drugs, a population likely to be at great risk of HIV infection in Bulgaria. Although we recognize the special vulnerabilities of these persons and feel it would be appropriate to document their experiences, the timeframe of the project did not allow us to include them in our study.

2. Methodology

This report highlights results from the data collection undertaken in Blagoevgrad in 2006 and 2007 and from the data analysis of relevant document, policies and other research already conducted in Bulgaria. This section provides an overview of the structure of the study, its methods, details on the sites selected, the study sample, and the data collection and analysis processes.

2.1 Data collection process

2.1.1 Research methods

Due to the sensitivity of the topic, it was decided that a qualitative approach would be most appropriate. The primary methods used to collect data were in-depth interview and focus group

discussions (FGDs). Other methods used included observation and the use of participatory techniques during FGDs and workshops such as matrix mapping and brainstorming. Before conducting interviews or FGDs, researchers obtained the consent of respondents to participate and their permission to record the discussion.

Secondary sources were also consulted widely. Academic journals, research reports, books, newspapers and TV broadcasts on HIV and AIDS were explored, and further information was obtained from the members of the research team.

Focus group and interview guidelines were developed by the team, based on findings from some workshops and discussions with experts from relevant fields. These guidelines were refined and eventually finalized and compared with tools developed mental health related stigma and discrimination studies conducted by other professionals in Sofia and Blagoevgrad.[1] Data collection instruments were pretested and further refined during the fieldwork process.

2.1.2 Study sample

The research sample included professionals, working in the fields of HIV/AIDS prevention and care and mental health services, people living with risk of infecting with HIV and AIDS, their family members and people living in their communities.

Several in-depth interviews were conducted with local administrators, policy makers, professionals, community leaders, including persons responsible for the creation of the HIV/AIDS and mental health related policy at the municipality of Blagoevgrad, persons, responsible for the social and labor policy at the local government etc. Additional key informant in-depth interviews were conducted with local health workers, teachers, students and other members of the community. The total number of participants in the study – over 50 - exceeded our original expectations.

2.1.3 The research team

The fieldwork was carried out by the research team at the Expert Centre on HIV/AIDS in Blagoevgrad, which included researchers with particular experience conducting qualitative research on sensitive topics with hard-to-reach groups. Before conducting the fieldwork, members of the research team were trained on the conceptual framework of the study, interview guidelines and the other data collection techniques.

Each FGD was tape recorded and facilitated by a senior researcher. A note-taker recorded the proceedings and documented observations. Indepth interviews were conducted directly between the researcher and a study participant in his or her working place.

2.1.4 Data processing and data analysis

Following data collection, all taped interviews and FGDs were transcribed, with around 20 percent translated into English. Through the preparation process, key domains for analysis were identified, data was collected and a reference list with relevant publications was developed.

[1] Okoliyski, M. Needs and attitudes regarding the mental health and the community mental health services in the town and the region of Blagoevgrad, Journal of Social Medicine, 1, 2007

2.2 About the method of the study

In the first phase of the analysis after some preliminary researching it became apparent, that the collected statistical, epidemiological and qualitative information needed to be interpreted against knowledge of the local context in Bulgaria and the region of Blagoevgrad in order to begin to make sense in terms of concrete actions and relevant policy for reducing stigma and discrimination towards the people living with mental illness, HIV and AIDS.

Some opportunity for comparison was provided indeed by already issued publications on attitudes towards mental health, HIV and AIDS but this felt insufficient because first-hand experience of the reality was missed. A need for a local Bulgarian reference point was strongly felt. It transpired that the team hesitated whether the view its members held on the problem counted as "legitimate" or "valid" and increased the need for further research in the field. For this reason the Focus groups with students, relatives and professionals and structured interviews with specialists, working in the field of mental health and the HIV/AIDS prevention and services were prepared, conducted and analyzed.

One of the FGDs was carried out with students from South-West University in order to assess stigma and discrimination. The students were 20-25 years old. The FGD was held in February 2007 in South-West University. The process of interviewing relevant stakeholders and people from the communities included questionnaire among health personnel and other services providers. The respondents included in the research represented different fields: beautician, hairdresser; health personnel – gynaecologists, surgeons, orthopaedists, nurses, hospital attendant etc. In- deph interviews with health personnel included two interviews were carried out with nurses. One of them works in the Emergency and other works in the Maternity ward – Blagoevgrad.

The FGDs and the interviews turned out to be a tricky detail. Investigating attitudes and policy by using a fully visible method and out of pure scientific curiosity could lend credibility to the team and render the findings worthy in the eyes of the local community. By the same token it could be seen as a politically motivated attack on the authorities disguised as research - a reading of the situation that would lead the authorities to reject the findings on the grounds that the study had not been correctly commissioned. This dynamic clearly showed that grounding policy in evidence to ensure support for it was not necessarily the case in Bulgaria, at least not until it became a fully functional democracy. Policy in Bulgaria apparently pertained much more to the domain of common sense, intuition and opportunity than a researcher would be glad to believe.

The above illustration of specific cultural context has immediate implications for the methodology of the study. If HIV/AIDS and Mental Health policy was to be made intelligible in countries like Bulgaria, where intuition rather than evidence guides minds, the researcher should go beyond gathering facts about the technical components of the system of care. He should also get into studying the minds of the actors involved in their context to begin to understand how intuitive policy comes to be. In order to do this the researcher should step beyond the observer-observed frame of care and enter the social studies domain, where meaning loads interactions, and where learning through research precipitates changes in behavior while evidence is still being gathered.

3. Background

3.1 Societal context in Bulgaria

Bulgaria has a population of under 8 million, which is shrinking at a rate of about 50000 per year because of low fertility rate, rising mortality and emigration. The literacy is high but dropping and so is enrollment in school. Suicide rates are moderately high and stabilized, homelessness is increasing and unemployment is of dire proportions in agricultural areas. Infant mortality is higher than that of the old EU countries, the toll due to cardiovascular disorders is huge, poorly understood, and responded to with confusion. The economy of Bulgaria is not picking up significantly in spite of all hopes and the income is lower than in most countries from former Central and Eastern Europe. This discourages all, increases faith in imported solutions, and breeds resignation and mistrust. It is a constant reminder that Bulgaria does not have the capacity to develop a long-term social and economic policy. Before 1989 poverty was dealt with by involving the state heavily in redistribution of wealth at the expense of suppressed economic incentive. Fifteen years after the collapse of the totalitarian regime a poverty culture has emerged but has not been seriously studied. This is a cause for serious concern because of the association of poverty with brutal violation of human rights, with crime and with stagnated transition to civil society. Being a PLHA or being mentally ill is not regarded as a special case of economic deprivation and HIV/AIDS and mental health care does not provide sufficiently for the financial hardships associated with AIDS and severe mental illness.

3.2 STDs and HIV/AIDS in Bulgaria

The rate of sexually transmitted non-HIV/AIDS infections, which is an indicator of HIV infection, has increased over the last ten years. Since 1990, there has been an alarming trend in the number of syphilis cases. Whereas in 1990 the number of newly recorded syphilis cases was 378 (4.5 out of 100,000), in 1999, there were 2,509 new cases (30 out of 100,000). According to the World Health Organization (WHO) criteria, some regions of the country are on the verge of an epidemic outbreak. The Hepatitis B and C infection rates in Bulgaria are several times higher than that in some European countries. The large number of chronic cases resulting in disability and death, combined with the considerable expenditures for their treatment make them socially and economically important.

The first HIV-positive in Bulgaria was diagnosed 18 years ago, in 1989. At the start of the epidemic in the country (1985-1986) in most of the cases the virus was imported from Africa, and infection sources were sailors who had had sexual intercourses in the ports of Zaire, South Africa, and other African countries. In 1986-1987, all hemophiliacs living in the country were subjected to obligatory testing, and 11 HIV-positive were found among them. They were probably infected before 1985 (i.e. before testing of each donated blood unit was introduced). A few years later, after 1991, the picture was totally changed. At present, in over 70 percent of the time transmission is from infected Bulgarian citizen to other person within the country.

Bulgaria is still considered a low HIV/AIDS prevalence country. As of the 31st of December, 2006 there have been 689 HIV-positive_individuals registered at the Ministry of Health**.** The analysis of the data shows that about 67 % of the infected are men and about 33 % - women. About 25% of all HIV-positive people are in age-group of 15-25 years. There is no change in the most common way of infection transmission – 87% via sexual contact, via intravenous drug use – 9 %, via blood and blood products – 3 % and 1 % are infected in a "vertical way" /mother-child/. In the infection via sexual contact, the prevalent cases come from heterosexual contact, about 80% and about 20% from homo/bisexual contact. According to specialists' opinion, the actual number of infections via homo/bisexual contact is a lot higher than the official data. The reasons for these false reporting is the stigma associated with the homo- and bisexual behavior. The transmission of HIV via blood is observed with haemophilics, patients

that received blood transfusion and intravenous drug addicts. The last cases of HIV infections of haemophilics and due to blood transfusion were registered in 1996. In the last two years, there has been an increase in the number of intravenous drug users infected with HIV. The total number of officially registered HIV-positive drug addicts for the period 1986 to the 31st of December 2006 is 64. This worrisome fact was already noted in 2005 when 13 drug addicts were confirmed as HIV-positive. The data analysis from the second generation epidemiological research of HIV, hepatitis B, hepatitis C and syphilis that was carried out in November and December of 2005 shows that 63% of the intravenous drug addicts are infected with hepatitis C and 8% - with hepatitis B. These particularly troublesome findings indicate that the use of common needles and syringes is widespread and that the genuine threat of quick HIV spread does exist. 32 new HIV-positive intravenous drug users were actively sough out in 2006 and the study of their contacts continues. The data shows that about 63% of all registered HIV-positive individuals are registered in Sofia, Bourgas, Varna and Plovdiv.

Regarding the geographical distribution of HIV-positive in the country, it is notable that the biggest concentration of infected people is found in the following cities: Sofia, Burgas (mainly sailors working on fishing ships, who have stayed for a long time in African ports and had heterosexual relationships there).

The HIV virus has spread among almost all social groups and professions, though regretfully not all registered HIV-positive people declare their profession. A large number of them have been transferred to less physically demanding jobs following recommendation by their carers.
The WHO record ranks Bulgaria seventh of the ten countries most at risk of infection over the next 10 years. Based on the prognosis, if effective measures are taken now, the HIV epidemic could be contained in Bulgaria.

The health experts revealed the main determinants in the rapid growth of HIV/AIDS infection in Bulgaria. The following factors directly affect the infection rate: risky sexual behavior (unprotected sex); high incidence of sexually transmitted infections; and risky injecting drug use practices (shared needles and syringes). Some of the indirect factors are: poverty (economic insolvency); prostitution; drug and alcohol abuse; low health awareness; low general education of some vulnerable groups; and high (labor) mobility. The lack of an overall policy addressing high risk behavior and HIV/AIDS prevention, as well as the ineffectiveness of the relative institutions, agencies and services, and the transition are other indirect factors.

In the medical practice, blood products and invasive procedures pose the highest risk. Among the indirect factors are: lack of standards and good practices; insufficient skills for diagnosis, consultation and treatment of HIV/AIDS.

At the end of 2006, 201 people were on highly active antiretroviral treatment in Bulgaria. Provision of antiretroviral therapy is covered by the budget of the Ministry of Health and is provided free-of-charge for all patients, who meet the criteria of the European treatment guidelines.

In February 2001, the Bulgarian Government adopted the National Strategy and the National Action Plan for Prevention and Control of HIV and STIs, which covers the period 2001 – 2007 with approximately US$ 4 million annual budget allocations provided by the state for its implementation — especially in the areas of ensuring blood safety, free- of-charge HIV testing and free-of-charge antiretroviral treatment provision and monitoring of HIV patients. The programme "Prevention and Control of HIV/AIDS", financed by the Global Fund to Fight

AIDS, Tuberculosis and Malaria in the amount of US$ 15.7 million for the period January 2004 – December 2008 will potentially be successful in significantly scaling up access to and coverage of services for HIV prevention among the target groups. Specific health and social services are provided primarily by 52 nongovernmental organizations in priority to 19 of the 28 country districts and 138 pilot schools in 13 districts. During 2006, the following coverage of services for most-at-risk populations was achieved: 1906 new individual injecting drug users were reached and 45 674 contacts were established; 5090 Roma representatives were reached; 2436 new individual sex workers were reached and 30 482 contacts established. All activities are coordinated at national and local levels. [2]

The challenges and emerging issues for 2007 are to reach sustainability of existing and future HIV prevention, treatment, care and support services due to limited government and municipal funding for HIV prevention for most-at-risk populations and human resources; to reduce the extremely high prices of antiretroviral treatment.

Prevention is still not the focus of the health-care system. There is still a very low knowledge among the general population on how HIV is and is not transmitted. Social inequalities and disparities among regions and groups in the country still exists and is growing. The national HIV/AIDS/STI monitoring and evaluation system still needs to be finalized. Only partial programmes have been implemented among some of the most-at-risk populations such as men who have sex with men, prisoners and mobile groups. **Criminalization** of high-risk behaviours with respect to HIV transmission (single dose drug possession) exists.

4. Causes of stigmatization and discrimination in Bulgaria

This section outlines and describes some of the main findings of this research study. We first discuss and describe what we found to be the principal underlying causes of HIV and AIDS-related stigma and discrimination, which derive from practical, moral, economic, cultural and political dimensions of people's lives. We then explore the principal forms that stigma takes, including the use of demeaning and hurtful language when referring to or speaking with a person living with HIV and AIDS; the isolation, marginalization and avoidance of PLHA; and self-stigma, or the internalization of stigma due to experience or fear of the above behaviors. We highlight the main places in which stigma takes place and discuss the role of the media in perpetuating stigma. We conclude this section with an overview of the principal impact that stigma is having on PLHA, their families, communities and the Bulgarian nation as a whole.

4.1 Factors determining HIV-related stigma in Bulgaria

The conceptual framework below illustrates that HIV-related stigma occurring within society, within communities and within individual families and households will all combine to influence the nature and degree of stigma experienced by an individual person living with HIV and AIDS. Selfstigma, or stigma internalized by PLHA, is also evident. Through the data analysis process, it was discerned that stigma is caused by factors in the social, cultural, political and economic environment. Key factors affecting the nature and degree of stigma also include the stage of the disease and sexual orientation. We found that the media is having a negative impact by reinforcing, rather than challenging, the prevailing fears, misapprehensions and stereotypes that fuel and exacerbate HIVrelated stigma. These findings resonate strongly with findings from studies on stigma conducted elsewhere (Nyblade et al. 2003; Bond et al. 2003).

[2] Programme "Prevention and control of HIV/AIDS" Bulgaria

4.1.1 Prevention and education programs at schools and universities

For effective AIDS prevention among Bulgaria's youth and others target groups, health professionals need insights into the behavior patterns and motives, which hide behind epidemiological data. Different studies[3] have shown that there is very poor structured HIV/AIDS and sexual education for the youth and the teenagers at the Bulgarian schools fromtrainned professionals and at their homes from their parents.

In a study made in 1998 in the context of Bulgaria[4], 84.7 percent received their sexual knowledge from friends, and 20.3 percent through the media. Only 15.3 percent received sex education from their parents. This confirms the claim of many Bulgarian educators that sex is still a taboo subject in most Bulgarian families. The fact that only 13.6 percent learned anything about sex from their teachers reflects the general absence of sex education in Bulgarian schools, where students are taught a total of only two hours about the biological differences between the sexes. There is a total lack of formal education with regard to the psychological and social aspects of sex. As a result, Bulgarian adolescents feel abandoned by their elders as far as their own sexual problems are concerned. They still get their sexual knowledge "in the streets" (Table 1).

Table 1: Sources of Sexual Knowledge

	Parents	School	Friends	Media
Bisexual behavior	6.7%	20%	80%	6.7%
Homosexual behavior	15	5	85	81.8
Heterosexual behavior	15.4	5.4	92.3	23.1
IV drug use	27.3	18.2	81.8	27.3

Knowledge about HIV/AIDS is obtained in a quite different way. Most Bulgarians learn about it from the media, since friends and peer groups are largely uninformed due to a lack of any intensive government campaigns. Again, parents and schools play a very modest role, illustrating once again the inadequacy of formal sex education. There is one relative difference between our target groups, however: Persons with bisexual and homosexual behavior receive more AIDS information from their friends and peer groups (Table 2).

Table 2: Sources of Information about HIV and AIDS

	Parents	***School***	***Friends***	***Media***
Bisexual behavior	6.7%	6.7%	73.3%	40%
Homosexual behavior	5	30	50	75
Heterosexual behavior	14.3	14.3	21.4	71.4
IV drug use	16.7	8.3	16.7	68.7

Confusing messages about AIDS has repeatedly irritated the general public in Bulgaria. Modest government efforts have been undermined by contradictory reports in the mass media and by various journalistic horror scenarios that failed to become true. It seems that[5], in actual fact, the majority is hardly as well informed as it believes. Thus, it is striking to note that few

[3] A.S.A. 1995, Argirova et al, Okoliyski 98
[4] Okoliyski, 1998, Humboldt University, Berlin
[5] Conditions of AIDS prevention in Bulgaria, Okoliyski, 1999

actually change their risky behavior. For example 66.7 percent of the iv drug users believe themselves to be well informed, but only a few practice "safe sex" or "safe use"[6]. Moreover, fewer persons with exclusively heterosexual behavior consider themselves well informed (50 percent) in comparison with the other target groups (drug use: 66.7 percent, homosexual behavior: 60 percent, bisexual behavior: 60 percent). This can only mean that the latter groups get their information not from public campaigns, which are still mostly directed at the heterosexual majority, but from friends and peers. Finally, although a majority feels sufficiently informed, 66.5 percent maintain nevertheless that there is not enough AIDS information and AIDS counseling in Bulgaria.

The contradiction between feeling well informed on the one hand and, on the other, believing the information to be inadequate, suggests that Bulgarians, inside or outside of any particular target group, have a different concept of AIDS prevention and expect future prevention campaigns to be different from what has been offered so far. In particular, it seems that AIDS prevention in Bulgaria should be more specifically tailored to specific groups.

HIV/AIDS awareness among Sofia students in 2000 (A.S.A UNDP/MH 2000) is almost the same as in 1995. Indicators of awareness such as the understanding that *the disease is incurable* and that *a week after sexual intercourse transmitted virus cannot be identified* are rising. The basic knowledge that *the virus is transmitted through sperm, blood, and vaginal secret* remains at the same level for all samples (76 percent to 78 percent).

HIV/AIDS awareness, as with prevention attitudes, depends on the type of school, size of settlement, and ethnic background. Thus, for instance, the knowledge of the long latent period of HIV is common for 35.7 percent of vocational schools students, 51.1 percent of secondary schools students, and 70.0 percent of high school students. Other indices do not show such substantial differences among students in vocational and secondary schools. The basic line of division is between vocational and secondary schools, on the one hand, and high schools, on the other.

Understanding of the subjective HIV infection risk is an important indicator of awareness of the problem. Available data shows little development in the understanding of the subjective HIV infection risk. The majority (50 percent) of students do not *worry* that they personally can be infected. On the national level, only 19 percent perceive HIV as a big danger and are thinking about that. An important fact is that this attitude is higher in smaller settlements and teenagers of families of lower social and economical status. Additional analyses show an important connection between HIV/AIDS unawareness and subjective risk perception. Thus, for instance, teenagers, who are not aware that the HIV virus is transmitted through blood, sperm, and vaginal secret, perceive this risk as higher.

Be it so, this concern has changed only a fraction in the last five years. And this is only natural from the point of view of insignificant changes in HIV/AIDS awareness. Nevertheless, there is a slight increase in subjective risk perception in the last 12 years (Table 3).

[6] Okoliyski, 1998

Table 3. How big is the possibility that you become AIDS infected?

	1988	1995	2000 16-years old
No risk exists	26.1	27.7	21.4
The risk is small (I am not worried)	46.5	42.0	40.3
There is some possibility	15.5	21.0	22.2
The risk is considerable, I often think about it	9.1	5.7	10.7
There is very big possibility	2.8	3.6	5.3

Source: Medical Academy, 1988; NHC/ASA, 1995; UNDP/MH/ASA, 2000.; Comparable Sofia Samples

A significant fact is that the influence of information sources in Sofia is different from that for the country as a whole. Despite this conditional status of data, it is evident that the influence the same channel (information source) exerts in Sofia and in the countryside is different. Obviously, the influence potential of Sofia schools is higher than that of the countryside (including the region of Blagoevgrad). On the other hand, friendships in the province are probably closer and more influential.

We can conclude that young people have **not developed** sufficient social and life skills necessary for making responsible decisions about their sexual activities and behave tolerant to PLHA.

4.1.2 Prevention and attitudes towards most vulnerable groups in Bulgaria

Several groups have been identified from UNICEF and the International Organization for Migration (I.O.M.) (2002) as the most vulnerable to HIV/AIDS and STIs.

Injecting Drug Users.

Over the past few years, the number of injecting drug users has increased consistently. Currently, the number of the HIV-positive cases among injecting drug users in Bulgaria is increasing. And experts indicate that there is an enormous risk of a dramatic increase of HIV among injecting drug users in the near future. One indicator is the high rate of Hepatitis B and C among IDUs. In addition, many IDUs engage in risky sexual behavior. Methods for early detection of the virus among IDUs are necessary to prevent the rapid spread of the virus through unsafe injecting practices.

Prostituting Women and Men.

This is a non-homogeneous and difficult to access group, which is highly vulnerable to HIV/AIDS and other STIs. The risk factors include: the criminal element of the commercial sex business, violence and trafficking, marginalized social status, risky sexual practices, and social stigma.

Men who have Sex with Men.

There are three main subgroups within the gay community: the elite, which is highly restrictive; the middle, which is mobile and versatile with a high rate of mixing; and the lowest subgroup, composed mainly of outsiders and Roma. This subgroup is especially vulnerable. It is mobile with the lowest level of information, which makes intervention difficult. They engage in very risky sexual practices, they seldom use condoms, and many of them prostitute. The MSM community as whole is vulnerable to HIV/AIDS and other STDs die to several risk factors: inconsistent condom use, multiple casual sex partners, and relatively short permanent relationships.

Roma Community, Gypsies.
Available information indicates that the Roma community is the most vulnerable among the ethnic minorities. This is due to a number of inter-related factors: a rapidly disintegrating patriarchal system, which is not being replaced by a new, sustainable social structure; ever increasing social isolation accentuated by a 90 percent unemployment rate; a poor economic culture; absence of social skills and motivation for socialization; increasing rate of prostitution, drug abuse, crime, and mobility; and other practices increasing risk of HIV/AIDS and other STIs. In addition, health experts suggest that most Roma women have banal STIs, which increases the risk of more serious infections, such as HIV and Hepatitis B.

The available data regarding the level of risk in Roma' sexual behavior are limited and to some extend contradictory. There is a sociological survey by A.S.A.[7] conducted according to which 58 percent of Roma populations begin their sexual life before reaching the age of 16.

Impressions of liberalization of sexual behavior are voiced, which by the way is characteristic for Bulgarians too (A.S.A -UNDP/MH. 2000). What is of importance is that with low awareness liberalization of sexual values can bring about an increase in the risk of sexual behavior. According to quoted NGOs, repressive attitudes towards sexual relations with members of other ethnic groups decline. The opinion is that this is more valid for men than for women. Anthropological observations by Haralan Alexandrov show that Roma values impose repressive attitudes towards sexual behavior of women and permissive towards that of men. This places Roma women in a status of double minority, which makes them an especially risk group.

NGOs have confirmed conclusion made earlier in discussing prostitution about prevalence of highway and street prostitution among Roma girls. It is considered that Roma prostitutes come from the lowest social and economical strata of the community, quite often from broken families or disintegrated clans. These girls are usually brought from another settlement – at great distance from their place of work. Roma NGOs emphasize that there exist no restrictive values suppressing the business of procurers. The community is inclined to blame the *guilt* of prostitution on the *alien* girl (that comes from another settlement) rather than on the procurer – the man who brings income into the quarter.

Isolated Groups and Imprisoned Individuals.
Very often the lack of opportunities for heterosexual intercourse, stress, altered values, violence within the group, and the lack of contact with the outside world result in risky homosexual behavior and prostitution, which increases the risk of HIV and STIs. This persons are suffering high stigmatization by the society as well.

4.2 The causes of HIV and AIDS-related stigma in Bulgaria

Stigma is a complex social phenomenon involving interplay between social and economic factors in the environment and psycho-social issues of affected individuals. Erving Goffman (1963) describes three types of stigma: "abominations of the body," or stigma related to physical deformities; stigma related to "blemishes of individual character," for example those who are considered weak willed, to have unnatural passions, or to be dishonest; and "tribal stigma," or stigma relating to race, nation or religion, or membership of a despised social group. Because one typically inherits membership to this type of group, "tribal" stigma can equally adhere to and affect all members of a family.

[7] Mirchev and ASSA-M in 1996

While Goffman focuses on the individual aspects of stigma, Parker and Aggleton (2003) offer a framework that emphasizes stigma as a social process that produces and reproduces relations of power and control and examines how stigma is used to turn difference into inequity - including inequity based on gender, age, sexual orientation, class, race or ethnicity - thus allowing some groups to devalue others on the basis of these differences. According to this analysis, stigma and discrimination are used by dominant groups to produce, legitimize and perpetuate social inequities and to exert social control through the exclusion of stigmatized groups, thus limiting ability of the stigmatized groups and individuals to resist or fight back against the stigma.

The findings from this study resonate well with these explanations. In the communities of our study, we found that stigma stems largely from practical, moral, economic, cultural and political factors. The practical dimension of stigma relates to the stigma that adheres to all chronic (such as severe mental illness) or infectious diseases to greater or lesser degrees. Because HIV is considered to be a serious, communicable and incurable illness, it is greatly feared. This fear is exacerbated by the vague and sometimes conflicting messages conveyed by the media and through everyday gossip and talk about the mechanisms by which HIV is transmitted. Even when people seem to understand, or at least are able to repeat, the three main modes of transmission, they do not trust this knowledge. Rather, they fear that HIV can be transmitted through casual everyday contact, in the way that other viral or bacterial infections can be.

The moral dimension of stigma relates to the fact that up until the present time, HIV and AIDS have been strongly linked in policy, programs and in peoples' minds with homosexual contacts, injection drug use and sex work, considered to be social unacceptable. Both drug use and sex work have long been stigmatized in Bulgaria because they are regarded as behaviors that deviate from traditional moral norms and values. Moreover, it is generally believed in the community that homosexual behavior, drug use and prostitution *inevitably* lead to AIDS, and that those with AIDS likely contracted it from one of these three means. Thus, people living with HIV and AIDS, injection drug users and sex workers are all multiply stigmatized, as all are considered to either be dangerous for the society (homosexuals, drug users and prostitutes), or ill as a result of their risky and unresponsible behavior (people with HIV and AIDS). This situation appears to be further exacerbated by the current government programs combating drug use and sex work, which capitalize on the notion of dangerous categories to encourage people to give up these practices, or for others to turn those engaging in them into the police.

We argue below that in order to effectively combat HIV and AIDS-related stigma in Bulgaria, it will be necessary to delink the illness from dangerous and risky social categories in social policy and in the minds of the general public.

4.3 Stigma related to fear of HIV and fear of casual transmission

In some cases study participants voiced concern about the risks posed to the wider community by the presence of HIV-positive individuals living in the community. This is due in part to the fear of HIV as an incurable and fatal infectious disease, and in part to the fact that people have inaccurate and incomplete information about the ways in which HIV can be transmitted.
Both issues stem from fear, and both can be positively influenced by appropriate and well considered interventions.

Although the majority of participants noted that they would try to treat PLHA with understanding and demonstrated high level of awareness about HIV/AIDS some of them share that they will very cautious in the contact with the person belonging to this group.

Regarding help, everyone is willing to do so, but...getting close—hugging or even burying—

that's what they are reluctant to do. People are even reluctant to hold hands [of PLHA]. Everyone is in the spirit of helping, but many times they do not dare to visit the house or to get physically close. (participant in FGD)

According to health professionals they don't have a sufficient knowledge about protection means and emergency prevention of HIV/AIDS transmission at providing surgical interventions, at deliveries and other manipulations related to blood. They also say that protection means include only gloves. Protection glasses are available only in a limited amount.[8]

I am a health professional. I know that HIV is transmitted only in three main ways. But when I come into contact with them [people living with HIV and AIDS] I still worry and feel nervous... In my case it is my duty, my responsibility to work with them, to go to them. But in fact I am fearful. (participant in FGD2)

Results of the research indicate that fear of HIV and AIDS is one of the principal causes of stigma against people living with HIV and AIDS and their families. This is related in part to fear that accompanies other infectious diseases, such as other STDs and also to the fact that people are uncertain about the ways in which HIV can be transmitted or do not fully trust the knowledge they have acquired. We found that some of the messages about HIV transmission are both terrifying and vague - a combination that seems to have led to greater confusion and fear than to solid understanding and awareness. And out of this confusion and fear arises stigma.

In fact, many people are concerned about the risks posed to their health merely by co-existing with community members who are living with HIV, as the following quote illustrates:

…in terms of theory, we should not discriminate, but in our minds fears remain. As my colleague here said, I will not sit by those infected people if I meet them in a café because I also worry whether it is transmitted by any other way… For example my neighbor who is a teacher has an infected son. Whenever meeting him by chance we only greet him summarily. We don't want to touch him.
(participant in FGD2)

5. Extend and forms of S&D

5.1 Degrees of stigma

Not all HIV infected persons bear the same level of stigma. A number of participants feel that moral judgments against PLHA should be based on how that person acquired HIV and on their lifestyle. According to some community members, PLHA can be classified into two different groups according to reasons of infection. The first are those who are "degraded" and become infected due to deviant behaviors such as drug injection and prostitution. This group deserves blame and social opprobrium.

5.2 Culpability of the family

As indicated by Goffman (1963), stigma adheres not only to the person or persons with the discrediting characteristic, but sometimes to their families as well. In Bulgaria, the families of IDUs or sex workers who become HIV infected are also criticized heavily. It is felt that the family has neglected the education of its children, causing them to become degraded. Many use traditional sayings such as "strike while the iron is hot" (one must educate children when they are still small) to emphasize the family's responsibility (and particularly the mother father's responsibility) for ensuring that their children do not get involved in "bad behaviors" that make them vulnerable to acquiring HIV infection (Casper Hauser documentation 2006).

[8] In-deph interviews with nurses

In reality, many families, knowing that their child is using drugs, try to educate and encourage him or her to give up. If these children later become infected with HIV, the parents despair of what happened to their family.

Bulgarian culture does not prescribe a code of behavior in encounters with cases of people carrying the stigmata of belonging to the group of PLHA. Too much is left to individual choice for the present arrangement to be found satisfactory. Bulgarian culture has not maintained for more than half a century now the tradition of charity. Most, left unguided as they are in this domain of life since childhood, feel at a complete loss when faced with HIV/AIDS or mental illness

Another point of interest was aimed at finding out, at what extent the respondents themselves are afraid of becoming of victims of stigma. In order to do this, questions were asked whether they would inform anyone (their friends, acquaintances, and colleagues) if a member of their family is HIV positive (FGD2). Everybody said that the HIV- positive have to decide to inform or not anyone, but this will not change their attitude to him/her. The explanation of this was that they have no chance. All the participants were talking about the fact that the most important thing is what relations they have with HIV positive. So if HIV positive is a close family member, they would feel sympathy towards this person, they would feel compassion towards this person, would try to understand and help him/her in obtaining qualified psychological help.

Communities by and large comply with the policy of the government to determine itself the needs of the PLHA and to decide on the approaches to meeting them including the assignment of responsibilities to agencies and individuals in roles. This top-down regulation is a leftover from the times of total control. It is a malfunctional approach by design, and leaves out of consideration much of what is going on through informal networks of relatives and friends. The helping professions do not tune into the self-evolved support systems well but improvement in this respect is apparent. For examples, care coordination as a new service offered to the PLHA is now offered by the care facilities in the country.

6. Recognitation, policies and management of S&D

6.1 General public health interventions and government efforts to combat HIV and AIDS in Bulgaria

All programs to improve HIV/AIDS prevention, care and population's attitudes towards PLHA have been developed by the Ministry of Health and the other stakeholders on the tacit assumption that rational health behavior is inherent to people so long as they are duly informed of the health hazards they submit themselves to. Consequently, no attempt has been made to estimate the expected response rates. Similarly, the outcome from these programs, critically dependent as it is on the activity of the targeted populations, has not been assessed in ways that could prompt improvements in the design. In addition, in none of the areas, in which health improvement programs have been launched, campaigning has been made contingent on tapping the opinion and attitude of those targeted. Consequently the implementation groups were left blind to the response they were likely to face coming from those whom they had to serve. Public accountability has not been integrated into the design; beginnings and ends of the activities were not marked in any significant ways in most cases; and acknowledgment by the media was inappropriate.

Most of the above critical comments concern the non-medical aspects of the activities, but are nevertheless important as the flaws in the design and the execution of the programs may have critically impinged on the justification of such efforts or may have undercut their public health impact.

The observance of human rights of the PLHA have been incorporated in the legislation after 1989. However, the enforcement of the human rights legislation is not making progress, the obstacles being largely attitudinal and cultural. Violations are believed to be many but unreported. Watchdog organizations are explaining the situations in terms of low awareness of the notion of human rights in a culture, which is still very much in the grips of the paternalistic tradition.

First steps in direction of prevention were taken as early as 1996, when the National Committee on AIDS and STDs Prevention was formally established under a Decree of the Council of Ministers. Later, in 2001, the Bulgarian Government endorsed the National Strategy and the National Action Plan for Prevention and Control of AIDS and Sexually Transmitted Diseases which cover the period 2001-2007.

The National Strategy and the National Action Plan incorporate a multisectoral approach and active cooperation at different levels to address all aspects of the problem. The National Action Plan represents the overall policy of the country not to allow an outbreak of HIV/AIDS epidemic. The four major components of the National Action Plan are as follows:
1. Health promotion aimed at young people and most-at-risk groups;
2. HIV/AIDS and STDs epidemiological surveillance and testing policy;
3. Health care and social services for people living with HIV/AIDS and STDs;
4. Medical care and treatment of HIV/AIDS and STDs.

Since 2001 and the adoption of the National Action Plan for Prevention and Control of HIV/AIDS, the Ministry of Health has been making considerable annual budget allocations that cover the country needs for ensuring blood safety with regard to HIV, hepatitis B and C and syphilis; universal and free-of-charge HIV testing; universal and free-of-charge HAART.

In 2002, on behalf of the Country Coordination Mechanism (CCM) the country applied for a grant by the Global Fund to Fight AIDS, Tuberculosis and Malaria. CCM was established and is functioning based on the existing National Committee for Prevention of AIDS and STDs. In its membership the Country Coordinating Mechanism is a unique body. It functions as a forum to promote true partnership development and participation of multiple constituencies, including governmental agencies, donors, non-governmental organizations, PLWHA. The country proposal was approved and a Grant Agreement for approximately 6,9 million US dollars was signed on 6 June 2003, and the implementation of Program "Prevention and Control of HIV/AIDS" started in 2004. The major focus of the GF-funded Program, in addition to the government-funded activities and services, is HIV prevention among the groups most-at-risk, young people and PLHA.

Later in 2004, through the implementation of Program "Prevention and Control of HIV/AIDS" and in collaboration with UNAIDS the process establishment of a national HIV/AIDS monitoring and evaluation system was initiated. During all that time, important financial and technical support has been provided by international donor organizations, such as UNAIDS, WHO, UNICEF, UNDP, UNFPA, USAID and others, which further contributed to the implementation of the activities and provision of accessible services in the national framework for action. With a view to ensuring not only an effective national response to HIV/AIDS but

also joining the mobilization of efforts at regional and global level, the Government of the Republic of Bulgaria undertook several important steps to state its commitment.

In the light of joining the European Union, Bulgaria has been included much earlier and is participating in all major European networks and initiatives related to HIV prevention and control and testing policies and practices in Europe. The country has taken part in the development of the Communication from the Commission to the Council and the European Parliament on Combating HIV/AIDS within the European Union and in the neighbouring countries, 2006-2009.

The National program achieved its goals in supplying the appropriate equipment and material base for epidemiological surveillance, drugs and medical goods, in the development of national network for epidemiological surveillance of HIV/AIDS and the sexually transmitted diseases.

Some other goals were not fully achieved. The quality of treatment, health care services and the provision of adequate health care services to all people living with HIV/AIDS and STIs was achieved only in Sofia and recently in some major cities – Varna, Plovdiv, Stara Zagora. The non-discriminatory access to health care services for PLHA was not guaranteed also because GPs and other medical staff were not trained to provide general medical care and counseling for people living with HIV/AIDS and STIs. Also regional centers for counseling and monitoring of people living with HIV and STIs were not established. A secure and effective system for treatment and clinical surveillance of patients which guarantees confidentiality and respect for patients' rights was not successfully established and often confident information about the clinical status of the patients was misused by the medical staff.

As a result the support from the social environment was not present or was very weak and there were no significant changes in the social acceptance of PLHA by the society. The Programs failed in its attempts to focus on the development of a rapid response to help this most vulnerable social group and laying the foundations of a sustainable process of reducing the stigmatization that contribute to the vulnerability of PLHA to negative social reactions of isolation and marginalization. During its realization the plan never provided an adequate response to the need of coordination between a number of institutions and agencies as well as of the society and NGOs.

Currently, key roles and functions related to monitoring and evaluation of the country's situation and response are primarily taken by the Department of HIV/AIDS and STIs Prevention and Control Monitoring and Evaluation Unit at the GF-funded Program. This unit, however, is collecting and combining data coming from the second generation sentinel surveillance system and the system for programmatic reporting and monitoring of organizations contracted as sub-recipients of the Global Fund grant. As previously described, services and activities under program "Prevention and Control of HIV/AIDS" ensure to a great extent geographical equity and high coverage rates at the subnational level, but still not fully nationwide. A challenge is still the establishment of a National HIV/AIDS Monitoring and Evaluation system, which includes as steps: establishing a Monitoring and Evaluation Task Force; development of a National Monitoring and Evaluation Plan in parallel with update of the National Strategy and National Action Plan; establishment of an operational Monitoring and Evaluation Unit at the Ministry of Health as part of ensuring necessary monitoring and evaluation mechanisms and structures in place; development of a central national database.

7. Conclusions

This report has discussed the root causes of stigma, its manifestations and its impact on the lives and well-being of PLHA and their family members. Findings suggest that the most important causes of stigma are people's fear of casual transmission and moral judgments and assumptions made about the lives and lifestyles of those affected. These underlying causes appear to be reinforced by some media portrayals and inadequate messages about HIV and PLHA that promote negative and fearful images - heightening people's fears and uncertainties, rather than exposing them for consideration and debate.

The main forms of stigma and its manifestations range from social isolation due to fear of infection, to the use of demeaning and hurtful language, to more drastic forms of discrimination and social marginalization of PLHA and their family members.

It is clear that stigma prevents people from disclosing their HIV status to others and stands in the way of access to care and support. This can have a profound impact on the epidemic. It may mean that transmission occurs that could otherwise have been prevented, it means that individuals and families suffer unnecessarily, and it means that the community is deprived of the important contributions of PLHA and their family members.

However, our findings indicate that there are reasons to hope that the situation will improve. On the whole, people have good intentions— they do not mean to hurt others and want to be seen as caring and supportive to neighbors and friends. This is true of community members as well as some of the media and others with influence. The information provided by this study can assist in developing a process for building on these good intentions to find effective and appropriate solutions to the problem of HIV-related stigma. In addition to improving the lives of PLHA and their families, tackling stigma now may in fact ultimately result in stemming the further spread of the epidemic.

The current anti-stigma campaign of the government of Bulgaria has made important initial inroads in tackling stigma, instilling the notion that it is important to support those living with HIV and AIDS and their families. However, we found that despite these efforts, many — if not most — people remain afraid and uncertain. Many are aware of, but hesitate to act according to, the anti-stigma messages because their knowledge about HIV transmission is clouded in myth, fear and ambiguity, and their feelings about PLHA and their families are grounded in negative moral judgments. People have become confused by the contradictions between the anti-stigma campaign ("Living with HIV") and what they hear in the anti- IV drugs campaign (IDU = criminal act).

The data from this project indicates that antistigma efforts need to do more to address those factors that currently underpin stigma: people's fear of casual transmission and the moral judgments against PLHA and their families. Effectively addressing these root causes of stigma will enable and encourage those infected and those at risk to take necessary and appropriate measures to prevent further transmission and to live healthy, productive lives.

8. Recommendations

8.1 Reduce fear of casual transmission

Evidence from this study clearly indicates that most people have internalized some information about HIV transmission—that HIV is transmitted "through blood," from mothers to their children and through unprotected sexual intercourse. However, it is equally clear that very few people actually trust what they have learned. Much of the information is vague and ambiguous. The ways in which HIV is different from other types of infection are not clear in people's minds. Consequently, fears and uncertainties remain that lead directly to stigmatizing behavior and the imposition of unnecessary and inappropriate "prevention" measures. It is therefore vital that programs deepen people's knowledge about HIV and AIDS by:

- Delivering specified information about how HIV is and is *not* transmitted and why for the different target groups;
- Highlighting real and discussing imagined risks that people are exposed to in the community, in the household and in intimate relationships;
- Providing opportunities for direct questions to be asked and direct factual answers to be
- given;
- Ensuring that universal precautions are taken;
- Training health staff, teachers, social workers, general practitioners and others in HIV prevention, promotion, strategies for reducing stigma and discrimination and providing them with the necessary equipment for universal precautions as appropriate.

8.2 De-link HIV and PLHA from "social threats"

The second set of recommendations from this study stems from the need to tackle the "moral" roots of HIV and AIDS-related stigma. Moral judgments about people living with HIV and AIDS and their families inhibit people from disclosing their HIV status. As people acquire better and deeper knowledge about HIV and AIDS, policies and programs can reinforce this knowledge to promote appropriate care, support and prevention by:

- Delivering positive images of respected people having direct contact with people living with HIV and AIDS; and
- Involving leaders and respected people in activities combating HIV and AIDS-related stigma.

Injection drug use and sex work are important problems in Bulgaria — we do not mean to downplay or underestimate their importance, or the importance of finding a way to reduce the prevalence of these activities and their impact on the community. And there is an important epidemiological association between these behaviors and HIV transmission. But the facts presented in this study clearly indicate that great thought needs to be given on how to ensure that the disease (AIDS) can be delinked from injection drug use and sex work in the minds of the community, health care providers, teachers and public leaders. On the basis of the findings from this research, we recommend the following:

- Remove the criminalization of CSW and drug use from legal documents and programs on HIV and AIDS;
- Disassociate HIV and AIDS from "social and health threats" in the media;
- Deal with HIV and AIDS separately from behaviors such as injection drug use and commercial sex work in policies and programs.

8.3 Promote positive messages on HIV and people living with HIV and AIDS

Much of the current approach to HIV and AIDS education and information in the media and in programs is based on prevention through fear. Efforts tend to focus on the negative and sensational and do not provide a factual picture of what it really is like to live with HIV and AIDS. This research found that these messages create fear, panic and stigma, thus impeding care and support efforts. We recommend that the media revise its programming around HIV and AIDS to include a more realistic and pragmatic perspective, including discussions about new treatment and prevention technologies. Using positive images of healthy people with HIV will encourage greater understanding about HIV and AIDS, that HIV is not a death sentence; that people living with HIV and AIDS can lead productive lives and make valuable contributions; and that care and support make a difference. In addition, messages about treatment and new technologies can inspire hope, and programs that discuss best practices can show how other countries have tried to move forward in the face of their own HIV and AIDS situations.

On the basis of the results from this analysis we would like to recommend a next phase of this study, where partners from different sectors (partner organizations from the SEE region, Europe, the media, people living with HIV and AIDS and others) would begin a process of moving the findings from this research and its recommendations into practice. In this connection we would like to recommend the further support and strengthening of the established Expert Center in Blagoevgrad. The continuation of the creation and spreading of the information leaflets and materials on specific HIV/AIDS prevention for different target groups, publication of articles at the local media are from critical importance. One of the outcomes of these steps would be the increase of the sensitivity to the problem, the shortening of the way between the risky behavior and the search for advice or help. It would be very efficient to devise a set of "HIV and AIDS Fact Sheets" specifically designed to address the fears and uncertainties that emerged from this study as key causes of HIV-related stigma and discrimination. In a second phase, the team from the Expert Centre could adapt a "Anti-Stigma Toolkit" for the Bulgarian context, and later implementing the toolkit in workshops with members of the community in all of Bulgaria's provinces.

Future policy and programs that build on this sentiment will help ensure that HIV-related stigma and discrimination become a thing of the past in this country:

"Concerning the community, we clearly define that we should not avoid those persons [withHIV and AIDS] but be close to them and console them. We know that they have to die sooner or later, so the more we are close to them and we show our consolation, their lives will be longer, because they are also human beings."[9]

[9] FGD 1

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Mirchev and ASSA-M in 1996: Behavior patterns and attitudes in most vulnerable groups

Casper Hauser documentation 2006

ANNEXES

Annex 1: Questionnaires for medical staff and general public

People have many different feelings when they think about people who have AIDS. As I read each of the following feelings, please tell me how you personally feel.

1. How about feeling angry at them? Would you say you feel:
   (a) very angry,
   (b) somewhat,
   (c) a little, or
   (d) not at all angry at people with AIDS?

2. (How about) afraid of them?

3. (How about) disgusted by them?

Now I'm going to read a list of statements people have made. As I read each one, please tell me how much you agree or disagree.

1. How about "people with AIDS should be legally separated from others to protect the public health?" Would you say you:
   (a) agree strongly,
   (b) agree somewhat,
   (c) disagree somewhat, or
   (d) disagree strongly?

2. (How about) "The names of people with AIDS should be made public so that others can avoid them?"

3. (How about) "People who got AIDS through sex or drug use have gotten what they deserve?"

1. Suppose you had a close friend or relative who developed AIDS.
   (a) Would you be willing to take care of him/her, or
   (b) is that something you would not be willing to do?
   IF (b): Is that because
   (c) you wouldn't want to take care of someone with AIDS, or
   (d) for some other reason?

   [supportive response = a; avoidant response = c]

2. And suppose you had a young child who was attending school where one of the students was known to have AIDS. What would you do? Would you:
   (a) send your child to another school, or
   (b) leave your child in the same school?
   IF (b): Would you
   (c) encourage your child to be especially nice to the student with AIDS,
   (d) discourage your child from contact with him/her, or
   (e) encourage your child to treat him/her as always?

[supportive responses = c, e; avoidant responses = a, d]

3.Now suppose you had an office job where one of the men working with you developed AIDS. Would you:
(a) still be willing to work with him,
(b) ask he be assigned someplace else,
(c) or ask to be assigned with someone else.
IF (a): Would you
(d) go out of your way to help him,
(e) try to avoid contact with him, or
(f) treat him the same as always?

[supportive responses = d, f; avoidant responses = b, c, e]

4.Suppose that you found out that the owner of a small neighborhood grocery store where you like to shop had AIDS. Would you:
(a) continue to shop there, or
(b) probably go someplace else to shop?
IF (a): Do you think you would shop there
(c) more often or
(d) less often than you did before you found out the owner had AIDS, or
(e) would you continue to shop there as much as you did before you found out?

[supportive responses = c, e; avoidant responses = b, d]

These next questions are about the different ways some people think AIDS might be spread. As I read each of the following, please tell me how likely you think it is that a person could get AIDS or AIDS virus infection in that way.

1.How about kissing someone on the cheek who has the AIDS virus? Would you say if someone does that they're:
(a) very likely,
(b) somewhat likely,
(c) somewhat unlikely,
(d) very unlikely to get AIDS, or is it
(e) impossible to get AIDS by kissing someone on cheek?

2.How about sharing a drink out of the same glass with someone who has AIDS?

3.How about by using public toilets?

4.How about from being coughed on or sneezed on by someone who has the AIDS virus?

5.How about from mosquito or other insect bites?

We're also interested in knowing what you think the chances are that certain types of people will get AIDS in certain types of situations.

1.First, think of two healthy homosexual men – *neither* of whom is infected with the AIDS virus. Now suppose they have sexual intercourse. If they use condoms, would you say

that at least one of them is:
(a) almost sure to become infected,
(b) has a fairly strong chance,
(c) has very little chance, or
(d) has no chance of becoming infected

2. Now suppose the same two healthy men have sexual intercourse but this time they *do not* use condoms.

3. Now think of someone who uses drugs intravenously (and who is not a homosexual). If this person *does not* share needles, what do you think this person's chances are of becoming infected with the AIDS virus?

Annex 2: FGD guidelines

Focus group questionnaire:

1. According to you which are the most serious problems of PLHA?
2. According to you what kind of attitude has people towards those living with HIV/AIDS?
3. According to you is there have been taken action towards:

- Fight against stigma and discrimination
- Integration of PLHA

4. Are there people who have enough information about HIV/AIDS?
5. According to you which are the ways of improvement the social information load?
6. Do you organization working in this field?
7. According to you in which direction should things start to change?
8. Do you know what is the situation in Bulgaria and how many HIV infected there are in the country by the moment?
9. Do you thing that you can initiative some activities by your self or you prefer to become a part of community activities in order to prevent spread of HIV infection?
10. Do you have any information about national politic toward prevention of spreading the HIV infection; towards discrimination of PLHA.
11. If a member of your family becomes a HIV infected will you be agree to take care of him/her at you home?
12. If you know that the sells person for you grocery store is HIV positive will you continue to bye food from this store?
13. If a teacher is HIV positive do you think that he/she will be permit to continue his work in the school?
14. If a member of your family is a HIV positive would you like to keep than in secret?