

# **Mental health problems of people living with HIV/AIDS in Bulgaria**

*Qualitative analysis on mental health problems  
of PLHA*

Expert Center for Mental Health and HIV/AIDS

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Dr. Michail Okoliyski,  
V. Lendzhova,  
A. Gotseva

## **Contents**

<b>1. Introduction.....</b>	<b>3</b>
<b>2. Methodology of the survey.....</b>	<b>3</b>
<b>3. Legal Framework of the rights of PLHA to receive medical, mental health or stomatological services.....</b>	<b>5</b>
<b>4. Background and epidemiological trends in Bulgaria.....</b>	<b>6</b>
<b>5. Forms and manifestations of stigma and discrimination towards PLHA in Bulgaria and their impact and consequences for the mental health of the PLHA..</b>	<b>10</b>
<b>5.1 Isolation and avoidance as a means of “prevention”.....</b>	<b>10</b>
<b>5.2 Isolation and marginalization within the family.....</b>	<b>12</b>
<b>5.3 Stigma and fear of transmission at health care facilities.....</b>	<b>14</b>
<b>5.4 Expressions of stigma relating to HIV as a sign of moral misconduct.....</b>	<b>15</b>
<b>5.5 Moral and economic issues and stigma in the family.....</b>	<b>15</b>
<b>5.6 Self-stigma - shame and feelings of hopelessness and despair.....</b>	<b>15</b>
<b>6. Appearance and forms of chronic mental health and psychological problems in the group of PLHA in Bulgaria.....</b>	<b>16</b>
<b>7. HIV/AIDS and People with Chronic Mental Illness.....</b>	<b>19</b>
<b>8. Psychotherapy with PLHA.....</b>	<b>20</b>
<b>9. Some reasons for hope: love, affection and good intentions.....</b>	<b>20</b>
<b>10. Conclusions and recommendations.....</b>	<b>21</b>
<b>11. References and suggested reading.....</b>	<b>23</b>

## **1. Introduction**

HIV and AIDS are as much about social phenomena as they are about biological and medical concerns. As HIV invades the human body, it creates rippling and profound biological and social consequences for those persons infected. In addition to attacking the immune system of the body and causing a broad spectrum of health complications, HIV may present a host of mental and emotional problems by disrupting the infected person's emotional equilibrium, sense of self, relations with others, and purpose in life. HIV also has socioeconomic consequences that affect one's most basic human needs, such as housing, food, financial security, and employment. Substance abuse confounds these issues, leading to deteriorating physical and mental health, and the poor judgment that may result in risk-taking behaviours of both a sexual and criminal nature. When addictions become severe and refractory, every aspect of life is affected.

The very complexity of these biological, psychological, and social needs springing from HIV infection argues in favour of an integrated and coordinated approach to care. Failure to address the needs in any one sphere can lead to a breakdown in the effectiveness of treatment in the others. As HIV approaches its third decade of existence in Bulgaria, the changing demographics of HIV infection reinforces the need for service integration and coordination.

Across the western European countries and the USA the global epidemic of HIV/AIDS has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities. But in Bulgaria and in the most countries of the former totalitarian regime the disease is rather associated with stigma, repression and discrimination, as individuals affected by HIV have been rejected by their families, their family members and their communities. This rejection holds as true in Bulgaria as it does in the poorer countries of the World.

As a result of the negative attitudes of the society and the institutions since the advent of the AIDS epidemic in Bulgaria, PLHA who also have mental and/or substance use disorders have been forced to navigate complex, fragmented, and uncoordinated health care systems in order to access the services they need. Over time, health and human service providers have begun to recognize that these problems are interwoven and present a broad range of challenges for the service provider on practical, economic, and treatment levels.

## **2. Methodology of the survey**

The first cases of infection with the HI-Virus in Bulgaria were officially diagnosed in 1987. The relatively short period and the small number of patients are the reason that most of the medical professionals in their practice have not encountered patients who are HIV-infected or they did not have information about the HIV status of the patient. Psychological and psychiatric care for patients with HIV/AIDS is a new and unexplored field for most of the professionals in the country. The insufficient information and the small number of trainings for medical professionals and workers makes this problem new and not enough studied among the community.

The novelty of the problem and due to the sensitivity of the topic, it was decided that a qualitative approach would be most appropriate method for research. This approach is most effective while studying the circumstances around the appearance of a comparatively

new disease and the relationship between the professionals, the patient and the community caused by it.

The findings of this report are based mainly on the results from the data collection undertaken in Blagoevgrad in 2006 and 2007, from the research of the Foundation for support of people affected by HIV/AIDS Casper Hauser in 2006<sup>1</sup> and from the data analysis of relevant documents, policies and other research already conducted in Bulgaria. The primary methods used to collect data were in-depth interview and focus group discussions (FGDs). Other methods used included observation and the use of participatory techniques during FGDs and workshops such as matrix mapping and brainstorming. Secondary sources were also consulted widely. Academic journals, research reports, books, newspapers and TV broadcasts on HIV and AIDS were explored, and further information was obtained from the members of the research team.

During the research conducted by the Foundation Casper Hauser in 2006, the team decided to interview the utmost possible number of people who are from the target group of the PLHA. For this purpose the consultative cabinet of the Foundation, which is regularly visited by large number of people who live with HIV/AIDS from the whole country was used for the interviews and for the forming of focus groups. All persons who agreed to participate at the survey gave their informed content. The methodology of this research was oriented towards gathering information about:

- Lack of insurance of accessible medical treatment.
- Refusal of medical treatment
- Lack of protection of health for pregnant women, mothers and children
- Reveal of the patients' secret
- Lack of informed content of the patient when it is obligatory by law

Table 1 is showing the division of sex and age to PLHA that took part in the research of the Casper Hauser Foundation

<b>Age</b>	<b>Under 30 years old</b>	<b>Under 40 years old</b>	<b>Under 40 years old</b>	<b>Total</b>
<b>Male</b>	16	29	42	87
<b>Female</b>	15	13	5	33
<b>Total</b>	31	42	47	120

The participants in this research are PLHA from Sofia, Plovdiv, Varna, Ruse, Burgas, Targovichte, Gabrovo, Vidin, Montana, Khaskovo, Stara Zagora, Iambol, Blagoevgrad and other smaller towns and villages.

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<sup>1</sup> Study "Violation of the patients rights of PLHA with concomitant diseases", Open Society Institute, Sofia, 2006

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

Focus group and interview guidelines were developed by the team, based on findings from some workshops and discussions with experts from relevant fields. These guidelines were refined and eventually finalized and compared with tools developed mental health related stigma and discrimination studies conducted by other professionals in Sofia and Blagoevgrad.

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

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

One of the FGDs was carried out by the team of the Expert Centre in Blagoevgrad with students from South-West University in order to assess stigma and discrimination. The students were 20-25 years old. The FGD was held in February 2007 in South-West University. The process of interviewing relevant stakeholders and people from the communities included questionnaire among health personnel and other services providers. In-depth interviews with health personnel included two interviews were carried out with nurses. One of them works in the Emergency and other works in the Maternity ward - Blagoevgrad.

### **3. Legal Framework of the rights of PLHA to receive medical, mental health or stomatological services**

#### **3.1 Patients' rights**

In the Republic of Bulgaria a great number of legal acts in connection with patients' rights exist.

##### **3.1.1 The Constitution of the Republic of Bulgaria**

Clause 52 claims that the right of health insurance as basic citizens' right that guaranties them accessible medical treatment and free of charge medical service.

1. General declaration of human rights. It shows some measures for realization of this right in paragraph 2 – prevention of the diseases, medical help, rehabilitation etc.

2. European social charter claims the right for health and the means for its prosecution as common right of citizens – clause 11

##### **3.1.2 Other relevant laws**

###### **1. Law for public health**

Each citizen of Bulgaria has the right for accessible medical treatment and health insurance.

Right for information and informed content

Right for confidentiality of the patients' secret  
Protection of the health of pregnant women, mothers and children

2. Law for health insurance.

Right for accessible medical treatment and a choice of executor

3. National frame contract

The obligations of people who offer medical and stomatological services that correspond to the rights of the patients are as follows:

To provide accessible medical care and to keep the rules for good medical practice according to the conditions of the National frame contract;

Not to announce information about the personality of the health insured person, which information was revealed during providing medical or stomatological service;

Grounds for sanctions:

Groundless refusal for medical or stomatology service when such should be provided according to contract that have brought to immediate change in the condition of the patient.

3.2 Criminal Code.

Punishment is imposed to a person, who has medical practice if after being invited does not provides help to ill person or woman in child-birth without considerable reason.

Basic right of the patient is keeping the facts and the circumstances around him/her, which he/she or his/her relatives have interest to be kept in secret. Clause 145 CC hints at the hypothesis according to which if one person illegally reveals other person's secret, threatening the image of the person, which information was confided or became known during his/her work.

From the specialized literature it becomes clear what cases can be defined as violation of the patients' rights of PLHIV in unequal conditions:

1. Lack of insurance of accessible medical treatment.
2. Refusal of medical treatment
3. Lack of health protection for pregnant women, mothers and children
4. Revealing the patients' secret
5. Lack of informed content of the patient when it is obligatory by law.

#### **4. Background and epidemiological trends in Bulgaria**

In the early days of the epidemic in Bulgaria, HIV primarily affected males with homosexual behaviour from a broad range of socioeconomic strata but since 1994, when the HIV/AIDS National Program in Bulgaria was launched, HIV rates have increased rapidly among the heterosexual majority and women. Today, those infected are more often from communities of poverty (i.e., intravenous drug users and their partners, people who are homeless etc.) and those engaged in the sex trade. According to the official statistic of the Ministry of Health in Bulgaria more than the half of the new infected cases are young persons between the ages of 18 and 30. Recent estimates indicate that about 25 percent of those living with HIV in the U.S. were infected through unsafe injection drug use. New and effective medical treatments for HIV have had a profound effect on those living with HIV. The hope that HIV, for some, has become a chronic, treatable condition instead of a fatal one brings with it an energizing optimism—and a host of additional psychosocial complications. At the same time, there are widespread treatment implications for the future.

While the death rate from HIV-related complications decreased, the rate of HIV infection has remained steady for some populations and is increasing in others. With those who are infected living longer, caseloads will increase, and the demand for services supporting adherence to a complex array of medical treatments will climb.

These epidemiological changes, coupled with the complex biological and social needs of a growing number of people living with or affected by HIV, call for a comprehensive, coordinated, and integrated approach to care - one that recognizes the importance of mental health issues in providing services to PLHA. A specialized approach to HIV mental health service delivery carries many advantages for the client.

Sharing the struggle with others who are living with HIV can provide a sense of mutual support, alleviate the stigma encountered in society, and promote a sense of safety. Issues of confidentiality, risk reduction, advocacy, and medication adherence may be emphasized and effectively addressed with appropriately trained staff. Efforts to reach this alienated and heavily stigmatized population require specialized and targeted approaches that involve close collaboration among a broad range of disciplines and service providers.

As this report was being developed, three themes repeatedly emerged that bear special significance for the provision of mental health services to people affected by HIV - stigma, sensitivity to the societal context, and a bio-psycho-social approach to care.

### **Stigma**

In Bulgarian culture **stigmatization** would constitute avoidance leading to marginalization as a result of spreading information by word of mouth about why and how a certain individual is implicated in what is believed to be a hazard to the public. Recourse to stigma as a regulatory means in everyday culture, which operates outside the realm of reason is common. As an act of discrimination in Bulgaria would be considered any obstructing of opportunities for jobs, careers, positions, services and the like, presumed or judged to have as motifs race, gender, sexual orientation, nationality, ethnic origin, religion, age, or other individual or group characteristics. Common sense culture tolerates discrimination against the PLHA and mentally sick and puts up with disregard and violence in severe case beyond what would be acceptable in a developed democracy.

In Bulgaria the condition of being infected with HIV and AIDS is often seen as shameful and the infection is associated with minority groups or behaviors. In some cases HIV/AIDS may be linked to “perversion” and those infected are punished. Also, in some of the reported cases HIV/AIDS is seen as the result of personal irresponsibility. Sometimes, HIV and AIDS are believed to bring shame upon the family or community. And whilst negative responses to HIV/AIDS unfortunately widely exist, they often feed upon and reinforce dominant ideas of good and bad with respect to sex and illness, and proper and improper behaviors.

Central to an understanding of the person with HIV who seeks mental health services is an understanding of the concept of stigma and its corrosive and debilitating effects. The HIV-infected client often finds himself/herself stigmatized in many ways - for having a fatal, transmittable disease; for being “guilty;” for being gay; for being sexual; for being a substance user; for being Roma; for being poor; for being unemployed; for being homeless. HIV-related stigmatization constitutes an epidemic in itself - an epidemic of fear, prejudice, and discrimination. The fear of being stigmatized keeps many from seeking services. It also

can prevent many clients from remaining in treatment or adhering to a treatment regimen. The feelings resulting from stigmatization may include fear, shame, distrust, rejection, exile, guilt, isolation, hopelessness, helplessness, alienation, lack of self-worth, powerlessness, and aloneness. Empathy for those facing the painful reality of this multiple stigmatization is what propels many to work in the HIV field.

### **Sensitivity to the societal context**

Typically chronic illness or disability (including HIV/AIDS and chronic mental illness) is kept inside the family in the Bulgarian context until resources are depleted, whereupon the affected are handed over to institutions. This is done with feelings of failure or betrayal of loyalty to kin and family. Social cohesion falls short to sustain communal involvement in long-term activity concerned with development rather than immediate survival. The notion of development and a gradual build-up towards a future prosperity fail to motivate constructive social action. For example, unmet health needs are attributed to lack of finances, rather than to lack of community engagement with health issues. Solidarity may show in the case of death, when neighbors are inclined to collect money in order to arrange the funeral but not in rallying for political action.

Unsurprisingly at present there is little community support for the PLHA in Bulgaria. A good part of it is the erosion of trust in any social cause in general. The rest is the belief that HIV/AIDS and the accompanying mental health problems specifically are beyond control. The psychiatric institution is credited with little expertise, human potential and good will in this respect both by the patients and relatives and by the profession itself.

Sexually transmitted diseases are well known for triggering strong responses and reactions. In the past, in some epidemics, for example Syphilis the real or supposed contagiousness of the disease has resulted in the isolation and exclusion of infected people. From early in the AIDS epidemic a series of powerful images were used that reinforced and legitimized stigmatization.

- HIV/AIDS as punishment (for immoral behavior)
- HIV/AIDS as a crime (in relation to innocent and guilty victims)
- HIV/AIDS as war (in relation to a virus which need to be fought)
- HIV/AIDS as horror (in which infected people are demonized and feared)
- HIV/AIDS as otherness (in which the disease is an affliction of those set apart)

Together with the widespread belief that HIV/AIDS is shameful, these images represent available but inaccurate explanations that provide a powerful basis for both stigma and discrimination. These stereotypes also enable some people to deny that they personally are likely to be infected or affected.

In some situations laws, rules and policies can increase the stigmatization of people living with HIV/AIDS. Such legislation may include compulsory screening and testing, as well as limitations on international travel and migration. In most cases, discriminatory practices such as the compulsory screening of 'risk groups', both furthers the stigmatization of such groups as well as creating a false sense of security among individuals who are not considered at high-risk.

An effective HIV treatment team includes clinical providers who are dedicated to the work and possess a depth of knowledge of HIV, mental health, substance abuse, and community



resources. The successful worker possesses a sensitivity to, and understanding of, individual differences, different cultures, and subcultures, as well as a broad understanding of the bio-psycho-social effects of HIV infection on the client's everyday life.

The context competent provider must be able to interact in a way that demonstrates an openness, understanding, and respect for the experiences, value systems, and beliefs of others. The context sensitive provider will convey to the client an appreciation of the varied cultural perceptions of power and control over one's life and an understanding of why and how clients may have learned adaptational skills that seem to promote dependency and social marginalization. Prejudgments - of how persons should have lived their lives, avoided HIV infection, or adjusted to a majority culture that all too often discriminates, stigmatizes, and oppresses - lead to a breakdown of trust. As a result, the therapeutic alliance that is the bedrock of effective intervention may be severely compromised. HIV infection has different meanings in different contexts, cultures, communities, and families. A person's internal perceptions of his/her external life is unique and evolves in large part from the individual's cultural roots. Cultures and subcultures have contrasting interpretations of what constitutes pathology, and the culturally competent provider must tread carefully in making a diagnosis and prescribing treatment. Providers should be comfortable with diverse educational levels, sexual orientations, physical and mental disabilities, substance use, class, and other psychosocial variables. Staff competence and sensitivity results from ongoing self-reflection that diminishes judgmental thinking and promotes tolerance and a sensitive curiosity toward care. By accompanying clients to public agencies to access services, providers gain an appreciation of power and control differentials. Developing a sensitivity to certain marginalized contexts requires a willingness to enter a "virtual reality" that sees events and attitudes from the client's perspective.

### **A specialized bio-psycho-social approach to care**

In 1990, AIDS was described as a paradigm of an illness requiring a bio-psycho-social approach. With the advent of new and effective medications, such a designation is increasingly apt. HIV infection is a medical illness caused by a virus often transmitted through socially stigmatized behaviours - unprotected sex and injection drug use - that biologically affects the brain and the immune system. At the same time, a diagnosis of HIV creates a series of immense psychological burdens that occur within a larger, more complex psychosocial arena. As the importance of adhering to complex antiretroviral medication regimens gains acceptance, the spotlight focuses increasingly on the whole person and his/her capacity for medication adherence. To increase the likelihood of treatment adherence and to promote wellness, the provider must address client-specific concerns on many levels:

- **Context: Social and Environmental Circumstances.**

These include poverty, access to care, family relationships, housing, financial needs, food, child care, transportation, and legal status. Such concerns may be further complicated by homelessness, incarceration, and prostitution.

- **Psychological Factors.**

These include stress; depression; anxiety; cognitive impairments due to HIV-associated dementia; psychosis; mania; preexisting serious mental illness, including schizophrenia and bipolar disorder; and poor judgment and impulsivity associated with personality disorders. Defence mechanisms, such as avoidance and denial, also may interfere with seeking and accepting treatment.

- **Biological Aspects.**

The health issues associated with HIV include the client's medical condition; health of the immune system; symptoms and common opportunistic infections (e.g., of the brain); medications prescribed both prophylactically and for symptom relief; and co-existing chronic illnesses, such as diabetes, renal and liver disease, and high blood pressure.

The bio-psycho-social framework is a useful guide in assembling a specialized HIV mental health delivery system. The model helps the treatment provider to remain alert to the interactivity of disorders and stressors, to frame a complete diagnostic picture of the client, and to construct an appropriate and comprehensive treatment plan.

To provide examples of the need for this bio-psycho-social approach to service delivery and how it may be implemented throughout different stages in the treatment process, the report will try to share some experiences of PLHA.

## **5. Forms and manifestations of stigma and discrimination towards PLHA in Bulgaria and their impact and consequences for the mental health of the PLHA**

The principal causes of HIV and AIDS related stigma in Bulgaria as suggested above are fears of casual transmission that stem from the nature of the disease and misunderstandings or lack of understanding about the nature of the virus and modes of transmission and the association of HIV with socially risky groups - particularly sex workers and injection drug users - who are already stigmatized by Bulgarian society at large.

Sometimes it was quite clear when stigmatizing behaviours stemmed directly from fear of casual transmission - as when people are telling that they maintained physical distance from people living with HIV and AIDS, although they were generally sympathetic with their plight. Just as often, however, such fears combined with beliefs that those with HIV acquired their infection through moral misconduct, and so should be avoided or excluded from society.

Although there are many ways in which stigma is manifested, in this report we will highlight only those that we observed to be the most prevalent: stigma expressed through avoidance of those living with HIV and AIDS due to fear of infection, and stigma related to moral causes, expressed through the use of demeaning and hurtful language and intentional social marginalization.

The third form of stigma discussed is "selfstigma" - also sometimes referred to as "internalized stigma," or the ways in which people living with HIV and AIDS may turn the negative behaviours, attitudes and expressions of those around them inwards, manifesting in depression, hopelessness, despair and sometimes self-isolation and withdrawal from contact with loved ones and the community.

### **5.1 Isolation and avoidance as a means of "prevention"**

People with HIV and those close to them are subject to numerous stressors that can impact their mental health. Among these stressors are fear and anxiety following the initial disclosure of HIV seropositivity, stressful and confusing medical treatment regimens, the prospect of serious medical problems, and the sadness and grief associated with having a foreshortened future. Thus, HIV-affected individuals are challenged to find ways of coping with stress, anxiety, and feelings of depression throughout the course of HIV disease. A person's history of coping with adversity or illness, the amount of social and emotional support they receive

from friends, family, and community organizations, and their ability to access mental health services can all be important protective factors for an HIV-affected person's mental health.

One expression of stigma found in the research is the isolation and avoidance of people living with HIV and AIDS and sometimes their close family members. As noted earlier, this stigma sometimes stems directly from people's fears of becoming infected with HIV through "casual" or everyday contact with people living with the disease, and is thus generally perceived as a form of "prevention." Knowing that HIV is transmitted "through blood" should allay these fears but does not because this mode is so vague and poorly understood, and because it is at odds with other information people have about disease transmission more generally. There is widespread confusion, for example, about the difference between the transmission of HIV and the transmission of other infections, such as the common cold, the flu, hepatitis or tuberculosis, all of which people know through experience can be acquired simply by being in close proximity or sharing utensils and dishes with those who are sick. This leads to some confusion - even among those in the medical profession—between stigmatizing behaviour and legitimate prevention.

Thus, the pervasive perception that HIV can be relatively easily transmitted leads to behaviours that may be experienced as stigmatizing, although not necessarily intended to be so. This can include the isolation of HIV patients in hospitals, isolation within families and avoidance by neighbours and the community more generally. Even those who want to show compassion to avoid hurting the feelings of people living with HIV and AIDS often are cautious and distant: *Our people have compassion, but despite compassion, we should be watchful.* (participant in FGD1)

This type of avoidance by the community, while not necessarily intended to be stigmatizing, can have a devastating impact on PLHA. In the communities where we conducted the fieldwork, social relations and communication are relatively close and adhesive. This is usually expressed in a neighbourly concern and willingness to help each other in times of crisis.

Moreover, the narrow living spaces of the alleys, and the fact that many neighbours share a common place of employment or occupation, also nurture close relationships between neighbours. On the positive side, these features of daily life in urban Bulgaria foster the development of close relationships and a readiness to provide mutual assistance. However, the high value placed on cohesive community relationships, and the importance of these relationships, intensifies the impact of the social isolation that can result when one's HIV status becomes public knowledge. This social isolation has implications for a family's economic and social status as well as their emotional well-being:

*Now she [the person living with HIV] cannot do anything. When they know she is in such state they keep far from her, they do not dare to be close to her. If they really understood about this disease, they would not be so afraid. This made my friend feel so inferior.* (Okoliyski study 1998)

Many in the community are aware that PLHA and their families need sympathy and assistance, and most feel that these members of their communities should not be stigmatized. Nevertheless, many also express that people living with HIV and AIDS should not be allowed to live in the community, but should be sent away to live in separate areas to protect the community from infection. They feel this is about prevention, not stigma or hate:

*In newspapers, it is written that people [with HIV] still can have a normal life. That is what's documented in papers, but in practice, people in the community do not accept this is possible. People will keep away and fear anyway. Therefore, it is best to have separate areas for people with HIV and AIDS... if they live in the society, everyone would be afraid. It's difficult to treat [PLHA] normally. (Okoliyski study 1998)*

Similarly, some participants agree that job creation for PLHA is necessary, but feel that they should work in segregated areas.

## **5.2 Isolation and marginalization within the family**

Avoidance, isolation and marginalization due to an HIV-positive status was in some ways most striking within the family setting, perhaps because the expectation is generally that families will provide unconditional love, support and care. Indeed, we found that the family setting is a place of many contradictions for PLHA. Attitudes and behaviours of family members toward PLHA range (sometime in the same household) from love, pity, care and support to scolding, hatred and isolation, or a mix of all of these. Attitudes or behaviours also tend to change over the course of the illness and can be very different at different stages of the disease.

Although the majority of families provide care for those living with HIV and AIDS at home, the fear of infection can have a profound impact on the type of care they receive. Some families are too fearful of infection to provide care when their family member becomes very sick with AIDS-related infections. They may choose to hire others - sometimes other people living with HIV and AIDS -to provide care, as in the following example:

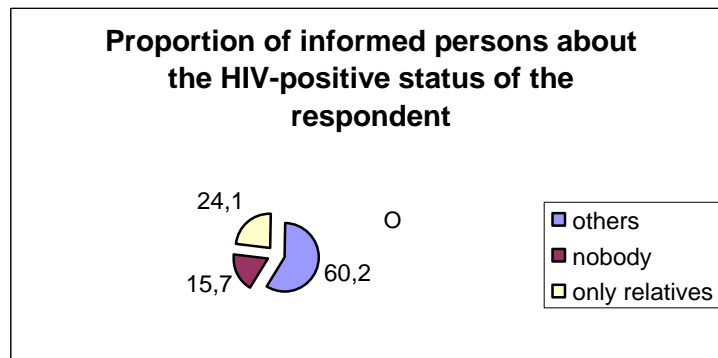
*Many families, although they love the child, still keep away, they are so afraid. So they hire somebody else to provide care for him at the last stage, but they do not dare to provide care directly by themselves. They hire those persons, let them inject drugs and feed them so that they care for their child. (Okoliyski study 1998). One mother of an IDU living with HIV says she will send him to a health facility when he develops AIDS because the living space of the family is too small, and there is no separate place to care for him (Casper Hauser 2006).*

Because of the negative attitudes connected with HIV/AIDS the PLHA are more afraid of the consequences of the stigma and discrimination than the disease itself and often decide not to take precautions about their physical and mental health in order to keep their secret.

According to research, conducted by the team of Casper Hauser in 2006, the presence of stigmatizing and intolerant social attitudes are the main reasons why every sixth HIV-infected person keeps this secret only for himself/herself.

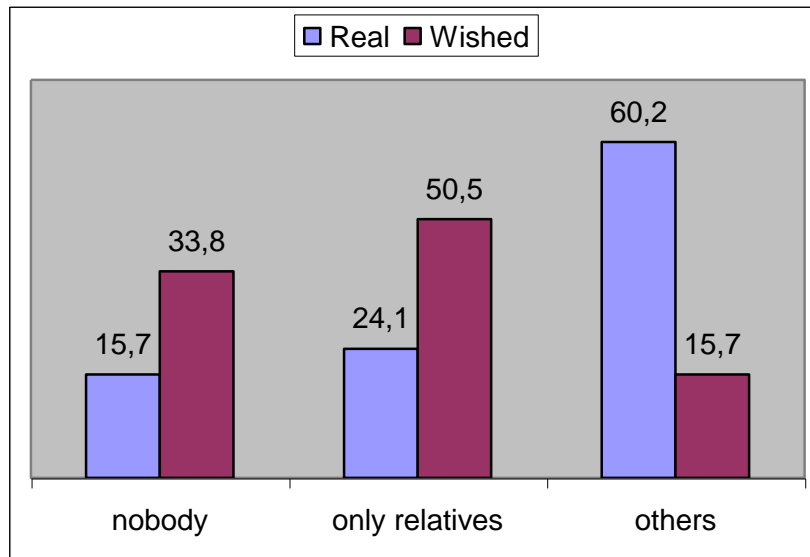
Approximately every fourth person has trusted only his/her closest relatives. In fact less than 1/3 of them do agree that the information about their HIV-positive status become public to people besides the group of the closest relatives. Obviously for the rest 2/3 revealing the HIV-status to other people happened without their content and therefore to some degree by force. These statistical data is shown on Fig.1:

Fig. 1: Ratio in percentages of the level of protection confidentiality of HIV-positive status of people, according to the interviews.



The comparison of this data reveals the existing of a significant high number of people from this group with a **confidentiality** problem. Fig.2 shows the misunderstanding between what is wanted and what is the real level of confidentiality. Most of the HIV-affected people are forced to reconcile the fact that not only their relatives are aware of their problem, despite most of them don't want this.

Fig.2. Ratio in percentages between the real and the wished level of confidentiality regarding the HIV-positive status of PLHA



Obviously what is considered here is the consciously formed defense reaction towards existing stigma and discrimination. After being diagnosed, HIV-infected people often are forced to leave their job or are fired and the consequences of this are connected with the loss of social status and surrounding, deprivation of resources, sharp narrowing of their social circle and sometimes total corruption of the stereotypes that have worked till the moment of their diagnose, which is the reason for negative social and self-isolation of this group of people.

### 5.3 Stigma and fear of transmission at health care facilities

Due to public stigmatization and discrimination towards PLHA keeping the patient secret is very important for those people because this can make them pretty vulnerable in their community. Disclosure of the secret from doctors or other medical workers is reason for breaching the links between the patient and the doctor and this is the reason why PLHA do not disclose their status even to the professionals because otherwise they risk not receiving appropriate treatment. There are several statements from the research, made by the Foundation Casper Hauser where are shown typical situations of breaking the confidentiality:

*“...The ambulance driver told to everyone in the town and when I got back there two months later everyone thought that I was dead. I couldn't stay any longer in this town and I left it - I have to work and to take care of the family...”* (40 year old male patient).

*“...I didn't have any intention to tell my parent about it but the doctors did that without asking me. Now I am afraid to go home and I have nowhere else to go, right now I have very bad relationships with my parents...”* (24 year old female patient).

*“...When my GP find out that I am HIV+ she told to other GPs and then the whole town find out. I am very concern of my child, he is pupil and I don't know what will happen with him...”* (30 year old married woman).

Most of the respondents in this survey didn't have a chance to choose to whom, when and how to tell about their diagnosis in case they want to do it so. In most of the cases they didn't want to share it with their relatives because they didn't want to disturb them but also because they knew that they won't receive any support and they are going to be judged and blame for the infection and their lifestyle.

Health care workers are also concerned about the risks of HIV transmission through casual contact. This fear leads to the adoption of excessive and unnecessary measures that are experienced as stigmatizing by those living with the disease.

*“...They refuse to treat me. They said that there is special ward for us in Sofia where we are supposed to get treated. What are we and what are you, if I had gone to his private cabinet and paid for the examination without telling my diagnosis I am sure that he will be offered me even coffee...”* (25 years old woman)<sup>2</sup>

Many PLHA feel that health workers' attitudes toward them are negative. These negative attitudes are expressed through avoidance and sometimes through rudeness. Some PLHA feel that health professionals they deal with, though providing care, only do so reluctantly. PLHA recall their experiences in the hospital with some bitterness:

*The doctor and nurse who gave me injection and medicines take overt measures to protect themselves that make me feel that they despise me.* (Okoliyski study 1998)

Women living with HIV and AIDS met difficulties when giving birth at health facilities because the providers were fearful of contracting the virus. This led some to hide their sero-status. Some women living with HIV and AIDS in Sofia report that health workers in some health facilities tried to send them elsewhere when learning that they were HIV-positive. Thus, many simply avoided the public health services altogether, instead seeking out a private

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<sup>2</sup> Foundation Casper Hauser 2006

or other health facility to give birth; and many tried to hide information about their HIV infection status.

#### **5.4 Expressions of stigma relating to HIV as a sign of moral misconduct**

The forms and manifestations of stigma relating to fears of infection discussed above are applied generally to *all* of those living with HIV, regardless of how they have, or are thought to have, acquired the illness. Stigma also stems, however, from the perception that the virus is acquired through behaviours that contravene important social norms of morality and conduct. These expressions of stigma include the use of demeaning and hurtful language and the way people often conflate HIV with drug use and sex work. In addition, the discriminatory actions taken by family and community members are sometimes justified on the basis that HIV was acquired through “indulging in play” and through behaviours that caused hardship to others. Health care providers also refer to the presumed immorality of those living with HIV and AIDS to explain actions that are both stigmatizing and discriminatory.

#### **“Labeling” and the use of demeaning language**

One of the ways in which stigma stemming from moral causes is expressed is in the way people refer to those living with HIV and AIDS. Sometimes people are unaware that the language they use is unkind - the stigma is unintentional, but nonetheless hurtful. Often people in Bulgaria are commenting: “that person (with HIV or AIDS) deserves to die”; “it serves him right”.

People living with HIV and AIDS described how the language and actions of those around them made them feel “despised” and “hated”:

*They dislike [people living with HIV and AIDS] very much, of course. They do not know that I am also [HIV] infected so they talk to me as to normal people. They hate people living with HIV and AIDS very much. They curse them, saying “Let all such persons die.” (Okoliyski study 1998)*

Indeed the linkage between drug use and HIV and AIDS that is assumed in the previous quote is a key source of stigmatizing language. In Bulgaria, those who use illicit drugs, as well as sex workers, are often labeled by society as “deviant” or “bad.”

#### **5.5 Moral and economic issues and stigma in the family**

As indicated above, there are many families in which people living with HIV and AIDS are helped and cared for, but there are also those families that ignore and isolate their members living with HIV - particularly if those family members are also injection drug users who have already created economic problems, for example by stealing family assets to sell for drugs. The negative attitudes of family members are much more painful for PLHA than the negative attitudes of other community members. The reproaches and criticisms enhance and exacerbate the shame felt by many.

Stigma toward injection drug users who are also living with HIV and AIDS extends to the health care setting. Some health workers in charge of providing treatment for AIDS patients in the local area state that they do not fear the disease, but they are uncomfortable working with patients who inject drugs (Okoliyski study 1998).

#### **5.6 Self-stigma - shame and feelings of hopelessness and despair**

The terms self-stigma and internalized stigma frequently are used to describe the almost universal tendency of those living with HIV and AIDS to turn the expressions of stigma

inward. The intensity of self-stigma varies according to the individual, depending on factors such as support from family and friends, the family's relationship to the wider community, the stage of the illness, overall understanding about the disease and the presence of public discourse about HIV and AIDS. However, almost all people who receive an HIV diagnosis experience, at some point, feelings of self-hatred, guilt and shame that can be expressed as depression and despair and can lead them to withdraw from family and social life to simply await their death. Some make drastic changes to their living style, relationships and other necessary social communications.

Interviews with people living with HIV and AIDS and their family members indicate the shame that people living with HIV and AIDS feel when their family shuns them, one of the most important factors in shaping self-stigma.

Some injection drug users living with HIV and AIDS state that their self-esteem is lower when they are in the community than when they were living in the rehabilitation camp. In addition, they worry about being seen with their close relatives, because they fear that their relatives could also be stigmatized:

Many of the PLHA consider their illness is as the "end of life" and that they have no viable future. This leads to a feeling of despair and an unwillingness to try and improve one's life. This is especially difficult for those who are still young and unmarried, who feel their chances for marriage and a family are over.

## **6. Appearance and forms of chronic mental health and psychological problems in the group of PLHA in Bulgaria**

According to different scientific sources approximately 50% of PLHA have mental health problems<sup>3</sup>. HIV/AIDS is often accompanied by depression, as many as one in three persons with HIV/AIDS may suffer from depression. (National Institute of Mental Health, USA, 2005).

The psychiatric manifestations of HIV/AIDS encompass a broad spectrum of clinical presentations. A number of these are discrete neurological conditions. Other conditions include mood and anxiety disorders, impairments in cognitive and motor functioning, and alterations in personality and behavior. The assessment of psychiatric disturbance in patients with HIV/AIDS is complicated by the many possible underlying etiologies for these disturbances, including the direct and indirect impact of HIV on the central nervous system, the impact of medical illness, and preexisting psychiatric illness, as well as the psychological distress and adjustment difficulties discussed previously.

HIV/AIDS has a particularly complex psychological dimension because it taps three great reservoirs of conflict: sex, death, and difference. The epidemic has done severe psychological as well as physical harm, causing anxiety and depression among people infected and at risk. The first step to combat psychological problems around HIV infection is to recognize your anxiety or depression. Talking with others who are also worried about HIV infection has helped many people. Actively working with HIV/AIDS non political and service organizations to fight the epidemic can reduce feelings of powerlessness and isolation.

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<sup>3</sup> Anderson J, Rowe C (2003)



There is a general belief in Bulgaria that the serious psychological and psychiatric symptoms caused by HIV/AIDS are very difficult problem, but that they are not equal important as the biological and physiological symptoms and that there is little one can do to restore mental functions. A consequence of this belief is that funding received, social significance attached, or public attention involved is low in comparison with both other fields of health and with the potential benefits from investing in mental healthcare. In terms of prevention or promotion mental health in the group of the PLHA is not deemed very important either largely because of the incomprehensibility of the concept and the failure to communicate convincingly that there are ways for individuals to contribute significantly to their personal mental well being and to that of others.

Recent studies of attitudes to mental health in Bulgaria<sup>4</sup> reveal reluctance to engage in a community effort for the accommodation of the mentally sick as equal in rights. On a daily basis this reluctance shows in avoiding involvement with the mentally disabled, their needs and problems. Under this circumstance relatives appear to shoulder too much of the psychological, social and economic burden of life with mental illness without meeting the understanding of neighbors, employers, even social services.

Families with a person living with HIV/AIDS experience pity and guilt but also shame and anger. The latter can be very destructive in some families and usually comes with the full realization of the scope of the calamity and its grave consequences. The pressure of the culture is that the family shows dedication to the patient. In most cases families learn how to contribute. Life in an extended family household is still a common practice although it is no longer governed by the strict paternalistic rules of the past.

For PLHA the psychological and social implications can be devastating. Biologically, the slow deterioration faced by PLHA raises issues of the own mortality and the limitations of the helpers, carers and family members, which may naturally cause them to shy away from treating patients with this condition.

Approximately 60% of PLHA will develop are developing or will develop cognitive difficulties over the course of the illness. According to McArthur and others (1993), 15% to 19% will develop cognitive problems severe enough to meet criteria for dementia in that the cognitive difficulties adversely affect their everyday work and social function. Fatigue, apathy, anergia, amotivation, and dysphoria are particularly troublesome symptoms that have a significant impact on a person's quality of life.

Although people living with HIV frequently report symptoms of mood disturbances, the prevalence and incidence of mood disorders in the HIV-infected population is not known. Clinicians working with persons with HIV/AIDS have been careful to point out that transient mood changes are frequent in this population because of life stressors that are significant in terms of mental health and quality of life, but these mood changes must be differentiated from clinical depression. Examples include multiple episodes of mourning as friends and partners die, sadness associated with the prospect of a foreshortened life, and stress associated with discrimination and social stigma.

Also of particular importance in assessing and treating depression in persons with HIV/AIDS is the difficult task of differentiating symptoms of depression that overlap the physical

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<sup>4</sup> Tomov, T. et al. 2004

symptoms of HIV/AIDS. For example, fatigue, weight loss, sleep disturbance, and low libido are classic symptoms of major depression but are also common nonspecific signs of HIV-related medical illness.

The literature on the prevalence of mania in the HIV-infected population is very scarce. Lyketsos and Federman (1995) found no greater prevalence of mania or hypomania in the general HIV-infected population but higher rates (prevalence of 8% in six months or 10 times the rate in the general population) in people living with AIDS. A new presentation of mania may be the first sign that someone is HIV-infected.

Bereavement is often an important issue for people living with HIV, particularly gay men who have lost friends or a partner to AIDS. A diagnosis of HIV infection frequently triggers a general process of mourning. People diagnosed with HIV often need to mourn several important losses, sometimes rather abruptly, which may be abstract (for example, a sense of unlimited longevity, certain future ambitions, the opportunity to have a child, and sexual freedom) or concrete, such as the loss of job, financial security, relationships, health and, eventually, life. Whatever treatment is undertaken with someone living with HIV, it is essential to address these multiple losses.

Several modalities of psychotherapy alone have been tried and proven effective. Psychotherapy is an integral part of the treatment of depression in people living with HIV but is not available at the Infectious Hospital in Sofia, responsible for the treatment of the PLHA.

When people are first diagnosed with HIV, many people react with disbelief, anxiety, and fear of what may lie ahead. They may become depressed and develop suicidal thinking. Effective pre- and posttest counselling can help reduce the risk of depression and suicide at this stage of the disease. PLHA may become increasingly suicidal when their medical condition deteriorates. A drop in CD4 counts, an opportunistic infection, a hospitalization, or onset of treatment with antiretrovirals can trigger suicidal thinking. Suicidal ideation also increases in times of pain.

Several other studies have also shown an increase in the frequency of suicidal thoughts and attempts for persons with HIV. The risk that a person with HIV/AIDS will actually attempt suicide appears to be correlated with a history of psychiatric treatment, substance abuse, HIV-related interpersonal and work difficulties, and the perception of inadequate social support.

Suicidal thoughts and intent are more prominent at some stages of HIV disease than others. Monitoring thoughts and feelings about quality of life, death, and suicide is an ongoing process that should take place in the context of an honest, open relationship between the person living with HIV and his or her caregiver. Many people living with HIV talk about the value of having a safe and confidential place to discuss their fears about their illness, the uncertainty and unpredictability they live with day to day, and their desire to avoid the protracted pain, dependence, and financial decline that can be associated with advanced HIV disease.

HIV disease is characterized by a great deal of uncertainty and unpredictability and so anxiety is an understandable reaction.

Many individuals living with HIV can have symptoms of anxiety, without having an anxiety disorder, but all of the anxiety disorders defined by DSM-IV can be seen in the HIV-infected population. Some will have had these disorders before they were diagnosed with HIV. Others are developing them during the course of their illness. In PLHA, anxiety can be a manifestation of side effects of medication, a symptom of an illness associated with HIV disease or most commonly, the psychological response to the stressors of the illness

## **7. HIV/AIDS and People with Chronic Mental Illness**

According to research by Brady and Carman (1990), the risk of HIV infection in the chronically mentally ill population was underemphasized during the first decade of the AIDS epidemic. This was due, in part, to the view that people with chronic mental illness are probably not at risk because:

- they engage in sexual activities less frequently as a result of their mental illness or its treatment. For example, people with chronic depression complain of low libido. Sexual dysfunction can be a side effect of psychotropic medications, especially with neuroleptics and selective serotonin reuptake inhibitor antidepressants.
- most people with chronic mental illness lack social skills and do not have regular intimate relationships.

As a result, clinicians have not routinely taken a detailed sexual history when doing psychiatric assessments of people with chronic mental illness. Recent studies, however, particularly the work by Cournos and Backalar (1996), indicate that this population is actually at higher risk for HIV disease than the general population.

Several factors, besides lack of information, may prevent people with chronic mental illness from complying with recommended guidelines for drug-use practices and safer sex. For example:

- they may not perceive themselves as being at risk for HIV infection.
- the social cost of prevention may be perceived as too high. Low self-esteem and fear of rejection may cause people with chronic mental illness to “give in” to the demands of their partners.
- they may lack faith in their ability to negotiate safer-sex practices. Women with a chronic mental illness tend to be more vulnerable to exploitation by partners, including those who use parenteral drugs or have HIV disease.
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The persons with serious mental illness also have other risk factors for infection, including:

- impulsive behaviour or decreased judgement attributable to a personality disorder, mania, psychosis, or concomitant substance use
- financial difficulties that may lead people with chronic mental illness to trade sex for money or accommodation
- a chaotic lifestyle that may include multiple sexual partners

People with mental illness are at risk for HIV infection not only because their symptoms may affect their judgement but also because they may suffer from multiple diagnoses, such as substance abuse and/or personality disorders, which can lead to impulsive behaviour. In addition, people with chronic mental illness living in relative poverty are more prone to engage in high-risk activities. An effective prevention program should be based on:

- good history taking, which explores lifestyle issues
- individual counselling, which provides education about high-risk activities and preventive measures

- focus groups, in which people with chronic mental illness can discuss interpersonal relationships, high-risk behaviour, assertiveness training, and specific risk-reduction strategies based on the groups' members' personal experiences

## **8. Psychotherapy with PLHA**

HIV disease is a complex, difficult illness that challenges people's sense of themselves and their ability to cope. PLHA are facing a series of crises that may stress and overwhelm their usual coping strategies, especially in the post-totalitarian countries in Eastern Europe. At these times, when they are trying to manage distressing affects and make difficult decisions, they will benefit from support and guidance. HIV represents a serious threat to life and is associated with profound stigmatization. PLHA often feel alone and isolated, and that experience can be a catalyst in therapy. The disease will often highlight problematic patterns in a person's interpersonal relationships. Given the nature of this illness and the stresses associated with it, psychotherapy should be an integral part of psychiatric care for someone living with HIV. In all cases, psychotherapy should be tailored to the person's needs and capacities.

Significant proportion of the PLHA, interviewed during the research by the Foundation Casper Hauser in 2006 reported that nothing could have prepared them for the impact of the news of being infected with HIV. For many, diagnosis is a traumatic event, and their reaction is often one of shock, overwhelming anxiety, or depression with feelings of hopelessness, helplessness, and despair. When the person expects to test negatively, the intensity of the reaction is likely greater, but this is not always the case. Even those who expect to be HIV-seropositive may feel overwhelmed by the news. Some react with disbelief and denial; in these cases, the psychiatrist can anticipate a delayed reaction.

PLHA do not differ significantly from other psychotherapy patients. The main differences are the ongoing risk of crisis and the strong countertransference reactions these patients evoke. Loss is central to the work of HIV-related psychotherapy. PLHA must deal with a series of humbling and humiliating losses, including the loss of hopes and dreams, a normative future, body image and integrity, loved ones, and career. Psychiatrists should not impose their own attitudes on how vigorously someone should pursue treatment. As in all psychotherapeutic situations, helping patients relate treatment decisions to their underlying defences and conflicts will enable them to choose what is best for them.

For everyone living with HIV, it is vital to maintain a sense of hope. Hope is fostered by a sense of control, both in medical decision making and in connecting with others, often after years of feeling alienated and alone.

## **9. Some reasons for hope: love, affection and good intentions**

This report has highlighted the principal underlying causes and manifestations of HIV-related mental health problems of PLHA in Bulgaria and has discussed some of the impact of the experienced stigma on the social and emotional functioning and well-being of PLHA and their families. While it is vital to understand and address the presence and impact of HIV-related stigma, it is also vital to acknowledge that this stigma is occurring alongside sympathy, support and the provision of care to PLHA. The outputs of the research indicate that the majority of family and community members have good intentions toward PLHA. Sometimes these good intentions are tempered by fears and moral concerns, but as a whole they benefit those living with the disease and striving to continue to have meaning and purpose in their

lives. When a person living with HIV and AIDS becomes sick with AIDS, the family will usually endeavour to find ways to make him or her comfortable. The principal family care provider is normally the mother or wife of the person living with HIV and AIDS, and she will seek medicine, wash his or her clothes, prepare and serve food (sometimes actually by hand-feeding) and will try to meet his or her particular psychological demands. Some family caregivers have received knowledge in the care of PLHA by the GP or the district health centre and are following the advice and guidance received. Unfortunately, the health centre staff may not be competent enough to give the best advice.

Community relations also play an important role in the lives of Bulgarian people. Close relationships of mutual assistance are maintained and nurtured, and people take great interest in the affairs of the surrounding households. Therefore, although HIV and AIDS-related stigma and discrimination exist, most participants feel that PLHA and their families need sympathy and support of the community - that they should not be kept away and stigmatized, but supported and encouraged.

This attitudes must be cultivated in the future activities of the government campaigns encouraging "Living together with PLHA." In addition nongovernmental efforts have to contribute for the success in encouraging provision of care and support PLHA and their families.

## **10. Conclusions and recommendations**

Ongoing research to uncover the underlying risk mechanisms associated with HIV/AIDS risk is essential to understanding and curbing the AIDS epidemic in Bulgaria. The most successful HIV prevention and intervention strategies are not new to mental health practitioners, but they have simply not been used in this context. Most clinicians regard HIV/AIDS as a public health and not a psychiatric issue, and, thus, most of the psychological needs of PLHA have been considered outside the realm of psychotherapy. HIV/AIDS has significant mental health implications, and HIV prevention programs could be more effective if they include a mental health component. Mental health professionals are in a unique position to influence sexual behavior and drug use among persons in psychiatric care and to assist families affected by HIV disease. Successful risk-reduction strategies can be incorporated into traditional clinical settings, and commonly used approaches to treat psychiatric disorders can be readily adapted and applied to HIV prevention and intervention. Mental health practitioners can employ a variety of strategies to personalize information to enhance motivation for prevention.

The following recommendations reflect the experience of the study about the mental health problems of PLHA in Bulgaria. These recommendations are based on the knowledge gained by the team since the opening of the Expert Centre in Blagoevgrad and in collaboration with the team of Foundation Casper Hauser and are developed to provide guidance to administrators, program planners, and service providers as they establish and implement HIV-specific mental health care service programs. While not empirically based, these recommendations represent the experiences of the research team:

- PLHA need access to comprehensive primary medical, mental health, substance use, and related support services. Some clients will need access to free or affordable transportation to attend appointments. Others will need assistance obtaining affordable housing, food, child care, permanency planning, HIV risk reduction education services, medications, and supportive residential services.

- Services should be flexible and client-centered. Clients will present with a broad range of medical, mental health, substance use, and psychosocial needs. While some clients will benefit from psychotherapy, others may need only support groups or case management. Service plans need to be adapted to meet changing client needs.
- HIV, mental health, and substance use treatment services should be adequately coordinated and integrated. Often, service providers from different systems of care do not communicate with one another, even though they may be responsible for delivering care to the same individuals. Service systems should establish formal linkages and networks to enhance service coordination and integration.
- Services should promote individual self-respect and personal dignity. Services can only be delivered effectively when an individual's self-worth and contributions to society are recognized. In addition, people with HIV who also have mental and/or substance use disorders typically have been stigmatized by both society and the traditional health care delivery system. To meet their needs, service systems must take steps to ensure the confidentiality of PLHA and that the system itself does not stigmatize its clients further.
- Service delivery programs should work to reduce barriers to care for "hard-to-reach" populations. Some service systems have failed to reach populations that desperately need access to HIV primary medical treatment and mental health services, including people in prisons, people who are homeless, substance abusers, and individuals with severe mental illness.
- Programs should develop and deliver services that are clinically informed and research-based. Many programs have developed and conducted evaluations of their clinical services. The knowledge gained from these undertakings, as well as the latest research on HIV-related mental health services, can be used to enhance service delivery and program policy.
- PLHA need to be empowered to make decisions in collaboration with the service provider. In addition, all segments of the community, including consumer and family advocacy groups, should be actively involved in the establishment, delivery, and quality improvement of services.
- Programs should work to create an "HIV Community." Service systems can play a major role in creating a community of individuals, agencies, and organizations that work in partnership to increase access to the broadest, most comprehensive range of services possible and to foster the development of an HIV Community that offers a sophisticated network of support for clients.

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