

# Mental Health and HIV/AIDS Structure in Serbia

GIP Expert Centre for Mental Health and HIV/AIDS in Serbia

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# 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 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**

Global Initiative on Psychiatry 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. Their 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.

# Abbreviations

AIDS - Immunodeficiency Syndrome CAFOD - Catholic Agency for Overseas Development CBO - Community based organization CC – Clinical Centre CIDA – Canadian International Development Agency CMHC - Community mental health centre **CT-Computed tomography** DFID - Department for International Development GDP - Gross domestic product **GIP-** Global Initiative in Psychiatry GF – Global Fund GFATM - The Global Fund to Fight AIDS, Tuberculosis and Malaria GO - Governmental Organization **GP** – General Practitioner EAR – European Agency for Reconstruction HAART – High Active Antiretroviral Therapy HIV - Human Immunodeficiency Virus HPVPI - The HIV Prevention among Vulnerable Populations Initiative IDU – Intravenous Drug Users IAN- International Aid Network IFRC – International Federation of Red Cross IOM - International Organization for Migration IPH - Institute for Public Health ISH - Institute for Student's Health KAP study - Knowledge, Attitude, Practical study MSM - Men who have sex with men MRI-Magnetic resonance imaging NCMH - National Committee for Mental Health NGO - Non-Governmental Organisation PLHIV – Persons living with HIV/AIDS PCR-Polymerase Chain Reaction RAC – Republican AIDS Committee SFRY - Socialist Federal Republic of Yugoslavia STI - Sexually transmitted infections SW – Sex worker UN – United Nations UNTG - United Nations Team Group on HIV/AIDS UNAIDS - The Joint Nations Programme on HIV/AIDS UNDP - United Nation Development Program UNHCR - United Nations High Commission for Refugees UNICEF - United Nation Children's Fund VCT - Voluntary counselling and testing WAD - World AIDS Day WB – World Bank WHO - World Health Organisation

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In research activities we have received much assistance from our colleagues from the Serbian Expert Centre's parent organization, International Aid Network (IAN), as well as associations of PLHIV, including: AID Plus, Q Club and UPSZ. We would like to thank, first of all, the director of AID Plus and his assistants and to all participants of the focus groups whose personal experiences were key components of the report. We owe our gratitude to the professionals in the area of mental health and HIV who also gave their contribution and took active part in this assessment.

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# **1.** Introduction

The aim of the project "Mental health and HIV/AIDS in south-eastern Europe, Caucasus and Central Asia" is to improve the quality of life and to decrease the suffering of persons living with HIV/AIDS who have problems with their mental health, as well as their partners, their care-takers and their families. This study represents one step forward towards the fulfilling this goal in Serbia, through the situational analysis of those services which already exist for mental health and HIV domains.

Serbia has a low level of HIV epidemic, however situational and structural factors correspond to creating an HIV risk environment. Political, social and economic transition as a result of major conflicts in this region during the 1990's have resulted in poverty, weakened public health infrastructure, deteriorization of the health system, decreasing management capacity, and insufficient health care network. During this recent period of political, economic and social turbulence in Serbia, the health sector faced many challenges in responding to the health needs of the population. The subsequent conceptualisation and agreement on the direction of the required health care reform, involving restructuring, improving efficiency, and decentralizing the system has posed serious problems<sup>1</sup>. The lack of information in regards to a management system within the health sector has resulted in problems both with monitoring the health status of the population and understanding their health trends.

Mental health and HIV are both marginalized in Serbia, with no awareness about the consequences that living with HIV could have on the mental health of the people, as neither the National Strategy for HIV nor the National Strategy for Mental Health recognize the connection between these two issues. However, due to the fact that both HIV and mental health problems are mainly treated as health care system issues, there has been a considerable lack of impact in Serbia's response to those issues. The circumstances of conflict compounded with a dual marginalization of mental health and HIV/AIDS issues has halted further development in both areas, which has resulted in a lack of connection between mental health and HIV.

Wars and political crises involving Serbia, created an environment in which nongovernmental organisations (NGOs) were perceived as "anti governmental", regardless of their field of activities like democratisation, health issues, disabled persons, human rights, etc. Because of this negative view towards NGOs by both the government and, often, the general public as well, there was a lack of proper cooperation between governmental organizations and NGOs. Hence, vulnerable people were not reached by NGOs because they were not allowed to contribute to the response of these issues.

Combating HIV/AIDS is a Millennium Development Goal endorsed by the United Nations and WHO. Access to HIV counselling, testing, treatment and care is central to WHO initiatives, which are resulting in increasing numbers of people coming forward for testing and will inevitably make more people aware of their HIV status. This increase in numbers creates a corresponding increase in the need for mental health care and treatment, and it requires different sectors of health and social care to work much more closely together.

Little has been documented about the services for mental health and HIV in Serbia. This study is the first in Serbia aimed at exploring the services that are already available for mental health problems of PLHIV.

<sup>&</sup>lt;sup>1</sup> UNFPA Assessment Serbia and Montenegro, 2005

# 2. Methodology

The instruments for data collection were desk review, interviews with representatives of relevant governmental organisations, international and domestic non-governmental organizations and individuals, focus group discussion with professionals, mainly psychologists, psychiatrists and doctors, and PLHIV (focus group guideline can be found in Appendix 1).

#### 2.1 Desk review

At the beginning of this research, the research team reviewed relevant documentations available in Serbia including available research reports, situation analysis conducted by other organizations and institutions concerning the quality of life and the needs of  $PLHIV^2$ .

#### 2.2 Interviews

Interviews were held with representatives of organizations and institutions who are involved in the HIV field, with the aim to identify the resources available as well as gaps in those services which are geared toward the mental health of PLHIV.

A total of 15 meetings were held in order to collect data, establish contacts, and explore the potentials for cooperating with this research project. These meetings included the following stakeholders: Neuropsychiatry Institute's "Dr Laza Lazarevic," National Office for HIV, Drug Rehabilitation Centre, JAZAS (an NGO from Belgrade), Institute for Infectious and Tropical Diseases, "Red line" (an NGO from Novi Sad), Network of NGOs fighting HIV in Vojvodina, "Duga" (an NGO from Sabac), "Philanthropy" - the Charitable Fund of the Serbian Orthodox Church (an NGO from Belgrade), HIV Prevention Among Vulnerable Populations Initiative (HPVPI), Institute for Student's Health, and Special Prison's Hospital in Belgrade. Most of the organizations contacted were willing to cooperate and had positive reactions to GIP's initiative to conduct this kind of research.

Those organizations who have contributed most significantly to this research, thus far, have been the NGOs: AID+ and Q Club. The interview with Sarah Bernays and Ana Prodanovic from HIV Prevention among Vulnerable Populations Initiative (HPVPI), published the qualitative study about HIV treatment access delivery and uncertainty, was also especially useful and informative for this research.

All interviews were done individually with representative of each organization, asking the same questions. Results of the interviews were used in obtaining information on existing situation in the field of services for mental health of PLHIV and developing recommendation for further development of the structure.

The topics of most significance discussed during this interview, included:

- a) Type of services their institutions offer to PLHIV/advantages/gaps
- b) Mental Health services their institutions provide to PLHIV
- c) Users (PLHIV or other group IDUs, prisoners)
- d) Needs for training of their staff on Mental Health issues
- e) Previous research that could help to this research
- (The list of questions is in Appendix2)

<sup>&</sup>lt;sup>2</sup> Specifically: National Strategy for Mental Health, National Strategy for Fighting HIV/AIDS, Informational pack for PLHIV "Living with HIV", UNGAS Country report on HIV, and Country Report on HIV Epidemic.

#### 2.3 Focus group discussion

Focus groups were held in Expert Centre premises and lasted between 60-90 minutes. Focus group discussions were held with following groups:

#### 2.3.1 PLHIV

For the PLHIV focus group, there were four participants, of which three were members of AID+ association. Gathering PLHIV for a focus group discussion was quite a challenge, because most of them have disclosed their seropositive status very selectively and hesitate from any kind of public appearing related to it. Most of PLHIV were ready to participate only in a protective environment, after establishing a relationship with the research team, and with other PLHIV with whom they already have a good relationship. The participants were mostly retired, single and living in a big city; and the range of living with HIV was 6-23 years. There were two main topics discussed, including the general influence HIV positive status has had on the lives of participant's and their health seeking behaviour.

#### 2.3.2 Stakeholders

The focus group for stakeholders included representatives of institutions that work with PLHIV who were psychologists, psychiatrists, doctors, and one PLHIV. This focus group was concentrated on evaluating existing services, disadvantages of the current health system and what support is currently available for PLHIV. We feel that the presence of the PLHIV individual, who is a user of the services, greatly contributed to a more realistic debate about the advantages and disadvantages of existing services. Judging from non-verbal behaviour of the members it seems that the presence of the person living with HIV/AIDS had a significant influence on group dynamics. During the debate members were often both speaking or looking at the PLHIV, which may imply how important this individual's opinion was in the discussion.

# 3. Mental Health and HIV in Serbia – Epidemiological Overview

#### 3.1 Mental Health in Serbia

In recent years, mental health of the general population in Serbia has deteriorated. According to the Institute of Public Health of the Republic of Serbia, during the period of 1999-2002, the number of diagnosed cases of mental and behavioural disorders (F00-F99) has continually increased, from 271.944 (in 1999) to 309.281(in 2002). These types of disorders now hold the second place of major health problems of the population following cardiovascular diseases.

There has also been an increase of non-psychotic, stress-related disorders in recent years; likely developing as a consequence of disastrous events that the population of Serbia was exposed to in the last decade of the 20th century. These events posed a great threat to mental health because of loss of economic security, resulting often in poverty, with atmosphere of uncertainty; rising rates of crime, posing threat to physical safety; forced or willing emigration; mobilisation for participation in wars, injuries and death, and a great number of refugees further burdening the society in such a crisis. All of this resulted in depriving people of basic safety and network of close people which is very important for prevention of mental health problems.

Stress related disorders are not the only consequence of the past disastrous years. Other types of disorders are also escalating, including: depression, suicide, psychoactive substance abuse, psychosomatic disorders, delinquency, and violence. Burnout syndrome among physicians is also frequent.<sup>3</sup>

The mental health problems are also increasing among the youth in Serbia, predominantly depression, suicide and behaviour disorders like drug abuse and delinquency<sup>4</sup>. Morbidity and mortality at a young age are also increasing.<sup>5</sup>

#### 3.2 HIV and AIDS in Serbia

Accurate HIV epidemiological data is unclear in Serbia. According to the available data, Serbia has a relatively low prevalence of HIV infections, with an estimated HIV prevalence as 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. Between 1984 and 2006, 2,088 HIV infected persons registered in Serbia, and 1,339 (64%) of those who registered already had AIDS; 915 of who have since died of AIDS. According to UNAIDS estimates, there are about 10,000 (6 -17. 000)<sup>6</sup> HIV infected people in Serbia and Montenegro.

PLHIV are predominantly grouped in the territory of central Serbia (90%), 80% of who are 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 the period when there was a continuous growth of registered people with the clinical manifestations of AIDS, in 1999 it was observed that the number was gradually in decline, and the estimate is that the tendency is going to continue in the

<sup>&</sup>lt;sup>3</sup> National Committee for Mental Health, Ministry of Health of Republic of Serbia: National Mental Health Policy and Action Plan, Belgrade, October 2004. Available at http://www.imh.org.yu/nacionalni\_zakon.htm <sup>4</sup> The National Strategy for mental Health, Belgrade 2007

<sup>&</sup>lt;sup>5</sup> National Committee for Mental Health, Ministry of Health of Republic of Serbia: National Mental Health Policy and Action Plan, Belgrade, October 2004. Available at http://www.imh.org.yu/nacionalni\_zakon.htm <sup>6</sup> http://www.unaids.org/

period to come. Also, from 1997, the continuous decrease in the number of those who died from AIDS was 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 accessing the HIV treatment (according to recommendation of infectologist) in Serbia and Montenegro<sup>7</sup>.

This decrease in the number of people with AIDS and those dying of AIDS, however, has not been followed by a decrease in the number of people newly infected with HIV. So, accompanied with a prolonged life span, the number of people who are HIV positive is also rising.

HIV transmission among intravenous drug users (IDU) is as high as 44%. Drug users, along with people suffering from haemophilia and blood transfusion recipients, comprise over half of those with AIDS; as they were infected through blood derivatives. Another large transmission group is comprised of people infected through sexual intercourse, at 35.5%. HIV transmission from mother to child is rare, at a mere 1.4%. For more than 10% of those infected with HIV/AIDS, mostly men, the way 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 years<sup>8</sup>.

#### 3.3 Mental Health of People living with HIV and AIDS in Serbia

Regarding mental health problems among PLHIV, there is no official data available. It appears that mental health problems among PLHIV are undiagnosed and under treated due to the general situation in Serbia's mental health system.

As the National Committee for Mental Health (NCMH) has stated, general practitioners on the primary health care level do not have sufficient knowledge and skills in psychiatry and mental health care. For that reason, they are often unable to provide adequate diagnosis, treatment and referral of the patients in regards to mental health, and tend to rely excessively on the secondary and tertiary mental health care services in this regard<sup>9</sup>. And, cooperation between the secondary and tertiary services and the primary health care is inadequate.

As previous research examining the basic needs of PLHIV in Serbia has shown<sup>10</sup>, only 49% of PLHIV visit general practitioners. Not only that, but PLHIV rarely use other services in the public health care sector, which makes role of general practitioner in recognizing mental health issues especially important for the quality of life of PLHIV. The most commonly used service for PLHIV is condensed/limited/reduced to the HIV Clinic at the Institute for Infectious and Tropical Diseases (78%), considering this is currently the only referent institution for specific treatment and care of PLHIV in the whole of Serbia.

There is a widespread stigma attached to both mental disorders and HIV/AIDS in general. Because of these stigmas, people deny the problems they have related to

<sup>&</sup>lt;sup>7</sup> this data was obtained through communication with Global Fund Serbian Country Coordinating Mechanism member

<sup>&</sup>lt;sup>8</sup> 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

<sup>&</sup>lt;sup>9</sup> "National Mental Health Policy and Action Plan", National Committee for Mental Health, Ministry of Health, Republic of Serbia

<sup>&</sup>lt;sup>10</sup> Centre for continuous development (2005): Evaluation of the basic needs of the persons living with HIV/AIDS, Belgrade

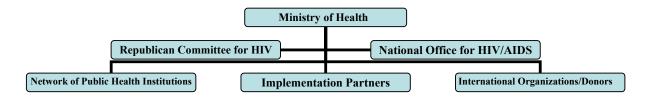
mental health, hesitating to ask for professional help, which often only worsens the illness.

And, because of the serious stigma attached to HIV/AIDS within medical health care workers in Serbia, PLHIV face significant problems accessing health care in general. The difficulties PLHIV face in accessing non-HIV related medical care, and the negative reactions they must often endure when visiting health institutions other than the Clinic for Infectious and Tropical Diseases have resulted in many PLHIV visiting the Clinic for Infectious and Tropical Diseases for all of their medical needs. Often PLHIV have 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. Having doctors arrange these appointments, often by calling on personal favours, is seen by professionals as the most pragmatic strategy to manage the situation.

# 4. HIV/AIDS Care Structure and Policies

#### 4.1 Organizational framework

Tab 1 - HIV structure in Serbia



#### 4.2 Ministry of health and Republican AIDS Committee

After Serbia's democratic changes in 2000, conditions were ripe for a more systematic and active approach in the fight against HIV/AIDS. Once the government of the Republic of Serbia had reformed, a new committee for the fight against HIV/AIDS was created in June 2004. This recently formed Republican AIDS Committee (RAC) has aimed to strengthen managerial capacity and improve coordination in the HIV/AIDS field. The RAC, with the Minister of Health at its head, represents a governmental body with many sectors, which has 22 members, including the representatives from the Ministry of Health, Ministry of Internal Affairs, Ministry of Justice, Ministry of Work, NGOs, PLHIV; observers from UNAIDS, UNICEF, UNDP, WHO; and individuals from academic institutions and the health department. The major tasks of RAC were stated as:

1. Establishing and implementing National Strategy for fighting to HIV/AIDS

2. Analysing and monitoring HIV/AIDS situation in the country, especially epidemiological status

3. Mobilizing all recourses in the country for better respond to epidemic

The Ministry of Health was appointed to coordinate all the activities in this field, and RAC approved this first national strategy to fight against HIV/AIDS for the period 2005-2010. All of these changes within Serbia did so with the support of the Global Fund, which had approved this undertaking in Serbia from 2003 till 2005. Unfortunately, an action plan for implementing the national strategy has not yet been fully developed due to insufficient funds.

The National Office for Fight Against HIV/AIDS was opened in February 2006, under establishment of the National Institute of Public Health "Batut", with the support of the UN agencies UNAIDS and UNDP. The aim of this office is to give logistic support to RAC so that the national strategy could be carried out, and to facilitate the coordination of appropriate HIV/AIDS related activities in Serbia. One of the aims of the National Office for Fight Against HIV/AIDS included data collection on various activities, projects and research which represented the national response thus far to HIV/AIDS in order to help RAC plan and implement future activities in an informed manner. Unfortunately, the National Office for Fight

Against HIV/AIDS stopped working completely in January 2007 due to a lack of financial support from government and international agencies.

#### 4.3 Governmental organizations

#### 4.3.1 Treatment of people living with HIV and AIDS

The leading institution providing treatment for people living with HIV/AIDS is the HIV Clinic at the ward six of Institute for Infectious and Tropical Diseases at the Clinical Centre of Serbia, Belgrade. Since the beginning of the HIV epidemic in Serbia, it has been the only institution providing treatment and follow-up for PLHIV. The Centre has data on the number of PLHIV on HAART therapy, as well as information about the entire number of HIV infected people under medical supervision. After a person receives a preliminary HIV positive diagnosis, a confirmatory test is conducted at the Centre for HIV/AIDS. In the usual procedure, a person with a preliminary positive result is given a referral paper (which is sometimes difficult to obtain if the person does not have health insurance) for the specialist exam at the HIV Clinic. Usually SWs, IDUs and Roma are outside of the health care system and therefore do not have health insurance. In this situation, they do not go to the HIV Clinic.

If necessary, PLHIV can receive medical and psychological help at the HIV Clinic, as well as information about where to go if they need some other help.

Clinical management of HIV/AIDS includes following: hospital treatment, treatment in a day care hospital and out-patient follow-up. Hospital treatment is prescribed to patients who suffer from a serious opportunistic infection or tumours. Regardless of being on a HAART regimen or not, all patients receive outpatient and follow-up care. There are three doctors working at the Centre and the patients have faith in the competence and expertise of all three doctors. As well as their technical expertise, for many clients the staffs provides significant emotional support and plays a key role in the management of their conditions, both medical and psychological.

HIV therapy is prescribed by the Clinic doctors for the following month, and the patients then obtain the medication at the pharmacy of the Clinical Centre of Serbia. HIV therapy and monitoring tests have been financed by health insurance since 2003, when Serbia put these medications on the list of medications approved for health insurance coverage.

Related to the medical care PLHIV receive is the key finding of the UNDP qualitative study examining HIV treatment access, delivery and uncertainty<sup>11</sup>– the overriding concern of PLHIV in Serbia is anxiety about the continuity of supplies of HIV therapy and monitoring tests. Although there is a statement from Ministry of Health that HIV treatment is free for all citizens, fragility of access and delivery remains an ongoing problem for PLHIV. <sup>12</sup> Also, problems with the availability of supplies for CD4 and PCR tests were reported by service providers and clients alike. The inconsistency of supplies makes it very difficult for doctors to predict and plan how to monitor the conditions of patients and ensure there is an equitable distribution

<sup>&</sup>lt;sup>11</sup> Bernejs, S., Rouds T., Prodanovic, A.: HIV treatment access, delivery and uncertainty: a qualitative study in Serbia and Montenegro, January 2007, UNDP Report, Belgrade.

<sup>&</sup>lt;sup>12</sup> Among some service providers' accounts there was disagreement about the extent and gravity of the treatment supply problems. Whilst some felt that it was an inevitable result of managing HIV in a resource-stretched health service and that consequences were minor and manageable.

of resources. This was identified as a cause of concern in a number of PLHIV accounts.<sup>13</sup>

It is clear that just one Centre for HIV treatment and three doctors are not adequate to provide high quality care for PLHIV in for all of Serbia. Since 2006 there has been a plan to open new centres for HIV/AIDS outside Belgrade (in Niš, Novi Sad, and Kragujevac) in order to increase the capacities of other institutions to provide quality care for PLHIV. However, these centres haven't started working yet, because they are not fully equipped with adequately trained staff, so the HIV Clinic, with its limited capacities, is still the only institution where PLHIV can be treated in an appropriate way.

According to the results of UNDP, whilst participants were unhappy that they could not access HIV healthcare in their own area, many are anxious about the quality of care that they will receive in the new clinics. This doubt appeared to stem from a number of concerns. Firstly, participants appeared confused about what services would be available to them and how it would affect their relationship with the clinic and doctors in Belgrade. Secondly, there appeared to be some concern about the ability the doctors in the local clinics would have to treat the patients, both in relation to their expertise and experience, as well as what kind of equipment and facilities would be available. As a result many participants expressed a desire to continue going to Belgrade. Some PLHIV also spoke about a lack of trust they had in the doctors in their local areas, due to past experiences with them.

#### 4.3.2 HIV Testing

The number of persons being tested for HIV in Serbia is very low; the average registered rate of 4.7 per 1000 people is among the lowest in Europe<sup>14</sup>. All blood donations have been routinely screened for HIV since 1987, but this is the only policy about HIV testing in Serbia. The testing is offered only by medical institutions and private laboratories, but not by NGOs, meaning that a lot of vulnerable people (SW, IDU, and Roma) who are outside of the health system do not have proper access to HIV testing.

HIV testing is offered in different institutions:

1. The laboratory of the HIV Clinic at the Institute for Infection and Tropical Diseases which provides HIV screening and confirmatory HIV tests

2. Institutes for Public Health (IPH) which provide both screening and confirmatory tests

3. The VCT centre of the Institute for Student's Health (ISH) in Belgrade offers screening HIV testing

4. Private laboratories

There is a network of 28 Institutes for Public Health covering the whole territory of Serbia. These Institutes have an epidemiological department which provides HIV testing besides testing for other purposes. Blood screening is the most common method of HIV detection and is generally performed using the ELISA testing method. The testing in these institutes was free of charge during the years of GF funding, but before that and when the GF money was depleted, each person who wants to know their HIV status has to pay for their own HIV testing (approximately 12 EUR).

Besides the voluntary testing which was promoted during the GF funding, there is still a lot of mandatory HIV testing – HIV testing prior to surgery or other medical

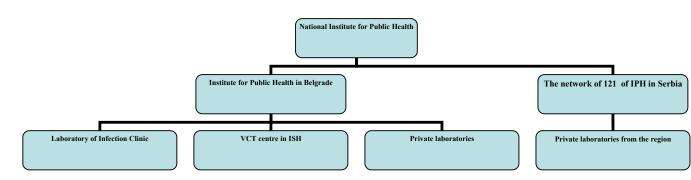
<sup>&</sup>lt;sup>13</sup> Bernejs, S., Rouds T., Prodanovic, A.: HIV treatment access, delivery and uncertainty: a qualitative study in Serbia and Montenegro, January 2007, UNDP Report, Belgrade

<sup>&</sup>lt;sup>14</sup> Ministry of Health of Republic of Serbia: National Strategy for the Fight against HIV/AIDS, 2005

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 all tested clients were tested specifically for medical reasons.

There are also requests for the test from people who want to work abroad (China, United Arab Emirates, and America) as well as for citizenships (Bulgaria, Slovakia)<sup>15</sup>. In these situations, the HIV costs are not covered by health insurance.

The communication and referral system between the institutions that provide HIV testing is very poor. The table below shows the formal structure for reporting HIV testing, which is meant to provide the National Institute for Public Health all the information about HIV testing. However, this structure does not work in practice, and the National Institute for Public Health does not have a clear picture of HIV testing in Serbia.



The number of private laboratories in Serbia is practically unknown. Although it must be registered, it is registered as any other form of company, so there is no unique register of private laboratories.

There are no clear procedures for the confirmation of HIV positive results. The decision is made by a doctor at the Infection Clinic and is based on a number of factors: the reputation of the clinic, type of tests used a power struggle between institutions, and the relationship between clients and staff at the institution. For people who test positive, this situation has a strong influence on increasing their fear and anxiety around the testing and diagnostic process. More effort needs to be made to develop and implement a unified procedure for confirming HIV positive status, so people undergoing this procedure are not exposed to more uncertainty than necessary.

Anonymous HIV testing is promoted, but everybody who tests HIV positive is required to give all personal data to the staff in testing centre (according to the law) in Serbia. This is an additional factor that increases the anxiety and fear of people who test HIV positive, making them vulnerable to mental health problems and influencing their health seeking behaviour.

Voluntary pre- and post-test counselling does exist, but only in limited circumstances. VCT has been promoted by UNICEF since 2003 by education of counsellors (mostly epidemiological department staff in IPH), but still there is no strong commitment by the Ministry of Health and RAC to follow the recommendations of UNAIDS and WHO in developing VCT. The National Strategy for HIV recognizes VCT as a surveillance tool, with no recognition of its roles in HIV prevention as well as in improving early access to HIV treatment and support. Generally, the capacities of the institutes for HIV testing and counselling are different in different parts of the country due to the fact that VCT is still underdeveloped in

<sup>&</sup>lt;sup>15</sup> Data base of VCT centre in Student's Policlinic

Serbia. The role of VCT is not recognized by managers of these institutes as important, and work conditions often fail to fulfil some basic standards of VCT practice (e.g. privacy).

Staff in these institutes, especially outside of Belgrade, lacks ongoing education and support. Knowledge and skills for working with vulnerable populations, and especially post-test counselling with people diagnosed as HIV positive, are main issues.

In our community counselling is not recognised as a skill in its own right<sup>16</sup>. There are different interpretations among the decision makers and general public related to the techniques and aims of the counselling processes.

The institution that is trying to follow recommendations of UNAIDS and WHO in VCT development is the Institute for Student's Health in Belgrade (more about this institution can be found in the section on Mental health care for PLHIV).

#### 4.3.3 Treatment of pregnant PLHIV women

Prevention of vertical transmission and care and treatment for pregnant women with HIV is centralized in one clinic in Belgrade – the special gynaecology clinic "Narodni front". Those who are tested HIV positive in other towns in Serbia are referred to this clinic. There are just two obstetricians in the clinic who work with HIV positive pregnant women. All pregnant women are offered HIV testing as a part of routine testing in every hospital, counselling centre for family planning, and private gynaecology clinic.

#### 4.3.4 The PLHIV in the Prison's Hospitals

As of June 2007, 22 of the 5616 prisoners in Serbia's prison system were HIV positive<sup>17</sup>.

The prisons usually have their own health care service, and there is one Special Prison's Hospital in Belgrade treating persons with acute somatic disorders that cannot be treated in other penitentiary institutions. This includes those who need security measures associated with compulsory psychiatric treatment and custody in health institutions, or those who are in compulsory treatment of alcoholism or drug abuse. There are 2 PLHIV in the Special Prison's Hospital at the moment. Patients with HIV/AIDS in this clinic are not separated from other patients. However, their fellow patients who are in regular contact with them are informed of preventive measures that need to be taken and the nature of this transmittable disease<sup>18</sup>. According to the report of the Helsinki Committee for Human Rights in Serbia,<sup>19</sup>this clinic constantly petitions the Ministry of Justice to release every AIDS patient and enable him to get treatment. If such an attempt fails, a patient, accompanied by security officer, has been taken to the Clinic for infective diseases in Belgrade. If not, the patient remains in the hospital without proper treatment. Since the medical staffs in the prisons is educated about HIV in terms of modes of transmission and safety behaviour, but not about the effect of HAART on the mental health of PLHIV or the

<sup>&</sup>lt;sup>16</sup> First counselling centres in our country provided counselling related to pregnancy and main activity was medical follow up of the pregnancy. Staffs of those centres were medical doctors and nurses in their standard roles.

<sup>&</sup>lt;sup>17</sup> Annual report for 2005, Ministry of Justice, Administration of the Execution of Penitentiary Sanctions, p. 65

 <sup>&</sup>lt;sup>18</sup> Analysis of situation in Serbian penitentiary system, International Aid Network, Belgrade 2007
<sup>19</sup> Prisons in Serbia, April 2003-April 2004, Helsinki Committee for Human Rights in Serbia, http://www.helsinki.org.yu/doc/reports/eng/TortureEU-eng.pdf, p.69

connection between mental health and HIV, we could say that mental health problems connected to HIV are not properly addressed in the prisons.

HIV testing in the Special Prison's Hospital is mandatory and is part of routine testing, although this goes against international advice. If the result of the HIV test is negative, the result is not given to the prisoner. If the result is positive, the psychiatrist gives the result to the prisoner and explains the advantages of disclosing HIV status to other prisoners or family members. The prisoners usually do not want to disclose their HIV status, but the psychologist organizes additional counselling sessions for HIV positive prisoners in order to help them make the best decision about disclosing their HIV status. Basically, there is a pressure that the prisoner discloses his HIV status to his cellmates, and all of them have agreed to do so.

There are 21 psychiatrists in the Special Hospital, with psychologists, social workers, therapists, nurses, and laboratory, pharmaceutical and x-ray technicians making up the rest of the staff (60 medical officers in total). Since the institution can not afford a variety of full-time specialists, it engages so-called "consultants" who regularly come once a week.

Prisoners, who have mental health problems, including PLHIV, are treated individually and/or in groups. Most of the treatments are done by psychiatrists using medications, as well as group therapy. There is a need for individual psychotherapy, although it can not be provided.

#### 4.3.5 Treatment of people living with HIV and AIDS who are injecting drugs

When a person receives a confirmation of his/her HIV status, and he/she is an intravenous drug user, a possibility to enter a methadone program is offered. Criteria for entering the program are established by a board of specialists from The Institute for Addiction Related Diseases. In practice all HIV positive patients who have been intravenous drug users for a long period of time have been offered this kind of therapy.

The patient needs a prescription from a doctor, and then access to the therapy is regulated by a special contract between the patient and the Institute. Carrying out the methadone therapy is possible even in prisons.

The following institutions in Serbia provide methadone therapy:

- Institute for Addiction Related Diseases, Beograd
- Clinical-Methadone Centre, Novi Sad
- Clinic for Mental Health Protection, Niš
- Psychiatric Clinic, CC Kragujevac

Injecting drug users have access to HAART as well. If they want to go to a clinic for the treatment of a drug addiction, they are required to be tested for HIV. This is not the best practice, since entering the treatment is a stressful event and additional stress connected to HIV testing could seriously affect their mental health and the success of the proposed treatment.

Beside the Institutes for Drug Addiction that provide detox treatment in Belgrade, Nis, Kragujevac and Novi Sad, there is one private clinic for drug addiction, "Special Clinic for Alcohol and Drug Dependency". This clinic has operated in Belgrade and Novi Sad. The clinic has 4 psychiatrists and 1 psychologist, because the mission of the clinic recognizes psychotherapy and care for the mental health of injection drug users as an important element of treatment.

The client of the clinic also has to know his/her HIV status before the treatment, but there is no information available regarding what is happening with those who test positive. The health insurance does not cover the costs of treatment in this clinic, and clients are typically members of a more affluent social class who do not wish to be exposed.

There are a few more places for drug addiction treatment in Serbia settled in monasteries. The treatment of drug addiction is based on spiritual needs of injecting drug users, religion ceremonies and work therapy.

#### 4.4 The role of Non Governmental Organizations

In the field of HIV/AIDS, there are several active NGOs. These agencies are on different levels of organizational development and cooperation with officials. NGOs in Serbia are perceived to be implementing small and non-systematic projects as a means to reach clients in the field. Views and recommendations of NGOs in decision and policymaking are often neglected, even though they have many more capacities and resources than government institutions. Changing this perception of NGOs is one of the challenges. The beginning of these changes has been marked by more frequent cooperation by GO employees and NGO staff, initialized by GO employees. NGO activists in the field of HIV/AIDS are working with different aspects of prevention and different target groups. Staff of these organizations are experienced and educated for work in the field of HIV/AIDS prevention.

• The HIV/AIDS section of IAN is active in development of voluntary counselling and testing as a tool in fighting HIV according to standards of UNAIDS and WHO, in conjunction with the Institute for Student's Health in Belgrade

• Yugoslav association against AIDS (JAZAS) is active in HIV/AIDS prevention through education and outreach work with vulnerable populations, mostly sex workers

• Youth of JAZAS are active in HIV/AIDS prevention through information and education, especially through peer education programs

• 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

• VEZA is implementing a harm reduction program for intravenous drug users, including voluntary counselling and HIV testing for its beneficiaries. Other NGOs that also carry out the harm reduction program are association PREVENT from Novi Sad and civil association PUTOKAZ from Niš

• Out-reach HIV prevention activities (education and information) among MSM population are carried out by NGO SPY (Safe Pulse of Youth) with a cooperation of the public health institutions

• HPVPI Network (HIV prevention among Vulnerable Populations Initiative) is active in the field of solving the problems related to the health and human rights of vulnerable groups

• Centre E8 is an NGO that gathers young people who work mostly on HIV prevention through education about HIV and STIs, destigmatization campaigns, campaigns for the rights of PLHIV, and promotion of the use of condoms and healthy life styles

• The Roma Children Centre is an organization dedicated to working for the education of Roma children. They work directly with Roma in their settlements providing group education on HIV and AIDS and sensitization for HIV testing • Anti trafficking Centre is a citizens' association with a mission of promoting universal human rights in Serbia and in the region. As a part prevention and education programme they work on HIV prevention through education about HIV and AIDS.

• The Red Cross of Serbia is permanently working in different ways on HIV prevention, especially among youth

• A network from Vojvodina gathers more than 20 organizations, both government and non government, in the field of HIV/AIDS in the territory of Vojvodina

Cooperation and connection between government and non-government sectors isn't adequate at the national level. As mentioned above, NGOs are often not recognized as equal participants in decision making, although they give a considerable contribution in the field of HIV/AIDS prevention, especially among the younger generation and particularly vulnerable groups. Although the National Strategy for HIV recognizes the importance of NGO contributions, it does not define clearly the element of cooperation.

#### 4.5 International Organizations in fighting against HIV in Serbia

Many international organisations redefined their programs to meet the challenges of the epidemic in Serbia. International organizations' activities in this field have intensified after the UN Thematic group for HIV/AIDS was established in Serbia and Montenegro in 2001. UN agencies (UNDP, UNICEF, UNHCR, WHO, IFRC, IOM, WB) took part in establishing it and take part in its work; the main aims of their activities refer to establishing coordinative mechanisms and joint actions with the government in the field of control of HIV and AIDS in the country and support in establishing effective responses of the state. The goal of the UN Thematic Group on HIV/AIDS is to contribute in complementarities with the individual agencies' response to the design, set-up and the coordination of a sustainable and affordable national/republican response to the HIV/AIDS challenges. More on UNTG specific objectives in Appendix 4.

Some agencies have their HIV/AIDS activities fostered in the UNAIDS plan of action and some will develop activities in coordination with their own plan of actions All agencies operate according to their mandate.

The Global Fund program has an important role in HIV prevention; it helped in the development of the National strategy and also made it possible for a large number of activities to be carried out. The role of Global Fund is very important because the support is directly oriented to the National bodies, and it improves the collaboration between all sectors in the field. The most important improvements in HIV field in Serbia have been made by GF support.

Other important projects are: The HIV Prevention among Vulnerable Populations Initiative (HPVPI), which represents a partnership of United Nation Development Program (UNDP), Open Society Institute from New York (OSI) and Imperial College from London (IC), which was founded with the help of the Department for International Development (DFID). The project aimed to prevent HIV among vulnerable groups such as SW, IDU, MSM and Roma.

Canadian International Development Agency (CIDA) is Canada's lead agency for development assistance. CIDA supports HIV projects, especially preventive programs and programs for advocacy and lobbying in the area of HIV.

#### 4.6 Human and financial resources

Since 2001, the costs of treatment for PLHIV, with a doctor's prescription, are covered by the Republic fund. The entire HAART treatment is covered from state funds (USD 3.6 million in 2005, Republic Fund for Health Insurance<sup>20</sup>). But not all the medicines are available free of charge. The medicines that are paid completely by the fund are on the positive list of medicines, which is composed and revised by the Ministry of Health. Those that are not on the positive list are available with the participation, when the patient needs to pay a certain sum of the expenses. The current system of health care is functioning in financial conditions that are not satisfying, which makes it difficult to satisfy health needs of the patients according to the widely proclaimed rights to health care. Consequences of such conditions are that it is even more difficult for HIV/AIDS patients to receive appropriate health protection.

All the blood units are voluntarily donated and have been routinely screened for HIV since 1987. The costs of testing are fully covered by public sources (USD 2.3 millions in 2005, Ministry of Health<sup>21</sup>).

Thanks to the support of international organizations, since 2000, the activities in controlling HIV/AIDS have been intensified. In 2002, GFATM in its first round approved a grant of USD 3.5 million over four years for implementation of the Coordinated Country Proposal titled Controlling HIV/AIDS in Serbia: "A Comprehensive Country Strategy and Emergency Plan". Also, in 2003 UK DFID provided a grant (USD 1,3 million) for a two-year funded Project "HIV Prevention among Vulnerable Populations Initiative" (HPVPI) in Serbia and Montenegro which was implemented from 2004 to 2006 by UNDP.

In 2006 the Global Fund approved, in the 6<sup>th</sup> round, 4.6 million EUR, for implementing the project "Scaling up the national HIV/AIDS response by decentralizing the delivery of key services", but the grant agreement has not been signed yet.

It is not possible at the moment show the full amount of money spent, and/or set aside for the activities in the field of HIV/AIDS, because the process of gathering information and their analysis is still in progress.

Additionally, from 2000 to 2005, the European Agency for Reconstruction (EAR) provided funds to the country in the amount of about 90 million EUR, addressing the pharmaceutical sector, health system management and health service delivery. There is no information about amount of money that was spent for HIV and AIDS but still if the money was spent for health service delivery or health system management, we can say that HIV services indirectly benefit from the EAR support.

#### 4.7 The National HIV/AIDS Strategy for fighting HIV/AIDS

National strategy was created as a framework to give direction for development, implementation, monitoring and evaluation of HIV/AIDS programs and activities within the national context. The general goal is the prevention of HIV infection and STIs, as well as support and treatment provision for PLHIV. There are four main components of the strategy. Within the framework of each component there is an action plan to define specific goals, sub goals, target groups, organizations and competent persons responsible for carrying out the measures.

The four main components of the strategy are:

<sup>&</sup>lt;sup>20</sup> http://www.rzzo.sr.gov.yu/

<sup>&</sup>lt;sup>21</sup> http://www.zdravlje.sr.gov.yu/

• HIV/AIDS prevention among the general population, young people and specially vulnerable groups ( IDU, sex workers, MSM, prisoners and soldiers);

- Treatment, care and support for PLHIV
- Support to the community in controlling HIV/AIDS

• Epidemiological supervision of HIV/AIDS, including tracking and reporting

The following activities were implemented according to the National HIV/AIDS Strategy for fighting HIV/AIDS.

4.7.1 HIV prevention

HIV prevention implies several specific goals, defined by National strategy:

• Reduction of the number of newly infected, and early detection of HIV infected persons and persons suffering from AIDS

• Maintenance of low rates of STIs, which constitute one of the key factors in spreading of HIV

• Increasing the quality and volume of health care services related to prevention

• Creation of an environment within GOs and NGOs conducive to a more efficient response to the needs of the persons living with risk

Civil society engaged in HIV/AIDS preventive activities particularly in 2003 (the first year of the GFATM grant implementation) when civil society organizations were actively working with hard to reach populations, and a couple of new NGOs were created. As a result of the first phase of the implementation of the GF supported program many operational researches were conducted, many documents and broad discussion were performed as brochures and posters, and many media campaigns had been held on different prevention topics.

4.7.2 Education of teachers, peer educators and school children

As of May 2005 around 250,000 young people received peer-education in and out of school settings. Also, 535 schoolteachers were included in the HIV/AIDS special training on how to transfer the newly gained knowledge to their students (50% of schools have at least one educated teacher).

A qualitative and quantitative survey among 635 young people from 4 rural settlements and Belgrade as comparative urban settlement about HIV/AIDS knowledge, behaviour and attitudes on condom promotion and use demonstrated that the respondents from both settlements had different critical but insufficiently active attitudes on many issues. 37% of 74 respondents who answered on the question state that he/she used a condom in the last month and 55% thought that the campaign of promotion of condom use would have an influence on the fight against HIV/AIDS (Idea plus DDB, December 2003). Based on data given by PR of GFA grant (Economic Institute) a total of 800,000 condoms were distributed.

4.7.3 Education of healthcare personnel

In November 2003 Republican IPH conducted the KAP study on HIV/AIDS among 1694 healthcare workers in 7 districts and the results showed unexpectedly low levels of knowledge and risk perception in everyday activities and a high level of

discriminatory attitudes towards HIV positive persons. A direct activity based on this study in a GF granted Programme was the education of healthcare personnel on epidemiology, diagnosis, management, care and support of PLHIV, universal precaution measures in healthcare settings, HIV vulnerability and the importance of implementation of different preventive activities. As of the end of 2005, a total of 1028 healthcare workers were educated through 18 two-day seminars in 14 districts.

### 4.7.4 Reduction in mother-to-child transmission

Special attention was paid to the prevention of mother-to-child HIV transmission. Through the end of 2004, pregnant women were tested for HIV in the first trimester of a wanted pregnancy by epidemiological indications. The Global Fund supported HIV/AIDS Programme allowed the implementation of the routinely voluntary counselling and HIV testing of pregnant women based on an "opt-out strategy" in 5 districts (in 15 of the biggest Primary healthcare centres). As a result, the number of tested pregnant women is rising from 2003. A total of 500 healthcare professionals were educated on topics regarding implementation of the «opt-out strategy» on 13 seminars and 3 VCT trainings.<sup>22</sup>

4.7.5 Care and support to the people living with HIV and AIDS

Within the National Strategy there are several specific goals on care and support:

• Promotion of the health condition and quality of life for PLHIV;

• Creating an environment conducive to timely identification of the newly infected and newly diseased with the aim of providing efficient treatment;

• Provision of continuous health care at all levels;

• Provision of an environment conducive of timely laboratory testing of the persons with HIV/AIDS with the aim of having ART successfully implemented

In the existing health care system PLHIV receive medical services but their social and health needs are not addressed in a comprehensive manner. All these services are provided at the central level while there is no possibility to provide medical services in the community where the patients live and work. Home care and treatment services are not provided in accordance with the needs of the PLHIV. Moreover, palliative care is not organized. In addition to the health needs strictly related to HIV/AIDS, according to current legal regulations and current health care system resources, PLHIV may obtain health care services in the same way as all other people. However, they refrain from obtaining medical services because of the health personnel's potentially discriminating attitude towards them. Even though the Republic Health Insurance Fund have included the medicines for treating AIDS in the list of the medicines subsidized by the Fund, financial resources for procurement of the components necessary for effective implementation of HAART protocol are still lacking.

Also, simultaneously with making effort to improve the conditions for treating the persons suffering from this disease, it is necessary to initiate activities focused on lowering the price of the medicines for HAART, taking into account the fact that their price in our country is among the highest in the region.

<sup>&</sup>lt;sup>22</sup> Republican AIDS Commission, Ministry of Health, Institute of Public of Serbia "Dr Milan Jovanovic Batut", Republic of Serbia: Report 2003-2005. Belgrade

In general, a holistic approach is not recognized as the key principle in providing treatment and care. Therefore there are no solutions for referral in our health system. Although many changes have been made in treatment and care of PLHIV in Serbia, development of isolated components of the care continuum is limited by a lack of progress in other components.

As for the role of the society in the fight against HIV/AIDS and support to PLHIV, National strategy determines specific goals:

• Creating an environment free of discrimination and stigma;

• Raising the level of social awareness about the interconnection between the social determinants of health and HIV/AIDS;

• Support by the government authorities and organizations through establishment of legal framework and implementation of the measures needed;

• Inclusion of the institutions outside the health care system (education, social care, etc.) and NGOs in the equality partnership.

In practice, however, these goals are hard to achieve, and a holistic approach to achieving these goals is still missing. Since the beginning of the epidemic many campaigns were carried out, with an aim to raise awareness about the problems PLHIV face in Serbia, and to decrease the level of stigma and discrimination. Several NGOs in the field of HIV/AIDS are leading in promoting different activities, like conducting an active media campaign, producing video-clips and brochures, condom distribution, organizing tribune, lectures and other cultural events. World AIDS day and Candlelight Memorial Day are main events in which NGOs and GOs focus their activities and promote them throughout the country. Cooperation with Ministry of Health is often obtained, as support of international organizations. More and more organizations drive public attention to the problems of the people living with HIV/AIDS not only on these events, but throughout the year.

Still, there is a need to put more effort in connecting GOs and NGOs, including other stakeholders within community, and for more active role of PLHIV in advocacy and lobbying for their rights and the in process of destigmatisation.

# 4.8 The role of people living with HIV and AIDS in fighting against HIV – perpetual cycle

One of the leading principles of the HIV/AIDS strategy is to give PLHIV crucial part in the policy development and planning the program of support and protection<sup>23</sup> (See leading principles of National Strategy for HIV in Appendix 3). In that direction it is important to support activities of PLHIV and to help them unite.

Still, after decades of fighting HIV in Serbia, community response to the HIV epidemic is still lacking in meaningful participation of people living with HIV. PLHIV are not supported to take a bigger role in fighting HIV by RAC. Even when there are a few HIV positive members in RAC, their suggestions are usually neglected. The possible reason is that RAC is pushed by GF and other international agencies to include PLHIV in fighting against HIV but still there is no understanding why they need to be included and support in how to do that.

One of the main conclusions of the UNDP study<sup>24</sup> is that there is a perpetual cycle in Serbia, in which stigma and discrimination are prevailing and PLHIV have

<sup>&</sup>lt;sup>23</sup> Ministry of Health of Republic of Serbia: National Strategy for the Fight against HIV/AIDS, 2005.

<sup>&</sup>lt;sup>24</sup> Bernejs, S. , Rouds T., Prodanovic, A.: HIV treatment access, delivery and uncertainty: a qualitative study in Serbia and Montenegro, January 2007, UNDP Report, Belgrade.

problems in treatment access, access to the other health services, face 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. The UNDP study found that the interlocking factors of fragile treatment access and the highly stigmatized environment are key obstacles to HIV community action and participation of PLHIV. This context constrains both PLHIV's capacity and their opportunity to effectively respond to the situations they face.

Also, study found that some PLHIV were disillusioned with NGOs, as through experience or hearsay they had become sceptical about NGO sustainability. 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. On the other hand, among those who did participate in community action through NGOs and self support groups, there were a number who described them as having a very positive influence in their lives. NGOs also do not understand the importance of PLHIV inclusion in programme development and implementation. They usually prepare the projects and implement them without consultation with PLHIV.

Because of great stigma and discrimination toward PLHIV in Serbia, they are afraid to disclose their HIV status. Their involvement in campaigns, advocacy and lobbying action for their rights is very poor due to the fact that they do not want to be exposed.

Misunderstanding of the key role that PLHIV could play in fighting HIV leads to the situation that associations of PLHIV are underdeveloped. Several associations were established and then closed without implementation of planned activities and usually without any funds received. Recently, two new associations were registered (Q club, AID+), but they still lack proper funding, knowledge and skills. Because of that they try to find ways to cooperate with other NGOs active in the HIV/AIDS field (IAN, Youth of Jazas) in order to get support. IAN helped in the founding of NGO AID+ with its experience in service development and ongoing capacity building through free of charge computer courses and English lessons. AID+ holds its meeting once a week at IAN premises, based on voluntary user access, organizational autonomy, self-help elements and other activities initiated and carried out by PLHIV. Also, IAN helped Q Club in developing educational/promoting material and supported them financially. Youth of Jazas supported Q Club activities, also.

The general idea of association AID+ is to recognize the problems of PLHIV and how to include them, directly and indirectly, into the ways of solving their own problems, as well as to prepare them through education and trainings for the challenges of active involvement. They advocate for improvement of quality of life for PLHIV, decreasing stigma, discrimination and marginalization, and increasing human rights protection. Also, they address treatment delivery problems.

The support that PLHIV associations are getting from NGOs is important but since NGOs are project-driven organisations, this support is going to be time limited.

PLHIV and GIP - PLHIV, mainly members of these two organisations, are involved in Expert centre activities in different ways: they act as participants and trainers at trainings, as well as research subjects in focus groups. In the future, cooperation with them could be wider, in terms of involving them in other activities of the Centre, such as publications and advocacy.

#### 4.9 Legal framework

Ever since HIV/AIDS become known in the territory of former SFRY the relevant government authorities and institutions have been working on adoption of the appropriate legal acts representing the organized response to HIV/AIDS. The most important among those acts that were passed in the period between 1986 and today are the following:

• "Decision about the Measures for Protection of the Population against the Immunodeficiency Syndrome"

• Law on Amendments and Additions to the Law on Protection against Infectious Diseases Affecting the Entire Country

• Law on Protection of Population against Infectious Diseases

• "Decree on the Health Care of the Population against Infectious Diseases"

- "Health Care Policy of Serbia"
- Poverty Reduction Strategy
- National Action Plan for Children of the Republic of Serbia

There are no adequate laws, however, which are specialized for PLHIV, and other groups vulnerable to HIV. Therefore, there is no adequate legislation provided. By the Criminal Law of Serbia, article 387, any racial or other discrimination based on personal quality is forbidden and will be punished with jail sentence from 6 months to 5 years. This is general article used for all kinds of discrimination. There are no special articles of Criminal Law protecting PLHIV. There is still no single case of discrimination towards PLHIV in courts of Serbia.

In 2007, two Laws are expected to come into Parliament procedure: Discrimination Law and Law on Rights of PLHIV.

# 5. Mental Health Structure and Policies

#### 5.1 Organizational framework

The health system in Serbia is organized by territories. Each district (roughly about 250,000 inhabitants) has the Community Health Centre consisting of the General Hospital and the Health Centre. Health Centres are organized as institutions of primary health care with ambulant services where general practitioners are holders of the practice. There are a total number of 177 health centres in Serbia. The General Hospital provides hospital and ambulatory treatment and it is organized as the institution of secondary health care with specialists in different fields of medicine. Every General Hospital has a psychiatric service, including a psychiatric department with 20-40 beds. Psychiatric services, besides hospital departments, include specialist's services for ambulatory patients, and, in some towns, a Day Care Hospital too. Special Psychiatric Hospitals in Serbia are also on the secondary health care level. They are not part of the regional institutions. There are five of them and they are admitting the patients from all over the country. University Centres are on the tertiary health care level and they include Clinics and Institutes which include Clinics and Institutes for psychiatry.

The first contact for a person with mental health problems is a GP in the Health Centre, who can, if necessary, refer the patient to psychiatrists who work in the psychiatric service in the General Hospital. This service, considering the needs of the patient, provides hospital and non-hospital treatment. If they estimate that "long term hospitalization" is necessary, psychiatrists from regional General Hospitals send patients to one of five Special Psychiatric Hospitals, which in that case, according to the existing organizational scheme, represent an asylum for those patients.

Regardless of the relatively good regional distribution of psychiatric services, closing of the asylums is not possible, because there is no protected accommodation for people with mental disorders. The only Centre for mental health that provides community-based services (and in the patient apartments) is in the Niš municipality Mediana.

#### 5.2 Human and financial resources

The Mental health care system in Serbia is generally characterized by relatively good distribution of institutions and a fairly large number of professionals.

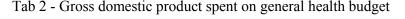
There are<sup>25</sup> 46 inpatient psychiatric institutions in Serbia (specialized hospitals, psychiatric clinics, psychiatric institutes, clinics for child and adolescent psychiatry and psychiatric departments in general hospitals). Further more, there are 71 outpatient services in the municipal health centres .The entire mental health sector has the total of 6,427 beds at its disposal, approximately 50% of which are beds in large psychiatric hospitals.

The condition of human resources is as follows: per population of 100,000, there are 2.7 psychiatrists, 9.93 neuropsychiatrists (earlier version of this specialization, now separated in psychiatrist and neurologist), 2.3 psychologists, 1.57 social workers and 21.55 nurses/technicians. The total number of psychiatrists in the country is 947<sup>26</sup>.

<sup>&</sup>lt;sup>25</sup> February 2007

<sup>&</sup>lt;sup>26</sup> National Committee for Mental Health (2006): *National Mental Health Policy and Action Plan,* Ministry of Health, Republic of Serbia

In spite of deterioration of services in the past decade, the personnel are motivated for continuous education. It is important to emphasize some of the weak points of the mental health care system in Serbia, related to the topic. They are: insufficiently developed cooperation between different sectors, and between governmental and non-governmental organizations dealing with mental health and undertaking psychosocial projects; insufficient funds from the general health budget of the state allocated to the mental health services; and decisions regarding mental health fund are most often made by people in no way connected to mental health care. There is no separate mental health budget, so the following graph represents GDP on the general health budget. The share of expenditures on health care in the social product of Serbia (excluding Kosovo and Metohija) varied over the last five years from 12.2% in 1996 to 7.4% in 2001.





#### 5.3 Activities on Mental Health

Prior to 2003 there was no mention of reforms of mental health system or a system of health care in general. Ministry of Health established a National Committee for Mental Health (NCMH) in January 2003, with the mandate to organize reforms in the country. This body consists of ten psychiatrists from different parts of the country; no other professionals are included. NCMH is also responsible for implementation of the South East Europe Mental Health Project "Enhancing social cohesion through Strengthening Community Mental Health Services in South Eastern Europe" in Serbia. The overall aim of the Project was initiation of mental health reforms in eight countries of the Stability Pact. Tasks were: 1. assessment of the overall situation in the mental health system; 2. producing the mental health policy and action plan; 3. writing a new legislation on protection of rights of the mentally ill; 4. endorsement of these documents within the government and in a parliament; and 5. establishment of the pilot CMHC. Of these tasks, NCMH has produced the National Mental Health Policy and Action Plan which was sent to the Ministry of Health, and has just been adopted by the Government. A Law regarding protection of individuals with mental health disorders has been drafted and sent to the Ministry, but is not yet submitted to Parliament for adoption. A pilot CMHC has been established in municipality Mediana in Niš.

#### 5.4 Legal framework

There is no particular law in Serbia at this moment regarding the rights of persons with mental disorders. The National Committee for Mental Health has prepared a draft of the law and it waits for regular Assembly procedure. A special paragraph in existing legislation regarding Health Care Law<sup>27</sup> protects the rights of all patients (not particularly psychiatric). Paragraphs of this law protect rights on information, free choice, privacy and confidentiality of information, self-decision making and consent, availability of medical documentation, confidentiality of data, objection, damage compensation and rights of the patient under the medical examination.

Existing law does not regulate rights of patients with mental disorders (inability to comprehend the information, role of legal guardian and attorney of law...), neither the specific rights regarding the ways and conditions of treatment of persons with mental disorders.

The same law has a paragraph regarding the obligation of referring patients to a psychiatric institution (paragraph 44). The main criterion for involuntary hospitalisation and obligatory referring to the psychiatric institution is the estimation of the doctor that the patient, because of the nature of the illness, could endanger his/her life, or some other person's life or property. In that case, the general practice doctor or psychiatrist refers the patient (they can demand police assistance) to the psychiatric institution and the doctor in that institution can admit the patient in hospital without consent. The day after admission, a team of the doctors in hospital decides if the patient needs to stay in the hospital. After the admission of patient into a psychiatric hospital without consent, the hospital is obligated to inform a competent court of law within 48 hours.

<sup>&</sup>lt;sup>27</sup> http://www.zdravlje.sr.gov.yu

# 7. Mental Health Care for People Living With HIV

#### 7.1 Psychological support service at the HIV Clinic

The only service specialized in dealing with mental health problems of PLHIV is the psychologist's office at the HIV Clinic at The Clinic for Infectious and Tropical Diseases in Belgrade. There is just one psychologist working at the Clinic, who is a crucial person for mental health problems of PLHIV. There is no psychiatrist working at the Clinic. This service is described in more detail in Appendix 5.

Before we discuss the services for mental health problems of PLHIV, it is important to note that the HIV Clinic and its staff are perceived by PLHIV as the only place where they feel comfortable to go for any kind of help, even help unrelated to HIV. The patients have faith in the competence and expertise of all three doctors and the psychologist. As well as their technical expertise, for many participants the staffs is a significant support and plays a key role in the management of their conditions, both medical and psychological:

"People from the Clinic are of the greatest importance for problems of PLHA .For me, it was especially valuable help of psychologist at the Clinic, who helped me very much, giving me support and useful information". male, 45, Belgrade

The first contact clients have with the HIV clinic is when they need to do confirmatory HIV testing. If the confirmatory test is positive, the doctors give the result to the clients. Clients are then sometimes referred to the psychologist, but at other times they are just informed briefly about results and possibilities of further medical assistance, depending on the work load of the doctors. The level of support needed when receiving a final HIV positive diagnosis is not available. One of the consequences of this is the fact that many people in this situation of confusion decide to stop coming to the clinic, or develop other forms of maladaptive behaviour.

All decisions and referrals about health problems, including mental health problems of PLHIV, are made by specialists for HIV. There is no clear procedure for referring PLHIV to a psychologist. Referral from a specialist to a psychologist is based on her/his judgment and understanding of the nature and seriousness of the mental health problems of particular patient. In most cases, the specialist who treats the HIV gives prescriptions for medications relieving certain mental problems that are related to AIDS (those are usually anti-depressives and anxiolytics). Both PLHIV and the psychologist recognise differences between the three specialists for HIV in their willingness and readiness to initiate a conversation about mental health problems of PLHIV.

PLHIV who make the first contact and relationship with the psychologist can continue to come for psychological support and counselling without further referral from the specialist.

In cases of serious mental health problems (acute psychosis or neurological problems), the psychologist can not refer the patient - the specialists refer PLHIV to neurologists or psychiatrists. If the person is an inpatient and she/he needs a psychiatric exam, the head of the department invites a psychiatrist consultant working on the level of Clinical Centre<sup>28</sup> who provides treatment for the inpatients. The psychologist working in the HIV/AIDS centre recognizes that collaboration with

<sup>&</sup>lt;sup>28</sup> Clinic for Infectious and Tropical Diseases is a part of the Clinical Centre of Serbia

psychiatrists is unsatisfactory because they are not fully aware of the needs of PLHIV and there are signs of stigmatization towards PLHIV. Official policies and procedures defining collaboration of the different clinics of the Clinical Centre are not put in practice and a majority of the referrals are made using personal contacts. Characteristic of the general operation in the state health system is a lack of collaboration between health institutions. This affects PLHIV even more since wages of the system allow silent discrimination. Since AIDS is a highly stigmatised disease there is very limited number of medical professionals who are available for these informal referrals.

It is obvious that collaboration between specialists and the psychologist at the Clinic is crucial for the mental health care of PLHIV. On one hand, the psychologist has enough power to negotiate with the medical doctors from the Clinic about the importance of mental health care for PLHIV but, on the other hand, she does not have enough time to see all the PLHIV that need her support. A very important role of the psychologist in providing information to PLHIV concerning practical issues (first of all paper work needed to obtain ongoing medical care, more information about transmission of HIV) is therefore undermined.

The psychologist from the Clinic thus emphasised the quality of the cooperation between the VCT centre operated by ISH and IAN (see chapter on VCT), and the need for a simple referral procedure that lessens anxiety for the clients and helps her with time management. She also emphasised the importance of collaboration with VCT counsellors for her personally:

"I felt lonely for years. Now I feel more supported and more comfortable. I have people who understand me and my work".

PLHIV who use the service of the psychologist at the HIV/AIDS centre are pleased with the psychological treatment itself:

"You have no idea how much it means to me to be able to see in the hallway for minute or two, after all these years." male, 45, Belgrade

PLHIV are satisfied with quality of care and the commitment of the psychologist who they feel does her best with the resources available, and speaks of her frustration that she is not able to provide more for PLHIV. Even though the patients are generally pleased with the quality of the service they do feel that the single psychologist who works there is "torn" between limited time and the great needs of the patients.

"It is great for me to talk to her because she understands me, but I do not like coming to see her all the time because she has a lot of other patients as well." male, 22, Belgrade

The results of a focus group discussion organized by Expert Centre for this research about their usage of services demonstrated that the most important issues regarding living with HIV are: stigma and discrimination experienced among friends and within health care system, and problems they face in intimate relationships. Participants also focused on risks of disclosure and difficulties in finding a partner who will accept their HIV status. Participants reported low usage of existing capacities of health care services, especially services for mental health. The main reasons they reported are insufficient knowledge of mental health professionals, discriminatory attitude among health care workers and the fact that services are not

user friendly. Broad consensus confirmed the importance and value of the staff at the Clinic for Infectious and Tropical disease.

A focus group discussion with professionals revealed the need for improvement of health service delivery for PLHIV, concentrating on the following issues: need for further education on stigma and discrimination issues with health care workers and improvement of knowledge and communication between services and professionals active in the area of mental health and HIV/AIDS. Also, all participants agreed on a lack of institutional importance of HIV/AIDS and therefore restricted and insufficient human and financial resources. There was broad discussion about the advantages of opening a special Centre for PLHIV. While some felt that such a centre would provide adequate help, other thought that it would only increase stigma and lead to isolation of PLHIV. Therefore, they suggested work be done with service providers on decreasing stigma and improving collaboration between institutions.

#### 7.2 The role of VCT Centres in addressing the mental health needs of PLHIV

#### Voluntary HIV Counselling and Testing

is the process by which an individual undergoes counselling enabling him or her to make an informed choice about being tested for HIV.

VCT has a vital role to play within a comprehensive range of measures for HIV/AIDS prevention and support, and should be encouraged. The potential benefits of testing and counselling for the individual include improved health status through good nutritional advice and earlier access to care and treatment/prevention for HIV related illness; emotional support; better ability to cope with HIV related anxiety; awareness of safer options for reproduction and infant feeding; and motivation to initiate or maintain safer sexual and drug related behaviours.

#### (Voluntary Counselling and Testing – Technical Update, UNAIDS, May 2000)

VCT is an important entry-point to both HIV prevention and HIV related care, and plays a large role in mental health care for PLHIV. People who test positive in VCT centres benefit from the emotional support given at the moment when they receive the HIV positive result. They also benefit from the continued counselling and support that VCT counsellors offer them.

In our community counselling is not recognised as a skill of its own right<sup>29</sup>. There are different interpretations among the decision makers and wide public related to techniques and aims of the counselling processes, but the most common is that "counselling is giving advice". Another prejudice is that only psychologists and psychiatrists can do psychological support and counselling. This misunderstanding has influenced the development of VCT in Serbia, leading to the development of vCT (emphasising the role of testing compared to counselling), as opposed to VCT<sup>30</sup>. The benefits that people who come to the VCT centres could have from HIV counselling for decreasing stress around HIV testing, HIV status, sexual orientation, disclosure of

<sup>&</sup>lt;sup>29</sup> First counselling centres in our country provided counselling related to pregnancy and main activity was medical follow up of the pregnancy. Staffs of those centres were medical doctors and nurses in their standard roles.

<sup>&</sup>lt;sup>30</sup> VCT is recognized in National Strategy for HIV as a surveillance tool due to the fact that Serbia has a lowest number of tested people per capita in Europe

HIV status and other stressful issue connected to HIV, are not recognized. The role of VCT in support to PLHIV is neglected. The government and the Ministry of Health usually support VCT development in order to finance HIV test kits. The majority of finances for education of counsellors and their support are spent by international agencies (CAFOD, UNICEF and GF).

VCT in Serbia is still underdeveloped in its ability to offer proper on going counselling and support for people who test HIV positive<sup>31</sup>. There is no standardized education for VCT counsellors, and VCT counsellors from different centres attended different education programs on pre- and post-test counselling, which do not usually include a component addressing on-going support or counselling for PLHIV. This leads to the situation in which counsellors at different VCT centres have different (very low) levels of knowledge and skills for psychosocial support.

In these centres, PLHIV are able to get support from the moment of revealing the HIV positive results to getting the person in touch with the HIV Clinic, but follow up and ongoing counselling is still lacking.

One of the most developed VCT centres that could offer good quality ongoing counselling and support is the VCT centre at the Institute for Students' Health. This centre was developed through the joint project of NGOs IAN and ISH during the last 3 years. More about VCT centre in ISH in Appendix 6.

#### 7.3 Mental health institutions addressing mental health needs of PLHIV

There is a developed system of services in Serbia to deal with mental health problems. The system consists of primary health care in the form of counselling services for mental health that is part of every health centre existing in every municipality. There are hospitals, clinics and institutes for mental health, located in the larger towns and covering greater territory. Persons who live with HIV/AIDS have access to these services as do all other citizens who go to the general practitioner for a prescription, so they can go to the clinic for infectious diseases or any other health service. Even though these services are available to everyone, persons with HIV/AIDS rarely go to these places.

In 2005, the Centre for Continuing Development (non-government organization which does not function anymore) examined the basic needs of persons living with HIV/AIDS, based on a sample of 138 people. The research did not explore problems concerning mental health issues, but it did examine how much PLHIV use the existing services. Only 2.9% of those questioned reported that they used the services of The Counselling Service for mental health at The Health Centre. By comparison, the same research showed that 21.7% of 138 questioned used the services of The Dentist Clinic at The Health Centre.

There are at few reasons for this. First of all, procedures for seeking this kind of mental health care are complicated. If somebody wants to see a psychologist or psychiatrist on the institutional level, she/he needs to have an official referral from a general practitioner. This implies that the general practitioner needs to obtain the client's personal information to fill in the referral form. For PLHIV perspective this situation means that their HIV status is publicly displayed because it means asking for a referral to a mental health professional because of problems related to HIV status. They are also afraid of being exposed to stigma and discrimination when addressing the institution or professional they have been referred to.

Specialists who work at these services are not trained for work with PLHIV who have mental health issues (the kind of problems associated with the disease, HAART,

<sup>&</sup>lt;sup>31</sup> There are two VCT centres in Belgrade and 12 more in the provinces of Serbia

social pressure, interaction between the usual drugs prescribed by the psychiatrist and HAART, and so on) and they sometimes do not prescribe the proper medication.

PLHIV reported facing significant problems accessing health care in general and they feel anxious about seeking care and treatment outside of the HIV Clinic. PLHIV who participated in this research also agreed about the existence of discriminatory attitudes of health care workers. They emphasize the role of general practitioners and the importance of working on education and decreasing stigmatization.

The PLHIV reported that the reactions they receive from doctors are usually negative. They were not refused treatment for mental health problems, but they were not satisfied with the treatment quality. One participant reports his experiences with the Institute for Mental Health:

"Nobody talked to me or looked at me, they just gave me the drugs, and they don't have the time. Nobody asked me about my feelings and emotions. I do not go there anymore." male, 48, Belgrade

Since the psychiatrists are not always aware of the client's HIV status, these reactions of staff at the Institute for mental health are common reactions not connected only with HIV status of patients but are the generally poor practices common in these institutions.

There is one more reason which contributes to better understanding of PLHIV mental health seeking behaviour. The impression of the moderator of the focus group discussion is that they deny the mental health problems they have, therefore rarely asking for help. PLHIV reported that mental health care is important for them but majority of them do not recognize their need for mental health care.

»I think that psychological help is very important for PLHA, but they do not recognize the need for such kind of help» male, 50, Belgrade

One of the UNDP study's conclusions<sup>32</sup>, based on the learned experience, is that those persons frequently do not recognize their need for professional help concerning mental health issues, as they do not identify their issues as mental health related. The experiences of establishing a support counselling centre for PLHIV indicated the same conclusion. During the UNDP's study, the interviewers learned from the participants that they need psychological support and counselling from professionals. The interviewers contacted IAN in order to help PLHIV have these services available. However, although all of the participants were informed about the new psychological service at IAN providing free of charge psychological support, only three of them utilized the service.

Since the importance of mental health issues, as well as mental health care, is not recognized generally as important for good quality of life, it is easy to understand why PLHIV do not recognize their mental health needs. Poverty and poor economic and social situations affect care for health generally, and especially impact participants' attention to mental health care.

#### 7.4 Mental health care for PLHIV injecting drugs

<sup>&</sup>lt;sup>32</sup> Bernejs, S., Rouds T., Prodanovic, and A.: *HIV treatment access, delivery and uncertainty: a qualitative study in Serbia and Montenegro*, January 2007, UNDP Report, Belgrade

Concerning other services that work with PLHIV, there is also the Institute for Addiction Related Diseases, which conducts detoxification programs as well as substitution therapy. At this moment, out of 120 patients receiving substitution therapy, 75 of them are HIV positive. The Institute for Addiction Related Diseases employs three neuropsychiatrists, four psychiatrists and two psychologists who offer mental health counselling to PLHIV that receive treatment at the institute. However, employees are not educated on the mental health issues of PLHIV and how to treat them; these patients are instructed by doctors to come to them. In addition to the insufficient capacity of the existing services for mental problems of PLHIV, and the lack of a standard level of training for professionals in other services, another weakness of the existing system is isolation and lack of communication between services.

Therefore the doctors are forced to decide whether the particular patient's priority is to be treated for HIV/AIDS, substance abuse, or mental health problems, and to direct him or her to a particular institution where he or she will not be treated for other problems. Due to the serious situation in relation to AIDS as well as the low degree of knowledge among other professionals concerning HIV, the patients with multiple problems are usually treated at the HIV Clinic at the Institute for Infectious and Diseases, which puts additional pressure on the limited resources at the clinic. Concerning this issue, other professionals suggest additional training in the connection between mental health problems and AIDS as well as the improvement in communication between services so that the patients can get help from specialists who are competent in the specific field.

# 7.5 Non governmental organizations and self - help groups for mental health of persons living with HIV/AIDS

Before the foundation of the Expert Centre for HIV/AIDS and Mental Health, there were no non-governmental organizations in Serbia specialized in addressing the mental health problems of PLHIV.

Because NGOs active in the field of HIV/AIDS prevention and treatment are already described in chapter 4.5 of this report, the following paragraphs will describe in more detail only the activities of those organizations that are related both to the fields of mental health and HIV/AIDS.

Philanthropy is the charitable fund of the Serbian Orthodox Church. Philanthropy's mission is based on Christian values, and the agency adheres to principles and high standards set up by leading international humanitarian aid agencies. The basic principle in the work of Philanthropy is the respect of human rights related to dignified livelihood. This is reflected in assistance to all those in need. The provision of psychosocial, palliative care to PLHIV is a primary activity of this organization. This care consists of visits to the beneficiaries at the HIV Clinic at the Institute, individual home visits, group meetings, and social events. During specific periods of time, Philanthropy also organizes psychological support for PLHIV, together with the psychologist from the HIV Clinic. In this way they also offer support to the psychologist at the HIV/AIDS Centre. The patients expressed positive opinions of this program because there aren't many people they can talk to about their problems and they feel generally isolated. Besides providing psychosocial support, an additional goal of this project is to raise awareness about HIV/AIDS within Serbian Orthodox Church structures and society in general.

Since 2003, the International Aid Network (IAN) has had an HIV/AIDS section which employs 6 psychologists and one doctor. IAN cooperates with two of the

biggest VCT Centres in Belgrade (Public Institute for Public Health and The Institute for Students' Health) where trained psychologists work together with the medical staff. The main contribution of IAN is introducing the regular supervision of counsellors and continuing professional education, as well as means that are necessary for insuring that quality work is done at the VCT centres.

The Youth of JAZAS is a nongovernmental humanitarian organization founded 1994 with its main aim to fight against HIV/AIDS through prevention and to provide support to the people living with HIV/AIDS. A program of support to people living with HIV/AIDS implies provision of psycho-social support to PLHIV, and material support to the AIDS Centre at the Clinic for Infectious Diseases in Belgrade. Part of these initiatives is also AIDS Info and SOS Line. It not only addresses HIV/AIDS and sexual and reproductive rights issues from a prevention aspect but also from a perspective of PLHIV. Through this line this organization offers assistance, advice and support to PLHIV.

Echo-The Red Line Centre: This project aims to improve the quality of life of all PLHIV, STI and hepatitis patients in Vojvodina; to strengthen the prevention of HIV/AIDS, other STIs and hepatitis's in Vojvodina; and to contribute to efforts on creating general public information about epidemiological situation in Vojvodina. Main activities of this centre are focused on offering practical, psychological, medical, legal and material assistance and support to people living with HIV/AIDS, STIs and hepatitis. This is achieved by means of the helpline, e-mail, in-person at the Red Line contact centre, through education and information on relevant topics, as well as by empowerment of people living with HIV/AIDS and fighting prejudice.

The Centre for Positive Social Changes, Novi Sad, is nongovernmental organization with the aim of improving quality of life of PLHIV in all areas of social life and activities. Positive gathers PLHIV in order to strengthen their capacities and support them. Also, they organize self help groups on a regular basis.

AID + More Than Aid and Q Club advocate for improvement of quality of life of PLHIV, giving PLHIV different kinds of help including legal, psychological, and access to information.

In the context of other organizations there are counselling services for PLHIV but they are not specialized in dealing with the mental health issues and do not have the ability to give continuing professional help to persons living with HIV/AIDS with mental health problems.

### 8. Conclusions

#### 8.1 Weaknesses

• The healthcare system in Serbia is deteriorated, outdated and weak, as consequence of years of wars, isolation and economic sanctions.

• Issue of HIV is neglected in Serbia. Although it is a country with a low prevalence of HIV infection, the epidemiological situation can be characterized as insecure with the tendency of becoming worse, taking in to account the poor social and economic conditions and risk behaviour.

• Mental health is also neglected. Poverty, wars and economical transition have made our society vulnerable for increasing mental health problems. In addition, comparing to total health care budget, funding for mental health is insufficient.

• There is no comprehensive National Strategy for HIV and mental health. The connection between mental health and HIV as an important problem which needs to be addressed is not recognized. This leads to the situation in which services for mental health and HIV are outside of the scope of policy makers.

• HIV treatment is available but the fragility of access and delivery remains an ongoing concern. As with many other issues formal availability of HAART is not put to practice and PLHIV are often exhausted through efforts to get needed medications

• There is only one psychologist working specifically with mental health problems of PLHIV at the HIV Clinic at the Institute for Infectious Diseases in Belgrade. There are also couple of initiatives among non-governmental organizations to give help to PLHIV with mental health mental problems, but this kind of help is only available to a small number of people and is of questionable viability because it is project based and supported mostly by foreign donors.

• Although most PLHIV are from Belgrade and seek medical care at HIV Clinic in Belgrade, those who live in provinces have absolutely no help available for mental health problems related of PLHIV. Furthermore, although planned, treatment of PLHIV is not yet decentralized.

• VCT is undeveloped and the role of VCT centres in ongoing psychosocial support for PLHIV is not recognized. VCT centre counsellors are not specially trained for giving psychosocial support and dealing with mental health problems of PLHIV and therefore don't have the needed sensibility to recognize and address the mental heath needs of PLHIV. Although initially trained, counsellors do not have supervision and continuous professional education.

• Cooperation between all HIV/AIDS organisations and the mental health structure is lacking. Networking and referral is a weak point in Serbian health care system in whole. This presents a great threat to PLHIV who are in need of help by different kind of professionals.

• Beneficiaries' involvement is not priority as with any kind of service in Serbia. This is particularly damaging for PLHIV because it is a chronic disease and they are often patronised and their potential for formulating their needs and proposing changes is under utilized.

• The viability of the reforms in mental health issues and innovation in the HIV/AIDS services are at risk because of the poor economic situation in the country. Most of the changes are financed with donations from abroad, which are not viable sources of financing. Situations of overburdened staff, insufficient

economic stimulation, and inadequate work conditions lead to increased burnout. In addition, there is a low level of consciousness about the frequency and importance of treating mental health problems in the general population, and HIV treatment professionals who work with mental health issues are not adequately trained for working with mental health problems of people living with HIV/AIDS.

#### 8.2 Strengths

• Relatively good coverage with institutions that deal with mental health and that could be the foundation for quality mental healthcare provision to PLHIV.

• Well trained staff active in the field of mental health as well as in the field of HIV/AIDS (specialist for Infectious diseases)

• Good coverage of the country with VCT centres that could be the starting point for seeking professional help in dealing with mental health problems of the persons living with HIV/AIDS.

• Formally existing referral system, which is a foundation for comprehensive support, and care for PLHIV.

• Existing system that guaranties health care for every citizen of Serbia, which includes HAART available free of charge, if recommended by an infectologist

• Many NGOs are active in the field of HIV/AIDS, mostly in prevention. This is a potential for networking and cooperation and a base of experience and creative approaches for addressing this issue

• Although they have just made first steps, there are PLHIV initiatives that could advocate for better services in the field of mental health of PLHIV

• IAN's involvement in the field of mental health and HIV/AIDS. Most of IAN's staff are professionals from the field of mental health and could bring great expertise in recognizing and treating mental health problems of PLHIV.

• Existence of Expert Centre for mental health and HIV/AIDS, supported by Global Initiative on Psychiatry. This is the first such initiative in Serbia and it will promote this issue.

# 9. Recommendations for Mental Health and HIV Structure Improvement

In order to respond efficiently to the situation concerning mental heath and HIV structure in Serbia, it is necessary to provide continuous activities and carry out the co-operation of all relevant participants.

#### 9.1 General Recommendations

## a) Expand the capacities of existing services for mental heath problems of PLHIV

Due to the fact that PLHIV reported commitment of the HIV Clinic staff and perceive the Clinic as a safe place where they can be assured of a kind reception, there is a great need to build capacities of the Clinic in order to address mental health needs of PLHIV. One psychologist at the HIV Clinic could not address all mental health needs of PLHIV and there is a need for employing more mental health professionals at the clinic, including a psychiatrist. Other professionals at the Clinic need to be educated on mental health issues of PLHIV so that they are able to recognize mental health problems and refer patients to professionals. These recommendations are also for the three new HIV Clinics in Novi Sad, Kragujevac and Nis. Since they are at the beginning of work, they need to be aware of importance of mental health needs of PLHIV in order to set up the Clinic in such way to be able to address mental health needs of PLHIV.

#### b) Promote the role of VCT in addressing mental health problems of PLHIV

VCT centres could play a bigger role in addressing the mental heath problems of PLHIV. It is necessary to promote this role among the VCT centres and PLHIV and to better educate VCT counsellors on mental heath problems of PLHIV. It is also necessary to give counsellors additional support through on going education and supervision.

### c) Develop the system of cooperation between GOs and NGOs addressing the mental health problems of PLHIV

A task force of representatives from NGO and GOs interested in addressing the mental health needs of PLHIV would be an appropriate starting point for improvement of the system in terms of support for PLHIV. The cooperation needs to be closer and more intensive in order to change experiences and knowledge around mental heath problems of PLHIV. This cooperation could play a key role in creating strong mechanism for advocacy and lobby actions that will be oriented to mental health and HIV decision makers.

### d) Address stigma and discrimination around mental health and HIV and promote the importance of mental health for well-being

The history of the region coupled with the significant reports of stigma and discrimination around HIV and mental health issues point to the problem of stigma and discrimination toward PLHIV. This brings to focus the urgent need for Serbia to be able to make progress on improving human rights of PLHIV and mental health patients and touch stigma and discrimination through campaigns for the general

population. PLHIV who have mental health problems need to take a part in these campaigns in order to raise awareness about their problems and isolations.

### e) Include PLHIV, their partners and family members in all actions around mental heath and HIV

PLHIV could play crucial role in improving the services for their mental health. It is not enough just to have PLHIV representatives in all bodies that decide about issues related to mental health and HIV, but those who support them also need to be more actively included in decision making process. People who are impacted by HIV (family members, partners of PLHIV, colleagues) also could bring to the decision making process the new perspective of the problems. VCT centres need to educate PLHIV and include them as counsellors or team members in daily work. The Clinic for HIV also could have PLHIV as volunteers who could be extremely helpful for inpatient PLHIV.

#### 9.2 Recommendations for GOs

#### a) Improve the communication between services and professionals active in the area of mental health and HIV/AIDS so that every patient can get treatment according to his needs

Although it formally exists, the referral system is usually very weak and based on personal contacts and relationships between professionals. This is very time consuming for professionals and stressful for patients. It is necessary to have an official and formal referral system on an institutional level, regularly evaluated and monitored by the Ministry of Health.

# b) Give the psychiatrists additional education about the interaction between mental health issues and HIV/AIDS, and adequate ways to treat the mental health problems of HIV/AIDS patients

Even though there is a relatively good system of mental health services in Serbia with sufficient capacities for prevention and treatment, it is not fully used to address mental health problems of PLHIV. The professionals in the mental health services lack sufficient knowledge and hold discriminatory attitudes about HIV. Ongoing education could give them opportunity to learn more and to change the attitudes.

#### 9.3 Recommendations for NGOs

#### a) It is necessary to act on behalf on non-government organizations in the field of mental health issues so that their innovative programs have constant sources of financing

PLHIV perceive NGOs as unsustainable organizations oriented only to the shortterm, and they therefore do not expect that NGOs could support them continuously. From the other side, PLHIV associations are usually supported by NGOs. NGOs should be more active in addressing problems of PLHIV, in order to achieve sustainable action that could improve PLHIV perception of NGOs.

#### b) Support associations of PLHIV and include PLHIV in the programs

Cooperation with PLHIV associations could be mutually beneficial: NGOs could improve the quality of their services from direct contact with PLHIV lived experience and needs, and NGOs can help PLHIV associations in building their capacities. Together they can be very influential in addressing PLHIV needs and advocacy for improving their position in society.

#### 9.4 Recommendations for GIP

# a) Educate the professionals working in primary health care about the connection between mental health and HIV/AIDS and how to recognize the mental health problems

There is a strong need to educate not just mental health professionals, but also health care workers on the primary health care level, as they play a very important role in the referral process for PLHIV by recognising their health care needs. This could influence the health seeking behaviours of PLHIV, as well as their use of mental health services. GIP could organize trainings on issues of mental health and HIV/AIDS for general practitioners. These trainings could be organized so that in every health centre at least one of GPs is trained in recognizing and properly addressing mental health issues of PLHIV.

## b) To improve the activities around lobbying for mental health and HIV issues

The majority of advocacy and lobbying actions have been done by NGOs, but these actions could be more effective if government and PLHIV associations supported them. GIP, as an international organization with great experiences in mental heath issues, could help these efforts through financial and technical support of the joint projects between GO, NGO and PLHIV associations. GIP could organize study visits for members of PLHIV associations and other NGO activists, aiming at gathering experience in this kind of advocating activities from other countries.

## c) To support organizations active in the field of HIV in beneficiary involvement strategy

Even though one of the leading principles of National HIV strategy is active participation of PLHIV in the HIV response, they are not involved in the practice in a proper way. One of the reasons could be their reluctance and lack of trust, but also this could be result of non-existing practices in beneficiary involvement in Serbia in every field, not just HIV. Since GIP has experience and knows how to involve beneficiaries, they could educate people in the HIV field in order to improve their knowledge and skills. GIP could organize trainings for professionals active in the field of mental health and HIV/AIDS on how to promote beneficiary involvement, as well as give examples of best practice from other countries.

## d) Support developing national policy for addressing mental health issues of PLHIV

GIP could support consultations process involving all relevant stakeholders and resulting in working groups that could give recommendations for addressing these issues on the level of health care system in Serbia. With adequate involvement of relevant stakeholders and GIP expertise and experience from other countries, this policy could present a framework for ensuring adequate help for PLHIV.

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### **Appendix 1 – Guides for Focus Group Discussions**

#### FGD guideline for professionals

1. What kind of services does your institution provide concerning the mental health issues of the persons living with HIV/AIDS?

2. How do persons living with HIV/AIDS come to you, who send them?

3. How many members of the staff do you employ who give services concerning the mental problems to persons living with HIV/AIDS and what is their profile (qualifications, specific kind of education for this kind of work)?

4. How often do the persons living with HIV/AIDS who suffer from mental problems come to you?

5. What kind of problems are the most often?

6. How do you treat those kinds of problems?

7. How satisfied are you with the extent and level of services concerning the mental problems you provide to the persons living with HIV/AIDS? What steps are necessary so that those services can be improved?

8. How would you organize the system for helping the persons living with HIV/AIDS who suffer from mental health issues?

Participants of focus group with professionals from the field of mental health and  $HIV/AIDS^{33}$ 

Institution	Profession	
Institute for addiction related diseases	Psychologist	
Institute for addiction related diseases	Internist,	
	immunologist	
HIV/AIDS centre Clinic for infectious diseases	Psychologist	
Institute for psychiatric diseases Dr Laza Lazarevic	Psychologist	
More than help	Adult Education	
Guidance clinic for mental health issues Institute for students' medical care	Psychologist	
More than help, AID+ Association of people living with HIV/AIDS	Person living with HIV/AIDS	
Human Kindness church organization giving psychosocial support to persons living with HIV/AIDS	Psychologist, volunteer	

<sup>&</sup>lt;sup>33</sup>since none of the participants had formal authorization to represent institution in this kind of activity (which would take an enormously complicated procedure) they all agreed to participate stating their own opinions and experience

#### FGD guideline for PLHIV

1. How did learning of your HIV status affect your life?

2. After learning of your HIV status did you have need for psychologicalpsychiatric support?

3. Whose support meant the most to you?

4. Did you seek professional help? Where? If yes: Did received help meet your need and in what degree? What were you satisfied with? And what was missing? If no: What was the reason?

5. What should be changed in health system, in order to better meet your needs/ or How would you organise support system for PLHIV?

Issue	Discussed Issues/Services and Activities/ Gaps	Recommendations
What kind of service do they offer to		
PLHIV?		
Who are their users? (only PLHIV or other groups, or PLHIV from any particular group, e.g. IDU PLHIV)		
Did they notice that some of their clients have MH and HIV/AIDS?		
Have their staffs receive any kind of training on issues of MH and HIV/AIDS? If yes, what kind of training, who organized, what topics where covered.		
Do they feel their staff need training on MH and HIV/AIDS? What kind of training, what topics		
Have they performed any kind of research on issues of MH and HIV/AIDS, or on needs of PLHIV? If yes, can they give us a copy of research report?		
Are they aware of any research on issues of MH and HIV/AIDS, or on needs of PLHIV done by some other organization or institution? If yes, can they give us the contact of this organization or institution?		
Have they published any kind of literature (books, leaflets, brochures, articles) on issues of MH and HIV/AIDS, or on needs of PLHIV? If yes, can we have a copy of it to make it available to other professionals?		
Do they know of any kind of literature (books, leaflets, brochures, articles) on issues of MH and HIV/AIDS, or on needs of PLHIV published by some other organization or institution? If yes, can they give us the contact of this		
organization or institution? How can the expert centre help them improve their service?		

### Appendix 2 – The List of Questions for Interviews

# Appendix 3 - Leading principles of National Strategy for HIV/AIDS

The HIV/AIDS strategic plan of the Republic of Serbia is based on the following principles:

1. The PLHIV will play a key role in developing the policy and planning the support and protection program

2. The PLHIV will all have equal access to the health and social care in the whole territory of the Republic of Serbia

3. The treatment of the PLHIV will respect their dignity

4. During the testing, treatment and care, the privacy of all persons and confidentiality of all information will be respected

5. The significant role in planning, implementation, and evaluation activities of this strategic plan will be played by young people

6. The activities of this strategic plan will be publicly accessible

7. The development of a suitable legal framework to regulate rights and obligations of the PLHIV will be based on the EU recommendations and other international conventions which comply with the ethical principles and human rights and are guaranteed by the United Nations Declaration and other guidelines related to these issues

8. The response to the HIV/AIDS situation will take a multidimensional approach and will cover, in addition to biomedical aspect, also the social and economic factors which increase the risk of the infection

9. The cooperation between the government authorities and non-governmental organisations will be continuously maintained, with the participation of multidisciplinary and multisectoral teams which will make joint effort in the development for achievement of strategic goals

10. Continuous education will be organised and the efficient HIV/AIDS prevention measures implementation skills of all the participants involved in the strategy implementation process will be upgraded

11. The environment will be created that is conducive of the sustainability of strategic activities in the circumstances of the decreased contribution of international aid

### Appendix 4- Specific Objectives of UN Thematic Group in Serbia

1. The UN TG provides overall support to the government for the RAC functioning and preparation of the Republican AIDS Strategies and Proposals for GFATM

2. The UN TG provides assistance to the development of HIV/AIDS Monitoring and Evaluation System and to the improvement of the National HIV/AIDS surveillance system in order for it to be in line with system developed countries, regarding the collection and exploring of the data, reporting of data, data processing and using, good result based planning

3. UN TG coordinates the follow-up of the 2004 WAD campaign and develop the premises and partnerships for the 2005 campaign

4. UN TG develops preventive activities, targeting different groups: professionals, hard to reach groups, fighting stigma and discrimination of PLHIV, and inclusion of CBOs dealing with vulnerable groups in the response.

5. UN TG contributes to the expansion of the network against HIV/AIDS by organizing meetings, information sharing, and facilitating attendance of nationals to international capacity building gathering.

6. UN TG supports the dialogue among all stakeholders on HIV/AIDS in the country

7. Extension and/or initiation of co-operation with International Institutions and Agencies, for possible technical assistance or initiation of joint activities.

# Appendix 5- Psychological Service for PLHIV at the Centre for HIV/AIDS

Psychologist service at the HIV Clinic was established in early 90' with one psychologist employed. Psychologist's office is a room previously used as storage. The room is very small and it can accommodate only three persons. The office is near to the waiting room so PLHIV have easy access to the psychologist.

The service used to be open for 8 hours, but because of the health problems of psychologist, the service is now open only 4 hours a day. The psychologist asked for one more psychologists to be engaged at the Clinic but there was no understanding from decisions makers from the Clinic.

In this situation, hospitalized patients have the advantage to get psychological counselling while the patients who come to the HIV/AIDS clinic may schedule the appointment in advance. Sometimes, they need to wait for one month to see psychologist.

Psychologist does not have extra training for issues of mental health connected with HIV/AIDS or the special education for counselling PLHIV, but she has great experiences because she has been working from the beginning.

She also works with the family members and partners of PLHIV giving them psychological support and trying to include them in the support of their PLHIV family members. She supports PLHIV in approaching medical and other services, give them useful information about the importance of treatment, ways of transmission and help them to change risky behaviour. Sometimes, in order to help PLHIV as much as possible, she has to go beyond her professional responsibilities.

### Appendix 6- VCT Centre in Institute for Student's Health Summarise

VCT centre in ISH is integral part of the Centre for Prevention HIV and Sexual transmitted Diseases. VCT service consists from three counselling rooms, waiting room and laboratory. The centre has separate entrance and adaptation of the premises to lessen medical look as very user friendly. Service is open on working days from 8 am to 4 pm. There are also night counselling and testing offered from 8pm till midnight once per month. In cooperation with other NGOs, the counsellors work in drop in centre of NGO Veza (harm reduction program for IDU) and vehicle for outreach work with SW. The VCT model used in the centre consists of pre counselling, HIV testing, post counselling and referral and the model is always the same.

VCT centre was developed by joint work of ISH and IAN. UNICEF helped ISH with basic education of the counsellors and they started together to promote practice in whole Serbia (educating staff for pre and post HIV test counselling in other medical centres in Serbia) but greater contribution to centre development came from 2004 by joint project of ISH and NGO IAN supported by CAFOD.

CAFOD provided on going education for counsellors - 6 from IAN and 7 from ISH underlining the quality of counselling as a crucial element of good VCT practice.

Regular internal supervision (lead by psychotherapists) and external supervision (lead by CAFOD) provide mechanism for the updating and monitoring of the counselling process and at the same time provide the counsellors' with personal and professional development.

VCT counsellors are educated for Counselling PLHA that enabled them to provide on going psychosocial support for those tested HIV positive (as well as for those tested HIV negative). The education is based on Rodger's Client Centred Counselling. Counsellors are not educated on mental health problems that are associated with the disease and HAART effects on mental health but the centre has a good referral to the psychologist on HIV Clinic.

When somebody is tested HIV positive, counsellors offered on going counselling for the clients, their family members and partners. Also, counsellors support clients to go through the procedures of test result confirmation by making appointment with the psychologist at the HIV Clinic to meet the clients before HIV confirmatory testing. On this way, clients could get additional support from psychologist at the HIV Clinic in order to decrease the stress and anxiety around HIV testing.

The experiences of the counsellors from this VCT centre shows that clients usually attend these session but they stop counselling session when they go to the HIV Clinic at The Institute for Infectious and Tropical Disease. The possible reason is that VCT centres are recognized generally as centres that have nothing to do with psychological counselling. This misunderstanding gets PLHA out of the VCT centres and limits their benefits from counselling.