

# **MENTAL HEALTH ISSUES AND SUPPORT STRUCTURES CONCERNING PEOPLE LIVING WITH HIV/AIDS IN BULGARIA**

**Resource Center on Mental Health and HIV/AIDS - Bulgaria  
Global Initiative on Psychiatry**

**Prepared by: Antoaneta Mateeva**

**Sofia, Bulgaria  
2008**

## **Resource Centre on Mental Health and HIV/AIDS - Bulgaria**

**The resource centre for mental health and HIV/AIDS - Bulgaria** was established in September 2006 as part of the project “Mental Health and HIV/AIDS in South Eastern Europe, Caucasus and Central Asia”. The project is run by Global Initiative on Psychiatry and is integrated as an independent program in the Informational Center on Mental Health – Blagoevgrad.

The general purposes of the Resource Center are:

- To promote and strengthen mental health services for people living with HIV/AIDS their families and care givers; this includes prevention, treatment, care and consultation (the Resource Centre doesn't provide treatment);
- To improve the interaction between organizations providing assistance help for people living with HIV/AIDS and for people with mental disorders; non-governmental organizations and self-help groups;
- To reduce double discrimination of people living with HIV/AIDS who have mental health problems and to increase the information about their problems.

In pursuit of this purposes the Resource Center develops the following activities:

- plays the role of a center for collecting, systematizing and dissemination information on mental health and HIV/AIDS through booklets, bulletins, a website and video materials;
- organizes and conducts research on the needs of people with HIV/AIDS and mental disorder;
- publishes informational materials;
- organizes information and anti-discrimination campaigns;
- organizes trainings for professionals (physicians, medical nurses, psychologists and social workers) and other key stakeholders to become trainers.

## **ABBREVIATIONS AND ACRONYMS**

AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-retroviral Treatment
CRAFCT	Counseling Rooms for Anonymous and Free-of-charge AIDS Counselling and Testing
DDL	Dermato-Venerological Dispensary Laboratories
EU	European Union
FGD	Focus Group Discussion
GF	Global Fund
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GDP	Gross Domestic Product
GIP	Global Initiative on Psychiatry
GP	General Practitioner
HIV	Human Deficiency Virus
IDUs	Injecting Drug Users
IMF	International Monetary Fund
MH	Ministry of Health
MMU	Mobile Medical Unit
NCIPD	National Centre of Infectious and Parasitic Diseases
NCPI	National Composite Policy Index
NGO	Non-Governmental Organization
PLHIV	People Living with Human Deficiency Virus
PLHIV/IDU	People Living with Human Deficiency Virus who are Injecting Drug Users
STDs	Sexually Transmitted Diseases
STIs	Sexually Transmitted Infections
UN	United Nations
UNAIDS	United Nations Programme on HIV/AIDS
UNCT	United Nations Country Team
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children's Emergency Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

## **ACKNOWLEDGEMENTS**

The project “Mental Health and HIV/AIDS in South Eastern Europe, Caucasus and Central Asia” is financially supported by the TMF Programme, Netherlands Ministry of Foreign Affairs and by the OSI- New York.

We would like to thank the following people for the invaluable support and assistance: Dr. Galya Petrova (Dynamica – Center for psychotherapy, psychological and psychiatric consultation, Sofia); Dr. Michail Okoliyski (National Center of Public Health Protection, Sofia); Elena Yankova and Anna Lyubenova (Initiative for Health Foundation, Sofia); Antoaneta Radeva, Nela Ivanova (Dose of Love Association, Burgas); Dr. Ivailo Dimitrov (Director, Health, prevention, social activities, employment and sport, Municipality of Burgas); Mariana Stankova (Association “Adaptation”, Blagoevgrad); Dr. Elena Orozova (Regional Inspectorate for Prevention and Control of Public Health, Blagoevgrad); Dr. Georgi Dimitrov (Mental Health Dispensary, Blagoevgrad) and Antoaneta Mateeva (Bulgarian Institute for Human Relations, Sofia).

# TABLE OF CONTENTS

<b>EXECUTIVE SUMMARY</b>	8
<b>1. Introduction</b>	
1.1. Socio-demographic context of the study	12
1.2. The HIV/AIDS epidemic in the country	14
<b>2. Study Design and Methodology</b>	
2.1. Research setting and selection criteria	16
2.2. Research methodology	16
2.3. Research Team	17
<b>3. Policy and Structure of Mental Health and HIV/AIDS</b>	
3.1. National mental health policy and services in the field of HIV/AIDS	19
3.2. Policy and services in the field of HIV/AIDS	21
<b>4. Mental Health Problems of PLHIV</b>	
4.1. Mental health problems experienced by PLHIV	24
4.2. Stigma and discrimination situation: existed and experienced	25
4.3. PLHIV needs regarding to mental health issues	29
<b>5. Voluntary Counselling &amp; Testing Services</b>	
5.1. Service access, use and clients' satisfaction	31
5.2. Guidelines and protocols	34
5.3. Staff training and corresponding needs	34
<b>6. Mental Health Problems of PLHIV Who are IDU</b>	
6.1. Organisational structures, policies and management of PLHIV/IDU programs	36
6.2. HIV/AIDS and mental health services for IDU	37
6.3. Mental health needs of PLHIV who are IDU	39
<b>7. Conclusions</b>	41
<b>8. Recommendations</b>	43
<b>REFERENCES</b>	47
<b>ANNEXES</b>	49
Annex 1: Questionnaire for medical staff and general public	
Annex 2: Interview guides	
Annex 3: FGD guidelines	
Annex 4: List of key informants	

## EXECUTIVE SUMMARY

The present document is based on four rapid assessment studies carried out by experts from the Global Initiative on Psychiatry. Both the branch for South Eastern Europe situated in Sofia and professionals from the Resource Center for Mental Health and HIV/AIDS - Bulgaria situated in Blagoevgrad worked on these studies.<sup>1, 2, 3, 4</sup> The main aim of this initiative is to raise awareness and encourage discussion on appropriate, timely and culturally relevant preventive measures against the mental health problems among PLHIV.

This could include a range of best practices in the area of a) policy development, implementation and monitoring; b) advocacy and human rights protection; c) service provision and evaluation; d) civil society participation.

The objectives of this compilation and summarizing document are:

- Description of the general political, epidemiological and social context of Bulgaria in which the issue of PLHIV/AIDS' mental health and social welfare could be analyzed.
- Analysis of the current policy, legislation and administrative structures in the fields of mental health and HIV/AIDS.
- Description of the mental health problems of PLHIV including stigmatization and discrimination.
- Identification of the problem areas related to the provision of mental health care and support of PLHIV.
- Description of recommendations given by different stakeholders and provision of conclusions and priorities for the future development in the field of mental health care and social and public support of PLHIV/AIDS in Bulgaria.

The research sites included clinical and social support services, political and administrative bodies, international stakeholders, NGOs and consumer organizations, university structures. The background of the participants in the study was very broad representing policymakers, health administrators, mental health and HIV/AIDS professionals, GPs, PLHIV/AIDS and their relatives, lawyers, university students.

Variety of research methods was used in order to make rich and profound picture of the situation: policy and official documents analysis, desk review, individual in-depth interviews, observation of services, focus-group discussions, existing statistics and epidemiological studies, data from previous research in the field.

The *findings* from this research show that:

---

<sup>1</sup> Lendzhova, V. & Gotseva, A. (2007). Evaluation of HIV/AIDS voluntary counseling and testing services in Bulgaria.

<sup>2</sup> Lyubenova, A. (2007). Mental health structure for PLHIV who inject drugs in Bulgaria.

<sup>3</sup> Okolyiski, M., Lendzhova, V. & Gotseva, A. (2007). Mental health problems of people living with HIV/AIDS in Bulgaria.

<sup>4</sup> Okolyiski, M., Lendzhova, V. & Gotseva, A. (2007). Stigma, discrimination and attitudes towards people living with HIV/AIDS in Bulgaria.

- There are well developed policies and action plans in both fields of mental health and HIV/AIDS. Nevertheless the mental health issues of PLHIV/AIDS and their relatives are not a focus of specific concern there.
- Despite of the existence of political documents envisaging collaborative efforts between the structures there is a serious lack of such practices on the service provision level.
- Mental health and social support as well as HIV/AIDS services and structures do not recognize the specific emotional needs of PLHIV and there are no specific programs or intervention in place to address them.
- Many PLHIV don't use the HIV/AIDS services since they fear stigmatization and discrimination.
- The changes in the legislation ensure the provision of good quality, confidential and accessible services for PLHIV/AIDS but in the reality there are many instances of serious violation of these rights due to:
  - a) widespread ignorance and biases in relation to the AIDS and mental illness even between the professionals in both fields;
  - b) lack of effective monitoring of the health care and social support systems;
  - c) procedures and practices that threatened these rights.
- PLHIV who also have drug addiction, mental illness and/or emotional problems are experiencing a double or triple stigma from the society. This of course has a negative impact on PLHIV and their families.
- There is no planned systematic study of the issues of mental health and stigma related to the illness of PLHIV/AIDS. One of the first efforts of this kind is done by the Kaspar Hauser Foundation.<sup>5</sup>
- The preventive measures and services took their roots deeply and now they give their fruits in various programs and local initiatives including media and school system. Unfortunately the issues of mental health problems of PLHIV/AIDS are only incidentally included in them.
- Because of the low number of professionals like psychiatrist, clinical social workers, clinical psychologists, psychiatric nurses that are prepared to work with the emotional difficulties in the country such specialists are not included in the HIV/AIDS system of care. The culture of multidisciplinary work and the application of case coordination approach are still in their very beginning and are not part of the standard university education of clinical and non-clinical professionals working in the field.

The basic *recommendations* developed by the different stakeholders in the fields of HIV and MH care mainly suggest:

- Inclusion of MH issues of PLHIV and their relatives between the priorities of health, social and educational policy and programs.

---

<sup>5</sup> **Малинов**, Павел и др. Проучване нарушаването на пациентските права на хора, живеещи с ХИВ/СПИН при съпътстващи заболявания. (Study on the violation of human rights of the PLHIV/AIDS when having concomitant illnesses) Фондация „Каспар Хаузер”, 2006. Unpublished.

- Enlargement of the existed policies and action plans on HIV/AIDS with the aims and activities concerning staff training and provision of psycho-social services, needs assessment, service evaluation, and case management.
- Strengthening of collaboration between the ministries in the fields of mental health, AIDS and social protection.
- More active inclusion of the NGO sector in the overall cycle of policy development, implementation and evaluation.
- Raise public awareness in relation to the stigma and discrimination through development of campaigns and initiatives including all stakeholders and the local communities.
- Refining of the legislation and procedures that defend PLHIV rights of confidentiality and equal treatment and social opportunities.
- Supporting the widespread of the existed best practices developed by the NGOs engaged in psycho-social counseling and networking with mental health services.
- Inclusion of mental health specialists (psychiatrists, clinical psychologists, clinical social workers, mental health nurses) in the staff of the VCT services.
- Implementation of case work approach, individual and group supervision and peer-review in the practice of the services for this group of people.
- Development of appropriate programs for patients with double diagnosis – drug addiction and HIV.
- Reduction of the barriers to care for ‘hard-to-reach’ populations like people in prisons, homeless people, substance abusers, and individuals with severe mental illness.
- Development of more effective practice of monitoring health and social services in relation to human rights, confidentiality, and effective care for PLHIV/AIDS.
- Development of research on mental health problems experienced by the PLHIV and their relatives and friends.
- Systematic assessment of the mental health needs and problems of PLHIV/AIDS.
- Assessment of the needs of the services in order to provide adequate care and support. Assessment of the existed local resources and obstacles that prevent it.
- Development of an alliance of organizations working in the fields of mental health care, HIV/AIDS, drug addictions and social welfare (local, national and international) in order to promote the issues of mental health and to coordinate the efforts for development of programs and standards for service quality assurance.

- Provision of trainings of different professionals on the psycho-social aspects of the illness and on the methods of work with them, on human rights protection, stigma and discrimination and professional ethics.
- Inclusion in the curricula of courses or topics related to mental health issues of PLHIV and their relevant treatment and care as part of the professional education of health care and social work specialties (psychiatrists, nurses, clinical psychologists, social workers, narcologists, infectionists etc.).
- Strengthening of the efforts of different countries in the development of international policy, initiatives and programs related to the mental health and social wellbeing of the PLHIV/AIDS and their families.

# 1. Introduction

This document consists of eight chapters representing the main topics of concern in relation to the mental health of PLHIV/AIDS in Bulgaria. The **Introductory chapter** represents general information about the socio-demographic context and the HIV/AIDS epidemic in the country. **Ch. 2** describes the research settings in which the study took part, participant's selection criteria and research methodology used. In **Ch. 3** the issues are raised on the level of the existed policies and service structures in both fields of MH and HIV/AIDS. Mental health problems and needs experienced by PLHIV with specific focus on stigma and discrimination are concerned in **Ch. 4**. Voluntary counseling and testing services are represented in the **Ch. 5** in relation to their access, use and clients' satisfaction; existence of structured protocols and guidelines for the practice; staff training and corresponding needs. The difficulties and needs of people with double diagnosis – HIV and drug dependency – and organizational structures, policies and programs to serve this group of people are explored in the **Ch. 6**. **Ch. 7** and **8** summarize the findings and analysis done in previous chapters and offer conclusions and recommendations specific for each of the different stakeholders in the field.

## 1.1. Socio-demographic context of the study<sup>6</sup>

The country is situated in the middle of the Balkan Peninsula. The northern frontier passes along the Danube river that separates the country from Rumania. With Rumania, we also share a land frontier of about 80 km in length. To the west, Bulgaria borders upon Serbia and Macedonia - remnants of Yugoslavia that disintegrated following numerous bloody wars. To the south, the country borders upon Greece and Turkey. The eastern frontier is the Black Sea which is an outlet for Rumania, Ukraine, Russia, Georgia, and Turkey as well.

The territory is 111 thousand sq km. Bulgarian population is 7.6 million.<sup>7</sup> The ethnic distribution is 88% Bulgarian, 8% Turkish, 3% Roma, 1% Armenians and Russians. The distribution by religion is 85% Bulgarian Orthodox, 13% Muslim.

Bulgaria's economic situation has improved significantly over the past few years. Positive growth began to register from 1998. Privatization remains the focus of the government.

**Table 1. Recent economic indicators:**

	2001	2002	2003	2004	2005(a)	2006(b)
GDP (US\$bn) (current prices):	13.6	15.6	20.0	24.3	26.7	28.3
GDP PPP (US\$bn) (c):	53.5	57.1	60.8	65.9	71.2	76.7
GDP per capita (US\$):	1,713	1,979	2,550	3,127	3,459	3,686
GDP per capita PPP (US\$) (c):	6,736	7,238	7,756	8,464	9,223	10,003
Real GDP growth (% change YOY)	4.1	4.9	4.5	5.7	5.5	5.6
Current account balance (US\$m)	-986	-873	-1,8	-1,403	-3,153	-2,882
Current account balance (% GDP)	-7.3	-5.6	-9.2	-5.8	-11.8	-10.2
Goods & services exports (% GDP)	55.6	53.1	53.6	58.0	60.8	63.7
Inflation (% change YOY)	7.5	5.8	2.3	6.1	5.0	7.2

The standard of living is still lower in Bulgaria than in other Central European countries. GDP per head at PPP was around US\$8,900 in 2005. Eleven per cent of the labor force is employed in agriculture while the remainder is in industry and services. Unemployment, which reached 14.3 per cent in 2003, fell to 12.7 per cent in 2004, and in 2006 is sitting at an estimated 11.5 per cent. Economic growth is strongest in the fields of construction, tourism, services, and textile industry that were marketed throughout the closed socialist trade system.

<sup>6</sup> **Petrov**, Rumen & Mateeva, Antoaneta. (2008). *National Report – Bulgaria*.

<sup>7</sup> Wikipedia.

**Health care:** As a whole, health indices deteriorated in the course of the last 15 years: Paediatric mortality is growing, and mean life expectancy is reduced (especially for men) while birth rate is decreasing. Cardiovascular mortality is especially high. Alcohol consumption rate is also high. Smoking is widespread, among women and children inclusively. Demographic growth is negative. Mild increase of birth rate has been observed recently. The institutions of the Health Insurance Fund and of the general practitioner were introduced in 2000. Till the year 2000, the hospital conditions continuously deteriorated. The infrastructure rapidly declined both due to the total impoverishment in the period before and after the hyperinflation in 1996-97 as well as because of poor management and fund wasting at the health institutions. The practice of willingly “handing over money” on the part of the patient gradually turned from hidden act into a routine. During the last 6 years, the changes in this area involve only a rise of the investments in hospital buildings. Many hospital physicians maintain parallel private room or even clinics for diagnostics and consultations. Research practice is funded mainly by transnational pharmaceutical companies. The emigration rate of nurses is high.

**Social care:** A) **Unemployment** is still a serious problem of the country. Data from the Employment Agency show a serious decrease of the percentage of unemployment among the economically active Bulgarian citizens for the last 5 years – from 19.13% (January 2001) to 8.74% (August 2006). These data, however, should be discussed with skepticism. Firstly, because of the presence of the widespread and generally unbothered domain of gray economy where pertains the greater part of country’s poorest population, mainly of Romany origin, as well as the disabled. Some private Bulgarian and foreign businesses appoint their employees to work for the minimal wage without insurance, sometimes at drastic working conditions which are dangerous for their health and life. Special objects of exploitation are young people and individuals of the age before and after retirement. Secondly, the decrease of unemployment rate in the country might be due to the refusal of a great number of Bulgarians to register with the employment agencies. The rate of migration of Bulgarian citizens in active age is high, and this of course also takes out some part of the unemployed from the country and turns them into “guest workers” in Western Europe, USA and Canada. Thirdly, well-grounded and integral policies for overcoming unemployment in the country and protection of its especially vulnerable citizens from gray economy by the development of alternatives of legal employment are absent. The measures are usually partial, ineffective, and not accessible for the poorest population groups. This makes the situation of such vulnerable groups as PLHIV/AIDS, drug users and mentally ill people extremely difficult. It leads them to poverty, criminal behavior, and makes them subjects of abuse. If they loose their job or because of the stigma leave the town it becomes almost impossible for them and their families to find reasonable job again.

B) **Minorities:** The situation of the Roma minority is especially severe. Roma people in Bulgaria have the lowest social status, and a great part of them are living in ghetto areas of big cities. Usually, they are employed in professions of lowest status, and are illiterate. The severest social problems like poverty, unemployment, criminal acts, prostitution, mendicancy, trade of organs and newborn children abroad are a part of the way of live of the predominant part of this minority. The major service provided by the national care programs is the provision of financial and material aids – for heating, unemployment, and children’s schooling. Because of the poorest conditions of leaving this minority in Bulgaria is suggested as one of the groups most at risk of having HIV/AIDS. The Turkish minority occupies mainly the poor frontier regions of the country and is living predominantly in villages. This minority uses mainly underdeveloped and non-productive, very often manual technologies for agricultural production. The young people from this minority either emigrate abroad or are

involved as laborers in the construction business or other seasonal activities. Specialized programs for this minority are lacking. The problems of this minority are strongly politicized in the Bulgarian public and media space.

## **1.2. The HIV/AIDS epidemic in the country<sup>8</sup>**

Bulgaria is at crossroad of two epidemics with different dynamics and different driving forces. According to UNAIDS, the epidemic in the region of Eastern Europe and Central Asia is the most rapidly growing one, and 62% of the new infections in 2006 are among injecting drug users. At the same time, the epidemic in Central and West Europe continues to grow mainly among men who have sex with men, who represent 29% of new HIV infections in 2006, and the number of newly registers cases has doubled between 1996 and 2006.

Bulgaria is still a country with low HIV prevalence in the general population. However, the country faces a great challenge related to the possibility of rapid development of concentrated epidemics in separate group identified as most-at-risk. There is already such epidemiological and behavioural evidence for the groups of injecting drug users, men who have sex with men and sex workers. The risk is also related to the possibility of transmission of the infection to the general population, where the main mode of transmission is the heterosexual one, and where a generalized epidemic can develop.

In the period 1986-2007, the cumulative number of registered HIV cases in Bulgaria is 814, and new cases in 2007 are 125. In comparison to 2005, the annual number of newly registered cases grew with 50%.

From the total number of registered cases in the period 1986-2007 with a known route of transmission, 76% are heterosexual, 13% are injecting drug users, and 8% are homo-/bisexual. 17 cases (2% of all cases) were infected through transfusion of blood and blood precuts as such last were registered in 1996. A total of 7 children (1% of all cases) were infected by their mothers.

The increase in the number of registered cases after 2004 is to a great extent due to the active finding, provision of HIV prevention services among the groups most-atrisk, referral for testing, care and support within Program "Prevention and Control of HIV/AIDS", financed by the Global Fund to Fight AIDS, Tuberculosis and Malaria.

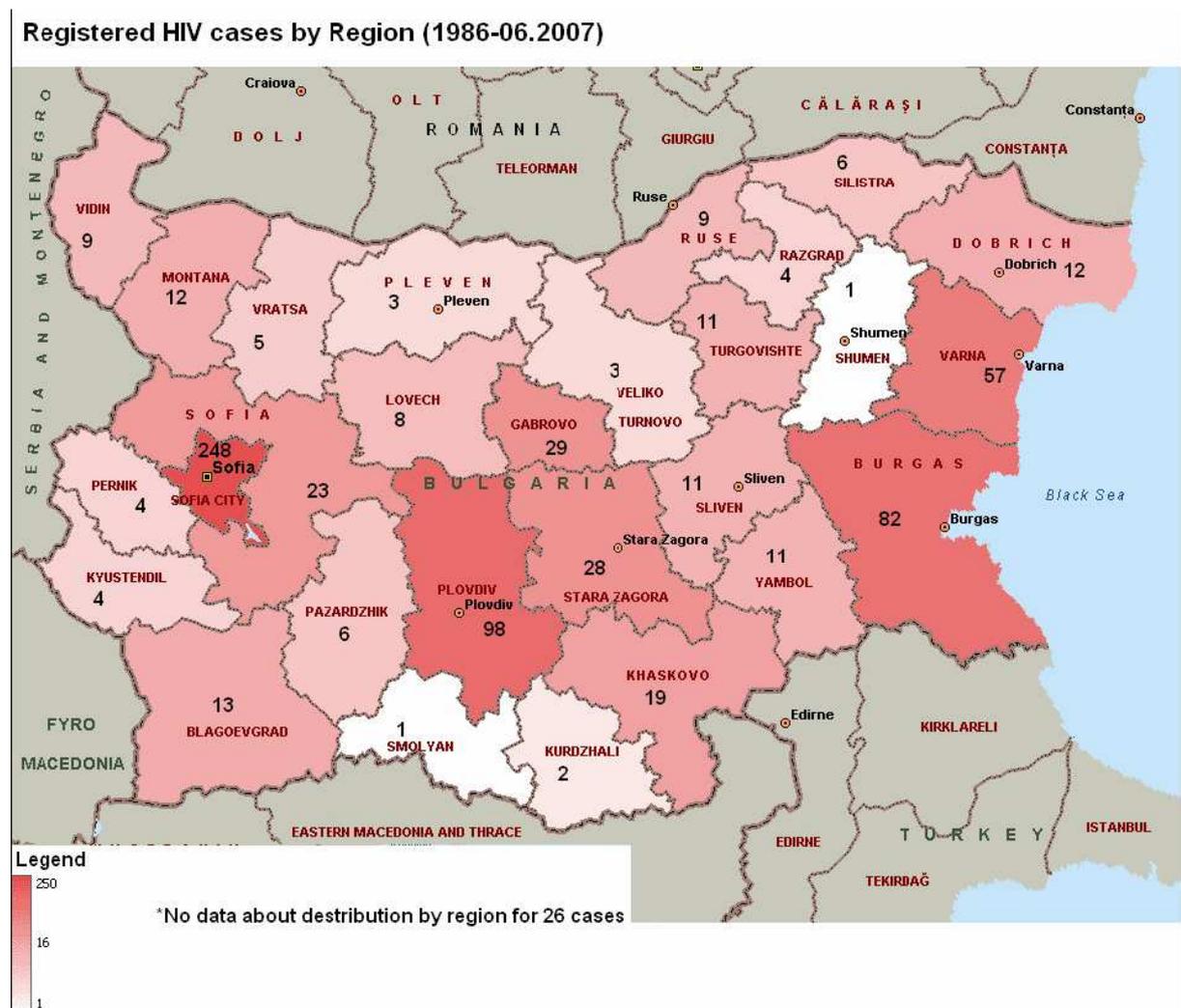
Distribution of newly registered cases in 2007 in age groups indicates high share of the 15-24 age group (28%), and it is worrying that the youngest person infected is 16-year old. It is important to highlight that the cases in this age group are mainly among injecting drug users and men who have sex with men.

Registered HIV cases are concentrated in large urban areas - Sofia, Plovdiv, Bourgas and Varna. A worrying tendency was observed the last two years the annual number of cases registered in Plovdiv (31 in 2006) is greater than that in Sofia (19 in 2006).

---

<sup>8</sup> The data for this part are taken from the Country Progress Report 2008.

Figure 1.



Source: Ministry of Health, Department for Prevention and Control of AIDS, Tuberculosis and STIs, Bulgaria

## **2. Study Design and Methodology**

### **2.1. Research setting and selection criteria**

Current research was developed during the years 2007-2008 with the aim to describe the care for the PLHIV/AIDS and their families with the specific focus on their mental health. According to this aim settings were chosen that can ensure the participation of all different stakeholders engaged on several levels:

- a) policy making and legislation;
- b) service and support provision structures;
- c) individuals and families;
- d) groups of professionals;
- e) general population and more specifically the young people;
- f) civil society sector;
- g) international stakeholders.

The research was located mainly in the capital of the country Sofia where the main political institutions and services are located. The other town in which significant part of the research was conducted is the middle-size town of Blagoevgrad where the new Resource center was developed and started to work. Three of the largest Bulgarian towns (Bourgas, Plovdiv and Varna) where the rate of infection is very high were included in the study through the experience of local NGOs that work in the field of HIV/AIDS services.

Participants of different target groups were included in order to gather diverse points of views. They included:

- policy makers and administrators on the national and municipality level;
- professionals from the HIV/AIDS and mental health in- and out-patient services (epidemiologists, gynaecologists, infectionists, nurses, psychologists, psychiatrists, social workers, narcologists);
- PLHIV/AIDS and their families from the whole country;
- community representatives;
- general practitioners;
- students;
- representatives of international stakeholders.

### **2.2. Research methodology**

Desk review

The first phase of the research was the desk review of the political documents, legislation, service documentation, programs, reports, newspapers and TV broadcasts on HIV and AIDS and previous research. The analysed data from these sources helped the researchers to analyse the collected data in relation to the broad political context.

Additionally to these basic methods the observations of the several services were made in order for the researchers to make direct sense about the atmosphere in there.

Qualitative methods

Qualitative methodologies were used to gather and analyse new data. This methods was used to develop hypothesis about the main causes of mental health problems of PLHIV and come up with suggestions and recommendations to counteract the main problems in this area

The qualitative methodology also helps best to understand the personal and often painful experiences of PLHIV and their relatives who face discrimination and stigmatization.

Two basic qualitative methods of data gathering were used

a) individual

in-depth interviews with 71 participants and

b) 9 focus group discussions.

Individual interviews were used for the contacts with key figures on the political and service level that have experience of acting in the field for years or are on a leading and powerful position. The interviews were helpful also when talking about the personal stories of the PLHIV and injecting drug users. The interviewed participants represented the groups of local stakeholders, policy makers, healthcare professionals (nurses, psychiatrists, social workers, epidemiologists, GPs, psychologists), lawyers, teachers and students from the university, community leaders.

Focus group discussions were used in order to collect and discuss in a group form the different positions that were obtained through the interviews and the data from the official documents and statistics. Possible explanations and recommendations arose during the discussions. Participatory techniques of matrix mapping and brainstorming were used during some of the FGD with the reason to facilitate the thinking and creativity of the participants. The focus groups were organized with professionals from NGOs that provide mental health support and counselling of PLHIV/AIDS, with PLHIV/AIDS and their relatives, nurses from the VCT services, GPs, professionals in the field of HIV/AIDS and MH services, university students, community members.

Quantitative methods

Questionnaires were also used when trying to reach more participants from the distant places and this way to broaden the geographical areas and groups of participant covered by the research. They were used to reach the management of 5 NGOs working in the field that are located in different towns in the country. Furthermore existing quantitative data from epidemiological research and national, local or service statistics were used in the analysis.

The research process went through two phases. In the first phase four particular studies were developed and conducted on each of the topics related to the mental health of the PLHIV/AIDS and separate reports were written.<sup>9,10,11,12</sup> In the second phase an expert in the field of research, mental health and psycho-social care summarised the data and did additional interviews and FGD to check and harmonize the particular analyses in this document.

### **2.3. Research Team**

The research was carried out under the leadership of the Resource Centre on Mental Health and HIV/AIDS in Blagoevgrad. In the beginning of this research project the staff of the Centre was trained in qualitative research methods and was provided with instruments and research guidelines that facilitated its work further.

---

<sup>9</sup> Lendzhova, V. & Gotseva, A. (2007). Evaluation of HIV/AIDS voluntary counseling and testing services in Bulgaria.

<sup>10</sup> Lyubenova, A. (2007). Mental health structure for PLHIV who inject drugs in Bulgaria.

<sup>11</sup> Okolyiski, M., Lendzhova, V. & Gotseva, A. (2007). Mental health problems of people living with HIV/AIDS in Bulgaria.

<sup>12</sup> Okolyiski, M., Lendzhova, V. & Gotseva, A. (2007). Stigma, discrimination and attitudes towards people living with HIV/AIDS in Bulgaria.

The team included 6 researchers with particular experience of conducting qualitative research on sensitive topics with hard-to-reach groups. They also have their professional background in the field of mental health and HIV/AIDS (clinical social worker, sexologist, sociologist, psychologist, economist, social worker). The research was done with the very active participation of the two NGOs in the field: Kaspar Hauser Foundation <sup>13</sup> and Initiative for Health Foundation<sup>14</sup> situated in Sofia.

---

13 Kaspar Hauser Foundation – is an non-governmental organization for supporting of people affected by HIV/AIDS, Kasper center is responsible for social adaptation of PLHA, consulting and social mediation

14 Initiative for health Foundation is a non-governmental organization working for reduction of the harms to health among the drug users and the sex workers, as well as for their acceptance and equality in the society.

### 3. Policy and Structure of Mental Health and HIV/AIDS

#### 3.1. National mental health policy and services in the field of HIV/AIDS

Since the political and economic changes in 1989, reform was initiated in the field of mental health care in Bulgaria as part of the needed changes in general health care. The main focus of the first policy in this area was on the people with severe mental disorders, mental retardations and substance abuse whose rights and welfare were most hardly violated through the traditional practices of institutionalized care. During the last almost two decades mental health policy was developed and launched with the aim to transform the existed medical and asylum approach in the services for this group of people into community and needs based approach. An Executive Board was established to the Ministry of Health to govern the process of change in the mental health field and to coordinate the variety of the ongoing projects.<sup>15, 16</sup>

The driving forces behind change were public bodies and organizations. They lead the way by raising awareness about the degrading nature of mental institutions, the lack of mental health services, and stigmatization; the political, professional and statutory bodies followed suit.<sup>17</sup> Several organizations of people with severe mental disorders and their relatives were established to force the changes and to challenge the existing stigma and discrimination against them in the society and in its structures and regulations.

Legislation in the area of health, education, social support and labor was revised in a way that could better protect human rights, facilitate the implementation of new practices and support people with mental disorders and their families to live with dignity.

Currently through the Ministry of Labor and Social Protection the establishment of new alternative services (day care centers, sheltered homes and information centers) and the transformation of old institutions are on their way. They are mainly supported by governmental and EU funds (PHARE Programs). The policy of decentralization and the recently accepted Law of regionalization (2008) emphasize again the tremendous importance of local authorities in the implementation of community based practices.

Despite of these positive steps current situation in the field of mental health as described in the mental health policy documents and by policy makers, professionals and consumers is still characterized by:

- traditional model of dispensaries and hospitals with a small number of outpatient services as individual or group practices;
- community model of care developed only on the pilot stage of few projects;
- psychiatric services unequally distributed on the territory and still organized around the biological understanding of mental illness;
- low awareness of the emotional and social needs of the people with mental health problems on the public, professional and political level;
- psychiatric stigma still strong and unrecognized that leads to social isolation and discrimination;
- lack of effective collaboration between different professionals and governing structures;

---

<sup>15</sup> Mental Health Policy 2004-2012.

<sup>16</sup> Jane-Llopis, E. & Anderson, P. (2006). *Mental health promotion and mental disorder prevention across European Member States: A collection of country stories.*

<sup>17</sup> The same as mentioned above.

- serious lack of specialists in the field of psychiatry, clinical psychology and social work prepared in case coordination and psycho-social rehabilitation of people with severe mental disorders;
- human rights of the people with mental health problems still violated in the practice;
- management of the system not based on health economic analysis and quality assurance of service provision;
- lack of adequate financial support for the implementation of the planned changes.

**In regard to the PLHIV/AIDS** such situation is not very promising. The positive part of it is the existence of a) initial recognition of the personal emotional problems as legitimate focus of care and support, b) development of structures and strategies for their provision, and c) an effort to democratize this process through the engagement of civil society as well as through the support of an international network of organizations and EU structures in the field.

In the same time common mental disorders that are closely related to the emotional problems experienced by PLHIV/AIDS were deemed a disavowed issue equally by the public, health policy and health care system. Little knowledge of common mental illness presenting as episodes of malfunction in the emotional domain could explain why negligence for the emotional well-being of self and others was so common. Prejudice and stigma were seen as major barriers to reporting for help, even when stress, depression or anxiety became overwhelming. It was recognized, however, that none of these insights could be tested against existing factual data because service statistics and epidemiological research were either unreliable or lacking.<sup>18</sup>

Several positive steps to challenge this reality however could be seen on the policy level. The currently run national epidemiological study on the stress related mental health problems (EPIBUL) is the bases on which policy and action plan will be developed to overcome common mental disorders.<sup>19</sup> In the area of mental health promotion and mental disorder prevention national programs were developed and implemented that can be of direct relevance to the mental health needs of the PLHIV/AIDS too:

- Suicide prevention program concerning the issues of capacity to assess suicidal behavior by specialist services and by generalists; sensitization of the public to attempted suicide and its precipitants; the association of mental illness and suicide.<sup>20</sup>
- School mental health program purporting to evolve a network of schools, which cater for the social and emotional development of children by providing a set of services and educational activities to overcome the risky behavior and stress in the school environment.<sup>21</sup>
- Substance abuse program in its preventive component that confronts the risks of addictive behavior, supports the changes in the legislation regarding possession and peddling of illegal drugs, as well as the development of regulations aiming to constrain availability of addictive substance.<sup>22, 23</sup>

---

<sup>18</sup> Jane-Llopis, E. & Anderson, P., p.36.

<sup>19</sup> Mental Health Policy 2004-2012.

<sup>20</sup> [www.ncphp.government.bg/projects.php](http://www.ncphp.government.bg/projects.php)

<sup>21</sup> [www.ncphp.government.bg/projects](http://www.ncphp.government.bg/projects)

<sup>22</sup> Jane-Llopis, E. & Anderson, P.

<sup>23</sup> [http://liternet.bg/drugs\\_prevention\\_society/programi/prevenia3.htm](http://liternet.bg/drugs_prevention_society/programi/prevenia3.htm)

Other promising steps on the policy level are related to the tasks outlined in the Mental Health Policy for coordination and strengthening of the network between the above mentioned programs and the Program for prevention and control of HIV/AIDS; education of the generalists in development of sensitivity to the mental health problems; inclusion of topic on mental health in the Health education course for the secondary education; development of programs and services for early detection of and intervention not only in the severe but also in the common mental disorders.

As a whole the mental health needs and problems of PLHIV/AIDS are not an object of special concern on the level of mental health policy and services.

“They (first people diagnosed with HIV in Bulgaria) had never yet received psychological support. They continue to fight with the trauma from rejection. They need to talk with someone but there is no one.”<sup>24</sup>

“Other people or organizations are not skilled to make assessment that there is a need of psychological support. ... They also have no resources to do this. There is no recognition of the need of specialized training.”<sup>25</sup>

The same is valid for the recognition of the vulnerability of the people with mental disorders through some risky behavior to the HIV and AIDS. Because of the stigma that keeps hidden the problems of bought people with mental disorder and PLHIV/AIDS and the underdevelopment of evidence based policy and services in the health care and social welfare in Bulgaria the systematic study of the reciprocity between both conditions is not seen as a priority.

### **3.2. Policy and services in the field of HIV/AIDS**

There is well developed national policy in regard to PLHIV/AIDS. It is based mainly on two political documents - National Strategy and National Action Plan for Prevention and Control of HIV/AIDS and STIs (2001 -2007). They were developed in order to structure the efforts of different governmental and non-governmental stakeholders to minimize the widespread of the infection and to keep low the number of the PLHIV/AIDS in the country. Activities and services are organized in four priority areas of action:

- Health promotion aimed at young people and vulnerable groups;
- HIV/AIDS and STDs epidemiological surveillance and testing policy;
- Health care and social services for PLHIV/AIDS and STDs;
- Treatment of HIV/AIDS and STDs.

Since the beginning of 2004 the Program “Prevention and Control of HIV/AIDS” (2004-2006) was implemented with a grant from the GFATM that followed the priorities in the Action Plan. The main goals of this Program were:

- to sustain the low HIV prevalence in the country through strengthening the infrastructure and capacity building;
- to reduce risky behaviors within the vulnerable groups;
- to ensure access to care and quality treatment for target groups and PLHIV/AIDS.

---

<sup>24</sup> FGD with NGO members.

<sup>25</sup> FGD with NGO members.

The main focus of the Program was the preventive work among the groups most at risk – injecting drug users, male and female sex workers, Roma people, PLHIV/AIDS, young people, men who have sex with men, and prisoners.

One of the preventive measures focused on the risky group of young people is envisaged also in the National Program for Child Protection (2007). It relates to the enlargement of the health education at school with the purpose to prepare them for responsible sexual behavior, self-protection from HIV/AIDS and STDs and drug use. Currently HIV health education is provided as free elected subject in 183 schools from 17 municipalities.

Main stakeholders that exert efforts in this area of care and support are: the Department for Prevention and Control of AIDS, Tuberculosis and STDs at the Ministry of Health, the National Unit for Secondary Generation HIV Sentinel Surveillance at the National Centre of Infectious and Parasitic Diseases, the National Centre of Hematology and Transfusiology, non-governmental organizations working in the field. There are international bodies too that support the initiatives like UN agencies (UNAIDS, UNFPA, UNICEF), WHO and GFATM.

Financial support for the implementation of the basic political documents was given during this period by three sources – state budget, UN resources and the GFATM grants. Table 2 shows the amount of money on the yearly basis given through each of these sources.<sup>26</sup>

**Table 2.**

<b>Year</b>	<b>State budget (BGN)</b>	<b>UN resource (BGN)</b>	<b>GFATM grant (BGN)</b>
2005	4,212,400	820,267	6,867,735
2006	4,965,376	834,754	4,369,791
2007	4,835,666	558,415	4,128,527
<b>Total for the period 2005 - 2007</b>	<b>14,013,443</b>	<b>2,213,436</b>	<b>15,366,053</b>

The preventive activities and services are implemented at the national as well as the local level in 19 municipalities in cooperation with 52 NGOs, 10 Regional Inspectorates for Protection and Control of Public Health, the National Center of Infectious and Parasitic Diseases, and 138 schools from 13 municipalities. They provide education, information and HIV VCT through mobile or stationary clinics.<sup>27</sup>

The treatment and care activities are mainly in the area of provision of free of charge ARV programs and active hospital care for the illness in three cities. PLHIV/AIDS are also given social support and pensions as for the other groups of people with disabilities. Psychological and social support is given by three NGO services in the country.

The legislation was provided to support the right of confidentiality of the information related to the illness and the procedures through which it has to be ensured.

However because of the still low number of PLHIV/AIDS in Bulgaria the main activities are focused more on the general population and certain groups at risk with preventive measures

<sup>26</sup> **United Nations** General Assembly Special Session on HIV/AIDS. Country Progress Report: Bulgaria. Reporting period: January 2006 – December 2007.

<sup>27</sup> Lyubenova, Anna. Mental Health Structure for PLHIV/IDU in Bulgaria.

than on the group of PLHIV and their treatment. As a result of this they report to experience difficulties like<sup>28</sup>:

- some problems with the provision of drugs related to their constant treatment;
- centralized system of care that is provided only in the few of the biggest cities in the country that made the system difficult to access;
- material environment in the hospitals in a very bad condition;
- recognition only of the medical side of the illness and neglect of the psychological and social needs of PLHIV/AIDS and their families;
- lack of specific services oriented to the complex and coordinated work with the individual needs of this group of people;
- practical contradictions between the right of confidentiality about the illness and the official procedures through which PLHIV receive social support, general medical care and defense in the court;
- existence of discriminative practices in some of the services in the health care system, at work and in the community due to the lack of information, education and effective monitoring;
- treatment and care services not well prepared to work with socially isolated groups – for example illiterate, homeless, having no ID, etc. - which could give rise to various problems if the number of HIV positive drug users suddenly increases.

Currently a process of revision of the existing National AIDS Plan is running that will be followed by development and acceptance of new National AIDS Strategy and Plan for the period 2008 – 2015.

---

<sup>28</sup> FGD with PLHIV and results from the National HIV/AIDS Consensus Meeting 2006.

## 4. Mental health problems of PLHIV

### 4.1. Mental health problems experienced by PLHIV

„Overcoming psychological and health problems of infected people is the main way to ensure better quality of life for them.” (P. Malinov, president of Kaspar Hauser Foundation)

There are two basic sources of mental health problems of PLHIV/AIDS identified by the interviewed consumers and professionals: a) the illness itself and the capacity of the individual to accept and integrate it in his/her self-image and life and b) the capacity of the close environment of relatives, friends, colleagues and health and social professional to understand and support this person to rethink and reorganize his/her life.

According to the professionals<sup>29</sup> that offer emotional support and treatment of different mental health consequences of the illness in Bulgaria PLHIV/AIDS experience a range of feelings during each of its stages. During the time right after the diagnosis was reported to them PLHIV/AIDS describe the feeling of shock and the wish to avoid the information. As a result of this part of the people refuse the treatment and try to overcome the painful feelings on themselves own. Such behavior makes their health condition worse. The period of acceptance of the illness is supported by the recognition of the unavoidable changes in their lifestyle and the fear from the inescapable losses and death. In this period most of the people get vulnerable to depressive conditions and self-destructive behavior like alcohol and drug use. Other very frequent fears during the period of treatment reported by the PLHIV are related to their body integrity and the drugs as something toxic and damaging. Than part of them resort to the help of some alternative to the traditional medicine ways of cure that are publicly acceptable in this country especially when the illness is terminal or related to shame. According to the professionals the interruption of treatment leads to its ineffectiveness and again to worse health. Serious anxiety is experienced also when treatment is changed or when the condition gets so bad that there is no more chance to be treated. The mental health professionals stay in the position that the theme on death has to be discussed openly during this stage.

The interviewed PLHIV take the position that such emotional problems are not taken into account in the process of treatment and their mental health needs rest unmet. The usual attitudes to them are that emotional problems are something private and person has to cope with them alone. So they are not recognized and included as part of the individual care plan and services.

Such kind of attitudes point out how important the counselling process is for the mental health of the PLHIV/AIDS. They need an environment which mirrors the worries and anxieties that they have and shows solidarity and support. Because of the lack of enough information about the illness from the one side and the family culture of keeping silence on the topics of sexual and emotional life from the other the usual reaction of those around is of fear of not being infected by the ill relative. Usually this fear is transformed in a view on this person that characterizes him/her as naïve, immoral or bad. Such kind of judgment leads further to stigma and discrimination towards him. Some of the interviewed describe drastic cases of rejection by parents and relatives, of discharge and lack of concern and respect to their personal dignity from some professionals. These attitudes provoke feelings of loss of

---

<sup>29</sup> Kaspar Hauser Foundation

prospects for their future and lead to risk of mental disorder. People feel guilty, ashamed, and hopeless and blame themselves about the situation.

“Stigma and discrimination evoke in people ... depression, low self-esteem and despair. The negative attitudes towards PLHIV/AIDS urge them to fear of stigma and discrimination more than from the illness itself. Due to the apprehension that other people could associate them with the illness many people prefer not to provide precautions against it in order to keep their secret.”<sup>30</sup>

Most of the PLHIV/AIDS in Bulgaria prefer to keep secret on their illness. This dooms them to constant fear of revelation, shame and collapses of the trustful relations with the important others. The feelings of absurdity of the situation, of decay and chaos disturb their ability to organize and prioritize the things in their life and lead them to emotional crisis. According to observations of some mental health professionals due to the lack of public and family culture of open discussion and sharing of personal problems even the pronouncement of the secret in front of professional and in confidential environment became traumatic experience for that person.

The existence of mental health problems in addition to the HIV/AIDS doubles the stigma and the painful experiences. Because of the inadequate response to these conditions they persist and get worse.

When the secret is dealt with the family the emotional burden of illness and stigma related to it broadens the group of people suffering from mental health problems. Unfortunately their emotional problems are not adequately recognized and provided with professional support. The only place where they can receive emotional support and treatment are the two NGOs that offer specific programs and referrals to mental health services.

Professionals from one of these services have identified specific group of PLHIV/AIDS that suffer from the experience of severe trauma and stress. These are the first people diagnosed of having AIDS in 1986. The first cases identified in the country have been a subject of harassment and violence. They was deported, closed and isolated from the world not being even informed about the reasons for that. Their relatives were forcibly tested. Later they and their relatives had to sign declaration that will not infect other people. When removed to the hospital part of the personnel refused to care for them. Now the professionals from the service that supports these people argue that “till now they continue to live with the anxiety of being persecuted” and need professional treatment for this.

All of the experiences described here have not been an object of systematic evaluation and study. The emotional aspects of the experience of being ill from HIV/AIDS and live with this in Bulgaria still rest neglected.

#### **4.2. Stigma and discrimination situation: existed and experienced**

Research findings suggest that the most important causes of stigma in Bulgaria are a) people’s fear of casual transmission from PLHIV/AIDS and b) moral judgments and assumptions made about the lives and lifestyles of those affected.

---

<sup>30</sup> Малинов, П. и др. Проучване нарушаването на пациентските права на хора, живеещи с ХИВ/СПИН при съпътстващи заболявания. С., Фондация „Каспар Хаузер”, 2006.  
(Malinov, P. Study on the violation of the human rights of PLHIV/AIDS when having concomitant illnesses.)

The fear is partly related to general fear that accompanies other infectious diseases, such as other STDs and partly to the fact that people are uncertain about the ways in which HIV can be transmitted or do not fully trust the knowledge they have acquired. Some of the messages about HIV transmission are both terrifying and vague - a combination that seems to have led to greater confusion and fear than to solid understanding and awareness. And out of this confusion and fear arises stigma.

According to the health professionals they don't have sufficient knowledge about protection means and emergency prevention of HIV/AIDS transmission at providing surgical interventions, at deliveries and other manipulations related to blood. They also say that protection means include only gloves. Protection glasses are available only in a limited amount.<sup>31</sup>

"I am a health professional. I know that HIV is transmitted only in three main ways. But when I come into contact with them [PLHIV/AIDS] I still worry and feel nervous... In my case it is my duty, my responsibility to work with them, to go to them. But in fact I am fearful." (Малинов, П. и др., 2006)

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

These underlying causes appear to be reinforced by some media portrayals and inadequate messages about HIV and PLHIV that promote negative and fearful images - heightening people's fears and uncertainties, rather than exposing them to consideration and debate.

The moral dimension of stigma relates to the fact that until this day HIV and AIDS are strongly linked in policy, programs and in peoples' minds with homosexual contacts, injection drug use and sex work considered to be socially unacceptable. That is why not all HIV infected people bear the same level of stigma. A number of participants in the study think that moral judgments against PLHIV should be based on how that person acquired HIV and on their lifestyle. According to some community members PLHIV can be classified into two different groups according to the reasons of infection. The first are those who are "degraded" and were infected due to deviant behaviours such as drug injection and prostitution. This group deserves blame and social opprobrium.

In Bulgaria the families of IDUs or sex workers who became HIV infected are also criticized heavily arguing that the family has neglected the education of children and they get degraded.<sup>32</sup>

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

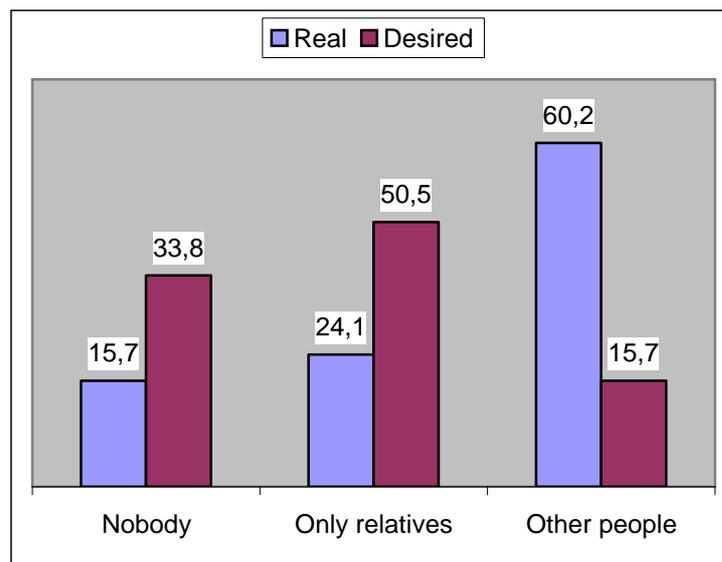
---

<sup>31</sup> Interviews with nurses and other clinicians

<sup>32</sup> Casper Hauser Foundation documentation

According to the PLHIV/AIDS there are two basic issues in relation to the existing stigma that they experience: a) leakage of confidential information about the illness and b) refusal of provision of medical care by some clinicians.<sup>33</sup>

Intolerant public attitudes are the reason that every sixth PLHIV keeps the secret on the illness. Almost every fourth of them has confided only to the very closest relatives. Despite of this the actual number of the people that know about the illness is much bigger than they would like to be. The reason for this discrepancy lies in the violation of confidentiality of information about the illness. In Figure 1 could be seen the distribution in percentages between the real and desired level of confidentiality about the HIV status of PLHIV/AIDS.



**Fig. 2.** Study on the violation of the human rights of PLHIV/AIDS when having concomitant illnesses. (Малинов, П. и др., 2006)

The conclusion could be made from these data about the high level of stigma that makes PLHIV keep the secret on it. After being positively diagnosed, these people are frequently forced to leave their job or are fired. As a result of this they loose their social status and environment. They leave in poverty and isolation. So the disclosure of the information about the illness makes these people rather vulnerable in such intolerable social environment.

“My mother asked me why I didn’t tell her that I have AIDS but I didn’t know yet, I though they treat me for pneumonia.” (Малинов, П. и др., 2006)

“The mayor called me and asked me if that is true that I am ill form AIDS. He told me that he has received an anonymous letter but didn’t show it to me. I didn’t believe him and I suppose that my family doctor has told him. My chief forced me to do test and I left the town.” (From the same source of information)

“In the emergency department the doctor asked me if it is true that my wife is ill from AIDS and if she is still alive...” (From the same source of information)

<sup>33</sup> Малинов, П. и др. Проучване нарушаването на пациентските права на хора, живеещи с ХИВ/СПИН при съпътстващи заболявания. С., Фондация „Каспар Хаузер”, 2006.

“I was tested in the prison and the whole prison learned about that. My life became unbearable!” (From the same source of information)

The data also show how deep are the neglect of the rights of PLHIV/AIDS and the lack of understanding in the society towards the difficulties that they experience. They are denied the opportunity to decide themselves when, how and to whom to tell about the illness.

PLHIV/AIDS in Bulgaria now receive specialized medical care in one of the departments of the Hospital for Infectious Diseases in Sofia. But this care is only for the opportunistic infections related to the illness. The other concomitant illnesses are treated in conformity with the general health legislation in the public health care system. The study shows two general discriminative tendencies in relation to this kind of care: a) Rejection to provide medical services to these people especially when related to blood manipulations; b) Lack of understanding from the personnel that the AIDS doesn't mean the patient is totally doomed and that it is not possible to control the illness. As a result of this their health needs are seriously neglected.

“I went to the doctors in my town and after the observation they told me that I have to be operated. I really had serious pain! But when I informed them about my diagnosis they refused to make the operation. They just refused it! I tried in another hospital and they refused too. I didn't know what to do. The pain was unbearable! Than I went to another town, didn't tell them anything about the illness, what I could do!, they made the operation and now I fell well...” (Малинов, П. и др., 2006)

“The doctor said, ‘Why you brought this patient to me with such diagnosis?’, and expelled us from the consulting room.” (From the same source of information)

“I told the dentist that I have AIDS and he said, ‘It can't be done here, not in my clinic.’. I said that I will pay but he refused. He said ‘I can't see you, here is not a place for people like you!’” (From the same source of information)

“To people like you the teeth just have to be extracted...” (From the same source of information)

Because of the severity of stigma PLHIV/AIDS prefer not to use clinical treatment and social support services. Some of the interviewed reported that they are afraid to go to social services in the municipality because they have to inform them about the illness when asking for some aids. This fact additionally leads to discrimination of the right of these people to receive equal opportunities and care as the other people.

“I just don't go to dentist. I have problems with the teeth but when imagining how they will react to my information about the diagnosis of AIDS ... however I can't go and keep the silence...” (Малинов, П. и др., 2006)

There is well developed legislation in Bulgaria concerning human rights including those of PLHIV/AIDS (Constitution of Republic of Bulgaria, Public Health Law, Health Insurance Law, National Frame Agreement, and Penal Code). But according to the PLHIV/AIDS the procedures in the court are very slow and ineffective. At the same time because of the stigma and its consequences the sanctions that the law provides couldn't be applied in reality. In

order to submit the case to the court PLHIV/AIDS which rights were violated have to reveal the secret and to be exposed again to the stigma.

However the optimism for the future comes from some anti-stigma efforts undertaken by governmental bodies and nongovernmental organizations and media. In the future they have to focus on those factors that currently underpin stigma: people's fear of casual transmission and moral judgments against PLHIV and their families. Effectively addressing these root causes of stigma will enable and encourage those infected and those at risk to take necessary and appropriate measures to prevent further transmission and to live healthy, productive lives.

#### **4.3. PLHIV needs regarding mental health issues**

The classification of emotional and social problems experienced by PLHIV/AIDS as described above could help policy makers and helping professionals to identify the mental health needs of this group of people and to develop specific methods of work with them. This kind of evidence based policy and practice is in its first steps in Bulgarian political and service culture.

According to the members of Kaspar Hauser Foundation PLHIV/AIDS need constant emotional support. That is why their center has developed system of services that support PLHIV/AIDS in the process of overcoming the emotional crisis and adaptation to the new living conditions. These services include:

- Health education that helps PLHIV/AIDS to orient in the consequences of their illness and to structure their behavior towards them in a constructive way;
- Crisis consultation to overcome the experiences of shock and loss;
- Case work to individually support each person to identify his/her personal needs and problems and to plane steps to resolve them;
- Psychological assessment with standardized instruments for early identification of mental health problems;
- Self-support group to minimize the isolation and sadness and to empower PLHIV/AIDS;
- Referral to specialized mental health care in case of serious mental problems.

Professionals also identify certain mental health needs of the families of PLHIV/AIDS that in most cases are the natural supportive environment that ensures better mental health of those people. So the centre offers as part of its mental health program of care psychological consultation and health education also to the relatives.

In the process of work with PLHIV/AIDS some of the professionals realized the importance of legal protection and education on rights of the PLHIV/AIDS. These kind of support increases their self-esteem and courage to face the situations of discrimination.

This good practice of the centre in the area of mental health needs of PLHIV/AIDS is recognized by the policymakers and recommendations were given to the services in the field of HIV/AIDS treatment and support to implement them. Unfortunately it is not part of the current situation of care because of two basic reasons:

- lack of purposeful investment in evaluation of the existing practices, lack of education of the staff and provision of mental health professionals in these services, lack of implementation of modern mental health approaches and technologies;

- lack of effective network for planning, implementation and monitoring of mental health services for those people working on multidisciplinary principles.

Part of the consumers suggests that psychological support is needed in the VCT centers where people learn about their diagnosis and are referred to specialized treatment. Currently only clinicians work there but they are not prepared to work with the emotional side of the illness. Up to now the only ITC that has implemented pilot service for psychological counseling is situated in Medical Academy in Sofia.

Both consumers and mental health specialists agree about the need of PLHIV/AIDS to talk about the illness and to discuss their fears. This will help them to overcome their fear of being seriously mentally ill and to validate their natural emotional reaction to the illness by anxiety and sadness. Some psychiatrists suggest that in the list of the services to be included such preventive measures as: a) standardized evaluation for depression and other mental disorders that are common for this group of people; b) prescription of antidepressants as a palliative measure; c) psychotherapeutic work with the focus on the topics of illness, loss, death and suicide.

The organization of the existing services and their monitoring in a way that will ensure respect for human rights and confidentiality will reduce the anxiety of PLHIV/AIDS. For instance one of the good practices implemented in Sofia is that the name of the illness is not present in the official documents that order support and relief funds for those people.

## 5. Voluntary Counselling and Testing Services

### 5.1. Service access, use and clients' satisfaction

Voluntary, confidential HIV testing is free of charge for Bulgarian citizens. Blood samples may be taken at any healthcare service unit. They are then sent to one of the 28 Hygiene and Epidemiology Inspectorates (Bulgaria is administratively divided into 28 regions) or regional Dermatovenerological Dispensary Laboratories (DDL) for analysis. If the result is positive, the sample is sent to the National AIDS Confirmatory Laboratory in Sofia. In order to observe confidentiality, copies of the records are submitted to the MH and regional DDLs by special delivery service. The MH reports the new cases of HIV/AIDS to the European AIDS Control Centre in Paris every six months.<sup>34</sup>

One of the four major components of the National Action Plan that represents the overall policy of the country is related to HIV/AIDS and STDs epidemiological surveillance and testing policy.

Since 2001 and the adoption of the National Action Plan for Prevention and Control of HIV/AIDS, the MH has been making considerable annual budget allocations that cover the country needs between which were the needs for universal and free-of-charge HIV testing and for supply of medical equipment for the needs of the NCIPD, National Reference Laboratories and laboratories performing HIV testing at the RIPCPH and DVD. Part of the activities in the Program "Prevention and Control of HIV/AIDS" (2004) concern the strengthening and promoting VCT services.

Under the leadership of the National AIDS Committee and the MH with the active support and participation of UNAIDS in 2006 broad participatory country consultations on the universal access to HIV services in Bulgaria were conducted. Draft report was produced and distributed for review and comments to key stakeholders, including UNCT and to more than 40 NGOs working with vulnerable populations under the GF program.

Strengthening and expansion of the network of VCT centres aiming to provide easily accessible, voluntary and non-discriminatory services is reported as one of the successful practices in the program.<sup>35</sup> Initially in 2003, 9 VCT centres were established with WHO financial support. Currently, the operation of these together with 10 new VCT centres is financially supported by the GF. Bulgaria is the first country in the region to implement concerted policy to encourage voluntary and free-of-charge counselling and HIV testing. At present, 12 of the 19 Voluntary Counselling and Testing centres are coordinated by Regional Inspectorates for Protection and Control of Public Health; 1 by the NCIPD (at the National HIV Confirmatory Laboratory) and 6 by NGOs. There are several major points to highlight regarding the provision of VCT services in the country:

- data analysis shows that there are higher rates of visitors to the fixed VCT centres from the target groups due to the active referral on the side of the NGO subrecipients;
- VCT services for the target populations are provided through different approaches including 19 stand-alone VCT centres, 5 low-threshold centres for IDUs, 8 health and social centres in Roma neighbourhoods and 12 mobile medical units;
- starting in 2004 and 2005, in collaboration with the Ministry of Justice, VCT centres started outreach work with inmates, for example in the prisons in Bourgas, Plevan, Sofia, and Stara

---

<sup>34</sup> Overview of HIV/AIDS in South Eastern Europe 2002.

<sup>35</sup> Country Progress Report 2008.

Zagora. In December 2006, a joint Order of the Minister of Health and the Minister of Justice, regulating the regular provision of VCT services in all 12 prisons, and 4 detention centres;

- three of the stand-alone VCT centres provide expanded services, including not only free-of-charge counselling and testing for HIV, hepatitis B and C, and syphilis, but also free-of-charge STIs testing and treatment, mainly for the vulnerable groups;

The increase in the number of registered cases after 2004 is to a great extent due to the active funding, provision of HIV prevention services among the groups most-at-risk, referral for testing, care and support within Program “Prevention and Control of HIV/AIDS”, financed by the GF to Fight AIDS, Tuberculosis and Malaria. The number of HIV cases found by the networks of VCT centers and NGOs implementing outreach activities, grew from 3 in 2003 to 40 in 2006

**Table 3. Number of newly registered HIV cases, Bulgaria, 2000-2006**

Year	All registered cases	Referred by health facilities	Referred by VCT and NGOs
2000	49	49	-
2001	40	40	-
2002	43	43	-
2003	63	60	3
2004	50	44	6
2005	83	69	14
2006	91	51	40
<b>TOTAL</b>	<b>419</b>	<b>356</b>	<b>63</b>

Data analysis shows that the case detection rate with VCT and NGO services is 6 times higher than the case detection rate in health facilities performing diagnostic and screening testing.<sup>36</sup>

Source: Ministry of Health, Department for

Prevention and Control of AIDS, Tuberculosis and STIs

The effectiveness of program activities is also ensured through boosting national standards and best practices in the community-based approach. The results of National Composite Policy Index (NCPI) part A and part B point out as main progress in the implementation of preventive programs in the country the increase of geographical and population coverage of the target groups reached with specific services. Significant increase was found in the interest of most-at-risk representatives, who were tested for HIV during the year 2006 in comparison to the year 2004.

In 2006, the percentage of sex workers who report having an HIV test and knowing their results is 53% (548 out of 1 041 respondents), which indicates a tendency of significant increase compared to baseline data for this group in 2004 - 35%. The tendency of significant increase is explained through the active provision of preventive services with the support of NGO implementing outreach activities and standalone VCT Centres. This is evidenced by the high percentage of sex workers reached with HIV prevention programmes in the same year - 77%, although this group, and street sex workers in particular, remain hard-to-reach due to more frequent police actions. The percentage of injecting drug users who report having an HIV test and knowing their results indicates a twofold increase (from 17% in 2004 to 38% in 2006). The percentage of men who have sex with men, who report having had an HIV test and knowing the result in 2006 is 29% (57 of 199 respondents).<sup>37</sup>

One of the best practices reported by the government is the situation analysis and assessment of local needs and resources to select districts from the perspective of potential rapid spread of

<sup>36</sup> Country Progress Report 2008.

<sup>37</sup> The same as above mentioned.

HIV to implement program interventions. According to this services to target groups were provided mainly in 19 of the 28 districts. Additional infrastructure has been established to ensure accessibility and coverage of specific services to hard-to-reach populations, including 19 Voluntary Counselling and Testing centres, 12 mobile medical units, 5 low threshold centres for injecting drug users and 8 community-based health and social centres for Roma people.



**Fig. 3.** The initiative of mobile support care started in the 90-es of 20<sup>th</sup> century when under a SOROS funded program 6 mobile medical units (MMUs) equipped and specialized for work with sex workers were started in Sofia, Varna, Rousse, Plovdiv, Haskovo and Bourgas. All of them functioned under the auspices of the Ministry of Health. Their maintenance was delegated to a number of local NGOs and medical staff was provided by the local STI clinics. This allowed the MMUs to function as a bridge between sex workers, STI clinics and other public health and social services.

Within the framework of Program “Prevention and Control of HIV/AIDS” in 2005 12 mobile medical units providing free and voluntary counseling and testing for HIV were indorsed and are operating in different cities to reach vulnerable groups – injecting drug users, sex workers and Roma population, where outreach work is conducted.

Interviewed consumers as well as professionals from the VCT centers agree that the access and use of these services is good and that the clients are satisfy with them. They explain this success with the information and initiatives represented in the media and also with the implementation of health education in the schools.

One of the problems identified by the professionals however is the provision of drugs on time. The other is the centralized system of care. So after the first test in the local VCT center the client with positive result has to go to the Confirmation Laboratory in Sofia for second testing. The lack of services that provide emotional and social support some times urges clients to go back to the VCT center where some trustful relationship has been developed.

Some of the VCT centers have questionnaire for evaluation of client’s satisfaction but it is not used regularly and for planning the policy and management of the service. This fact is part of the overall lack of evidence-based practices in the country. The only criterion for client’s satisfaction is if he comes again for consultation or help.

The other problem is that counselling in CRAFCT for instance is difficult to provide because of a) the lack of enough personnel to provided testing and b) the absence of well prepared professionals that are aware bought of the clinical part of the illness and the testing procedures and of the emotional experiences that people have during this procedures and psychological approaches that are appropriate to use in such cases.

In the smaller towns people are less inclined to test themselves as the local environment makes it impossible to guarantee confidentiality. Interviewed professionals report that these people usually come to them in the bigger towns and prefer to go to the NGO driven centers because of the lack of trust. They are afraid that the rule of confidentiality is much more easily to break in the small community or governmental structures. (‘They just know us there.’)

## **5.2. Guidelines and protocols**

In the light of joining the European Union on 1<sup>st</sup> January 2007, Bulgaria has been included and participates in all major European networks and initiatives related to HIV prevention and control and testing policies and practices in Europe. But much earlier in 2000 the first VCT centre was developed to the Medical Academy in Sofia with the financial and methodological support of Médecins Sans Frontières branch for Bulgaria. From the very beginning the tradition was developed to combine testing with pre- and post-test counselling.

Currently a network of VCT centers called Counseling rooms for anonymous and free-of-charge AIDS counselling and testing (CRAFCT) is developed in all county towns as part of the local departments of Hygienic and Epidemiological Inspectorate or as NGO run services. During this period MH with the support of NCIPD and UNDP developed several guidelines to support the work of professionals from the centers. One of them is “Manual for the Consulting rooms for anonymous and free-of-charge HIV/AIDS consultation and testing” (2003) where the procedures of pre- and post-test consultations are described. The main topics of the consultations are:

### **Pre-test consultation:**

- Explanation about the nature of the test that will be applied and how it works;
- Explanation about the significance of the results and what they mean in relation to the illness;
- Risk evaluation of the client that includes the potential factors for HIV infection;
- Information about the existing preventive measures to overcome certain risks of infection;
- Interview and assessment of client’s ability to cope with the stress related to the positive test if such occurs and how to proceed further when the test is negative;
- Negotiation with the client about the testing procedure and informed consent on it.

### **Post-test consultation:**

#### **A) For the positively tested clients**

- Announcement of the results;
- Emotional support;
- Discussion about client’s willingness to reveal the information;
- Negotiation about the referral to specialized care.

#### **B) For the negatively tested clients**

- Announcement of the results;
- Consultation about the risky behaviors and preventive measures;
- Negotiation for further consultations, if necessary.

“Revised Guidelines for HIV Counseling, Testing, and Referral” (2004) also is used by the professionals in VCT services. The specific topics there include the process of informing the client about the diagnosis, preventive counseling about HIV, who provides preventive counseling, possible barriers in the process of counseling, provision of high quality preventive counseling, referral to the specific services and typical needs of the clients during the referral.

## **5.3. Staff training and corresponding needs**

First VCT centres have been trained by foreign professionals from the funding bodies. For instance the team of the first centre in Bulgaria of this kind developed by Médecins Sans Frontières was prepared in this way.

After the development of policy and program under the GF regular trainings are provided specifically for the new professionals in the centres or for the overall staff in some specific topics. This training is part of the Component 3 activities of the Program concerning Development and implementation of voluntary counselling and AIDS testing system. Part of the planned activities in this component is related to education of professionals and development of manuals for them. Other task in this component is the development of instructions for professional counseling and provision of psycho-social support to PLHIV/AIDS.

For the centres driven by NGOs is difficult to plan money for additional training of their staff because of the lack of sustainability of their programs depending on the existence of projects to work on.

UNDP from the other side focuses on strategic planning and change, especially at the national level. Funds support training civic organizations to develop local plans, conduct rapid assessments, and implement plans of action using national funding as well as municipal budgets and small grants.

Specific training for GPs, medical students, and dental students to recognize and refer for HIV/AIDS services and more specifically to VCT services is not organized up to now. Interviewed GPs stay in the position that people usually go to more confidential places as VCT centers in order to make test and they do not use the GP care system. So they think they have no need to be trained in HIV testing or referral.<sup>38</sup>

---

<sup>38</sup> FG with general practitioners.

## 6. Mental health problems of PLHIV who are IDU

### 6.1. Organizational structures, policies and management of PLHIV/IDUs programs

In the area of **HIV/AIDS policy** there are two political documents that recognize as a specific group PLHIV/AIDS who are IDUs and envisage certain decisions for their problems. National Program for Prevention and Control of AIDS and Sexually Transmitted Diseases: 2001-2007 defines six groups at risk one of which is the group of intravenous drug users. The program puts special emphasis on prevention measures for drug users as outreach programs, health education, needle exchange as well as health and social care programs for development of effective and adequate home-based, outpatient and inpatient treatment; ensuring supportive social environment; tackling the problems of social status and employment<sup>39</sup>.

During the first years of program implementation, however, the funds provided by the government covered exclusively the testing system and the medical treatment of PLHIV. Prevention programs, as well as psycho-social services for PLHIV were funded by independent projects of foreign donors. In 2004 the situation changed significantly as the country received a grant from the GFATM for its project "Prevention and Control of HIV/AIDS among the groups most at risk in Bulgaria 2003-2007". The project is based on the National Program and targets generally the same vulnerable groups including the group of PLHIV who are IDUs. Among its objectives<sup>40</sup> is the Objective 4: Sustained low HIV prevalence in intravenous drug users' group.

**Policy on drugs** is based on National Program for Prevention, Control and Rehabilitation of Drug Addictions in the Republic of Bulgaria 2001-2005 and National Strategy against Drugs 2003-2008. The global goals of the National Strategy refer more to the reduction of supply than to the reduction of demand. Only first of the five goals is focused on the limitation of the use of narcotic substances through provision of effective treatment and prevention<sup>41</sup>. Section 5 of the strategy recognizes the reduction of blood-transmitted infections including HIV and other harm reduction measures. The activities and programs envisaged in the National Program<sup>42</sup> also include establishment of system for early treatment of blood-transmitted infections. Both the Strategy and the Program however do not state any specific interventions or measures targeted at HIV positive drug users. These two documents were never properly implemented in practice due to the fact that the planed for their implementation funds were never provided by the government.

---

<sup>39</sup> National Program for Prevention and Control of AIDS and Sexually Transmitted Diseases 2001-2007, Ministry of Health, 2002, p. 20-23

<sup>40</sup> Project proposal "Prevention and Control of HIV/AIDS/TB among the groups most at risk in Bulgaria 2003-2007", presented by the National Committee to fight AIDS and Tuberculosis

<sup>41</sup> National Strategy against Drugs 2003-2008

<sup>42</sup> National Program for Prevention, Control and Rehabilitation of Drug Addictions in the Republic of Bulgaria 2001-2005, available at: <http://www.ndc.government.bg/?l=bg&pid=documenti-programa>

The funds mainly serve the maintenance of the National Center for Addictions and the only state-run hospital for drug treatment as well as the supply of methadone for substitution programs in the country. Few funds have been distributed to NGOs for rehabilitation programs (after 2006) but none of them for prevention or other related activities. That is not to say that such activities were not present in the country. A number of NGOs are active in the area of drug prevention, harm reduction and rehabilitation but thanks to projects funded by foreign donors. Unfortunately these activities are not sustainable and coordination between them is difficult.

The **legislation toward drugs** has been intensively changing in the last 7-8 years. Especially important in regard to HIV prevention and care for drug users is the criminalization of risky behavior. In 2000 the Penal Code stated imprisonment of 10-15 years for all who produce, distribute or hold illicit drugs but there was a special article stating no punishment for individuals who were addicted to drugs and possess a small amount called “personal dose”. In 2004 this article was outlawed and a legal situation arose in which every possession of any amount of any illicit drug had to be punished with long imprisonment. This amendment of the Penal Code provoked stormy reactions in the civil society and the court system. It also created serious obstacles for harm reduction and other healthcare programs for drug users because the drug users’ group became more hidden and hard-to-reach for any intervention. In 2005 the Initiative for Health Foundation and the Open Society Institute published a report outlining the increased risk of HIV and other adverse health consequences among drug users due to the new legislative situation<sup>43</sup>. In the same time the Law for Control of Narcotic Substances and Precursors (1999) and its sub law regulation<sup>44</sup> arranged the operation of pre-treatment programs for reduction of the drug related harm and the Ministry of Health applied its broad HIV prevention project with 10 outreach programs trying to reach drug users. Therefore there was miss-coordination on the policy level in the area of prevention and care for drug users.

In 2006 after some public discussions and critical remarks from the European Union the Parliament adopted new amendment of the Penal Code with an article that lightens the punishments by decreasing the years of imprisonment and foreseeing only fine for the “insignificant cases”. However the main concern rests that drug use still remains criminalized and every drug holder would go to a trial which is rather restrictive then care-taking policy.

The HIV testing is arranged by Regulation 4/2.04.1992 of the Ministry of Health. According to it the testing is voluntary (with the exception of donated blood and blood products) and anonymous. The document strictly regulates the right of confidentiality.

## **6.2. HIV/AIDS and mental health services for IDU**

The system of **treatment of drug addictions** is linked to the overall healthcare system in the country. There are different types of programs in this field like in-patient and out-patient detoxification programs, rehabilitation programs, methadone maintenance, self-support groups. Unfortunately these are not always properly linked between themselves and accessible due to the fact that they are applied by many different actors and the participation of the state is not always on the necessary level.

---

<sup>43</sup> Tihomir Bezlov, *Heroin Users in Bulgaria One Year After Outlawing the Dose for “Personal Use”*, Initiative for Health Foundation, Open Society Institute, Sofia 2005

<sup>44</sup> Law for Control of Narcotic Substances and Precursors, art. 88 and Regulation N30/ 20.12.2000 of the Ministry of Health

**Outpatient detoxification** is widely available in the frames of the main package of primary out-patient healthcare, part “Psychiatry” which is funded by the health insurance fund. However it is significantly underused due to several reasons:

- 39% of drug users (according to data from 2007<sup>45</sup>) do not have health insurance rights since they are not able to pay for them;
- lack of psychiatrists trained and motivated to work with drug addictions especially in the small towns;
- bureaucracy and lack of confidentiality in primary out-patient healthcare.

The private treatment programs are of higher quality and in better conditions but are quite expensive for the majority of drug users and are available only in the bigger cities.

**Hospital detoxification programs** belong to the in-patient psychiatric care completely funded by the government that makes them accessible even for those who are not able to pay for any kind of healthcare. In 2007 there is only one state-run hospital specialized in treatment of narcotic and alcohol addictions with 14 beds for drug users. It is insufficient to cover the needs of the big population of 12,000 problem drug users in Sofia only. Hospital care for drug addicts is provided also in the psychiatric departments of the general hospitals as well as in the specialized psychiatric hospitals. The disadvantages of this kind of service that make it unpopular among drug addicts are:

- drug users staying in common departments with other psychiatric patients<sup>46</sup>;
- personnel is described as unfriendly and material base as bad;
- treatment programs provide simple medical detoxification with no rehabilitation follow-up which makes this kind of treatment poorly effective.

Although the **methadone maintenance** is available in Bulgaria already for 12 years its real development was observed only in last couple of years. In addition to the state-run programs there are four private programs where patients pay for their treatment. Methadone maintenance in state-run programs is not accessible even for local residents because their capacity is full and they do not accept more patients. Paid programs, where existing, are available just for those who can afford them.

As it refers to HIV positive opiate addicts it must be underlined that these are easily and without formalities accepted in the state-run methadone programs immediately after their HIV status has been discovered. However this raises a question of keeping their confidentiality as it is a well known fact among the IDU group that easy and immediate access is possible only for HIV positive people and pregnant women.

The available **rehabilitation programs** (therapeutic communities and day care centers) are usually provided by NGOs or private companies which are not directly linked to the healthcare facilities. The state-run healthcare programs lack funds to run such long term rehabilitation. Like many other health and social services provided by NGOs in the country these also lack stable governmental funding which makes their survival difficult and unsustainable though they usually provide services of good quality and are able to focus more on mental health problems than on the medical part of the addiction problem. All of them are forced to charge clients for their services. This makes them inaccessible for all in need and hard-to-link to the free state-run detoxification programs as a follow-up intervention.

---

<sup>45</sup> *Treatment Demand and Barriers to Access Among Problem Drug Users in Bulgaria*, National Focal Point, Initiative for Health Foundation, 2007, not published

<sup>46</sup> Interview with Elena Yankova, executive director of the Initiative for Health Foundation, September 2007

In 2007 there are 10 *harm reduction programs* for drug users in the country. All of them are run by NGOs and in 2004 GFATM ensured their significant financial stability with five-year funding. All programs apply outreach approach to target group of IDUs and in addition five of them also hold drop-in centers. The programs provide sterile injecting equipment and paraphernalia (syringes, needles, cookers, filters, disinfecting wipes, vein creams and others), distribute condoms, collect and destroy used syringes, distribute health information materials, provide counseling and referrals to healthcare services. Four of these programs are equipped with mobile medical units (vans) and provide on-site blood testing for HIV, hepatitis B and C and Syphilis. All programs work free of charge and anonymously which makes their services accessible.

The system of **treatment of HIV/AIDS** in Bulgaria consists mainly of VCT services, mobile HIV support clinics, ARV treatment, and mental health services. All of those services are available also for PLHIV/AIDS who are IDUs. Unfortunately the coordination of the treatment and care for the HIV/AIDS from the one side and the drug addiction from the other is poor and there is no multidisciplinary team work as a coordinated practice. The reason is that the technology of case management is not implemented and such difficult cases that include problems on the psychological, clinical and social level. So they are served in partial and sometimes contradictory way.

### **6.3. Mental health needs of PLHIV who are IDUs**

Having in mind the situation described above it is already clear that HIV positive IDUs are provided with basic services but there are still a lot of unmet needs.

One general great problem for PLHIV in the country is their poor economical status<sup>47</sup>. Some of them but only when they have serious health injuries are applicable for a disablement pension which is however extremely low (BGN85 = EUR44 per month<sup>48</sup>).

The problem is even more severe for those who don't have treatment available in their city or near it and have to travel every month to the hospital in other city. There is a regulation arranging the payment of these travel costs on behalf of the social system though it was not working properly for many years. Since February 2007 the Ministry of Finance started to release funds regularly to the municipalities to pay the travel costs of people who need medical treatment in other city so this problem is already addressed though it is sometimes impeded by bureaucratic obstacles. "A person, living with HIV in Burgas sometimes has to wait for long time and to collect five signatures from different municipality representatives in order to receive funds for treatment travel costs."<sup>49</sup> The problem is that these people have to reveal their double status of PLHIV and IDU in order to receive subsidies.

The problem with services not available in the city seems to be among the major obstacles for drug users living with HIV. In the cities Blagoevgrad and Bourgas – big cities with serious drug use problem – there are no methadone maintenance and HIV treatment programs. In both cities there is also a deficiency of professionals trained to work with patients having drug addiction problems and HIV<sup>50</sup>. PLHIV/AIDS and IDUs from those cities are directed to Sofia

---

<sup>47</sup> Interview with Pavel Malinov, Chairman, "Kaspar Hauzer" Foundation, August 2007

<sup>48</sup> Information from PLHIV.

<sup>49</sup> Interview with Antoaneta Radeva, Executive director, Dose of Love Association, September 2007

<sup>50</sup> Interviews with Antoaneta Radeva, Executive director, Dose of Love Association, and Mariana Mirkova, coordinator of harm reduction program, OBF-Blagoevgrad, September 2007

or Varna for medical treatment of their drug problem and/or HIV problem. This prevents some of them to seek treatment mainly because they lack finances, i.e. the centralization of services presents a barrier to access<sup>51</sup>.

*“A serious difficulty for drug users living with HIV in Plovdiv is the insufficient number of sites envisaged for them in the methadone program at the Regional Psychiatric Dispensary. The lack of identification papers presents an insuperable barrier, impeding their acceptance in the program. The counseling, provided by HIV services (VCT center, Dermatological Dispensary and Infectious Disease Hospital) is not adapted to the characteristics of the HIV positive Roma persons specifically, to their social, ethnic and religious belonging. The post-test counseling must be “translated” into understandable language for them. There is a lack of individual approach and sometimes even open discrimination toward Roma people.”* These impressions were shared by Assia Stoyanova, director of “Panacea” Foundation, an NGO that provides harm reduction services and HIV counseling and testing for drug users in Plovdiv.

It is hard to obtain information about the number of drug users who are on ARV treatment at least because they are not supposed to announce their drug dependence. According to the files of Kaspar Hauser Foundation they keep contacts with 11 drug addicts as their clients. The team however shared that they have received no training to work with drug users and this presents a serious challenge for them. According to their observations drug users are well accepted in the hospital and face no discrimination but still lack some specialized services. For example those who are on methadone maintenance and have to be hospitalized in the HIV department cannot get their methadone dose in the hospital and have to be released (often every day) to visit the methadone program. It is not clear however if this is a poor management from the side of the infectious diseases hospital or of the methadone programs which often require daily visits.

---

<sup>51</sup> Focus group with professionals from HIV prevention services in Blagoevgrad, May 2007.

## **7. Conclusions**

### **7.1. Policy and legislation**

There are well developed policies and action plans in both fields of mental health and HIV/AIDS. Despite of that fact PLHIV are not recognized as a group with specific mental health needs and problems and little concrete steps are planed to reach these needs.

Because of the still law number of infected people in he country the main focus of the policy on HIV/AIDS in on the prevention of the general population.

Mental health policy is underfinanced, the fact that prevents its practical implementation. Common mental illnesses to which PLHIV/AIDS are most at risk are not a policy priority up to now. It is but expected that the existence of national epidemiological research on these illnesses will facilitate the development of such political priority.

On the level of the ministries and administration there is a serious lack of collaboration on the issues of mental health as a whole.

The changes in the legislation ensure the provision of good quality, confidential and accessible services for PLHIV/AIDS but in the reality there is a serious violation of these rights due to:

- a) the ignorance and biases in relation to the AIDS and mental illness even between the professionals in both fields;
- b) the lack of effective monitoring of the health care and social support systems;
- c) the procedures and practices that threatened these rights.

Legislation still needs some adjustment to the reality of its implementation taking into account the stigma and the need of confidentiality in relation to the illness. There is no efficient control on the human rights protection and professional ethics implementation.

### **7.2. Services**

Despite of the existence of political documents envisaging collaborative efforts between the structures there is a serious lack of such practices on the service provision level. Mental health and social support as well as HIV/AIDS services and structures do not recognize the specific emotional needs of this group of people and do not plan specific programs to meet them. One exception of that situation is the existence of pre- and post-test counseling in the VCT services. There are developed guidelines for this. Unfortunately it is not applied regularly in this kind of services due to the law number of the staff and the lack of professionals from the field of psycho-social care in these services.

As a whole VCT services are well used and get more and more accessible through the development of continuously broadened network of such services on the territory. Public campaigns and school health education enforce the use of these services. The accessibility is difficult for the people from the small towns and villages and for all people with first positive test who have to go for the second control testing to one of the only three big towns with such laboratories. Social support is given for traveling expenses to those people but not all of them are eager to use it because hey have to reveil their illness in order to receive it.

Clients report of being satisfied by VCT services and some times they go back to the professionals there for additional consultations especially when the service provides counseling to them in an open, supportive and competent way.

Professionals from the general mental health services are not aware of the specific needs of the PLHIV/AIDS and their families. The still medicalized mental health care and the piloting stage of the community based psycho-social services in Bulgaria make the situation for this group of people not very optimistic. Only two NGOs in the field of HIV/AIDS services currently provide specific psycho-social counseling services and make referrals to the psychiatric care.

Even if the services and help are accessible for the PLHIV/AIDS because of the severity of the public stigma on them these people are urged to keep silence on their illness and the related to it problems and couldn't use the medical as well as the social support services in the same way as the other vulnerable groups.

The preventive measures and services took their roots deeply and now they give their fruits in various programs and local initiatives including media and school system. Unfortunately the issues of mental health problems of PLHIV/AIDS are only accidentally included in them.

Because of the low number of professionals like psychiatrist, clinical social workers, clinical psychologists, psychiatric nurses that are prepared to work with the emotional difficulties in the country such specialists are not included in the HIV/AIDS system of care. The culture of multidisciplinary work and the application of case coordination approach are still in their very beginning and are not part of the standard university education of clinical and non-clinical professionals working in the field.

### **7.3. Public attitudes and mental health of PLHIV/AIDS**

PLHIV/AIDS that suffer from drug addiction, mental illness and/or emotional problems related to the illness itself are doomed to double or triple stigma from the society that additionally affects in a negative way the life and the health of these people, their families, and their children. Due to the ignorance and negative attitudes in the society in relation to sexual behavior, homosexuality, drug use, prostitution, mental illness or minorities in Bulgaria these people are doomed to poverty, loss of job, home, relatives and friends. They are pushed to leave their neighborhoods and the towns and villages where they have been leaving for years. They are excluded from the society and are refused even medical services. To avoid such destiny most of the PLHIV/AIDS in the country prefer to hid the diagnosis even from their families and the very close friends. Unfortunately in both cases they suffer from the additional emotional effects of the surrounding environment. This changes for the worse their physical and mental health and the quality of their life.

### **7.4. Education and research**

The professional education in Bulgaria doesn't include specific courses on HIV/AIDS and mental health issues related to it in both clinical and psycho-social professions. Current education is not prepared to meet the challenge of the multidisciplinary team work. The research in Bulgaria is still closed in the academic institutions and is not part of the culture of the evidence-based practice and service and policy management. The research in both fields is poorly funded and depends on international sponsors.

## **8. Recommendations**

### **8.1. GIP program staff**

- Intercession for the inclusion of MH issues of PLHIV and their relatives between the priorities of health, social and educational policy and programs.
- Raise public awareness in relation to the stigma and discrimination through development of campaigns and initiatives including all stakeholders.
- Advocacy for better legislation and procedures that defend PLHIV rights of confidentiality and equal treatment and social opportunities.
- Supporting the widespread of the existed best practices developed by the NGOs engaged in psycho-social counseling and networking with mental health services.
- Exchange of service models and approaches in the field of mental health promotion and care for PLHIV between the countries.
- Provide additional counseling to the newly developed practices of NGOs in psycho-social care for PLHIV and their relatives engaging national and international experts from the field of mental health. (For instance, how to assess the needs and problems of children of PLHIVS and how to develop specific psycho-social support for them.)
- Further develop research on mental health problems experienced by the PLHIV and their relatives and friends. This should include research among mental health specialists on their understanding of the HIV problem and their preparedness to work with PLHIV
- Develop an alliance of organizations working in the fields of mental health care, HIV/AIDS, drug addictions and social welfare (local, national and international) in order to promote the issues of mental health and to coordinate the efforts for development of programs and standards for service quality assurance.
- Development of national network of media that fights stigma and raises awareness about the issues experienced by PLHIV.
- Lobbying on the EU level for the development of specific priorities and programs to ensure good quality of mental health care and social support for PLHIV.
- Train and sensitize general mental health specialists on topics related to HIV.

### **8.2. National AIDS program**

- Enlarge the existed policies and action plans on HIV/AIDS with the aims and activities concerning staff training and provision of psycho-social services, needs assessment, service evaluation, and case management.
- Strengthen the collaboration between the ministries in the fields of mental health, AIDS and social protection.
- Develop more effective practice of monitoring health and social services in relation to human rights, confidentiality, and effective care for PLHIV/AIDS.

- Collaborate with the commissions that provide expert assessment of the permanently reduced working capacity and social support services in order to ensure better confidentiality of the information about the illness.
- Initiate the implementation of evidence-based practice through the development of standards for mental health care of this group of people, service protocols and quality assurance approach.
- Provide trainings of different professionals on the psycho-social aspects of the illness and on the methods of work with them, on human rights protection, stigma and discrimination and professional ethics.
- Initiate inclusion in the curricula of courses or topics related to mental health issues and relevant treatment and care as part of the professional education of health care and social work specialties (psychiatrists, nurses, clinical psychologists, social workers, narcologists, infectionists etc.).
- Development of effective referral system between AIDS services from the one side and mental health and social support services from the other.
- Inclusion of mental health specialists (psychiatrists, clinical psychologists, clinical social workers, mental health nurses) in the staff of the VCT services.
- Implement case work approach, individual and group supervision and peer-review in the practice of the services for this group of people.
- Include more actively the NGO sector in the overall cycle of policy development, implementation and evaluation.
- Improve the public access to the statistics about the illness and information about the programs, activities, trainings, reports and monitoring.
- Initiate stakeholders' collaboration in the area of public campaigning, continuous education and interdisciplinary research.
- Ensure sufficient and sustainable governmental funding for the implementation of national programs on AIDS and drugs.
- Develop appropriate programs for patients with double diagnosis – drug addiction and HIV. This would include staff training, minimized bureaucracy, and ensured two-side services (for example, ARV and methadone) in one place.
- Reduce barriers to care for 'hard-to-reach' populations like people in prisons, homeless people, substance abusers, and individuals with severe mental illness.

### **8.3. National AIDS NGOs**

- Development of network between the NGOs in the field for self-monitoring, best practice exchange and research.

- Engage local communities in public campaigns against stigma and discrimination.
- Participation in policy development, training of professionals and NGOs, advocacy of concrete cases.
- Explore and multiply existing models of specialized programs for social and psychological support of PLHIV/AIDS.
- Study the obstacles and barriers to HIV services through the perspective of HIV positive drug users.
- Collaborate actively with healthcare services to ensure better access and conditions for socially isolated groups.
- Foster the incorporation of the HIV problems among the priorities of the social policy.

#### **8.4. International NGOs and organizations**

- Strengthen the efforts of different countries in the development of international policy, initiatives and programs related to the mental health and social wellbeing of the PLHIV/AIDS and their families.
- Facilitate the exchange of practices, experts and research between the countries.
- Enforce third sector initiatives and services through funding, expert knowledge and training.
- Monitoring of the existed practices in the field and develop recommendations on the international and country level.

#### **8.5. Additional study**

- Systematic and country specific study of the mental health issues among PLHIV including stigma and discrimination.
- Systematic assessment of the mental health needs and problems of PLHIV/AIDS.
- Assessment of the needs of the services in order to provide adequate care and support. Assessment of the existed local resources and obstacles that prevent it.
- Study of the HIV related risky behavior of the people with severe mental disorders.

#### **8.6. Possible approaches for programs or for further research**

- Development of trainings in the case work approach, multidisciplinary team work, evidence-based service provision and management, initial assessment of severe and common mental disorders, counseling and referral to mental health specialized care, psycho-social rehabilitation and psychodynamic methods of care.
- Development of criteria for service evaluation and monitoring.
- Training and inclusion of supervisors of the case workers in the services that will ensure the best quality of care and professional development of the staff.

- Engagement of the local authorities and the civil society in policy development and service implementation.

## REFERENCES

**Деинституционализация** посредством предоставяне на услуги в общността за рискови групи. Програма ФАР, Министерство на труда и социалната политика.

(Deinstitutionalization through delivering of community services for groups at risk. PHARE Program, Ministry of Labor and Social Protection.) In:

<http://ef.mlsp.government.bg/bg/project.php>

**Закон** за регионалното развитие. (Regional Development Law). Държавен вестник, бр.50, 30 май 2008.

**Малинов**, Павел и др. Проучване нарушаването на пациентските права на хора, живеещи с ХИВ/СПИН при съпътстващи заболявания. (Study on the violation of the human rights of PLHIV/AIDS when having concomitant illnesses) Фондация „Каспар Хаузер”, 2006. Unpublished.

**Национален** план за действие за осъществяване на политиката за психично здраве на Република България за периода 2006-2012 г. (National Action Plan for the Implementation of the Mental Health Policy of the Republic of Bulgaria during the period of 2006-2012) In:

[www.mh.government.bg/doc/mental\\_health\\_policy\\_final.doc](http://www.mh.government.bg/doc/mental_health_policy_final.doc)

**Национална** здравна стратегия 2008-2013. (2007). Министерство на здравеопазването. (National Health Strategy 2008-2013). In: [www.Pharmacy-bg](http://www.Pharmacy-bg)

**Национална** програма за закрила на детето 2007. (National Program for Child Protection 2007). In: [www.stopech.sacp.government.bg](http://www.stopech.sacp.government.bg)

**Национална** програма за превенция, лечение и рехабилитация на наркоманиите в Р. България. 2001-2005гг. Министерство на Здравеопазването.

[http://liternet.bg/drugs\\_prevention\\_society/programi/prevencia3.htm](http://liternet.bg/drugs_prevention_society/programi/prevencia3.htm)

**Национална** програма за превенция на суицидния риск и суицидното поведение в РБългария. Министертство на здравеопазването, 2000. (National Program for the Prevention of the Risk of Suicide and Suicidal Behavior in Republic of Bulgaria.) In:

[www.ncphp.government.bg/projects.php](http://www.ncphp.government.bg/projects.php)

**Политика** за психично здраве на Република България 2004-2012 година. (Mental Health Policy of the Republic of Bulgaria year 2004-2012) In:

[www.mh.government.bg/doc/mental\\_health\\_policy\\_final.doc](http://www.mh.government.bg/doc/mental_health_policy_final.doc)

**Програма** „Европейска мрежа от училища, утвърждаващи здраве”. (Program ‘European net of schools promoting health’) Национален център по опазване на общественото здраве.

[www.ncphp.government.bg/projects](http://www.ncphp.government.bg/projects)

**Ръководство** за кабинетите за анонимно и безплатно консултиране и изследване на ХИВ и СПИН. (Manual for the Consulting rooms for anonymous and free-of-charge HIV/AIDS counseling and testing) София, 2003.

**РЪКОВОДСТВО** за консултиране, изследване и насочване за инфектираност от ХИВ. (Revised Guidelines for HIV Counseling, Testing, and Referral). София, Министерство на Здравеопазването и др., 2003.

**Jane-Llopis**, Eva & Anderson, P. (Eds.) (2006). *Mental health promotion and mental disorder prevention across European Member States: A collection of country stories*. Luxembourg: European Communities.

**Lendzhova**, Vladislava & Gotseva, Anastasia. (2007). *Evaluation of HIV/AIDS Voluntary Counseling and Testing Services in Bulgaria*. Blagoevgrad etc.: Resource Centre for Mental Health and HIV/AIDS in Bulgaria etc.. Unpublished.

**Lyubenova**, Anna.(2007). *Mental Health Structure for PLHIV who inject drugs in Bulgaria*. Blagoevgrad: Resource Centre for Mental Health and HIV/AIDS in Bulgaria.Unpublished.

**National Strategy** for Prevention and Control of HIV/AIDS and Sexually Transmitted Infections in Bulgaria. (2001-2007).

**Okoliyski**, Michail. (1999). *Conditions of AIDS prevention in Bulgaria*. Berlin, Humboldt University. (Dissertation), [http://edoc.hu-berlin.de/browsing/dissertationen/index.php?l\[2\]=Autoren&paging=O&\\_bbda3f5073930f58a36812c2aab44b12](http://edoc.hu-berlin.de/browsing/dissertationen/index.php?l[2]=Autoren&paging=O&_bbda3f5073930f58a36812c2aab44b12)

**Okoliyski**, M., Lendzhova, V. & Gotseva, A. (2007). *Mental Health Problems of People Living with HIV/AIDS in Bulgaria. Rapid Qualitative Study*. Blagoevgrad: Resource Centre for Mental Health and HIV/AIDS in Bulgaria.Unpublished.

**Okoliyski**, M., Lendzhova, V. & Gotseva, A. (2007). *Stigma, Discrimination & Attitudes towards People Living with HIV/AIDS in Bulgaria*. Blagoevgrad: Resource Centre for Mental Health and HIV/AIDS in Bulgaria.Unpublished.

**Overview** of HIV/AIDS in South Eastern Europe. (2002). UNICEF & IOM.

**Petrov**, Rumen & Mateeva, Antoaneta. (2008). *National Report – Bulgaria*. (Part of the International research ‘Non-governmental actors in new governance spaces: navigating the tensions’) Unpublished.

**United Nations General Assembly Special Session on HIV/AIDS**. Country Progress Report: Bulgaria. Reporting period: January 2006 – December 2007. (2008). National Committee for Prevention of AIDS and STIs at the Council of Ministers.

**UNGASS Indicators Country Report**. Republic of Bulgaria. Reporting period: January 2003 – December 2005. (2006). National Committee on Prevention of AIDS and STDs at the Council of Ministers.

**Violation** of the patients rights of PLHIV/AIDS with concomitant diseases. (2006). Sofia, Open Society Institute.

# ANNEXES

## Annex 1: Questionnaire for medical staff and general public

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

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

2. (How about) afraid of them?

3. (How about) disgusted by them?

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

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

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

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

7. Suppose you had a close friend or relative who developed AIDS.

- (a) Would you be willing to take care of him/her, or
- (b) is that something you would not be willing to do?  
*IF (b):* Is that because
- (c) you wouldn't want to take care of someone with AIDS, or
- (d) for some other reason?

[supportive response = a; avoidant response = c]

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

- (a) send your child to another school, or
- (b) leave your child in the same school?  
*IF (b):* Would you
- (c) encourage your child to be especially nice to the student with AIDS,
- (d) discourage your child from contact with him/her, or
- (e) encourage your child to treat him/her as always?

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

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

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

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

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

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

11. How about kissing someone who has HIV on the cheek? Would you say if someone does that they're:
- (a) very likely,
  - (b) somewhat likely,
  - (c) somewhat unlikely,
  - (d) very unlikely to get AIDS, or is it
  - (e) impossible to get AIDS by kissing someone on cheek?
12. How about sharing a drink out of the same glass with someone who has AIDS?
13. How about using the same public toilets?
14. How about being coughed on or sneezed on by someone who has HIV?
15. How about mosquito or other insect bites?

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

16. First, think of two healthy homosexual men – *neither* of whom is infected with the HIV.

Now suppose they have sexual intercourse. If they use condoms, would you say that at least one of them is:

- (a) almost sure to become infected,
- (b) has a fairly strong chance,
- (c) has very little chance, or
- (d) has no chance of becoming infected

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

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

## **Annexes 2: Interview guides**

### **A. For service providers and consumers**

- Are there any problems in the legislation in regard to the PLHIV/AIDS in Bulgaria?
- What is already done in the legislation? How it works?
- What is the structure of the services for the PLHIV/AIDS? What kinds of services exist? With what quality and accessibility? What else has to be done on the service provision level?
- How are met the mental health needs of these group of people? Who is engaged in such kind of care and support? Is there any network between the different services in relation to mental health problems of PLHIV/AIDS?
- In what way the necessity to keep secret about the illness prevents the PLHIV/AIDS from equal opportunity to use social support services?
- Who is actively engaged in policy development? How you and your clients assess this engagement?
- Who is engaged in policy monitoring and evaluation? How you and your clients assess this engagement?
- Is there something that has to be added on the policy level in order to ensure best care and support for those people?
- What kind and in what degree are developed the existed services? Who provides them?
- What were the results from your research? What were the consequences of this research on the public and political level? Did anything change after the results were announced?
- What kind of services you provide in your centre for PLHIV? Are there similar programs in the country? How these services help with the emotional problems of PLHIV and how they support their social integration?
- How government supports programs for psychological care and services for PLHIV?
- What are the relationships with the system for mental health care in your country and of your service particularly?
- Have you ever provided training for psychiatrists who are working with PLHIV?
- Does your program work with drug users? How those people are treated in the state hospitals?
- What are the basic need and problems of PLHIV in Bulgaria?
- How the fact of illness affects the mental health and welfare of PLHIV/AIDS and their relatives?
- Is there any care for the needs of the relatives of those people?

- What is your opinion in relation to the last national strategy? What is the opinion of the service providers? And this of the consumers? What are the results from it?
- How you and your organization participate in the development of the next strategy?
- Which of the identified in the strategy groups at risk still stay in a serious risk and why?
- What about the VCT services: their accessibility; frequency of their use, client's satisfaction, existence of structured protocols or guides, staff trainings?
- What are the mental health problems of the PLHIV/AIDS who are IDUs? Is there any specific stigma and discrimination to them? What are their needs?
- What kind of recommendations you personally could give for the future changes, in what level? Who has to be responsible and included for the implementation of these changes?
- How many IDUs get HIV therapy (if you give numbers, please say if they are official or from your personal assessment)? Do they include methadone program as well? How clients manage to combine the two programs?

### **B. Specific questions for the consumers**

- What kind of services do you receive since you were tested positive and where do you receive them?
- Are you satisfied of the services you receive?
- What are your reasons for not searching for HIV therapy? Would you start looking for such therapy if it was situated closer to you or were in the same place as methadone program?
- What you think are your needs?
- What are the basic difficulties of PLHIV and IDUs in your town? Which services work with them?
- What are the basic needs of PLHIV and IDUs in your town?

## **Annex 3. Focus group discussions guidelines**

### **A. General focus group discussion form**

FGD topic:

Target group:

Number of the participants: (not more than 10 people)

Age of the participants:

Moderator:

Date:

Place:

Presentation of the purposes of the FGD:

FGD basic questions:

A. Questions for the identification of changes in the emotions and behavior of the respondents.

- How did you feel when you learned that you have HIV? Please, describe your feelings in that moment? How did you feel in the first months after that?

- Did your behavior changed in certain way right after you get the news and during the first months after that?
- Did you receive pre- and post-test consultations? Are you satisfied with the received counseling?

**B. Questions for the identification of the supportive and unsupportive environment.**

- What kind of medical services did you receive in the very beginning? Please, describe them.
- Which of these services you consider being helpful to you? Could you evaluate them? (medical, psychiatric, ARV therapy, from the NGOs, other)
- What other services from your point of view are needed for PLHIV/AIDS?
- Who were closer to you and supported you all the time?

**C. Questions for the identification and evaluation of stigma and discrimination**

- Did you inform someone about you positive HIV status and who was that person?
- How the person you have informed reacted towards you? Did he/she fall away or pay more attention or things stay unchanged?
- When visiting services did you inform about your status or you were afraid how they will react?
- Were there any cases in which you were discriminated by the staff of the medical service?
- Was there any case of refusal or limitation experienced by you in other public services?
- Did someone refuse to provide prescribed treatment to you related to your HIV/AIDS?
- According to you what are the most serious problems experienced by PLHIV/AIDS?
- According to you what are the attitudes of other people towards PLHIV/AIDS?
- According to you does any effort exist:
  - a) to fight stigma and discrimination;
  - b) to integrate PLHIV/AIDS in the society?
- Are people informed enough about the illness?
- What could be your participation in the process of change of current situation? What kind of activities you can take to fight against AIDS?
- Are you familiar with the national policy of Bulgaria for prevention of AIDS, against discrimination of PLHIV/AIDS?

Report of the FGD results:

**B. Focus group questionnaire for professionals working with PLHIV**

1. According to you which are the most serious problems of PLHIV?
2. According to you what kind of attitude people have towards those living with HIV/AIDS?
3. According to you was there any action towards:
  - Fight against stigma and discrimination?
  - Integrate PLHIV?
4. Are there people who have enough information about HIV/AIDS?
5. According to you which are the ways of improvement of the social information load?
6. Does your organization work in the field of HIV/AIDS only or you have other related activities too?
7. According to you in which direction should things start to change?
8. Do you know what is the situation in Bulgaria and how many HIV infected people are there in the country by the moment?

9. Do you think that you can initiate some activities by your self or you prefer to become a part of community activities in order to prevent spread of HIV infection?
10. Do you have any information about national policy for prevention of spreading the HIV infection and against discrimination of PLHIV?
11. If a member of your family becomes a HIV infected person will you agree to take care of him/her at your home?
12. If you know that the seller in your favorite grocery store is HIV positive will you continue to buy food from this store?
13. If a teacher is HIV positive do you think that he/she will be permitted to continue his work in the school?
14. If a member of your family is a HIV positive would you like to keep this in secret?

#### **Annex 4: List of key informants**

**Aneta Mirtcheva** – Coordinator of law program for people with severe mental disorders, Bulgarian Helsinki Committee.

**Antoaneta Radeva** – Executive director, Dose of Love Association, Burgas

**Assia Stoyanova** – Executive director, Panacea Foundation, Plovdiv

**Elena Yankova** – Executive director, Initiative for Health Foundation, Sofia

**Mariana Mirkova** - Coordinator of harm reduction program at OBF – Blagoevgrad

**Neli Angelova** – Senior nurse, Centre for Sexual Health, Sofia

**Pavel Malinov** – Chairperson, Kaspar Hauzer Foundation, Sofia and staff at the foundation

**Tony Mileva** – Chairpersons, Better Mental Health Foundation, Varna

**Vladimir Sotirov** – Chief-director of Dispensary for mental health “Adaptacia”

**Zdravka Seikova** – General practitioner, 22<sup>nd</sup> Consultative Centre, Sofia

## **Mission Statement on Mental Health and HIV/AIDS**

### **Mental Health and HIV/AIDS**

Mental illness is inextricably linked to HIV/AIDS, as a causal 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 resources and facilities available to treat both conditions pose major challenges.

### **Address the Needs**

The GIP Mental Health & HIV/AIDS Network 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 cross-over 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 understanding of the general public and health professionals and to decrease 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 throughout the world, and is particularly active in countries where mental health care is still usually substandard and service users' human rights are frequently violated. The work is based upon the underlying values 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, integrated system for providing ethical, humane and individualized treatment, care, and rehabilitation, and to counteract stigmatisation of and discrimination against people with mental disorders or histories of mental health treatment.

### **Project Mental Health and HIV/AIDS in South Eastern Europe and Caucasus and Central Asia**

Global Initiative on Psychiatry has been commissioned by the Ministry of Foreign Affairs of The Netherlands to run this innovative project. Its overall aim is to improve the quality of life and reduce the suffering of people in the region with HIV/AIDS who also have mental health problems, and of their partners, carers and families. HIV/AIDS is a major problem in the target countries of the project and is either taking the form of an epidemic, or runs the risk of developing into one. High quality care and recent innovations in treatment are often not available, while the nature and severity of the illness often leads to serious mental health problems for those infected as well as their partners, families and friends. HIV-positive people who are depressed or suffering other psychological problems such as drug and alcohol abuse are less likely to follow treatment/prevention regimes and more likely to behave in risky ways. In addition, some people with a mental illness or a learning disability are at greater risk of being infected. This cluster of interacting problems deserves special attention but is mostly neglected worldwide. In the target countries, due to the double stigma and lack of local resources, assistance can currently only be initiated with external expertise and funding. The focus of the project, which runs from January 1, 2005 until December 31, 2008, is to establish a network of expert centres on mental health and AIDS in the region. The countries in Phase 1 are Georgia, Kyrgyzstan and the Republic of Moldova. The Phase 2 countries are Armenia, Azerbaijan, Bulgaria, Kazakhstan, Serbia and Tajikistan.

The centres' role is to:

- develop and implement destigmatization and education programs for people with HIV/AIDS, carers, families and the general population;
- train professionals in mental health aspects of HIV/AIDS;
- develop effective ways of dealing with HIV/AIDS-related mental health problems;
- conduct research on epidemiology and needs assessment;
- act as resource centres with easy access to relevant publications and learning materials.