



Stigma and Discrimination towards People Living with HIV

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Mission statement on Mental Health and HIV/AIDS

Mental health and HIV/AIDS

Mental illness is inextricably linked to HIV/AIDS, as a casual factor and as a consequence, while mental health treatment and support for people living with HIV/AIDS is key to both improving their quality of life and preventing the further spread of the infection. The issue is of particular concern to central and Eastern Europe and the Newly Independent States, where the AIDS epidemic is growing fast while rates of mental illness are also rising, and the limited resources and facilities available to treat both conditions pose major challenges.

Addressing the needs

The GIP Mental Health & HIV/AIDS project is a project of the Global Initiative on Psychiatry (funded by the Netherlands Ministry of Foreign Affairs from 2005 - 2008) that addresses the often-overlooked connection between mental health and HIV/AIDS. The Network supports efforts to improve the quality of life and to diminish the suffering of people with HIV/AIDS. The Network strives for increased knowledge regarding the overlap between mental health and HIV/AIDS, and promotes the development of a comprehensive system of mental health assistance to people affected by HIV/AIDS. Furthermore, it supports efforts to increase the understanding of the general public and health professionals and to decrease the stigma associated with mental illness and HIV/AIDS. The Network works through local expert centres that focus their work on research and training, advocacy and awareness building, networking and a wide variety of other interventions.

Global Initiative on Psychiatry (GIP)

GIP aims to promote humane, ethical, and effective mental health care through the world, and is particularly active in countries where mental health care is still usually substandard and where patients' human rights are frequently violated. GIP's work is based upon the underlying principle that every person in the world should have the opportunity to realize his or her full potential as a human being, notwithstanding personal vulnerabilities or life circumstances. Every society, accordingly, has a special obligation to establish a comprehensive system for providing ethical, humane and individualized treatment, care, and rehabilitation, and to counteract the stigmatisation of, and discrimination against, people with mental disorders or histories of mental health treatment.

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ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome;
GIP	Global Initiative in Psychiatry
GF	Global Fund
GO	Governmental Organization
GP	General Practitioner
HAART	High Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HPVPI	The HIV Prevention among Vulnerable Populations Initiative
ICRW	International Centre for Research on Women
IDU	Intravenous Drug Users
IAN	International Aid Network
IPH	Institute for Public Health
JRRROL	Judicial Reform and Rule of Law
MSM	Men who have sex with men
NGO	Non-governmental organization
PEP	Post exposure prophylaxis
PLHIV	Persons living with HIV/AIDS
STI	Sexually transmitted infections
SW	Sex worker
UN	United Nations
UNAIDS	The Joint Nations Programme on HIV/AIDS
UNDP	United Nation Development Program
UNICEF	United Nation Children's Fund
VCT	Voluntary counselling and testing

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We are especially thankful to PLHIV and who, having taken part in focus groups and talking about their experiences, contributed to understanding of this problem. We express our outstanding gratitude for their courage!

We hope that this Report will help the decision makers, NGOs and PLHIV themselves in making their efforts more efficient and effective - in terms of improving the position of PLHIV in the society.

OVERVIEW OF THE REPORT

This report describes research done to explore stigma and discrimination toward PLHIV. The major issues covered by this report are:

- Overview of country context, HIV epidemic in Serbia and theoretical background on causes of stigma
- Causes, forms and extent of stigma and discrimination are explored using data from three focus group discussions (with PLHIV, medical professionals, volunteers engaged in psychosocial support of PLHIV), administered survey among medical professionals, content analysis of press clipping and interviews with stakeholders. Also, the same issue was explored by analyzing the data from a quantitative study done on representative sample of Serbian population by an other organisation ¹
- Reactions to stigma and discrimination towards PLHIV - policies, laws, approach to coping with and reducing stigma. Examples of approaches to reducing stigma are examined and strategies and reactions of PLHIV who experienced stigma are presented. Also, in particular in medical setting approach to services of those who have experienced stigma is described.
- Finally, drawing from conclusions of this report recommendation for program and policy makers on different levels were given

¹ Strategic marketing research (2006): Stigmatization, Belgrade

1. BACKGROUND

1.1. Country overview²

- The functioning of Serbian society, in terms of transition and social and economic crises is not a favourable social environment for the battle against HIV/AIDS. Organised crime related to drugs, tobacco, human trafficking, prostitution, physical violence, etc., increase chances of engaging in risky sexual behaviour. There is an insufficient volume of studies assessing behavioural risks to reveal the actual level of risk of HIV/AIDS transmission in the population.

- There is a high level of stigmatisation in the society towards persons belonging to marginalised groups- IDUs, MSM, prison inmates, SW

- The position of women in a transition society is very unfavourable and, due to a considerable number of factors (cultural, economic, and legal), adversely affects the possibilities of protection against HIV.

- The sex lives of young people are considerably disoriented and highly risky, primarily with regard to HIV/AIDS. They are only sporadically being informed and educated on the issue, and even then the focus is exclusively on young people in big cities. Furthermore, this education is predominantly associated with activities in the non-governmental sector, and there is no systemic implementation of programs within the school system or outside it.

- Serbia is characterised by a constant decline in the natural growth rate of the population, a high rate of abortion, and an increase in the number of children born outside of marriage. However, number of artificial abortions is continuously decreasing. It is interesting to note that in 1991 ratio between live births and number of abortions was 1:2, and in recent years is 2:1³

-The existing health care system is functioning in unsatisfactory financial circumstances, which imposes yet another obstacle in responding to the needs of beneficiaries in accordance with the widely proclaimed right to health care. This economic burden is borne by the population, for they pay privately for a portion of the expenses for medicine, laboratory services and special treatments. The consequences of such circumstances make it difficult or impossible for persons with HIV/AIDS to receive appropriate health care.

- Test results in population groups with elevated risk do not provide the level of quality information that could influence better assessment of the spread of HIV infection, as the tests are being performed on a small number of persons and on non-representative samples. Similarly, some high-risk population groups are not tested at all (members of national minorities, refugees, sexual partners of HIV positive persons)

² The National Strategy for HIV /AIDS, Belgrade 2007

³ <http://www.zdravlje.org.yu/>

- Health care for PLHIV is offered within a centralised system focused on clinical practice and hospital care, with the application of inadequately accessible antiretroviral therapy.
- A significant role in providing social support to PLHIV has been played by NGOs. They considerably contributed to raising awareness about HIV/AIDS in the younger population and, with regard to this, they have established an effective partnership with other actors in the fight against HIV/AIDS.
- Even though NGOs have a significant role in building social awareness and encouraging more responsive behaviour with regard to health, the mass-media have prevalingly concentrated their activities on the campaigns and marking associated with World AIDS Day.
- The linkage between the governmental and non-governmental sector, as well as the cooperation within the relevant institutions (systems of the health care, education, social care, justice, internal affairs), is inadequate both at the national and at local levels.
- No comprehensive program of HIV/AIDS prevention and social support to those impacted has been established and implemented in the health and social care system in Serbia to date.

1.2. HIV epidemic in the country

Accurate HIV epidemiology data is inadequate in Serbia. According to the available data, Serbia has a relatively low prevalence of HIV infections, with an estimated HIV prevalence of 0.05-0.1%. However, the testing rate in Serbia is very low, for in 2005 a mere 4.7 per 1,000 persons were tested. In 2006 2,088 HIV infected persons were registered in Serbia, and 1,339 (64%) of those registered had already been diagnosed with AIDS, 915 of whom have since died of AIDS. According to UNAIDS estimates, there are about 10,000 (6 -17. 000)⁴ HIV infected people in Serbia and Montenegro.

PLHIV are predominantly grouped in central Serbia (90%), and 80% are located within in Belgrade. The predominance of PLHIV in Belgrade could likely be due to the fact that most people are tested in Belgrade and the only HIV/AIDS Clinic in Serbia is located there.

After a period of continuous growth in the number of registered people manifesting clinical symptoms of AIDS, in 1999 it was observed that the number was gradually in decline, and the estimate is that this tendency is going to continue in the period to come. Also, from 1997, a continuous decrease in the number of AIDS related deaths has been recorded. The decrease in the number of AIDS deaths has been associated with the implementation of highly active anti-retroviral therapy (HAART), which became available in 1997 and it is free of charge. As of July 2007, there were around 600 people with access to HIV treatment in Serbia and Montenegro⁵. This decrease in the number AIDS diagnoses and AIDS related deaths, however, has not been followed

⁴ <http://www.unaids.org/>

⁵ this data was obtained through communication with Global Fund Serbian Country Coordinating mechanism member

by a decrease in the number of people newly infected with HIV. As such, the number of people who are HIV positive is rising, and these people are able to live longer.

HIV transmission among intravenous drug users (IDUs) is as high as 44%. Drug users, along with haemophiliacs and other blood transfusion recipients, comprise over half of those with AIDS, as they were infected through blood derivatives. Another 35.5% positive people are infected through sexual intercourse. HIV transmission from mother to child is rare, at 1.4%. For more than 10% of those infected with HIV/AIDS, mostly men, the mode of transmission was not established or reported. The epidemiological situation in Serbia has been characterized by a decline in the number of HIV positive IDUs, and an increase in the number of HIV positive heterosexuals and MSM, over the past ten years⁶.

Although, Serbia has a low level epidemic, situational and structural factors coincide to create an HIV risk environment. Factors contributing to the spread of HIV infection are various:⁷

- Low social and economic status of a part of the population;
- Absence of realistic assessments of the size of vulnerable populations (IDUs , SW, MSM);
- Inadequate and unsuitable systems of monitoring and evaluation regarding HIV/AIDS and the overall social response to the HIV/AIDS epidemic;
- Inadequate awareness of the general population about the risks of HIV transmission
- High levels of discrimination towards vulnerable populations and PLHIV
- Absence of legislative regulations addressing HIV/AIDS issues

1.3. Forms, effects and causes of S&D (problem tree)

HIV/AIDS is life threatening disease that people fear contracting. HIV/AIDS related stigma is result of interaction between various pre-existing sources of stigma and discrimination and fear of contagion and disease.

The various metaphors associated with AIDS have contributed to the perception of HIV/AIDS as disease that affects others, especially those who are already stigmatized because of their marginalized behaviour - MSM, SW, IDUs. Besides, it seems that our community, emphasizing individualism, also influence perception of HIV/AIDS as the result of personal irresponsibility and consequently these individuals are blamed for contracting the infection.

Traditional cultural values and religious believes about sexuality may also contribute to the explanation of HIV/AIDS-related stigma. Religious believes and institutions find a faithful marriage the only appropriate way for intercourse, hence sex outside of

⁶ Institute of Public Health of Serbia “Dr Milan Jovanovic Batut”, Centre for prevention and disease control (2006): Epidemiological Overview of HIV/AIDS in Serbia 1984-2006, Danijela Simic, available in Serbian

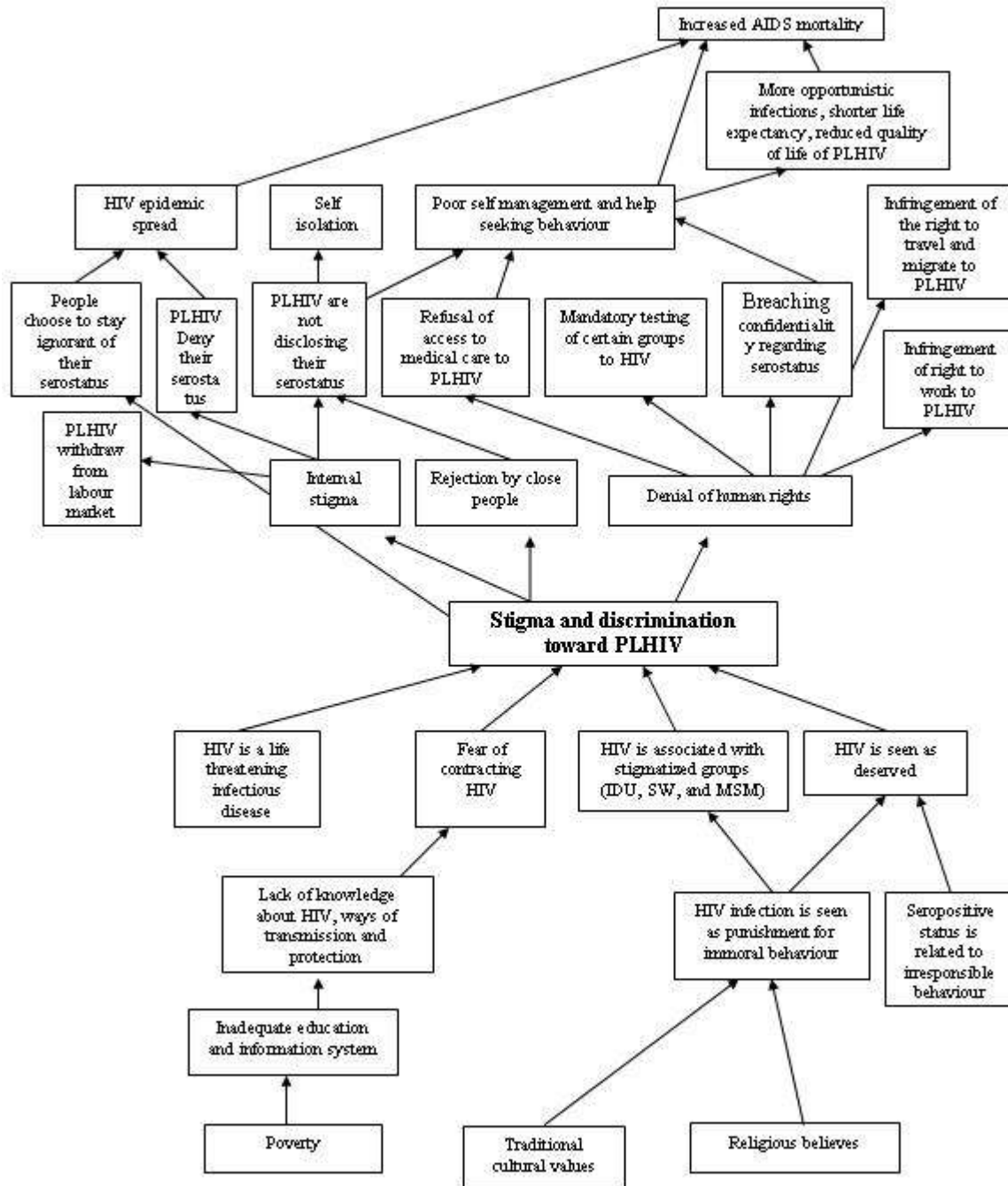
⁷ The National Strategy for HIV/AIDS, Belgrade, 2007

marriage is a sin. This could also influence perception of PLHIV as responsible for sins and immoral behaviour.

HIV/AIDS affects all communities, especially vulnerable populations, whose socio-economic situation and political or cultural context hinder accessing quality education, and obtaining appropriate information. This lack of appropriate education may contribute to the spread of infection and, partly, may explain maintenance of level of HIV/AIDS discrimination.

There are several levels at which HIV/AIDS related stigma may be experienced -societal and community levels, individual level, employment, health care setting, family and friends. Besides common, enacted stigma, felt stigma is also an important and influential dimension of stigma.

Internal stigma, fear of judgment and discrimination from others, can profoundly influence the way in which PLHIV view themselves, cope with their HIV status and asserting their rights to treatment and other social benefits. Both dimensions can have a profound effect on HIV prevention, treatment and care, resulting in continuing risk behaviour, and non-help seeking behaviour.



2. RATIONALE FOR RESEARCHING HIV RELATED STIGMA

Connection between mental health and HIV/AIDS is neglected and interdependence is often overlooked by people suffering from any (or both) of these problems as well as professionals. Mental health or addiction problems make a person vulnerable for HIV infection by increasing the chances of engagement in behaviour risky for contracting HIV. Also, people living with HIV (PLHIV) are vulnerable for developing mental health problems for several reasons: specific mental health disorders resulting from HIV itself; psychological difficulties of coping with chronic disease with an unfavourable outcome and exposure to stigma related to HIV. Most of the psychological burden of HIV infection is related to phenomena stemming from stigma connected to HIV: isolation, self-isolation and discrimination. These and similar experiences are permanently damaging one's sense of self-worth and dignity, enhancing suffering, reducing sense of having control over own life and increasing chances of developing a mental health disorder.

The dominant definition describes stigma as a "discrediting attribute" and stigmatized individuals as those who possess an "undesirable difference".

Stigma is a way the society might attempt to control individuals with certain traits by marginalizing, excluding and exercising power over them. Because of particular characteristics some individuals are seen as threat and since this threat can't be destroyed, stigmatizing these individuals is a way of escaping from the threat and a common response of the society. Also, there are other important social and psychological functions that stigma serves: it serves to distance the individual or group from the fear of infection by facilitating denial of risk and promoting a sense of invulnerability, it reinforces social norms around fidelity and family by moralizing around promiscuity; etc.

People in societies facing HIV epidemic often don't have enough and correct information and perceive it as a deadly disease, with unknown ways of transmission and uncertain ways of protection, resulting in great fear and sense of personal endangerment. Because of history of other epidemics, natural response to such fear is isolation and exclusion of infected people. Hence, HIV is attributed to some groups, previously marginalized and stigmatized in the society- sex workers, drug addicts and homosexuals. By seeing HIV as disease of only some people, unlike something that could happen to anyone, people are feeling more protected from this peril. Consequentially, seropositive people are seen as belonging to one of these groups and immoral, guilty of getting infected or dangerous. This perception of PLHIV leads to stigma; both enacted by other people or felt by PLHIV themselves (internal stigma).

The secondary targets of HIV related stigma include the partners, family members, friends and carers. This phenomenon is known as "courtesy stigma". This way, people surrounding PLHIV are also suffering and thus their capacity to provide support is diminished. Knowing the importance of adequate interpersonal relationships for mental health, it is easy to understand how courtesy stigma is depriving PLHIV from a very important resource for prevention or recovery from mental health problems.

Internal stigma is influenced by external stigma, and both dimensions result in disempowering PLHIV. Ignorance and failure in addressing stigma limits the potential of

PLHIV to live productive and quality life, and assert their human rights and social benefits.

Because of high influence of traditional and religious values in Serbian society, discussing issues related to sexuality is a great taboo. In this atmosphere of secrecy and mystifying, HIV is often ignored. The same secrecy is surrounding mental health patients. Taking this into consideration, the ground for stigmatization of PLHIV is very fertile. Everyday life of PLHIV is filled with secrecy, shame, blame, guilt and isolation.

2.1. Objectives of this assessment

This assessment is done using Qualitative method RAR (Rapid Assessment and Response) aiming at assessing the phenomena of stigma towards PLHIV and suggesting means of alleviating its causes and consequences. Qualitative methodology was used because it is enabling in depth understanding of the phenomena related to complex human behaviour.

This assessment was focused on exploring both external (or enacted) stigma and internal (or felt) stigma towards PLHIV. External stigma was explored with health workers and data for external stigma in general population were used from quantitative research done by Strategic Marketing called “Stigmatization” (Belgrade, 2006). Internal stigma was explored using focus group discussions with PLHIV.

The goal of this research was to explore causes, forms and possible interventions for stigma and discrimination toward PLHIV. It aims at promoting understanding of following issues:

- **What images are used to describe HIV and PLHIV and impact of these images on stigma?**
(Which metaphors are used when talking about HIV in media? What kinds of people are described as those who are seropositive? How is the future of PLHIV described?)
- **What are the factors underlying and justifying stigma and discrimination towards PLHIV?**
(Attitudes of general public and medical professionals towards PLHIV. Feelings of general public and medical professionals towards PLHIV (fear, disgust, anger). Consideration of guilt, shame and judgement related to HIV infection. Knowledge of ways of transmission and ways HIV can not be transmitted, knowledge on ways of protection from HIV.)
- **What are the forms of stigma towards PLHIV?**
(Are there differences in treatment provided to PLHIV by medical professionals compared to patients suffering from other chronic diseases, and what are those differences? How are PLHIV exercising their right to work compared to other people or time before disclosing their HIV status? Changes in behaviour and attitudes of family members, close friends and other people towards PLHIV after disclosing their status.)
- **Outcomes of HIV related stigma**
(PLHIV's reactions to stigma and discrimination. Policies, NGOs' and PLHIV's addressing HIV related stigma. Possible ways of reducing HIV related stigma)

3. METHODOLOGY

The research is based on data obtained through:

- A focus group consisting of social and medical workers (one internist, three general practitioners and three nurses) (*see Appendix4*)
- A focus group with volunteers from the "Philanthropy", organization which is providing palliative care for PLHIV (*see Appendix3*)
- Two focus groups with PLHIV, overall number of participants 13 (*see Appendix2*)
- Four interviews with representatives of organizations active in the field of HIV/AIDS (including the Head of the Centre for HIV/AIDS at the Clinic for Infectious Diseases in Belgrade, Head of Republican AIDS Commission, professor of Social medicine at University of Belgrade and Coordinator of legal and social programme within association of PLHIV-Q club) (*see Appendix1*)
- Propounding questionnaires to medical workers. In order to assess pervasiveness of stigmatizing attitudes and beliefs concerning AIDS among the health care workers we have used questionnaire from the survey: "Public Reactions to AIDS in the United States".⁸The aim of this survey was to measure the pervasiveness of stigmatizing attitudes and beliefs concerning AIDS among the American public. Our team used same questionnaire because it seems that it measures stigmatizing beliefs and attitudes in comprehensive manner. (*see Appendix5*)
- A review of available researches, relevant documents and literature, information, newsletters, and media reviews
- A media scan (1989-2006)

Focus groups

In June, July and October 2007, four focus groups on Stigma and Discrimination toward PLHIV were held in the premises of the Expert Centre for HIV and Mental Health. Members of the research team were involved in conducting the focus groups (moderator, note taker, and observer) and development of focus group questions. A dictaphone was used to record the conversations, with the permission of the participants given prior to beginning the session. Tape recording was used as a mean to expand observer's notes. Also, in order to make interpretation of focus group findings more objective and to validate our results, members of Expert centre and representative of PLHIV association -Q club were involved in process of analyzing data.

⁸ Gregory M. Herek & John P. Capitanio (1990-91): A Second Decade of Stigma: Public Reactions to AIDS in the United States, Department of Psychology, University of California

Focus group with health care workers

Focus group discussion with health care workers was held on June 14, lasting for two hours. The group consisted of seven health workers (one internist, three general practitioners and three nurses) from Zemun health centre and Institute for Students health, and one psychologist from the Social Centre. So, participants were representatives of governmental network of social and medical service provision.

The ultimate goal of this focus group was to gather information about the participants' authentic attitudes and feelings toward PLHIV.

The first part of the focus group session was reserved for checking participant's general knowledge about HIV. Participants were divided into two groups and different statements were read to them. Participants brainstormed together, recorded their answers onto a flip-chart, and presented them to the other group. A specific goal of this part of the focus group was to revisit and explore the common attitude that HIV ignorance very often leads to discrimination.

Following the knowledge assessment, we explored participants' attitudes toward PLHIV. The statements were read to participants, who then selected a response that best described their attitude (totally agree; totally disagree; partially agree; partially disagree). According to the similarities of their attitudes participants formed groups, recorded their answers onto a flip-chart, and presented them to others.

The aim of this process was to uncover authentic answers to a series of questions that normally launch an array of emotions and opinions. The overall purpose of this process was to identify prejudices responsible for creating discriminatory behaviours against people who are considered "different" from others.

Comments

Participants demonstrated a willingness to contribute to finding answers to the question "why are stigma and discrimination directed toward PLHIV?". They demonstrated basic knowledge about HIV and AIDS, which shows that ignorance, can not be considered the only cause of stigma and discrimination directed against PLHIV. As we expected, critical standpoints were reached in the second part of the session. The most blatant reactions were expressed about the statement "HIV positive women should not choose to get pregnant."

The overall impression was that this group of medical and social workers was well informed, politically correct and have shown acceptance of PLHIV. Through vivid discussion, they agreed that stigma and discrimination mostly happens due to the fear of illness and death held by people who come in contact with PLHIV.

Focus group with Philanthropy volunteers

Focus group with Philanthropy volunteers was held on June 18 and consisted of 7 participants, all of whom were volunteers from the Philanthropy organization. Philanthropy is the charitable fund of the Serbian Orthodox Church which is providing palliative care for PLHIV. It provides psychosocial, medical, spiritual and emergency

care for people who are living with HIV, mostly in the Centre for HIV/AIDS in the Infection clinic.

This focus group looked closely at stigma and discrimination through the point of view of people working with the PLHIV population, especially with AIDS patients. On one hand, through their work, they are able to recognize stigma and discrimination directed toward their clients, and, on the other hand, they themselves feel the effects of stigma and discrimination as a direct result of their involvement with PLHIV.

Comments

Volunteers seemed quite aware of existing stigma towards PLHIV, but not so aware of the impact their own prejudices have in producing stigma. For instance, they said that one way to destigmatize PLHIV would be to educate the public better, so they would know that not only drug addicts and homosexuals have AIDS- implying that it is normal to stigmatize AIDS patients who fall into these two categories.

It was very challenging to keep the focus of discussion on their personal experiences, feelings, and attitudes. On every question, after one or two relevant answers, participants started talking about general issues, such as about how there is no institutional support in society for the fight against AIDS, and how they are helpless and forgotten, etc.

Also, there are indicators that the burden of secrecy the volunteers are carrying is too big, because they repeatedly talked about events involving PLHIV without maintaining their confidentiality (mentioning names, professions and other patient data).

Focus group with PLHIV

First focus group with PLHIV was held on July 16, and second on October 4. Total number of participants was 13. Through these focus groups we wanted to learn more about stigma and discrimination as experienced by PLHIV. During these sessions we talked about reasons for discrimination, as well as actions that can lead to the reduction of stigma and discrimination in our community. Members of these focus groups are engaged in association of PLHIV (AID+), but mostly, they were NGO Philanthropy beneficiaries. Recruitment of these PLHIV was made through organizations' coordinator, whom they trust.

Comments

First focus group discussion did not reveal many examples of stigma and discrimination. Instead, they were very defensive and explained situations in which other people treated them with great care. However, taking this defensiveness into account, one could only imply that their original expectations were of insults and maltreatment.

The course of the discussion was spontaneously moving towards topics of vital importance for PLHIV (HAART, quality of treatment in different hospitals), rather than staying on unpleasant talk about stigma. It was quite a challenge to ask them to come back to issues of stigma, particularly because they seemed as though they were not ready to remember those situations.

We were under the impression that participants talked at greater length about their personal experiences of stigma and discrimination during other, less specific focus groups, rather than during this session in which they were specifically asked to talk about it. It seemed to be of a problem for participants to focus and keep their attention on this topic, for it evokes unpleasant experiences and emotions.

Group dynamic in the second focus group was different. Participants knew each other well, so they focused their conversation mainly on the moderator and observer.

Participants wanted to share difficulties they face in every day life, but each participant wanted to have the leading role. It seemed that everyone needed attention and help that is beyond the frame of focus group discussion.

As in previous focus group, participants were more interested to talk and focus on other topics, then on stigmatizing experiences. These participants were interested in IAN's project activities and their usefulness. They expressed doubt and dissatisfaction with the work of NGO in general. So, problem that we encountered was distrust and PLHIVs sense of meaningless of our work, comparing with specific kind of help that we are not offering- food, drugs, material support to hospital, etc. Dissatisfaction and expressed distrust influenced course of discussion to some extent, as well as the group atmosphere.

Medical workers questionnaire

In this study we have used questionnaire from the survey: "Public Reactions to AIDS in the United States".⁹

It includes assessment of the extent of stigma in a variety of manifestations: negative feelings toward PLHIVs, beliefs that they deserved their illness, support for punitive AIDS policies, and desires to avoid contact with PLHIVs. Also, this survey includes misconceptions about HIV transmission, which may contribute to stigma: assessment of perceptions that casual social contact can transmit HIV and beliefs that injecting drug use or male-male sexual intercourse in themselves cause AIDS (rather than acting as a route of transmission for HIV).

The medical questionnaire was implemented with a sample of 87 medical workers from two big, urban health centres- Institute for Students' Health and Zemun Health Centre. Considering the fact that PLHIV face high level of discrimination in health care setting (revealed in previous studies), in this study we included health care professionals of different background (doctors, nurses and laboratory technicians) in order to have overall picture.

Of the 87 completed questionnaires, eight respondents were male, 77 were female, and two chose not to disclose their gender. 77 female in this sample reflects the fact that women comprise majority in the professions that are traditionally consider

⁹ Gregory M. Herek & John P. Capitanio (1990-91): A Second Decade of Stigma: Public Reactions to AIDS in the United States, Department of Psychology, University of California

feminine. This is especially manifested in health and social sector, where female participation goes up to 80%.

Questioned health care workers had been working, on average, for 18 years. This means that these health care workers have a lot of working experience. Majority of participants work as doctors and nurses, and seven of them as laboratory technicians.

4. CAUSES OF STIGMA AND DISCRIMINATION

This chapter is based on data gained from focus groups with health workers, volunteers engaged in palliative care for PLHIV, and from a questionnaire aimed at exploring the attitudes and knowledge of health workers regarding HIV/AIDS.

Two main causes of stigma and discrimination identified in this study are: 1) fear caused by a lack of knowledge about HIV/AIDS; and 2) dominant values, norms and moral judgement.

People are often afraid that HIV can be transmitted through ordinary, daily interactions with PLHIV. This fear stems partly from the social construction of HIV/AIDS, as early metaphors used to associate HIV to death, guilt, horror and fear, and the fact that the disease is infectious and incurable.

According to volunteers from Philanthropy, many people, especially the younger population in Serbia, are well informed about HIV. Still, there is a general opinion that HIV infection happens to other people. Throughout the epidemic in Serbia, HIV has been associated with marginalized groups of IDUs, SWs, and MSMs. Due to this association, HIV related stigma actually builds upon already marginalized behaviours within society.

In some cases the root of stigma is indeed a lack of specific knowledge, but very often, despite awareness of how HIV is transmitted; a majority of people have irrational fears stemming from other sources. Often, the causes of stigma are deeply rooted in someone attitude and moral judgment.

“People around me know how HIV can be transmitted, but they are afraid. Still they lack other information on HIV and ignore the facts.” (Female, FGD participant, 41, volunteer, Belgrade)

It is the perception of volunteers in this study that the main reason people stigmatise PLHIV is fear, connected with their own perception of personal risk. People tend to underestimate their own risk of contracting HIV, and therefore HIV triggers personal fears that they tend to repress.

Medical professionals who participated in focus groups demonstrate an adequate level of basic knowledge about HIV, but their attitudes do not necessarily correspond with that knowledge, and because of this they do not always consider the human rights of the patient. However, it is the impression of the facilitator that professionals are open to discuss these issues.

4.1. Medical professionals' attitudes toward PLHIV

On the statement that HIV testing should be mandatory, 3 of 8 health workers point out that only high-risk group should have mandatory testing. On the statement if HIV positive woman should not have children, one doctor had the opinion that HIV positive women should not decide to give birth, although he was aware of low risks for vertical transmission. Discussing the statement «can we blame some HIV positive people for acquiring the virus, and other PLHIV not?», health workers concluded that as professionals they should not have discriminatory attitudes, but there might be a difference between someone who was infected via a blood transfusion, for example, and those whose HIV was a consequence of risky behaviour:

«We can't say we blame them (PLHIV), it is s a strong word, but maybe we might say that we have more compassion for a haemophilic, than a drug user, even though there is also a reason for that behaviour -why someone takes drugs. « (Female, 35, doctor, Belgrade)

It seems that there is a continuum between guilt and innocence related to "how" someone became infected. On the innocent side of the continuum are children, people who acquired HIV in transfusion, followed by health workers infected by treating their patients; while on the guilty end are the drug users, sex workers, and MSM. Given that sex work, drug use and homosexual practices are already socially unacceptable, the "guilty" infected are doubly stigmatized.

On the statement that HIV positive persons should not have sexual relationships, all participants agreed that it is not possible not to have sexual relationships, and that this statement reflects discriminatory attitude toward someone who is in need. They also pointed out that someone should be open and tell their partner about their HIV positive status.

Regarding the statement that PLHIV should not be working in health care settings, a majority of participants did not agree, but they noted that in some cases it is not recommended. Participants listed the most risky jobs that could put a patient at risk: working as dentist, surgeon or obstetrician can introduce the possibility of injuries and contact with blood. Questioned health care workers think that, regardless of taking universal precautions measures, there is still a risk of infection.

As one participant said:

“There is always a chance to be infected, consider for example a child playing in the park that could step on a needle “(Female, 37, nurse, Belgrade)

4.3. PLHIV position in health care system

Accessing health care is a challenge for people who are HIV positive, because the health care system itself is often a source of stigma. Studies carried out in Serbia identify a high degree of stigma among health care workers. A qualitative study by Imperial College and UNDP shows that discrimination is most evident in health care

settings.¹⁰ Stigma within the health care sector often represents for many PLHIV a greater source of concern than the uncertain medical prognosis of HIV and AIDS. Many PLHIV reported that they have been refused by doctors, directly or indirectly, because of their HIV positive status (aside from the Centre for HIV/AIDS, where they receive HIV-specific treatment). As a result of this fear and discrimination in health care institutions, many PLHIV refer to the Centre for HIV even for health problems that are not related to HIV/AIDS.

Health care professionals, particularly those who infrequently encounter HIV-positive people, can be insensitive to their patients' concerns about stigma. In addition, health care professionals are not always knowledgeable about appropriate procedures for maintaining patient confidentiality (Herek et al., 1998).¹¹ Even if patients' rights on "secrecy" of the data is regulated by the law (article 37)¹², it is not always followed in medical practice in Serbia. This study also provides examples of confidentiality breaches:

"I remember the institution where I used to work, we used to mark the referral form of infected patients with a spot, or even to place test results at the bulletin board, including positive results on HIV, or HCV. " (Female, 28, nurse, Belgrade)

Also, the procedures for precautionary are not available in all health institutions, and it is possible that this lack of clear procedures leaves room for speculations, fear, and disregard for the rules. As the research done on health workers' attitudes shows¹³, for 77.5% of respondents there is no written instruction on general protection from infections at the organizational level; 87.9% do not have instructions on HIV PEP; and almost one quarter of health workers do not know if this protocol (guidelines) exists in their institution. All of this may contribute to the uncertainty of health workers and, having in mind their lack of specific knowledge about HIV, it can add to their fear of HIV patients, consequently leading to discrimination.

Fear of discrimination among PLHIV, who have experienced or anticipate stigma, makes accessing health care more difficult. In this study, one FGD participant explains how this fear exists from the very start, when a person discovers her/his status:

"Someone who discovers that he/she is HIV positive is firstly advised from a doctor to change general practitioner, and, to go somewhere where he/she is unknown, so that gossip could be prevented. Stigma starts with the red HIV label on the medical file." (Male, 52, volunteer, Belgrade)

The health care workers who participated in the FG within this study, were very well informed about HIV, but still perceived that among their colleagues many people lack proper knowledge how HIV can be transmitted or not. A number of health workers

¹⁰ Bernays, S. , Rouds T., Prodanović, A. (2006): Accessibility, services providing and uncertainty in HIV treatment, Faculty for Hygiene and Tropical Medicine of London University, UK, DFID, HIV Prevention among Vulnerable Groups Initiative, United Nations Development Programme, Beograd/Podgorica

¹¹ hab.hrsa.gov/publications/stigma/stigma_and_access_to_care.htm - 10k, accessed 12.07.2007.

¹² <http://www.zdravlje.sr.gov.yu/default.asp?lang=1&poe=11>

¹³ Institute for Public Health of Serbia "Dr Milan Jovanovic Batut" (2003): Perception of risks, attitudes and knowledge on HIV/AIDS of health workers of Serbia, Belgrade

think that it is very important for a nurse or doctor to know whether a patient is HIV positive, so that they can protect themselves. At the same time, they deny having discriminatory attitudes:

“I do not make any difference on the basis of a patient’s HIV status. I would like to know; however, if the patient is HIV positive, though I would not have put my gloves, I would only be more careful” (Female, 40, nurse, Belgrade)

This statement represents a view of a number of health workers who think that by knowing a patient’s status they will be protected from the virus. Our impression is that health workers are not aware of the risks of violating confidentiality, and that the patient might be exposed to stigma and discrimination.

According to the Institute for Public Health in 2003, 77.3% of health workers think that it is more important to protect health workers of HIV, then to keep confidentiality of data.¹⁴

Related to the topic is the fact that there is still a lot of mandatory HIV testing- HIV testing prior to surgery or other medical interventions is common in Serbia. A lot of people who need medical intervention have to be HIV tested even though they do not engage in risky behaviour. In this situation, the costs of HIV testing are covered by health insurance. According to the data from IPH in Belgrade, from 2003 till 2007 almost 21% of tested clients were tested for medical reasons.

4.4 Role of the media in increasing stigma and discrimination towards people living with HIV

For this chapter we conducted analyses of press clippings, from 1989 to 2006. We found that powerful images were used that reinforced and legitimized stigmatization.

4.4.1. HIV/AIDS as war

One of the most frequent ways of writing about HIV/AIDS reflects a perception of HIV as a danger that needs to be fought. In this respect, HIV/AIDS is seen as a continuous threat, a killer of our time, a plague of the 21st century, and an evil that does not choose its victims. This perception implies a justifiable fight in terms of a frantic search for the inauspicious virus.

4.4.2. HIV/AIDS as punishment

Another dominant way of writing about HIV/AIDS displays infection as punishment for immoral behaviour. We have selected some of the headlines that represent this image, and also reflect the existing relationship between drug use, promiscuity and HIV/AIDS:

- “One mistake in her youth brought incurable disease and loneliness” (*Politika*, Belgrade, December, 1998)
- “Tripping with narcotics ended up tragically” (*Politika*, Belgrade, November, 1999)

¹⁴ Ibid.

- “Explosion of passion in African jungle resulted in death” (implying unprotected sexual intercourse with different women) (*Politika*, Belgrade, November, 1998)
- “Because of risky behaviour of the parents, 9 million children, orphans of AIDS are left alone” (*Blic*, Belgrade, December, 1997)

The press often uses powerful pictures that reinforce these relationships and may cause feelings of disgust, fear or anger towards PLHIV among the general public.



“Are we going to look how they are crawling down the street?! “(*Danas*, Belgrade, November, 2001)

4.4.3. HIV/AIDS as otherness

Widespread belief and perception identifies HIV/AIDS as Otherness. It seems, especially in the beginning of the AIDS epidemic, that HIV/AIDS was thought of as something that happens to other people. PLHIV stated in the focus group that it is still a very powerful image, and that changing this perception is one of the most important tasks of the HIV/AIDS campaign.

Part of the article below illustrates this conception:

THE MARKED (*Politika*, Belgrade, December, 1997)

Love each other! It is the only purpose of living! Only love brings Gods gratification. AIDS and its symptoms mark the unfortunate ones who are from some other side.

4.4.4. HIV/AIDS as horror

HIV/AIDS is often seen as horror and PLHIV are presented in a way that frightens the public. Some forms of advertising-based education, particularly, try to get the safer sex message across by making people afraid of the potential consequences of becoming infected with HIV. This can, in certain circumstances, be an effective way of bringing about changes in people's behaviour, but it also carries the risk of increasing stigmatization of positive people by making them appear to be at fault for having become infected. This is especially the case where targeted education campaigns highlight the dangers to specific risk groups - injecting drug users, for example, or prostitutes.

HIV/AIDS is presented like a horrible disease. Also, at the same time, it seems that AIDS is mystified and that you can not fight it (for example HIV attacks every 5 seconds)

This headline that illustrates the perception of HIV/AIDS as horror is very indicative:
Blic, Belgrade, December, 2001:

" I would rather to be killed in the street, than to find out that I am infected

PLHIV are also marked like persons you cannot trust, and who could harm others. One of the mental health professionals stated in the interview that PLHIV should be forbidden from working in health care and with children. This kind of statement makes discrimination justifiable and logical, but also reinforces misconceptions about the way that HIV can be transmitted.

Thus, these stereotypes provide a basis for stigma and discrimination, and together with a belief that HIV is shameful enable some people to deny personal risks and to legitimize discrimination.

However, from the start of the epidemic to this date, some changes in media presenting are evident, especially regarding perception of PLHIV. Headline and part of the article below illustrates these changes. This article represents testimonial of woman who lives with HIV for 22 years, her acceptance of disease and courage.

Vecernje novosti, Belgrade, December, 2006.

LIVING LIKE OTHERS

I did not let to be defeated by this disease; I continue to live like others, just more cautiously.

Also, media started to talk about medical treatment of PLHIV and medical workers attitudes towards PLHIV. Very encouraging article, describing positive example of one medical worker practice, appeared last year:

Nedeljni telegraf, Belgrade, December, 2006.

I am not afraid of AIDS. I put my gloves, mask and eyeglasses, concentrate and do not think about the risks.

Also, it seems that HIV/AIDS is not so linked with marginalized behaviours, as it was at the beginning of the epidemic. It seems that frequent public warnings about increased transmission through unprotected sexual intercourse and writings about non-possible ways of transmission discourage “it happens to someone else” attitude and misconceptions and mystification of HIV/AIDS.

4.5. Stigma and discrimination in the eyes of PLHIV

Discussion among PLHIV in the focus group included a question about the media presentation of PLHIV and HIV/AIDS in general. PLHIV are unsatisfied with journalists’ education and their knowledge about HIV and AIDS. They pointed out that the journalists often do not know the difference between HIV and AIDS.

Also they find that images of HIV/AIDS presented in the media are very demoralizing and inaccurate. PLHIV think that HIV/AIDS is not presented in appropriate way, like other chronic diseases. Instead, PLHIV are treated as persons who are on the waiting list for death.

”When I saw the headline-Clinic is the death waiting room, and PLHIV are its prisoners, I felt hopeless, and I think that this headline makes PLHIV feel more helpless and mistrustful towards doctors and treatment.” (Male, FGD participant, PLHIV, 46 years, Belgrade).

Regarding campaigns, PLHIV think that they are insufficient and irrelevant for PLHIV. Campaigns are most frequent on the 1st of December (World AIDS Day), but they are not focused on the treatment of PLHIV or the perception of HIV/AIDS as other chronic diseases, and they do not send the message that HIV could affect everybody.

“Campaigns are all about numbers, statistics, and that is not important for PLHIV. They need to include information about therapy and should bring some hope to this people.”(Male, 33, FGD participants, PLHIV, Belgrade)

5. EXTENT AND FORMS OF STIGMA AND DISCRIMINATION

5.1. Stigma by the general public

In 2006 a comprehensive study was carried out by Strategic Marketing Research in Serbia, exploring stigma toward different socially marginalized groups, including AIDS patients. The research used a representative sample of 1509 participants from the territory of Serbia without Kosovo.¹⁵

Some of the key results show a high degree of stigma among the general public:

- About 65% of people would not host a person living with AIDS in their home (the biggest part of the population age 18-70 would not receive in their home members of marginalized social groups: criminals 81%, drug users 80%, sex workers 76%, MSM 71% and alcoholics 66%.) Through demographic categories it is shown that younger people are far more tolerant than older people (50 to 65 years)
- 35% of people think that people living with AIDS should be fired even if they have done satisfactory work
- 32% of people would split a friendship if their friend was diagnosed with AIDS, while 19% were not sure about it. In regard to socializing with members of marginalized groups, the lowest tolerance is toward criminals and drug users. The highest percentage of people are willing to socialize with alcoholics (57% would not split friendship) and people living with AIDS (50%)
- 89% would not accept to live together with person living with AIDS, 8% were not sure, the majority of population would not accept joint life with person who is using drugs (93%), with alcoholic (89%), and with a criminal (85%)
- 49% would not share their office with someone who has AIDS, while 18% weren't sure; an even greater percentage of people would refuse sharing an office with a drug user (61%), alcoholic (60%), or MSM (50%)
- People who are more educated and from urban areas have a lower degree of animosity toward people living with AIDS.

Results from this study show that in general population exist high level of stigmatizing attitudes toward different marginalized groups. People feel threatened the most by the criminals, especially in rural settings, then IDUs (35%), alcoholics (30%), and then homosexuals and AIDS patients (22% and 23%). It seems that discriminating attitudes are related with situations in which somebody can get hurt (hostility or expressed aggression of criminals or IDUs), rather than specific marginalized behaviour.

¹⁵ Strategic marketing research (2006): Stigmatization, Belgrade

So, as findings of Strategic Marketing show, stigma may be even higher towards some of marginalized social groups in respect to AIDS stigmatization. On the other side, as in other countries worldwide, HIV in Serbia has also been associated with marginalized behaviour - IDUs, SWs and MSM. HIV related stigma is therefore underpinned by negative attitudes, prejudices which already exist toward marginalized behaviours of drug use, sex work or homosexual practices.

5.2. Stigma and Discrimination in the health care setting

In 2003, the Institute for Public Health carried out a study among health workers on attitudes, knowledge, and perception of risks health workers demonstrate in the field of HIV/AIDS. The study was carried out under the Global Fund project and included 1860 health workers from 8 urbanized regions.¹⁶

Some of the major findings of the study:

- Almost two thirds of subjects (63 %) have the opinion that all hospitalised patients should be tested for HIV, while one fifth did not agree with this opinion (22 %)
- 77 % think that it is more important to protect health workers from HIV than to maintain confidentiality, 13 % disagreed with this statement
- More than one third of subjects (34 %) think that HIV positive health workers should not be allowed to work in practice, while 38 % disagreed
- The majority of subjects (76 %) think that if someone becomes infected with HIV it is not his/her fault, while only 8 % thought it would be his/her fault
- The majority (72 %) think that HIV positive people should not hide their status. 12 % disagreed with this statement, and 16 % had no opinion
- More than half of health workers (52 %) had never received education on HIV/AIDS. In the last 5 years, 37 % of subjects received education about HIV/AIDS, and only 12 % received this education in the last year
- 76 % health workers think that they need additional education about HIV/AIDS
- 30 % health workers do not take precautionary measures to prevent infections during their work with every patient
- When HIV status is known, 83 % of health workers note that they take precaution measures in order to protect from infection, that are in excess of typical prevention procedures

5.2.1. Survey among health care workers

In order to assess pervasiveness of stigmatizing attitudes and beliefs concerning AIDS among the health care workers we have used questionnaire from the survey: “Public

¹⁶ Institute for public health (2003): Perception of risks, attitudes and knowledge among health care workers, Belgrade

Reactions to AIDS in the United States”.¹⁷ We assessed four different manifestations of stigma: negative feelings toward persons with AIDS, support for coercive AIDS-related policies, blame for persons with AIDS, and intentions to avoid a person with AIDS in various situations. We also assessed beliefs about HIV transmission through casual contact and beliefs that male homosexual behaviour or injecting drug use in them causes AIDS. As it was mentioned, this questionnaire was implemented with a sample of 87 medical workers from two big, urban health centres- Institute for Students’ Health and Zemun Health Centre.

Coercive Attitudes and Blame

Although a majority of respondents did not endorse statements of blame and coercion, a striking minority (16 from 87 respondents) felt that people with AIDS should be legally separated from others to protect the public health, and 14 affirmed that the names of people with AIDS should be made public. Furthermore, approximately one-fifth of respondents agreed that people who contracted AIDS through sex or drug use have gotten what they deserve.

Related to these attitudes are health care workers’ comments regarding this question. A majority of health care workers who added comments on the survey think that the best way of protection is to know each patient’s HIV status.

As one participant wrote:

“I think that medical workers should be informed about the HIV status of the patient, because they can put us (medical workers) at risk, and you did not mention that example in your survey” (Female, nurse, 10 years working, Belgrade)

Table1. Coercive Attitudes and Blame

Coercive Attitudes	Agree	Disagree
1. Legally separated	16	71
2. Make names public	14	73
Blame	Agree	Disagree
3. Gotten what they deserve	18	69

Avoidant Behavioural Intentions

Over one-fifth of respondents said they would not be willing to take care of a close friend or relative who developed AIDS, while nearly 10% said they would move their child to another school if it was discovered that another student was known to have AIDS.

¹⁷ Gregory M. Herek & John P. Capitanio (1990-91): A Second Decade of Stigma: Public Reactions to AIDS in the United States, Department of Psychology, University of California

Furthermore, five people stated they would ask that an HIV positive colleague be reassigned so they wouldn't have to work in proximity of that person, while one additional respondent said they would ask that they be assigned with someone else. It is demonstrative of the level of discrimination present that these medical professionals feel that their discomfort should be alleviated by the removal of the person with AIDS, instead of moving themselves. Even more indicative of stigma advanced by an uninformed social environment, 33 respondents stated they would begin shopping at a different grocery store if they found out the owner of their preferred store had AIDS

Table2. Avoidant Behavioural Intentions

Avoidant Behavioural Intentions	Avoidant	Supportive
7. Care for close friend	19	68
8. Child attending school	8	79
9. Office co-worker	5	82
10. Neighbourhood grocer	33	54

Feelings towards Persons with AIDS

All respondents were asked to rate their feelings of anger, fear, and disgust toward people with AIDS on a scale from “very,” “somewhat,” “a little,” and “not at all.” Nearly one-fifth of respondents reported at least “a little” angry toward people with AIDS, while almost two-fifths reported being at least “a little” afraid of them.

Furthermore, seven respondents said they felt at least “a little” disgusted by people living with AIDS. It is interesting to note the surprisingly high rate of misunderstanding that this group of medical professionals demonstrated regarding modes of HIV transmission (see below) as a possible explanation for the reported level of fear that they feel toward people with AIDS.

Table3. Feelings towards Persons with AIDS

Feelings	"Very," "Somewhat," or "A Little"	"Not at All"
1. Angry	16	70
2. Afraid	34	53
3. Disgusted	7	78

Analysis of possible reasons for these feelings reveals that:

- Medical workers attribute *fear* towards PLHIV to the fact that AIDS is a life threatening and incurable disease and to their continuous worry about contracting HIV, despite the level of their knowledge.

As one participant wrote:

“Despite knowing transmission routes, there is always a doubt about other possible ways of transmission” (Female, laboratory technician, 18 years working, Belgrade)

- Medical workers perception that PLHIV are responsible for becoming infected is causing feelings of *anger*. Questioned professionals reported that PLHIV should have been more careful and they should have taken care of their health. Also, this feeling is provoked by the perceived connection between HIV/AIDS and already stigmatized behaviours (such as sex between men and injecting drug-use).

As one participant wrote:

“It is personal choice to become infected, because someone’s homosexual preferences or choice to be a drug-user. They could protect themselves.” (Female, nurse, 15 years working, Belgrade)

- Feeling of *disgust* is also caused by the existing link between HIV/AIDS and already stigmatized behaviours. As findings of Strategic Marketing show¹⁸, 63% of participants think that homosexual preference is unacceptable, like the usage of drugs (87%).

“They had enough information, for sure. Why they should not have been more careful, and could not protect themselves? That makes me angry and even furious...” (Female, technician, 10 years working, Belgrade)

Transmission through Casual Contact

Respondents were presented with various scenarios and asked how likely infection was from each activity. As this was a group of medical professionals, a firm line was taken on their knowledge of transmission, and as such, responses including “very likely,” “somewhat likely,” “somewhat unlikely,” and “very unlikely” were all classified as a view that infection is possible, while a negative response was “impossible to get AIDS by [this activity]”.

Eleven respondents reported believing that infection is possible from kissing an HIV positive person on the cheek. Furthermore, two-fifths believe that drinking out of the same glass as someone with AIDS can result in transmission of the virus. 32 respondents affirmed the possibility of transmission from being coughed on or sneezed on by someone with HIV, and 28 say the virus is transmittable through insect bites, as well.

Most alarming, a majority (57) of 87 surveyed health professionals believe that transmission is possible via the use of public toilets.

¹⁸ Strategic marketing research (2006): Stigmatization, Belgrade

Table 4. Transmission through Casual Contact

Casual Contact	Infection Possible	Infection Not Possible
Kissing on cheek	11	75
Drinking glass	36	51
Public toilets	57	30
Cough or sneeze	32	54
Insect bite	28	56

Transmission through Homosexuality and Drug Use
 Regarding drug use, over 30% of respondents felt that HIV was at least slightly possible in

infection

the case of an uninfected, heterosexual person using intravenous drugs, even if that person does not share needles with anyone else. When provided a scenario of two healthy, uninfected homosexual men engaging in sexual intercourse while using condoms, 12 respondents felt that there was at least a slight chance, even if unlikely, that at least one of the men would become infected with HIV. Most telling, when presented with the same sexual scenario but supposing the men did not use condoms, less than half of the medical professionals sampled correctly stated that there would

be man from

Transmission through Homosexuality and Drug Use	Infection Possible	Infection Not Possible
Uninfected homosexual men using condoms	12	72
Uninfected homosexual men without condoms	44	38
IV drug use without sharing needles	27	56

Drug

no chance of either becoming infected that activity.

Table 5. Transmission through Homosexuality and Drug Use

Discussion of survey's findings

A report on HIV-related stigma in Ethiopia, Zambia, Tanzania, and Vietnam¹⁹ asserted that correct knowledge can coexist with incorrect beliefs about transmission, and there is often a lack of confidence about how HIV is *not* transmitted (ICRW, 2005). The ICRW report attributed this phenomenon to three factors: 1) lack of specific, in-depth information about HIV transmission; 2) fear-based public messaging; and 3) evolving knowledge on HIV and AIDS.

Lack of in-depth information

The report noted that standard HIV education focuses on how HIV *is* transmitted, that it has no cure, and that it kills. Messages rarely include information about how HIV is *not* transmitted, relative infectiousness (how much blood is necessary, how fresh, etc.), or how fragile the virus is outside the human body. This abundance of confirmative information, without the complementary disconfirming information, provides an environment in which people can continue to have doubts and misunderstandings about HIV transmission even when they are easily able to recite the three ways HIV can be transmitted. This could be an explanation for relatively high rate of misunderstanding that medical professionals demonstrated regarding transmission through casual contact.

Fear-based public messaging

The report also discussed the prevalence of highly emotive language and a focus on death in public messages related to HIV prevention. Not only is death marketed as the end result of infection, but the death is portrayed as painful, disfiguring, and shameful, as well as linked to immoral behaviours. Analysis of press clipping reveal that HIV/AIDS in our country is often seen as the result of personal irresponsibility, that infection is associated with minority groups/behaviours and that generally PLHIV are seen as shameful.

Evolving knowledge

The relative newness of the AIDS pandemic leads to frequent scientific and medical advancements, which are sometimes contradictory to one another. This prevalence of new and contradictory information leaves room for people to wonder about the accuracy of current information, leaving them with an attitude that it is better to be overly cautious in avoiding people with HIV.

Based on these explanations for a continuation of stigma in the midst of knowledge about HIV transmission, the ICRW report concludes that individuals are not being provided with information in a safe and interactive format that allows people space to think through information, discuss it, and ask questions. Due to the similar issues presented by medical professionals in the current study, we think that methods of staff education in medical settings in Serbia need to be evaluated, and similar problems addressed within the health care system.

¹⁹ Ogden, J., Nyblade, L. (2005): Common at its core, HIV related stigma, ICRW

5.3. Stigma and Discrimination as experienced by PLHIV

As the qualitative study carried out by Imperial College²⁰ found, many PLHIV anticipated or experienced discrimination in their daily lives. In differing ways this was felt at every level of social encounters, from relationships with close relatives and friends to bureaucratic procedures, for example collecting their pension. These experiences can not be understood in isolation from each other, for they are felt by the individual cumulatively.

Forms of discrimination are numerous and include: denial of the right to primary and high school education, loss of employment, refusal of medical care to injured PLHIV, media campaign and sensational media revealing events with PLHIV, refusing to put PLHIV on a list for an organ transplant, rejection by the family, police brutality and isolation of PLHIV in prisons, as well as physical maltreatment of PLHIV.

Regarding experience of discrimination, participants of these focus groups paid attention to discrimination within health care system. One of the possible reasons for focusing on this form of discrimination is the fact that they usually reveal their HIV status to medical staff, who are not allowed to discriminate. As one participant noted:

“I am shocked how much rudeness and ignorance among medical staff exist...they think that persons who are HIV positive deserved to have HIV because of their behaviour, for example, for being promiscuous..» (Female, 40,Belgrade)

They reported different forms of discrimination within health care system: medical workers requested PLHIV to wear two masks during medical examinations, or they themselves would wear two pairs of gloves. Also, PLHIV reported that medical workers often disinfect the room after they had finished their check-up. All participants experienced some form of confidentiality breach in the health care system: their medical files were signed with a red mark, or some medical staff disclosed their HIV status to others without their consent. For example, one participant reported that a nurse who treated him rumoured about his HIV status to all of his neighbours and told his employer. Because of that, the company lodged a complaint and the nurse lost her job six months later.

Although PLHIV reported different discriminatory experiences, the general impression is that these PLHIV mainly focused on examples of good treatment and practice towards them. It seems that they had expected negative reactions and rejection, not an adequate and humane relationship. As one participant said:

” I was expecting negative reactions from the laboratory technician when I had my blood checked .I wanted to be the last in line, so I could warn her about my status. Surprisingly, she accepted me, as any other patient” (Male, 46 years, Belgrade).

²⁰ Bernays, S. , Rouds T., Prodanović, A. (2006): Accessibility, services providing and uncertainty in HIV treatment, Faculty for Hygiene and Tropical Medicine of London University, UK, DFID, HIV Prevention among Vulnerable Groups Initiative, United Nations Development Programme, Beograd/Podgorica

Regarding discrimination in the health care institutions, participants discussed the usefulness of the Clinic for Infectious and Tropical diseases in terms of mitigating stigma and discrimination. All participants are very satisfied with the staff and service available at the Clinic, but some participants do not think that it is the best way to fight discrimination in the long term.

Findings of the UNDP study²¹ show the Clinic represents a safe haven where PLHIV can be assured of a kind reception. PLHIV often attend the Clinic for all their health concerns, even those unrelated to their HIV, because they do not feel able to seek medical treatment elsewhere for fear of discrimination. PLHIV have often had to rely on the doctors at the Clinic to personally facilitate appointments with other doctors who are known to be willing to treat PLHIV.

As one participant in focus group noted:

“I did not experience any kind of discrimination, because I did not have need for medical treatment, outside the Clinic. Even when I had to go outside the Clinic, I did not encounter any problem, because I had a recommendation from the doctor at the clinic.” (Female, 58 years, Belgrade).

On the other hand, some participants noted that this advantage could turn into a disadvantage. This tight connection with the Clinic leads to isolation, causing feelings of caught up in the same cycle. The words of one participant are illustrative:

«I would be very happy, if I could wait for my turn in the health centre and have reception like others» (Male, 46 years, Belgrade)

Considering other forms of external stigma, participants reported stigma and discrimination among family and friends. They all agreed that revealing HIV status to someone has a meaning of some kind of testing friendship, and that only real friendships pass through this test situation. Participants stressed how grateful they are for support of friends and family and they readily reported examples of received support. Participants also noted negative and painful experiences, although it was not easy for them to talk about these situations. These issues were discussed at the end of focus group discussion, after one and a half hour discussion.

“My sister revealed my HIV status to each member of my family and to all of my friends. Because of it some of our friends do not come in our house anymore and some acquaintances refused to host me... Then I started to think this way -I was a bigger threat for you when I did not know my HIV status, and feeling bad without knowing the reason why...but still they do not understand it..»(Male, 55 year old ,Belgrade)

Although participants discussed some forms of external stigma, they mainly focused on “internal stigma”, the product of internalization of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV positive.

²¹ Bernays, S. , Rouds T., Prodanović, A. (2006): Accessibility, services providing and uncertainty in HIV treatment, Faculty for Hygiene and Tropical Medicine of London University, UK, DFID, HIV Prevention among Vulnerable Groups Initiative, United Nations Development Programme, Beograd/Podgorica

Participants specifically paid attention on their way of coping with HIV and self protective action (i.e. mechanism to protect oneself from hurt and discrimination). They reported different manifestations of these protective actions:

- Subterfuge- this is dominant self protection action. In order to avoid being stigmatized and prevent their HIV status from becoming known to others, all participants reported that they often hide their HIV status or they choose whom to tell. This choice is based on the trust they have. PLHIV constantly monitor their disclosure within the family, among friends, and in public. As one participant noted:

“Why should I tell someone about my HIV, what is the use of disclosing your status to others? I would be fool to expose my self to discrimination and abuse” (Female, 56 years, Belgrade)

- Social withdrawal-self imposed isolation led some participants to exclude themselves from loving relationships or other social activities:

“I want to get out, but at the same time I feel apathy and I am not interested in meeting other people, probably because of fear of what might happen (Male, 30 years, Belgrade)

- Fear of disclosure-all participants felt fear of rejection and judgment. They think that their friends, members of family, and health care workers would reject them, so they choose to live in silence.

«If I tell someone, what would happen? 95% will run away, when they find out, and that makes me unmotivated to work, to get out... (Male, 33, Belgrade)

Internal stigma also affects the self-perception of PLHIV. Some participants perceived themselves as less valuable than those who are not living with HIV/AIDS.

It seems that majority of participants have deep-seated feelings of guilt and self blame because of being HIV-positive. Indicative example of internalization of guilt gave one participant:

«Although other people are or could be very promiscuous and heartless, when something like this come up (HIV) they are so judge mental and their only concern is to prevent secret from revealing....so, in the society like this, from whom to ask for forgiveness?»(Female, 40 years old, Belgrade)

Self blame is accompanied by other deep fears which an HIV diagnosis evoked: fear of hurting others and the fear of causing pain and suffering to others. Fear of hurting others is especially manifested in regard to doctors and intimate partners.

PLHIV feel obligated to inform them about HIV status and prevent even slight chance for putting them into risk.

«Although you are trying to be equal with others, you always have HIV in mind and that inhibits your behaviour» (Male, 21, Belgrade)

Low self esteem also manifests in overcompensation, through making more effort than people who are not living with HIV/AIDS. It is a very indicative example one participant gave regarding overcompensation in trying to access health care service:

”Even when you tell someone your code (medical diagnosis), you are in a position to wait for his/her reaction, wondering if she/he is going to throw your papers...then you start to make a fool of yourself, in order to be nice and funny» (Male, 46, Belgrade)

5.4 Stigma towards PLHIV caregivers

Caregivers, whether professionals or volunteers, risk what Goffman called “courtesy stigma,” in which they are stigmatized as a result of their association with HIV/AIDS and people living with HIV disease. That stigma may influence their willingness to work with people with HIV or may make their work more difficult (Snyder et al., 1999).²²

Volunteers of Philanthropy who participated in this study reported examples of courtesy stigma from their experience. A number of them had experiences of being rejected only because people found out about their engagement with PLHIV. One participant explains:

My friend told me in the cafeteria: “You were not shaking hands with those people (PLHIV), did you?- she runs away from the cafeteria, she got tested the next day, and refused to talk to me on the phone. She changed her attitude, as some other people did too” (Female, 36, Belgrade)

Research reveals that volunteers and non volunteers consider HIV/AIDS volunteerism more stigmatizing than other forms of volunteerism (Snyder et al., 1999)²³. Reports of having been made to feel embarrassed, stigmatized, or otherwise uncomfortable in connection with their volunteer activities are more common among HIV/AIDS volunteers than other types of volunteers (Omoto et al., 1998).²⁴

“People react differently. There are those who accept it, and those who advise me to leave, and go away from them (PLHIV). They ask if I am normal to be doing that.” (Female, 38, Belgrade)

There are also a number of people who are more curious and want to know more on HIV and STI from volunteers, but it doesn't mean that they are changing their attitudes towards PLHIV. The majority of participants in the volunteer focus group agree that the most efficient way to act against stigma is to have personal experience of knowing an HIV positive person.

²² http://hab.hrsa.gov/publications/stigma/stigma_defined.htm

²³ Ibid.

²⁴ Ibid.

"Personal contact is breaking the barrier. Stigma and fear disappear, working and living with those people is resulting in that professional's minimizing their fears. It was revealing for me" (Female, 42, Belgrade)

Volunteers were more prone to point out positive aspects of working with PLHIV: emotional satisfaction from helping others, opportunity to learn, personal growth. On the other side volunteerism sometimes can be hard and exhausting. As the most difficult aspects of their volunteer activities, volunteers notify: feeling of helplessness when working with HIV+ children, or socially disadvantaged people, delicate situations when the person discovers her/his status, or the sudden decline in health of a patient.

6. RECOGNITION, POLICIES AND MANAGEMENT OF STIGMA AND DISCRIMINATION

6.1 Government responses to stigma and discrimination

In 2005, the Ministry of Health issued the National Strategy against HIV/AIDS²⁵. This strategic plan is based on 11 principles, one of which mandates the protection of privacy for PLHIV during testing, treatment and care. The problem of discrimination and stigma towards PLHIV has been elaborated on as well. For example, in the explanation of factors that influence the HIV epidemic, one of the factors is the high level of discrimination towards PLHIV and persons engaging in high-risk behaviours. The National Strategy against HIV/AIDS presents the first significant step toward providing adequate treatment and health protection of PLHIV; however, further steps are missing in protection of PLHIV rights and the next step is legislative regulation.

As the Head of Republican AIDS Commission said: " *Discrimination is recognized at the highest societal level (referring to National AIDS strategy), but policy documents regarding PLHIV rights, or other important regulations do not exist yet*".

Report of the coalition against discrimination issued in the book, "Discrimination in Serbia"²⁶ emphasizes that there wasn't any reform to combat discrimination. There is no universal legislative regulation forbidding discrimination, just constitutional decree. The Constitution of the Republic of Serbia forbids all forms of discrimination. Health condition, which can refer to HIV/AIDS status, is not specifically addressed in the Constitution, but discrimination due to health status is clearly forbidden given the blanket provision against discrimination in any form.²⁷

Serbia is a member of many international instruments for human rights that forbid discrimination, but Serbia didn't adopt universal law prohibiting discrimination. There were a few proposition of universal discrimination law:

- Preposition of Institute for comparative law from 2002;
- Preposition of Centre for advance of law studies from 2004;
- Preposition of Coalition against Discrimination from 2006;
- The last preposition aroused within the UN Development Program (UNDP) in partnership with services for human rights and the rights of minorities.²⁸

This model contains a definition of basic conception and promotes the establishment of a Committee for the protection of equality and special trial procedure. Mentioned models are in the course of public discussion.

²⁵ Ministry of Health (2005): National Strategy against HIV/AIDS, Belgrade

²⁶ Centre for development legal studies (2007): Discrimination in Serbia, Belgrade

²⁷ Ibid.

²⁸ Belgrade centre for human rights (2007): Report of the group monitoring discrimination, Belgrade

We will quote parts of the Health Care Law²⁹ that are important for stigma and discrimination issues within Provision V, for human rights and patient rights³⁰, and issue two articles:

In article 30, the Right on privacy and confidentiality of information:

Every patient has a right on confidentiality of all personal information that he/she said to the competent health worker, including information which refers on his health status and potential diagnostic and therapeutic procedures, as well as right on privacy protection during diagnostic examinations, visit to the specialists and medical-surgical treatment in complete. It is forbidden to the competent health worker to tell other persons personal data about patient from paragraph 1 of this article.

In article 37, the Right on confidentiality of information:

Data from medical documentation are personal patient data and presents official confidential data.

Further, in the same article we can find all details of possible violations of the regulation, and the article concludes:

Persons from paragraph 2 of this article, as well as person who unauthorized, without patient or full age family member consent have data from medical documentation from paragraph 1. and 3. of this article and bring those data to the public unauthorized are responsible for giving away of the official confidential data according to the law.

Besides these proclaimed rights, Head of the Republican AIDS commission pointed out that HIV therapy and monitoring tests are available and have been financed by health insurance since 2003, when Serbia put these medications on the list of medications approved for health insurance coverage. Provision of good health care, particularly HAART for those in need, may lessen some of the fear associated with HIV/AIDS and diminish the need for distancing.

Differing from everyday life, domestic law practice hasn't processed many cases of discrimination in general. The most common discrimination cases which are processed are discrimination against minorities, especially the Roma population (case "SRC Krsmanovaca in Sabac" and "night club Acapulco"). In both alleged cases (discrimination towards Roma population) which were in our courts of law, "situational testing" was used as proof in process. The main issue regarding proofing the discrimination is limited possibilities for presenting evidence in court.

Situational testing is the only proof that is applicable in our courts. The use of situational tests involves exposing discriminatory behaviour by confronting those who are believed to be guilty of such behaviour with situations where their choices will betray their preferences for certain individuals on the basis of a "suspect" characteristic of other individuals who are otherwise in an identical situation. Situational tests therefore involve two groups, a "test" group characterized by a feature liable to give rise to discrimination, and a "control" group that is identical in terms of all relevant characteristics (professional qualifications, age, dress style, etc.). The comparability of the two groups must be beyond reproach; if discrimination is to

²⁹ <http://www.zdravlje.sr.gov.yu/>

³⁰ <http://www.zdravlje.sr.gov.yu/>

be proved using this method, it is necessary to check comparability on the basis of a list of features, as complete as possible, that are likely to influence the decisions of a restaurant owner, a landlord, an employer, etc., depending on the circumstances of the case. The idea is simple: if the “suspect” feature is the only element that differentiates two individuals who, for example, act as job applicants, as potential tenants, or who wish to enter an establishment open to the public, then, *a priori*, the difference between the treatment of them can only be explained by supposing that the decision was influenced by this suspect feature, which allows us to construct a *prima facie* case for discrimination.³¹

Use of this kind of evidence in the processes regarding discrimination of persons due their HIV status is not an adequate solution because it is a very specific disease and there aren't always obvious signs of the disease.

Even when someone tries to help to HIV positive persons, the treatment is discriminatory. A good example for that is the case of an HIV positive boy (1997)³² who had numerous problems during his registration for school; his rights were violated and it caused pain and suffering. When the boy's HIV status was announced to the other parents (which is against the law), the other parents complained and he wasn't allowed to attend class with the other children (which is against the law in many western countries as well). The Ministry of Education found a solution after many articles and media stories (which were sensationalistic and helped further abuse of this boy's story), and after a few months of unnecessary suffering. The solution was an individual education for the boy with a teacher who “agreed” to work with him. The boy's guardians were relieved that they found a solution, but in reality that solution was discriminatory.

6.2 Role of NGOs and international organisations in addressing stigma and discrimination

Many international organizations adapted their programs to meet the challenges of the epidemic in the country, including efforts to reduce stigma and discrimination that are usually part of broader preventive activities (UNICEF, UNAIDS, HPVPI, UNDP). We will mention some of these actions:

UNICEF capitalizes on the opportunity to prevent the spread of HIV/AIDS among young by:

- strengthening the national capacities to respond to HIV/AIDS,
- increasing quality and access to HIV/AIDS prevention services i.e. health education in and out of schools, youth-friendly health services, voluntary confidential counselling and testing for HIV, maternal services to address
- prevention of mother-to-child transmission, and
- supporting young people themselves, particularly those at highest risk of HIV, those living in poverty and exclusion, to actively engage in HIV/AIDS prevention through peer education and other communication and initiatives.

³¹ http://www.era.int/web/en/resources/5_1095_3057_file_en.4441.pdf

³² Blic (1997): “I also have a teacher”, Belgrade

UNDP also plays an important role in reducing HIV/AIDS stigma. JRROL (Judicial Reform and Rule of Law) portfolio is framed around key development issues that are contributing to the country's economic development, social cohesion and clear goal of EU accession.

Achievements of Human Rights department:³³

- UNDP is focusing on the development of institutions, laws and innovative practices intended to promote the respect for human rights.
- UNDP is seeking to accomplish their aim systematically by creating sustainable frameworks for human rights protection.
- Supporting the country in fulfilling its international obligations by establishing frameworks for human rights protection.
- And what is especially important, UNDP is concentrating on strengthening international human rights protection mechanisms, reforming the system of provision of free legal aid and creating and implementing a comprehensive anti-discrimination legislative and institutional structure

NGOs also have an important role in reducing stigma and discrimination. NGO are recognized as agents in building public awareness about neglected issues in the state. These agencies are on different levels of organizational development and cooperation with officials. Mainly, they focused their activities on HIV prevention, which we also can consider as way to reduce stigma, considering the fact that informing the community can contribute to mitigating stigma and discrimination. These campaigns are mostly organized during specific days in the year, such World Aids Day and Candle Memorial Day. A few activities were especially designed to target stigma and discrimination. During the last year several NGOs took part in this kind of intervention. We will mention some of them:

Yugoslav association against AIDS (JAZAS)—under the title „With HIV it is possible to live today“, JAZAS organized tribunals and delivered education material throughout the year

Youth of JAZAS—besides an information-based approach, they participated in the “Zone without discrimination” event that was held on Central Square, handing out condoms and promotional materials.

Q Club -Reducing stigma and discrimination was the main goal of their campaign “What makes these persons different? “.During this campaign Q-Club held conference for journalists at Media centre. Conference aimed at presenting Q club to public and problems that PLHIV faced. During campaign Q club especially paid attention on media and this resulted in intensive media appearance. They presented a very illustrative poster for this campaign: “*What make these persons different?*”

³³ <http://www.undp.org.yu/tareas/jrrol/hrights.cfm>



Twenty years have passed since the first HIV case was registered in Serbia. Although a lot has been done, most of HIV interventions were of small scale, or one time off. Preventive activities and interventions that have attempted to decrease AIDS stigma usually were not evaluated, nor well coordinated and planned. More continuous sustainable and planned investments are required. Interviewed stakeholders noted several gaps in conducted campaigns: lack of definition of community of interest (What is the community of interest? Who does it include? Not include? Are there subgroups within this community of interest? What are the shared social and cultural characteristics of this community?), lack of evaluation of intervention efforts, lack of involvement of key persons in public life (politician, celebrities).

Interviewed representatives of NGO and GO organizations agreed that undertaken interventions for mitigating stigma and discrimination are not sufficient, and that more comprehensive approach is needed. Words of professor of Social medicine at University of Belgrade are very illustrative: *"Message on infertile ground would not be heard"*.

Besides, all representatives agreed that the role of PLHIV in the fight against stigma and discrimination and their inclusion in society is essential, and they emphasized the need for further steps that need to be taken.

As the Coordinator from Q club said:

"Government does not have strategy for inclusion PLHIV in society, and NGO offer non-systematic support to them. GO and NGO do not leave space for long-term benefit."

7. PROGRAMMES AND ACTIVITIES TO COPE WITH AND REDUCE STIGMA AND DISCRIMINATION

7.1 Approaches to prevent stigma and discrimination among the general public

Laws and legal protections are essential components of the societal response to stigma and discrimination. Most of the literature addresses legal issues, but less attention has been devoted to programmatic interventions which attempt to change attitudes and behaviour. A multifaceted approach that goes beyond legal protections is necessary to address the social climate.³⁴

As professor of Social medicine at University of Belgrade noted:

“Stigma is an attitude, while discrimination is stigma with consequences. If we want to address stigma we need to organize long-term education and promote different societal values. Discrimination is a another thing-it is an obligation issue, and you need to introduce sanctions in the case of discrimination ,for example 20% lower salary.”

The National HIV/AIDS Strategy supported programmes related to care, treatment and support for PLHIV, and also recognized the role of the community in the fight against HIV/AIDS and support to PLHIV, while not much is done in implementing this idea.

NGOs have made a considerable contribution in the field of HIV/AIDS prevention, especially among the younger generation and particularly vulnerable groups, through implementation of information and educational activities .These programs were implemented in conjunction with the media, representatives of religious communities, and government authorities and organisations.

Most of these interventions in Serbia have not been aimed exclusively at reducing stigma, but have involved many other components as well, such as increasing awareness and knowledge, and promoting behavioural change.

Also, NGOs play a significant role in empowering groups for psychosocial support and self-help groups for PLHIV. Relevant NGOs and self help groups are predominantly located in Belgrade and Novi Sad.

7.1.1 Contact with affected group

Contact with infected or affected groups creates an environment in which the general population can interact with the stigmatized group, either directly or vicariously, through media. This type of intervention aims to demystify and dispel misinformation and generate empathy, which in turn reduces stigma and prejudice. PLHIV play an essential role in challenging misconceptions about who becomes infected, and encouraging people to examine their own risk of infection³⁵.

³⁴ <http://hab.hrsa.gov/publications/stigma/interventions.htm>

³⁵ AIDS CARE (2002):The paradox of public HIV disclosure, Australian research centre in sex, health and society, La Trobe University, Australia

On the other hand, disclosure is very stressful, difficult, and frightening, because it makes one vulnerable to perceived stigma of friends, family, and community. In Serbia, few people decide to disclose publicly in the media. It seems that in order to disclose their HIV status in the media, PLHIV need to be assured of their social and governmental support. Without considering failure in the existing care and support system, it seems that at this moment in Serbia, participating in this type of intervention can lead PLHIV to experience repeated stigmatization. As legal counsellor from Q club said:

"At this moment, with high level of stigma and discrimination in Serbia, I would not recommend to anyone (PLHIV) to go public in the media. This way, PLHIV only could harm themselves."

One testimonial demonstrates the amount of support needed to go public in the media, and benefits of such disclosure.

Part of the testimonial:

When I found out that I am HIV positive, I did not want to hide my status from anyone, I even told my acquaintances. I did not want to be ashamed of myself. PLHIV mostly do not want to disclose their status, because they are afraid of community reactions and rejection. My friends accepted me, probably because they are my real friends, who did not think that my disease is obstacle for friendship.

7.1.2 Information-based approaches

Information-based methods are used in nearly all utilized interventions and therefore impact a range of target groups. This approach includes a factual description of the disease, transmission mode, and methods of risk reduction.

The information is delivered through information packs, leaflets, lectures, advertisements, and peer education. Peer education is a frequent intervention used for young people. Lectures are mostly based on the active participation of young people during the lecture; in such enabling environment, young people are freed from taboos, barriers, and fears, and can openly ask questions and discuss concerns.

Although information-based approaches are generally didactic, there is a need for cooperation and harmonization between different activities in this field. It seems that programmes are unnecessarily duplicated and overlapped, while financial resources are not utilized systematically.

7.2 Involvement of PLHIV in education and stigma and discrimination programmes implementation

After decades of fighting HIV in Serbia, the response to the epidemic still lacks the meaningful participation of PLHIV. This affects their wellbeing, life expectancy, and

quality of life. Lack of PLHIV participation seriously curtails care and support efforts to HIV prevention.

A history of mistrust directed by PLHIV toward other stakeholders responding to the HIV epidemic is based both on negative interactions and the failure of NGOs to enter in meaningful communication with PLHIV on this issue. The UNDP study³⁶ found that some PLHIV were disillusioned with NGOs, as through experience or hearsay they had become sceptical about their sustainability. They were therefore reluctant to invest in becoming involved. The accounts of a few PLHIV also emphasized that PLHIV were not adequately respected within NGOs and government commissions, and that they were unable to make a significant contribution.

Associations of PLHIV are underdeveloped. Several associations were established and then closed without implementation of planned activities, and usually without any funds received (Associations HIVAID and ALEXO). Recently two new associations were registered, and both are still lacking proper funding, knowledge, and skills.

Above all mentioned, it seems that the main reason for the insufficient involvement of PLHIV is that uncertain access to medical treatment (both HIV and non HIV) weakens their ability to fight stigma. The layered effect of stigmatizing experiences undermines the capacity of PLHIV to engage and address stigma and discrimination. This cycle reduces the visibility of the problems PLHIV are facing and weakens the chances of them being resolved.

7.3 Access to services by PLHIV who experience stigma and discrimination

Stigma also affects the care of HIV positive individuals. After a person tests positive, he or she faces decisions that include how to enter into and adhere to treatment, and whether to disclose HIV status to partners, friends, family, colleagues, employers, and health care providers. At each level, a decision to disclose seropositivity may either enhance access to support and care or expose the individual to stigmatization and potential discrimination.

One of the main conclusions of mentioned UNDP study is that there is a perpetual cycle in Serbia in which stigma and discrimination are prevailing and PLHIV have problems in HIV treatment access, access to other health services, stigmatization and discrimination on the labour market, isolation within family and within wider society.

Thus PLHIV are reluctant to become more involved in advocacy activities and to seek and obtain support. For PLHIV, the existing fragile employment market is significantly worsened by the disclosure of their HIV status. Common reaction to experiencing stigma in work is withdrawal from work market and attempting to obtain financial security through other means (for lucky ones pension or social welfare).

This approach, however, prevents a person from fulfilling his potential in professional field. Loss of earning opportunities as a result of being HIV positive directly weakens

³⁶ Bernays, S. , Rouds T., Prodanović, A. (2006): Accessibility, services providing and uncertainty in HIV treatment, Faculty for Hygiene and Tropical Medicine of London University, UK, DFID, HIV Prevention among Vulnerable Groups Initiative, United Nations Development Programme, Beograd/Podgorica

financial independence and this also undermines the capacity to manage other HIV related problems, particularly uncertain HIV treatment access.

Besides, policies on HIV/AIDS in the workplace still do not exist, and that fact contributes to PLHIV's vulnerability.

Unlike other areas where coping strategies are not disclosing HIV status or withdrawal after (often involuntary) disclosure, in medical care none of these is an option. PLHIV are compelled to use medical services even after repeated experiences of discrimination.

PLHIV describe the fragility of access to general medical care as humiliating, exhausting and intensely stressful. This seems to be particularly acute in the specialist areas of dentistry, gynaecology and surgery; although a number of PLHIV reported that they had also encountered problems at their primary health centres. A number of trainings were introduced especially for health care workers, but it appears that a fear of treating PLHIV persists among a large number of medical staff. Inadequate maintenance of client confidentiality by healthcare personnel is also perceived as a problem (e.g. enquiring unnecessarily about the mode of transmission, discussing a patient's HIV status in public, etc). This problem can be attributed to an attitude more than to a lack of knowledge, and discrimination by health professionals' further fuels stigma in the general public.

CONCLUSIONS

Stigma and discrimination toward PLHIV in Serbia and its causes are pervasive throughout all layers of society as well as various factors which have come together to create a high risk environment for HIV transmission.

High stigma and discrimination, lack of systematic and accurate education, negative and prejudiced media are of the main causes related to this high risk environment.

Negative attitudes of many medical workers towards PLHIV have been pervasive, as have breaches in confidentiality and other discriminatory behaviour. This behaviour inevitably has consequences in the way PLHIV interact with the world and those around them. They must suffer blame and negative treatment, as do those associated with them, throughout their daily lives, with no laws to protect them from such discrimination.

Although the current problems surrounding discrimination of PLHIV are myriad and interrelated, there still remains hope for change through action. The following SWOT chart outlines what this study has discovered, as well as opportunities and challenges for fighting discrimination of PLHIV in the future.

➤ *Society response to HIV/AIDS*

Strengths:

- Although there is no universal legislative regulation forbidding discrimination, (just constitutional decree) several initiatives address the need for legislative regulations related to all kinds of discrimination

Weaknesses:

- Serbian society is in the midst of transition governments, as well as social and economic crisis; which is not a favourable social environment for the battle against HIV/AIDS.
- There is a pervasive view that HIV happens to 'others', along with a continuum between guilt and innocence related to "how" someone became infected.

Opportunities:

- PLHIV need to be personalized and humanized in educational campaigns.

Threats:

- People tend to underestimate their own risk of contracting HIV, and therefore HIV triggers personal fears that they tend to repress

➤ *Causes of PLHIV Stigma and Discrimination*

Weaknesses:

- Relative low level of knowledge on ways how HIV is not transmitted even among health workers
- HIV in Serbia has also been associated with marginalized behaviour - IDUs, SWs and MSM, which inevitably results in double stigma for those in these

populations who do contract HIV.

- There is a high level of stigmatization within general Serbian society towards persons belonging to marginalized groups, mainly caused by: dominant values, norms, moral judgment, and fear caused by a lack of knowledge about HIV/AIDS, and there is no legislature forbidding this discrimination.
- Fear of discrimination among PLHIV, who have experienced or anticipate stigma, makes attempts for them to access health care more difficult.

Opportunities:

- Antidiscrimination laws should be created and implemented to battle discrimination of marginalized populations, including PLHIV.
- NGOs comprised of PLHIV could work with other NGOs to prevent stigma, and promote support for themselves.

Threats:

- Writing laws, implementing them into the judicial system, and implementing them is a long and complicated process.

➤ ***“Internal Stigma” of PLHIV***

Weaknesses:

- “Internal stigma” of PLHIV is the product of internalizing shame, hopelessness, guilt, low self-esteem and fear of discrimination. This internal stigma manifests through fear of disclosure, social withdrawal, self-imposed isolation, feelings of guilt and shame, and overcompensation.

Opportunities:

- Current mental health staff and counsellors should be educated on the needs of PLHIV.

➤ ***Discrimination towards Caregivers of PLHIV***

Weaknesses:

- Caregivers, whether professionals or volunteers, risk stigmatization as a result of their associations with PLHIV.

➤ ***Discrimination within health care system***

Strengths:

- There are medical staffs that specialize and are concerned about HIV/AIDS, especially those who work at Clinic for Infectious and Tropical Diseases.

Weaknesses:

- The existing health care system is inadequate to provide for the needs of PLHIV, and others. It functions under unsatisfactory financial circumstances, is centralized, focuses predominantly on clinical and hospital care, is expensive and provides inadequate access to antiretroviral therapy

- The perception of medical workers towards PLHIV has been found to be negative blaming towards PLHIV, implying that they are responsible for becoming infected.
- Medical workers have been shown to have inaccurate views regarding HIV transmission through ordinary, daily interactions with PLHIV.
- Medical professionals have commonly breached confidentiality of HIV positive status, and are not always knowledgeable about appropriate procedures for maintaining patient confidentiality.

Opportunities:

- The latest information about HIV transmission and prevention should be available and readily accessible to all medical professionals.
- Education of professionals on the effects of violations of confidentiality.

Threats:

- Continued lack of funds to implement the previously created HIV part of the Health System.
- Frequent scientific and medical advancements, regarding HIV/AIDS have sometimes been contradictory, which has left room for people to wonder about the accuracy of current information.
- Health professionals may not be open to hearing information about the consequences of confidentiality breaches and PLHIV discrimination.
- Continued disregard by medical workers to change behaviour towards PLHIV.

➤ **Media: Fear-based public messaging**

Strengths:

- The media has proven willing to discuss HIV issues, even if it is just one day out of the year and often includes erroneous information.
- Some NGOs have begun discussing the possibility of using media as means to destigmatization HIV and PLHIV

Weakness:

- The media in Serbia continually portrays HIV/AIDS in a very negative and discriminatory manner, often fear-based and blaming, using highly emotive language, which exacerbates inaccurate public views of HIV and PLHIV.
- Examples of negative media portrayal include-a continuous threat, a killer of our time, punishment for immoral behaviour, happens to people who are 'other', a horror, a war, a painful death.

Opportunities:

- Educate media about how HIV is spread, how it is not spread, and the consequences of their attitudes not just to PLHIV, but to the general public.
- Combat stereotypes and stigmatization towards PLHIV by implementing a

program which tells true stories of PLHIV, giving positive example of living with HIV in order to humanize PLHIV, as well as to educate the public.

Threats:

- Gaining access to media professionals in order to inform them could be complicated process, with varied obstacles.
- Proper media coverage is hard to achieve because the way of portraying PLHIV depends on many other factors not just journalist's awareness on HIV (for example editing policy)

➤ ***Need for evaluation of educational programmes***

Strengths:

- Youth have been educated sporadically about HIV, by NGOs and other organizations or groups.

Weaknesses:

- There has been no systematic approach to educating youth and general public about HIV
- What education is provided regarding HIV is focused more on how it can be transmitted, with little to no information about how it is not transmitted (i.e. how much blood is necessary, how fresh, or how fragile the virus is outside the human body).

Opportunities:

- Create and implement a systematic approach to educating youth and general population which includes information on how the virus can be transmitted, what preventative measures work, and how the virus cannot be transmitted (involving government as well as NGOs.)

Threats:

- Actual creation and implementation of a systematic approach to educating about HIV transmission could be problematic, considering the difficulty thus far regarding consensus in the government.

RECOMMENDATIONS

Recommendations to governmental sector

- **Increasing ART accessibility** - although government ensures universal access to HAART therapy, there is a need for further improvement and provision of good health care, because these interventions may lessen some of the fear associated with HIV/AIDS and diminish the need for distancing and distancing PLHIV
- **Create and implement a systematic approach to educating youth and general population.** In order to reduce stigma and discrimination everyone needs to learn how and why not to discriminate against positive people. People who are not HIV positive must learn about how the virus could be transmitted and how the virus could not be *not transmitted*. People need to know that they cannot become infected from things such as sharing food, towels or toilets. This will help to reduce discrimination against positive people by reducing ignorance and fear.
- **Promoting positive role models**-opinion leaders should be encouraged to engage in efforts to mitigate stigma, through their leadership and creativity. So far, in Serbia none of opinion leaders engaged in these kinds of activities.
- **Addressing health service delivery:**
 1. Education of medical staff in Serbia need to be evaluated (what kind of information is offered, learning methods, etc.)
 2. There is a need for further education in medical settings, with attention on the following areas: the latest information about HIV transmitting and prevention, education about the need to maintain proper data in regards to PLHIV, while still keeping this information confidential, education on the effects of violations of confidentiality, education about universal precautions and PEP
 3. Current mental health staff, VCT counsellors and general practitioners should be educated on the needs of PLHIV, in order to reduce level of internal stigma and its consequences.

Recommendations to non-governmental sector and international organizations

- **The media education**
 1. Increase the quantity and quality of education about how HIV is spread, how it is not spread, and the consequences of media attitudes not just to PLHIV, but to the general public

2. Education about the need to change messages -much of the media still does not represent the broad face of the epidemic, but prefers to adopt the 'somebody else's problem' approach by focusing it's attention on risks to specific groups - young gay men, injecting drug users, and more recently people from Africa. Approach "HIV could happen to anyone" could raise awareness and convince people that they are not safe simply by virtue of having not being in one of these groups
3. Implementing a program which tells true stories of PLHIV. PLHIV need to be personalized and humanized in educational campaigns
4. Education for media representatives about the good model and programs of Destigmatization as well as about the role that media could play in fighting stigma and discrimination

- **Support of PLHIV**

1. Strengthening self support groups for PLHIV- an important and commonly-neglected aspect of AIDS education with HIV positive people is enabling and empowering them to improve their quality of life. HIV positive people have varying educational needs, among them are the need to be able to access medical services, need for improvement of their current treatment literacy and drug provision and the need to be able to find appropriate emotional and practical support and help ,need to be educated on their basic human rights;
2. Empowering PLHIV community participation through training in leadership skills, so that PLHIV can be involved in community development
3. Empowering PLHIV who interact with media-improvement PLHIV skills in working with media practitioners through workshops
4. Addressing internal stigma- facilitating internal stigma workshops-including following themes: definitions of stigma, personal experiences of stigma, recognizing ones own internal stigma, coping strategies to reduce internal stigma

- **Addressing "courtesy stigma"**

Facilitation of support groups for those experiencing courtesy stigma in order to help people close to PLHIV in processing the internal stigma they experiencing

Recommendations for GIP

- Addressing double stigma - HIV in Serbia has been associated with marginalized behaviour - IDUs, SWs and MSM, which inevitably results in double stigma for those in these populations who do contract HIV. It is necessary to direct efforts toward destigmatization of IDUs and homosexuals as well, and not

simply toward PLHIV, because these layers of stigma help to deepen the AIDS stigma. GIP could support Serbian expert centre in creation and delivering anti-stigma campaign aimed at mitigating double stigma

- Interventions for health care personnel: there is a strong need for interventions to reduce stigma among health care workers as they play very important role in treatment, referral process of the PLHIV and recognising their health care needs. It seems that besides standard presentation of the facts, it would be useful to include other types of approaches. For example, implementation of coping skills acquisition techniques could help in changing their attitudes towards PLHIV.

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Questionnaire for the representatives of organizations

1. According to your opinion, to what extent stigma and discrimination is present in our country and recognized as a problem?
2. Can you summarize types of intervention aimed at mitigating stigma and discrimination in our country (legislative solutions, strategy for disclosure HIV status, campaigns)
3. Can you describe the role of NGO, GO and international organizations in recognizing and dealing with stigma and discrimination?
4. According to your experience, what kind of interventions should be developed to reduce stigma and discrimination (societal level, PLHIV, legal system)

Focus group guide with PLHIV

1. When people are talking about PLHIV, how are they presented and how are they seen? How are PLHIV presented in the media?
2. Until now, have you disclosed your HIV status to someone? (Can you tell me more about this decision, circumstances...?)
3. Can you tell me if disclosing your HIV positive status has influenced your relationships with other people (friends, family, and colleagues)? This influence could be both in number and quality of your interpersonal relationships.
4. Since none of you is working, can you tell me more about your decision to quit your work? (Was there some pressure at you to leave your work? Did you yourself choose to quit work because you were afraid of consequences of disclosure?)
5. When you think of affirming yourself in different areas of life, like work, friendship, partner relationships, do you feel that you needed to make more effort than people who are not HIV positive? Can you explain this?
6. How about using different kind of services, for instance medical, legal, and social. Were there situations when one of these services was denied to you because of your HIV status? Can you tell me more about these situations?
7. Although it might be hard to talk about this, can you please tell me were there any situations that you were insulted, threatened, or physically abused because of your HIV status? What were the circumstances of these events?
8. When you think of all these experiences that we've just shared, can you think of how did they influence you? Can you tell me has HIV status influenced your sense of self worth and your self perception? If so, in what way?
9. Now, can you think of some actions or activities that could be undertaken in order to reduce stigma and discrimination toward PLHIV. Can you think of some actions by the society, professionals, PLHIV themselves could to in order to reduce stigma?

Focus group guide for volunteers in palliative care for PLHIV

1. When people are talking about PLHIV, how are they presented and how are they seen? How are PLHIV presented in the media?

2. Think about your experience with PLHIV. Can you think of some examples of discrimination that they have faced? Can you point to most frequent forms of discrimination of discrimination toward PLHIV?

- Family, in form of rejection
- Partner relationships
- Work- pressure to quit work or giving up work
- Friends- less friends or changed quality of relationships
- Denial of services- medical, legal, social welfare and similar

3. When you think of all these cases of discrimination, can you think of ways they influence PLHIV? In particular, how might such experiences influence sense of self worth and your self perception of PLHIV?

4. Could you make a comparison between your work with PLHIV and other kinds of work you are doing? Can you think of any differences, hallmarks, difficulties?

5. Now, can you think of how people surrounding you perceive and comment on your work with PLHIV?

6. Now, can you think of some actions or activities that could be undertaken in order to reduce stigma and discrimination toward PLHIV? (Can you think of some actions by the society, professionals, PLHIV themselves could to in order to reduce stigma?)

Focus group guide for medical professionals

I INTRODUCTION 15 min

Introduction (facilitator presents goals of the group and host organization)-5 min
 Participants' introduction-5 min

II EXPLORING KNOWLEDGE ABOUT HIV 30 min

Participants were split in three small groups. Each group got list of questions with instruction to discuss them and afterwards present the answers to the plenum.

The questions were:

1. What are the differences between HIV and AIDS?
2. Which fluids contain HIV and which ones carry the risk of HIV transmission?
3. What are the ways of HIV transmission?
4. What are the ways HIV can not be transmitted?
5. How long can one live with HIV?
6. What does your group know about treatment effectiveness?

Group discussion 15 minutes

Presentations 15 min (5 min each group)

III EXPLORING ATTITUDES 40 min

This activity enables exploring attitudes, emotions and thought about HIV/AIDS. The group was presented with the list of statements, one at a time. After presenting each statement the participants were asked to express their level of agreement by walking to one of positions marked with a level of agreement with the statement (*Definitely agree, Definitely disagree, Possibly agree, Possibly disagree*). Then people gathered at the same level of agreement were asked to discuss and present some arguments for this choice. After presenting the arguments a discussion for each statement was open for the group.

Statements were:

1. HIV testing should be mandatory
2. HIV positive women should not choose to get pregnant
3. HIV positive persons should not be sexually active
4. Some people can be blamed for being infected with HIV, while others can not be blamed
5. HIV infected persons should not be employed in medical service

IV CLOSURE 10 min

Sharing experience about discussions.

Questionnaire for survey among medical professionals

Dear colleagues,

Expert centre on mental health and HIV/AIDS was founded in Belgrade in October 2006, supported by non-governmental organization IAN and is a part of network of nine Expert centers in South Eastern Europe, Central Asia and Caucasus.

Expert centre activities aim at increasing knowledge of professionals from areas of mental health and HIV on problems with mental health PLHIV is facing.

One of the activities of Expert Centre is research on attitudes and feelings toward PLHIV. Different people have different feelings and attitudes when thinking about PLHIV.

This questionnaire is about your personal feelings and thoughts about people living with HIV.

This survey is anonymous and results will be used for this research only. Please answer the questions openly.

Thank you very much!!!!

In this section you can see a list of statements people have made about PLHIV. Please mark how much you agree or disagree.

1. "People with AIDS should be legally separated from others to protect the public health?" The level of your agreement about this statement is:

- (a) agree strongly
- (b) agree somewhat
- (c) disagree somewhat
- (d) disagree strongly

2. "The names of people with AIDS should be made public so that others can avoid them?" The level of your agreement about this statement is:

- (a) agree strongly
- (b) agree somewhat
- (c) disagree somewhat
- (d) disagree strongly

3. "People who got AIDS through sex or drug use have gotten what they deserve?" The level of your agreement about this statement is:

- (a) agree strongly
- (b) agree somewhat
- (c) disagree somewhat
- (d) disagree strongly

4. 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 your answer is (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]

5. And suppose you had a young child who was attending the same class where one of the students was known to have AIDS. What would you do? Would you:

- (a) Send your child to another class, or
- (b) Leave your child in the same class?

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 other students?

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

6. Now suppose you had an office job where one of the men sharing office with you got HIV or 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?

7. Suppose that you found out that the owner of a small neighbourhood grocery store where you like to shop has HIV or 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 HIV or 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]

People have many different feelings when they think about people who have AIDS. The following statements are about your feelings.

8. Do you feel angry at PLHIV and to what extent? Would you say you feel:

- (a) very angry
- (b) somewhat angry

- (c) a little angry
- (d) not at all angry

If you feel angry, what do you think is the cause of this feeling?

9. When thinking about PLHIV do you feel fear? Are you:

- (a) very much afraid
- (b) somewhat afraid
- (c) a little afraid
- (d) not at all afraid

If you feel fear, what do you think is the cause of this feeling?

10. Do you, and to what extent feel disgusted by PLHIV? Would you say you feel:

- (a) strongly disgusted
- (b) somewhat disgusted
- (c) a little disgusted
- (d) not at all disgusted

If you feel disgusted, what do you think is the cause of this feeling?

These next questions are about the different ways some people think HIV might be spread. In answering each of the following statements, please indicate how likely you think it is that a person could get HIV infected in that way.

11. Imagine someone kissing someone on the cheek who has the HIV/AIDS? Would you say if someone does the chances of getting HIV/AIDS are:

- (a) very likely
- (b) somewhat likely
- (c) somewhat unlikely
- (d) very unlikely
- (e) impossible to get HIV infected

12. Imagine someone sharing a drink out of the same glass with someone who has HIV. Would you say if someone does the chances of getting HIV/AIDS are:

- (a) very likely
- (b) somewhat likely
- (c) somewhat unlikely

- (d) very unlikely
- (e) impossible to get HIV infected

13. In your opinion what are the chances of someone getting HIV or AIDS by using public toilets?

- (a) very likely
- (b) somewhat likely
- (c) somewhat unlikely
- (d) very unlikely
- (e) impossible to get HIV infected

14. Imagine a person living with HIV coughing on or sneezing on someone. In your opinion what are the chances that this person gets HIV/AIDS?

- (a) very likely
- (b) somewhat likely
- (c) somewhat unlikely
- (d) very unlikely
- (e) impossible to get HIV infected

15. In your opinion what are the chances to get HIV infected from mosquito or other insect bites?

- (a) very likely
- (b) somewhat likely
- (c) somewhat unlikely
- (d) very unlikely
- (e) impossible to get HIV infected

The following statements are about your estimation of the chances that certain types of people will get HIV infected in certain types of situations.

16. 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

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

18. 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 HIV?

- (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

Finally, please answer some questions important for this survey:

1. Sex M F
2. Years of working as medical professional: _____
3. Your profession is: a.) doctor
 b.) nurse
 c.) laboratory technician
 d.) something else_____

Please add any comments or statements about this survey

Thank you for participating in this study!