

# **Monitoring of Rights of People Living with HIV/AIDS in Serbia**

*Holistic Report*

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**Publisher:** Philantropy, Charitable Foundation of the Serbian Orthodox Church

**Print:** Bernar Publishing Agency, Serbia

**Circulation:** 100 copies

April 2016

ISBN 978-86-88757-06-5

This publication has been produced with the assistance of the European Union. The contents of this publication are the sole responsibility of Philantropy , Charitable Foundation of the Serbian Orthodox Church and the authors of the texts and can in no way be taken to reflect the views of the European Union.

Dear Readers,

The holistic report on the human rights of people living with HIV/AIDS in Serbia was created as a joint report out of three separate reports, namely: the report on the monitoring of individual experiences of people living with HIV/AIDS, the report on systemic monitoring i.e. the review of relevant laws, policies and programs in the country, and the report on community attitudes towards HIV/AIDS, through the monitoring of media coverage.

This report was created within the project “Monitoring of Rights of People Living with HIV/AIDS in Serbia”, implemented by Čovekoljublje (Philanthropy), the Charitable Foundation of the Serbian Orthodox Church in partnership with COD, Center for Society Orientation from Belgrade and in cooperation with the Office of the Commissioner for Protection of Equality and organizations of people living with HIV/AIDS in Serbia. It is financially supported by the Delegation of the European Union to the Republic of Serbia, through the Civil Society Support Programme. The project is the result of the initiative made through an international cooperation project, Disability Rights Promotion International<sup>1</sup>, headquartered at York University in Canada through which, since 2002, a scientifically based methodology of participatory holistic monitoring of human rights has been developed. The methodology has been adapted for this project for the field of human rights of people living with HIV/AIDS.

We wish to thank the people that worked on the preparation of the report, as well as organizations of people living with HIV/AIDS from Subotica, Novi Sad, Niš, Pančevo and Belgrade, as well as all individuals, especially people living with HIV/AIDS who gave their immense contribution by sharing with us their life stories. With that they enabled us to gain insight into the scope and profile of human rights violations for this population in Serbia.

Our special thanks go to the Delegation of the European Union to the Republic of Serbia which has provided financial support for the project, the DRPI project staff from York University, the DRPI Europe Regional Centre headquartered in Belgrade, the Office of the Commissioner for Protection of Equality and the Office for Cooperation with Civil Society, Government of the Republic of Serbia.

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<sup>1</sup> <http://drpi.research.yorku.ca/>

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## Information on the project

Human Rights Monitoring for People Living with HIV/AIDS in Serbia is financially supported by the Delegation of the European Union to the Republic of Serbia, through the Civil Society Support Programme. The process of human rights monitoring for people living with HIV/AIDS aims to establish a sustainable monitoring mechanism of the respect for the rights of people living with HIV/AIDS in Serbia foregrounding the actual people living with HIV/AIDS as carriers of the human rights monitoring process. The project uses the approach based on human rights and GIPA principles<sup>2</sup> insisting on the active involvement of people living with HIV/AIDS in the human rights monitoring process and the use of information obtained by monitoring to achieve social change. Gaining insight into the extent of systemic discrimination and social exclusion of people living with HIV/AIDS is equally important as the process of monitoring and gathering information on human rights violations through which people living with HIV are empowered to monitor their rights and advocate change. Knowledge about human rights violations for people living with HIV/AIDS is an important tool for initiating social change and changes in policies and programs that act as the national response to HIV, which would lead to the improvement of the position of people living with HIV/AIDS in Serbia.

## Methodology

The project uses the methodology of participatory holistic monitoring of human rights. The methodology consists of three elements: monitoring of individual experiences of people living with HIV/AIDS, systemic monitoring and analysis of relevant laws, public policies and programs and the monitoring of community attitudes towards people living with HIV/AIDS through the monitoring of media coverage of this population. The above methodology takes into account the analysis of the key human rights principles contained in the Universal Declaration of Human Rights and other international legal documents in the field of human rights. We have grouped the above principles into five groups: ***dignity, independence, non-discrimination and equality, participation, inclusion and accessibility and respect for diversity***. All of the above five human rights principles have been analyzed in each of the three monitoring fields. The following table explains the significance of some of the human rights principles.

Table 1 - Interpretation of human rights principles

Human rights principles	Interpretation
<b>VIOLATION OF DIGNITY</b> To feel not respected and unvalued in one's experience and opinion and to not be able to form an opinion and attitude without fear of physical,	This principle is used whenever a person's feelings were hurt (sadness, sorrow, despair, depression, low self-esteem, lack of confidence) as a result of the treatment suffered due to their HIV status. Violation of dignity has to do with how a person feels, not the way they are treated

<sup>2</sup> [http://data.unaids.org/pub/briefingnote/2007/jc1299\\_policy\\_brief\\_GIPA.pdf](http://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_GIPA.pdf)

mental, psychological and/or emotional harm.	
<p><b>DISCRIMINATION AND INEQUALITY</b></p> <p>To experience any unreasonable distinction, exclusion or restriction based on HIV status or any other personal characteristic, preventing the enjoyment and exercise of human rights and fundamental freedoms on an equal basis with others.</p>	<p>This principle is present every time a person experiences a different treatment on the basis of their HIV status or other personal characteristic, either directly or indirectly.</p> <p>Situations involving the possibility of comparison between the treatment of people living with HIV and people without HIV, in which it is clear that a person living with HIV is at a disadvantage because of their health status are coded under the principle of discrimination and inequality</p>
<p><b>PARTICIPATION, INCLUSION, ACCESSIBILITY OR EXCLUSION</b></p> <p>To experience segregation and isolation based on health status, including lack of access to goods or services.</p>	<p>Whenever a person living with HIV is absolutely prevented from participating in an event or activity, or absolutely prevented from entering or using physical environment or services, such situations are coded as Exclusion.</p> <p>Code Exclusion also applies in situations where there is a lack of access to space, locations, services and programs, not allowing a person living with HIV to have the same opportunities that are available to others.</p>
<p><b>DISRESPECT</b></p> <p>Not being respected or being stigmatized on the basis of HIV status or other personal characteristics or situation in which the needs related to HIV have not been adequately considered or observed.</p>	<p>This code is applicable in situations where a person is judged, labeled or insulted on the basis of certain prejudices that others have about their health status or other personal characteristics such as belonging to certain key populations.</p> <p>It is also used in situations where the needs of people living with HIV (to be accepted or to perform certain adjustments) have not been taken into account.</p> <p>Finally, the code is used whenever a person emphasizes in the exact words that they do not feel respected.</p>
<p><b>LACK OF INDEPENDENCE</b></p> <p>To be unable to make decisions or to be forced to specific solutions based on health status in this context</p>	<p>This principle is chosen in situations where a person has no choice due to limited or inadequate information, no available options or when others influence decision-making concerning the person.</p>

During the **monitoring of individual experiences** 100 in-depth interviews were carried out with persons living with HIV/AIDS in Belgrade, Novi Sad, Niš, Subotica and Pančevo. The sample was defined based on the available statistics on people living with HIV/AIDS in these cities, including rural areas. Table 2 lists the characteristics of the sample.

Table 2 - Characteristics of the sample

Attribute	Number of respondents	Attribute	Number of respondents
<b>KEY POPULATIONS</b>		<b>LOCATION</b>	
Bisexual	10	Belgrade	34
Gay	4	Niš	17
Heterosexual	27	Novi Sad	23
Intravenous Drug User (IVDU)	10	Subotica	20
Person deprived of liberty, gay/lesbian	1	<b>EDUCATION</b>	
Person deprived of liberty and IVDU gay/lesbian	1	No formal education	3
Men who have sex with men (MSM)	34	Elementary school	1
Disabled people	3	Secondary school	58
Transgender people	1	Two-year post-secondary school qualifications	7
N/A	3	University qualifications	11
<b>EMPLOYMENT STATUS</b>		<b>SEX</b>	
Employed	28	Men	70
Unemployed	38	Women	24
Pension	15	<b>AGE GROUP</b>	
Retired - disability retirement	8	18 – 25	4
Retired - family retirement	4	26 – 40	42
Dependent	1	41 - 55	31
		56 - 70	14
		Over 70	1
		N/A	2

The aim of the interviews was to gain insight into the life experiences of people living with HIV/AIDS and the types of human rights violations caused by HIV+ status. All in-depth interviews were performed by people living with HIV/AIDS who had been previously trained to conduct interviews. As a result, organizations of people living with HIV/AIDS and their members have been empowered in the long run to be involved in human rights monitoring. All interviews were recorded with a voice recorder, and the audio recordings were then typed and made into text files that were subject to qualitative analysis based on the coding scheme developed for this project using qualitative analysis software NVivo 10. In the interview analysis, the obtained information and experiences of respondents were grouped into eight areas of living: social participation, access to justice, privacy and family life, providing income and support services, health, labour and employment, education and information and communication. For these experiences, within each area, the following human rights principles were analyzed: dignity,

non-discrimination and equality, respect for diversity, independence and participation, inclusion and accessibility.

For the report on **monitoring of media coverage of HIV**, articles in the print media were analyzed through press clippings, for the period from December 2014 to October 2015. In addition, articles published on the Internet via Google Alert were also analyzed, with HIV as keyword for the search. 91 newspaper articles were processed from eight daily newspapers and 13 weekly editions, as well as other newspapers. Included also were 81 texts published on the subject of HIV on web portals in Serbia. The subject of analysis was the manner the media coverage was performed on HIV and people living with HIV/AIDS, where a distinction was made between four different perspectives of reporting (medical perspective, criminalization perspective, victimization or mercy perspective and human rights perspective) in order to determine whether the media support prejudice against people living with HIV or contribute to their decrease.

An analysis of the legal framework was given through **systemic monitoring**, public policies that act as the national response to HIV/AIDS and the effects of their implementation, finding flaws in legislation and room for improvement of the government's systemic response to HIV infection. The matrix for systemic monitoring included questions that are derived from UN Guidelines on HIV and human rights<sup>3</sup> prescribing steps that governments should take to effectively respond to the HIV infection.

Direct involvement of people living with HIV/AIDS in the process of holistic monitoring forms the basis for the establishment of a sustainable independent mechanism for monitoring the rights of people living with HIV/AIDS. The respondents are not merely subjects of a survey, but through conversation they are also informed about human rights and the opportunities that are available to them for exercising those rights. The application of semi-structured questionnaire in the survey allows respondents to talk about things that are most important to them, rather than responding to the strictly defined and asked questions.

## **Report structure**

Monitoring of individual experiences of people living with HIV/AIDS is a key part of the report. Based on the interviews, an analysis was made of the most pressing issues and areas which where discrimination was noted in the largest number of respondents, in order to recognize the pattern of repetition of discrimination. The report indicated precisely those areas that have proved to be the most pressing in the monitoring of individual experiences: health, privacy and family life, social participation, providing income and support services, labour and employment area, and access to justice. In each of these areas, the experiences of people living with HIV/AIDS are viewed in the context of the basic human rights principles: dignity, independence, participation, inclusion and accessibility, non-discrimination and equality, respect for diversity. The last area was analyzed from the standpoint of the reasons for not reporting cases of human

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<sup>3</sup> <http://www.ohchr.org/Documents/Publications/HIVAIDSGuidelinesen.pdf>



rights violations. Each field also included parts of systemic monitoring and media monitoring that are connected and concern the given area.

One part of respect for privacy is addressed in the context of respecting rights in the healthcare system because the experiences of people living with HIV/AIDS report violations of this right to be the most common in this particular area. Also analyzed were the experiences of the last five years in the lives of respondents. For quotes in the report we have not indicated initials or other characteristics of the people that said them.

The report on situation testing is a separate entity. Situation testing of discrimination was conducted in the field of healthcare.

### **Partner organizations involved in the project**

The following joined the implementation of the project on monitoring of individual experiences, report writing and situation testing: STAV + from Subotica, Crvena linija from Novi Sad, Sunce and Putokaz from Niš, Nova + from Pančevo, Veza, USOP, AID+, Žena+, AS, JAZAS and Re Generacija from Belgrade.

## **1. INTRODUCTION**

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### **1.1. HIV and AIDS in Serbia**

According to the data from the Institute of Public Health of Serbia Dr Milan Jovanović Batut (IPHS), since the beginning of the epidemic in 1985 to the end of 2015 there have been 3,263 people infected with HIV in Serbia, of which 1,777 patients suffering from AIDS. So far, 1,085 people have died from AIDS, and 102 more from disease or condition not related to HIV infection. According to official data available, there are currently 2,076 people infected with HIV living in Serbia, and an estimated 1,100 people in our country is still not aware of being infected with HIV.

The dominant mode of transmission is through sexual contact, and more than half of newly diagnosed people in our country have been infected with HIV because of unprotected sexual intercourse, almost 90% as of 2012. Men who have sex with men are considered most at risk of HIV infection (about 60% of all newly diagnosed people as of 2008). Since 2002, there has been reported a rise in the share of young people aged 15-29 among the newly diagnosed HIV+ people. From 2005 to 2014, twelve children were registered who contracted HIV from their mothers who did not know that they were infected with HIV. From 2005 to 2014, more than 30 pregnant women were included in the program of prevention of HIV transmission from mother to child, and in all cases the children who were born were not infected with HIV.

The national response to HIV infection over the last ten years has been funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), and the First National HIV/AIDS Board which was established in 2004 as a multi-sectoral body whose task was to define the strategy and action plans on the response to HIV, monitor the performance of their implementation,

and also strengthen the administrative capacity and work to improve cooperation in the field of HIV. With the support from GFATM, the National Board adopted the first National Strategy for the Fight against HIV/AIDS for the period from 2005 to 2010, followed by a revised, new strategy for the period from 2011 to 2015. Methods of monitoring the performance of strategy implementation have been defined by the Plan for Monitoring and Evaluation of the Strategic Response to the HIV Epidemic in the Republic of Serbia, which includes monitoring national and international outcome indicators and impacts through which the trend of the HIV epidemic in our country is monitored, and allows for a comparison with the rest of the world. These indicators are obtained by conducting repeated (bio)behavioral research in key populations at increased risk of HIV infection. In 2005, the National Office for HIV/AIDS started its activities in the premises of the Institute of Public Health of Serbia Dr Milan Jovanović Batut. The Office took over the operational coordination of the response to HIV in Serbia, with a mandate to support the National HIV/AIDS Board, the Ministry of Health and the National Public Health Institutes in initiatives directed towards the effective implementation of the National HIV/AIDS Strategy.

The national response to HIV has narrowed significantly after the completion of the project funded by GFATM. A new National HIV Strategy has not been adopted after 2015 and with the new systematization as of July 2014, the role of the National Office has been assigned to the Department for HIV Infection, Sexually Transmitted Infections, Hepatitis and Tuberculosis, which operates as an organizational unit (Department) of the Disease Control and Prevention Centre of IPHS. It engages in the prevention and control of communicable and non-communicable diseases. In the domain of HIV, the Department has continued to implement the same activities regarding the national response to HIV. Apart from the significant contribution that the Department has been providing in the monitoring and evaluation and its significant educational and preventive role, the work of this body is not sufficient to provide an answer to the exercise of the basic rights of people living with HIV/AIDS, not only due to the lack of human resources capacity of this professional body, but also due to the partial approach to the response to HIV, which should provide answers to a large number of questions from different areas of social life and in relation to the exercise of a larger number of fundamental rights and freedoms.

The Department is currently the only functional body in the system of the national response to HIV, considering the fact that the National HIV Board has not been reconstituted after the last replacement of the Minister of Health who leads the activities of the Board

Since 1997, a combination antiretroviral therapy (HAART or ARV) for those living with HIV/AIDS has been available in Serbia, and the costs of treatment are borne by the National Health Insurance Fund. The availability of this treatment has improved the quality of life of people living with HIV/AIDS and opened the way for the creation of more adequate programs of prevention, care and support, and also programs to reduce stigma and discrimination. However, from the very beginning, there have been problems in the availability of the treatment, the use of older generation medication, the unavailability of tests for HIV infection monitoring and a small number of available combinations that can be used in treatment. Until 2008, the treatment and therapy were only available at the Clinic for Infectious Diseases in Belgrade.

However, later on, despite the concerns expressed then by the people living with HIV on accessing treatment and relationships with new doctors, a decentralization was made and treatment became available in Niš, Novi Sad and Kragujevac (in 2009).

During the project funded by the GFATM, significant efforts have been made to promote HIV voluntary counselling and testing. Since 2011, the Ministry of Health has been financing all these services, including the HIV test, in all district Public Health Institutes.

The civil sector in Serbia is active in the field of HIV and after the completion of the GFATM project it decreased significantly. There are eight associations which bring together people living with HIV/AIDS which are currently active in Serbia. Seven out of the eight associations are joined in the umbrella organization USOP in order to strengthen their influence in changing policies and practices at the national level and increase their participation in making important decisions.

The national UNAIDS report from 2014 indicates prevention programs for vulnerable populations and the sustainability of what has been done so far as the biggest challenges for the national response to HIV in the coming period. Also emphasized is the viability of universal access to good quality treatment, care and support, through better planning and management of procurement of medication and tests to monitor the progress of HIV infection, creating HIV testing strategies for patients suffering from tuberculosis and other tests initiated by health professionals, improving tuberculosis control in the centers for treatment of people living with HIV, and the sustainability of CD4, PCR and resistance testing in accordance with recommendations. The report further states that this will require a greater contribution from the national budget, taking into account the completion of the GFATM project that financed a large part of the national response to HIV.<sup>4</sup>

## **1.2. Human rights and HIV**

Since the beginning of the epidemic until today, HIV has been one of the biggest challenges for human rights at global, national and local levels. The virus has become a symbol of discrimination against people who are presumed to be at risk of infection for their behaviour, against people of different sexual orientation, gender or social characteristics. As the number of people living with HIV continues to grow in countries with different economies, social and legal systems, the issue of HIV in the context of human rights is not only becoming more obvious but more varied, as well.

The issue of HIV in the context of human rights is important in several domains. First, certain groups are more susceptible to HIV infection because they are not able to exercise their rights: civil, political, economic, social and cultural. For example, individuals who do not have the right to freedom of association and access to information may be prevented from discussing issues related to HIV, participate in organizations and self-help groups, and take preventive measures to protect themselves from HIV. Women, especially young women, are more susceptible to infection if they do not have access to the necessary information, education and services to

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<sup>4</sup> Available at the following website:  
[http://www.unaids.org/sites/default/files/country/documents/SRB\\_narrative\\_report\\_2015.pdf](http://www.unaids.org/sites/default/files/country/documents/SRB_narrative_report_2015.pdf)

ensure sexual and reproductive health and prevention of infection. The unequal status of women in the community also means that their capacity to negotiate in the context of sexual activity is insignificant. People living in poverty are often unable to access HIV treatment and care, including drugs for opportunistic infections.

Furthermore, the rights of people living with HIV/AIDS are often violated because of their HIV positive status, which consequently makes them lose other rights. Stigma and discrimination can hinder their access to treatment, but also affect their employment, education and other rights. HIV stigma and discrimination discourage people living with HIV/AIDS in their access to healthcare and social services. The result is that information, education and counselling will not be beneficial even where such services are available.

Strategies for responding to HIV/AIDS in an environment where human rights are not respected are ineffective. For example, discrimination and stigmatization of vulnerable groups such as intravenous drug users, sex workers and men who have sex with men. These communities are sidelined in matters concerning the response to the HIV epidemic.

Where there is open support for people living with HIV, where they are protected from discrimination, treated with dignity and where they have access to treatment, care and support, individuals more often require testing in order to know their HIV status. Also, those who are HIV+ are more efficient in dealing with their HIV+ status; they ask for and receive therapy and psychosocial support, as well as take measures to prevent transmission to others, reducing the impact of HIV on individuals and society.

The protection and promotion of human rights are essential to prevent the spread of HIV and mitigate the social and economic impact of the pandemic, influencing the reduction in vulnerability of certain communities. State obligations to protect and promote human rights associated with HIV are defined within existing international agreements. Human rights regarding HIV/AIDS include the right to the following: life, liberty and security of person, the right to the highest attainable standard of mental and physical health, non-discrimination, equal protection and equality before the law, freedom of movement, asylum, privacy, freedom of expression and opinion, freedom to receive and impart information, freedom of association, marriage and starting a family, work, equal access to education, adequate standard of living, social security, support and protection, participation in scientific advancement and its benefits, participation in public and cultural life and freedom from torture and other cruel, inhuman or degrading treatment or punishment.

Human rights instruments and mechanisms of the United Nations (UN) provide a normative legal framework and tools necessary to ensure the implementation of these rights. The Human Rights Council also requests the UN Secretary-General to solicit comments from Governments, United Nations bodies, specialized agencies, international and non-governmental organizations on the steps they have taken to promote and implement, where possible, programs that deal with the rights of people living with HIV, the right of women, children and vulnerable groups in the context of prevention, protection and access to treatment<sup>5</sup>.

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<sup>5</sup> Available at the following website: <http://www.ohchr.org/EN/Issues/HIV/Pages/HIVIndex.aspx>

### 1.3. International mechanisms of human rights protection for people living with HIV/AIDS

The rights of people living with HIV/AIDS are guaranteed by the fundamental international documents for protection of human rights and fundamental freedoms.

In September 2011, the international community established eight Millennium Development Goals as a framework for the implementation and monitoring of development activities in over 190 countries in 10 regions of the world by 2015, through the adoption of the **UN Millennium Declaration**<sup>6</sup>. **Millennium Development Goal No. 6** referred to the fight against HIV/AIDS, malaria and other diseases, and as special tasks it pointed out stopping the increase and reversing the expansion trend of HIV<sup>7</sup>. Another task within this goal was to reach a universal approach to HIV treatment by 2010 for all who need it, and the indicator was the percentage of population with an advanced HIV infection that have access to antiretroviral medications.<sup>8</sup>

At the **EU** ministers conference in Dublin in 2004, the **Declaration of Commitment on HIV/AIDS, known as the "Dublin Declaration"**, which became the basis for the agreement and more decisive action that European countries take to fight HIV/AIDS. The document puts special emphasis on the responsibility of European government leaders and civil society organizations and the need for their coordinated action to develop strategies for prevention, treatment and care of patients and fight against violations of human rights of patients.

The **Declaration on HIV/AIDS**<sup>9</sup> was adopted by the **UN General Assembly** in **2006**. In the preamble of the document, representatives of states and governments recognized that HIV/AIDS requires an exceptional and comprehensive global response, and confirmed that the full enjoyment of all human rights and fundamental freedoms for all is an essential element in the global response to the HIV pandemic, including in the areas of prevention, treatment, care and support.<sup>10</sup> The **Political Declaration on HIV/AIDS** was adopted at a special session of the General Assembly of the United Nations in New York in **2011**.<sup>11</sup> The requirements from the Declaration aim at establishing clear goals of treatment for at least 15 million people by 2015, and to completely eliminate the transmission of the virus from mother to child by the end of

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<sup>6</sup> Established by resolution No. 55/2, adopted and declared at the 55th plenary session of the General Assembly of the United Nations, on 18 September 2000, its text available at:

[http://www.ombudsman.rodnaravnopravnost.rs/attachments/013\\_Milenijumska%20deklaracija%20UN.pdf](http://www.ombudsman.rodnaravnopravnost.rs/attachments/013_Milenijumska%20deklaracija%20UN.pdf)

<sup>7</sup> ...according to indicators such as the prevalence of HIV in the population aged 15-24, the use of condoms in high-risk sexual relations and the share of the population aged 15-24 who possess adequate comprehensive knowledge of HIV/AIDS.

<sup>8</sup> The indicator is the percentage of population with an advanced HIV infection that have access to antiretroviral medications.

<sup>9</sup> Resolution (A/RES/60/262) adopted by the UN General Assembly on 15 June 2006, text available at:

[http://webcache.googleusercontent.com/search?q=cache:0\\_nZ5kIJfrEJ:www.zjzfbih.ba/wp-content/uploads/2006/12/hivdeklaracija.doc+&cd=3&hl=en&ct=clnk&gl=rs](http://webcache.googleusercontent.com/search?q=cache:0_nZ5kIJfrEJ:www.zjzfbih.ba/wp-content/uploads/2006/12/hivdeklaracija.doc+&cd=3&hl=en&ct=clnk&gl=rs)

<sup>10</sup> Combatting stigma and discrimination has been recognized as an important element in the fight against the global pandemic of HIV/AIDS and access to medicines is one of the basic elements needed to gradually achieve the full realization of the right of every person to the highest possible standard of physical and mental health.

<sup>11</sup> Text available in English at: [http://www.unaids.org/sites/default/files/sub\\_landing/files/20110610\\_UN\\_A-RES-65-277\\_en.pdf](http://www.unaids.org/sites/default/files/sub_landing/files/20110610_UN_A-RES-65-277_en.pdf)

2015.<sup>12</sup> Gender inequality, legal sanctioning and acts of discrimination continue to defer national responses to HIV, therefore collaborative effort is needed to overcome these lasting obstacles and to increase the number of services related to HIV for people who need them most.<sup>13</sup>

#### **1.4. Human rights and HIV in Serbia**

Despite a strong national response and commitment to human rights of people living with HIV/AIDS, which the state has shown by signing international documents, stigma and discrimination in the field of HIV have been identified as the leading challenges in the response to the HIV epidemic. The National HIV/AIDS Strategy recognized the importance of the fight for human rights and set targets for progress in this area, but the way the fight for human rights was conducted in the context of HIV was insufficiently powerful, largely because there was a lack of understanding of HIV in the context of human rights by decision makers, despite the fact that the relevant bodies and institutions report to international mechanisms on the progress in this area. Independent institutions in Serbia had little or no role in the creation of the National Response to HIV/AIDS, including the absence of the role of civil society organizations that are actively engaged in the protection of human rights in our country. The role of the Ministry of Justice, a member of the National HIV/AIDS Board, was more one of an observer than an active participant, and there was also no revision of laws and policies that would take into account the reality of HIV/AIDS. HIV is explicitly mentioned in the Law against Discrimination and the Penal Code.

Numerous studies conducted from 2003 to date, have identified clear stigmatizing attitudes towards people living with HIV/AIDS and the many problems they face regarding care and support, but also clear stigmatizing attitudes towards members of vulnerable groups to HIV infection. Repeated studies show some progress but the numbers are still high.

## **2. REALIZATION OF HUMAN RIGHTS OF PEOPLE LIVING WITH HIV/AIDS IN THE AREA OF HEALTH**

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Social status, realization of rights and quality of life of people living with HIV/AIDS are mainly linked to health and healthcare, which precisely is where they start to deal with the government apparatus system, as well as primary support guaranteed by regulations. Prevention, counselling, testing and detection of the existence of HIV, followed by therapy and

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<sup>12</sup> It is interesting that protests caused by this were organized by numerous organizations, including Health GAP, Act UP, Housing Works, Gay Men's Health Crisis and others. However, in the course of negotiations on the final document, conservative states refused to accept the mention of key populations in the Declaration, including MSM, sex workers, and workers and drug users, but these were eventually covered the final text. Source: AIDS resource, <http://www.aidsresurs.rs/aktuelnosti/ungass-2011-politi%C4%8Dka-deklaracija>

<sup>13</sup> Ibid.

controls, are carried out in healthcare institutions, so the response of the healthcare system is inevitably the first link in the chain, which influences the overall quality of life of people living with HIV/AIDS.

Article 68 of the **Constitution of the Republic of Serbia**<sup>14</sup> guarantees everyone the right to physical and mental health care. This right also includes prevention, treatment and control of communicable infections such as HIV, as well as the creation of conditions which would ensure full attention and adequate medical services in case of infection. The right to health is the equivalent of the obligations of governments to constantly aim towards providing conditions for everyone to be as healthy as possible<sup>15</sup>. In the context of HIV infection, the right to health includes the availability of timely, reasonable, affordable and high-quality treatment and care, as well as a wide range of methods of prevention and support for children and adults<sup>16</sup>.

Article 21 of the Constitution of the Republic of Serbia prohibits any discrimination, direct or indirect, on any grounds, and particularly on the basis of several explicitly listed personal characteristics, among which health status is not specifically indicated. However, it is indicated a protected personal characteristic in the definition of discrimination in the **Law Against Discrimination**, which prohibits discrimination against persons or groups of persons with regard to their health status, as well as the health status of their family members. Article 24 of the **Law on Gender Equality** prohibits discrimination on the basis of gender in healthcare services. Section 4.10. of the **Strategy for Prevention and Protection against Discrimination** regulates discrimination against persons with a health status that can be the basis of discrimination. One of the planned measures for achieving the overall objective of preventing violations of the prohibition of discrimination is also (5) detection and elimination of potential discriminatory practices against people with regard to their health status (particularly against people living with HIV, hepatitis-infected people, people with severe or rare diseases, etc.) in the provision of medical, social and other services, in employment, work, education, judicial proceedings, exercising their right to private and family life and in other areas.

**Law on Patients' Rights**<sup>17</sup> governs patients' rights when using healthcare services, the way of exercising and protecting those rights, as well as other issues related to the rights and duties of patients. Article 3 guarantees the equal right of patients to quality and continuous health care in accordance with their health status, the generally accepted professional standards and ethical principles, in the best interest of the patient and respecting their personal views.

Despite this, the practice of the institution of the Commissioner for Protection of Equality shows frequent discrimination against people living with HIV, most commonly in the healthcare system. Complaints to the Commissioner for Protection of Equality for discrimination based on health status in the previous two years have already been the second most frequent, right after complaints for discrimination based on nationality and ethnicity. **In 2014, the Commissioner for**

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<sup>14</sup> "Official Gazette of RS" No. 98/2006

<sup>15</sup> World Health Organization, "The Right to Health", information paper, available at: <http://www.who.int/mediacentre/factsheets/fs323/en/>

<sup>16</sup> Information on sexual and reproductive health and rights:

[http://www.ohchr.org/Documents/Issues/Women/WRGS/SexualHealth/INFO\\_HIV\\_WEB.pdf](http://www.ohchr.org/Documents/Issues/Women/WRGS/SexualHealth/INFO_HIV_WEB.pdf)

<sup>17</sup> "Official Gazette of RS" No. 45/13

**Protection of Equality recorded two cases of discrimination against people living with HIV based on their health status in the provision of health services.**

All research conducted in Serbia in the field of HIV over the last ten years, is mostly about the stigma present and the discrimination within the healthcare system. The research on the quality of life of people living with HIV, conducted in 2012, showed that more than a quarter of respondents (27.5%) experienced stigma and discrimination in healthcare institutions in the last year<sup>18</sup>. In research of HIV Stigma Index carried out in 2012 (results not published), over a third of healthcare workers (32.9%) showed a discriminatory or very discriminatory behaviour towards those who had revealed their HIV positive status to them, while almost a quarter (23.8%) of these people said that healthcare workers disclosed their HIV status to others without their consent. The research on knowledge, attitudes and behaviours of health workers in the field of HIV, published by IPHS in 2015, recorded a slight increase of positive and a decrease of negative attitudes of healthcare workers towards people living with HIV, compared to the same research conducted in 2010<sup>19</sup>.

This research also shows that one of the most important issues for people living with HIV/AIDS is precisely the question of exercising rights in dealing with healthcare institutions and professionals. Table 1 indicates data on the number of people living with HIV/AIDS and their experiences, classified according to human rights principles.

Table 3 - Experiences in the areas of health, habilitation and rehabilitation

Health, habilitation and rehabilitation		Number of people	Percentage	Number of experiences
<b>Dignity</b>	Dignity	16	17.0	23
	Violation of dignity	55	58.5	130
<b>Non-discrimination and equality</b>	Equality and non-discrimination	32	34.0	44
	Inequality and discrimination	69	73.4	172
<b>Respect for diversity</b>	Respect	25	26.6	35
	Lack of respect	25	26.6	39
<b>Independence</b>	Self-determination	27	28.7	44
	Lack of independence	28	29.8	39
<b>Participation, inclusion and accessibility</b>	Inclusion and accessibility	42	44.7	113
	Exclusion and lack of accessibility	42	44.7	79
<b>Total</b>		<b>86</b>	<b>91.5</b>	<b>720</b>

Table 1 shows that in the area of healthcare, people living with HIV had both positive and negative experiences, with the number of negative experiences being greater than the other (459 compared to 261). The largest number of negative experiences refers to the principle of inequality and discrimination and lack of dignity, while the number of negative experiences

<sup>18</sup> The research on knowledge, attitudes and behaviours of health workers in the field of HIV, <http://www.batut.org.rs/download/publikacije/HIV%20zdrastveni%20radnici%202015.pdf>, p. 9.

<sup>19</sup> The text is available at: <http://www.batut.org.rs/download/publikacije/HIV%20zdrastveni%20radnici%202015.pdf>



regarding inclusion and accessibility is lower compared to positive experiences. This means that, at least when it comes to the accessibility of health services, experiences are contrary to one another, services are provided to some people, while the same number of people had the experience of being refused in asking for medical services. Also, it is evident that the treatment in the health system is such that in many cases, it violates people's dignity.

Negative experiences reported by people living with HIV describe numerous instances of violations of their rights within the healthcare sector: disclosure of HIV+ status to other patients or friends and relatives without their knowledge, refusal to provide medical services because of HIV+ status, clearly marking HIV+ status on the cover of their medical records, bad treatment of HIV and unavailability of newer generation drugs for treatment in Serbia, unavailability of tests for monitoring HIV infection, ignorance of doctors of various specialties regarding HIV, and many others. Generally speaking, the majority of respondents faced some of these unpleasant experiences with the healthcare system in their lifetime, but it should be noted that there has been a downward tendency of these experiences over the last five years, compared to previous years. It is particularly interesting that the same people living with HIV/AIDS sometimes experienced extremely negative and other times extremely positive experiences in dealing with healthcare workers and it sometimes happened in the same health institution. When it comes to health, people living with HIV/AIDS have positive experiences mainly at the Infectious Disease Clinics where they are treated in relation to HIV/AIDS (mostly in Belgrade) and with their selected doctors in health centers, while the experiences concerning the rest of the healthcare system are more often negative. Due to the importance that the field of health has been gaining in all research concerning stigma and discrimination, we will present more detailed experiences that are connected to specific areas of health that have proved to be the most important in in-depth interviews. Since the disclosure of HIV+ status without the patient's approval refers to respecting privacy, this matter will be further discussed in the section on privacy and family life.

### **2.1. HIV testing**

Unlike other situations where people living with HIV/AIDS do not always disclose their HIV+ status (social and cultural life) in the healthcare system they usually disclose it themselves. However, it happens that their HIV+ status is disclosed without their knowledge. The initial discovery of one's HIV+ status is a dramatic experience in itself, not only for the one who learns about it, but also for the healthcare workers who then disclose the HIV+ status of the person to family members, colleagues, or place symbols in healthcare documents that clearly indicate the status. Although the questions in the interviews focused on the experiences of human rights violations during the last five years, a large number of respondents spoke in detail about their experiences of knowing about their HIV+ status for the first time, where we find numerous instances of human rights violations, regardless of the fact that for most patients the experience of discovering about their HIV+ status is over five years old. On the one hand, only to discover that someone is HIV+, is an emotionally draining experience and if in this situation people do not have adequate support from those who communicate the HIV+ result, it is likely that this negative experience will determine how those patients will take further steps in exercising their rights.

Respondents, who discovered their HIV+ status during the past five years, generally did not have unpleasant experiences related to communicating HIV+ results. Most respondents discovered their HIV+ status with counselling before and after HIV testing. They were afterwards sent to confirmatory testing and they were offered continuous counselling services to support their acceptance of HIV+ status. In the majority of cases, their results were communicated to them talking in a confidential atmosphere and with emotional support. In some smaller communities, this support is continuous and quite strong as evidenced by the experiences of people living with HIV from Subotica and Vranje that talk about how much this type of support helped them accept their HIV+ status and start treatment. However, respondents who had discovered their HIV+ status earlier, had a number of negative experiences: communication of the results to family members, not having results directly disclosed to them but sent to the Infectious Disease Clinic instead, not receiving enough information about HIV, and also there were instances of testing without the patient's knowledge, giving results in an envelope, receiving other people's results. Although this practice is no longer in power, respondents still have vivid memories of these experiences, quite emotionally coloured and with almost all respondents this experience negatively influenced their acceptance of HIV+ status.

Modern studies show that counselling before and after HIV testing is the most efficient and most cost-effective intervention in relation to other comprehensive methods in the fight against HIV. It has a role in prevention, but at the same time enables early access to treatment. Also, this practice provides an opportunity for a person not only to discover and accept their HIV+ status in a confidential environment, but is also a type of open door to emotional and social support, as well as medical care.

The practice of counselling before and after HIV testing has developed in Serbia during the last fifteen years, and the monitoring of individual experiences demonstrated the positive effects of investments in its development. Particularly significant progress has been made in organizing counselling and testing in the field, outside of medical institutions, and especially during the implementation of the project which was funded by GFATM in our country, and in use of rapid tests for detecting HIV+ status. These actions were organized in cooperation between the laboratories of Public Health Institutes and NGO activists, which as an excellent example of organizing services so to get it closer to users and at the same time maintain the required quality.

Counselling and testing for HIV in Serbia is implemented under the national VCT Guide, adopted by the HIV/AIDS Board in 2007, after which there was an increase in the number of HIV counselling centers that offered HIV testing pursuant to the rules of the National Voluntary Counselling and Testing Guide. From 16 counselling centers in 2008, this number rose to 26 in 2012 and 2013. However, even despite an increase in the number of HIV counselling centers, there was a decline in the number of people counselled and tested in 2011, where one of the causes is considered to be decreased activity of the counselling center Student Healthcare Institute (SHI), Belgrade, which was the counselling center with the highest number of clients.

Since 2010, SHI has been focusing their work almost exclusively on the youth population, and earlier additional counselling activities, such as night-time testing, ceased to be implemented<sup>20</sup>.

These data are discouraging, especially if joined with the fact of termination of continuity in the supply of HIV tests during the past year. UN Theme Group on AIDS (UNAIDS) and World Health Organization (WHO) do not support mandatory testing in public health and advocate for expanding counselling and testing because it not only allows for discover HIV status, but it is more respectful of human rights, giving freedom of choice. As regards the National VCT Guide, it requires revision because the Guide does not envisage and regulate rapid tests and testing in mobile units for particularly vulnerable groups.

## **2.2. Disclosing HIV positive status in the healthcare system and respect for privacy**

One of the most significant aspects of the practice itself is the fact that people should decide on their own whether they want to know their HIV status and to whom and how they want to communicate it.

International standards protect **the right to privacy in the context of HIV**, which includes the obligation to respect physical privacy, and obligation to seek informed consent before HIV testing and respect for confidentiality in relation to the HIV status of a person. Our legal framework in this area provides a relatively covered legal protection and it complies with international standards, but on the basis of information available from associations of people living with HIV/AIDS and on the basis of the data from the Commissioner for Protection of Equality, the right to protection of confidential information is often grossly violated in practice. Protection from cases of abuse and disclosure of personal data without legal grounds or the consent of the party, as well as excessive and unlawful processing of personal data must be sought individually or through associations of people living with HIV/AIDS and other human rights organizations within the Monitoring System in Healthcare Services<sup>21</sup>, and if there are grounds for it, they should also be reported to the Commissioner for Information of Public Importance and Personal Data Protection, as the professional body responsible for the protection of privacy at the national level.

Since the the Ministry supervises and inspects the legality of medical institutions and private practices through health inspectors and inspectors in charge of the area of drugs and medical devices, it is necessary that any case of reasonable suspicion of misuse of personal data be primarily reported to the competent health inspection.

According to the **Law on Personal Data Protection**<sup>22</sup>, protection of personal data shall be provided for each natural person, regardless of gender or other personal characteristics listed (Article 1). Data regarding health status is considered especially sensitive data under Article 16 and can be processed only on the basis of a free consent of the person. Information regarding health condition may exceptionally be processed without the consent of the person, if it is required by law (Paragraph 2 of the same Article), in which case processing must be specially

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<sup>20</sup> <http://www.batut.org.rs/download/izvestaji/HIVAnalizaOdgovoraNaHIVPeriod20082013.pdf> p. 5

<sup>21</sup> More about this below

<sup>22</sup> "Official Gazette of RS" No. 97/2008, 104/2009 - other law, 68/2012 - decision of the CC and 107/2012

marked and protected by protection measures (Paragraph 3 of the same Article). In the case from Paragraph 1 and 2 of this Article, the Commissioner shall have access to data and the right to verify the legality of processing ex officio or upon request of the person or handler. Nevertheless, not even after six and a half years after the expiration of the obligation to adopt the Regulation on the Special Protection of Particularly Sensitive Personal Data and after several governments have changed, this document has not been adopted. In order to have effective functioning of the protection of particularly sensitive data, the Commissioner asked for immediate adoption of the Regulation.<sup>23</sup>

In addition, due to non-compliance with EU standards, as well as the problems identified in practice, there has appeared a need for changing or adopting a new Law on Personal Data Protection. In 2012, the Ministry of Justice formed a Working Group with this task, but it yielded no results. In an effort to help the Government, the Commissioner prepared a Model of a completely new Law and put it at the disposal of the Government, but that as well, although it has been more than half a year, remained without results. Serbian Government did adopt the Personal Data Protection Strategy as far back in August 2010, at the initiative of the Commissioner and on the basis of the text that he had prepared, but has never been realized, although the Government committed to do so within three months, and make an action plan for its implementation, and they are now five years behind.

The right to confidentiality of data on the health status of patients is guaranteed by the Article 21 of the ***Law on Patients' Rights***. Data on health status, and data from medical records, are regarded as personal data and are particularly sensitive personal data of the patient, in accordance with the law. Data contained in paragraph 1 of this Article, shall be kept by all healthcare workers, medical associates and other persons employed in healthcare institutions, private practice, organizational units of higher education institutions in the healthcare field that performs healthcare activities, other legal entity that performs certain works within healthcare services in accordance with the law, an organization of compulsory health insurance, as well as a legal entity that performs voluntary health insurance, where the patient is insured.

Persons referred to in paragraph 2 of this Article, as well as other persons who, without authorization or without the consent of the patient or their legal representative, hold data from medical records in violation of this Article, and make this information public without authorization, are responsible for disclosure of particularly sensitive data, in accordance with the law.

In the context of disclosure of HIV+ status to partners or family members, according to Article 22 of the Law on Patients' Rights, competent healthcare workers or healthcare associates and other persons employed by employers referred to in Article 21, paragraph 2 of this law, can only be freed from the duty to keep the data referred to in Article 21, paragraph 1 of this Law upon the written consent of the patient or their legal representative, or by a court decision. Notwithstanding paragraph 2 of this Article, the healthcare worker may disclose data about the health status of the patient to an adult close family member, even when the patient has not

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<sup>23</sup>Press release from the Commissioner for Information of Public Importance and Personal Data Protection of 5 May 2015, available at: <http://www.poverenik.rs/yu/saopstenja-i-aktuelnosti/2083-neshvatljiva-docnja.html>

given consent to the disclosure of information about their condition, because the disclosure of such information is necessary in order to avoid health risks for family member.

Regardless of the legal regulations and international standards, in the experiences of people living with HIV/AIDS, who participated in the monitoring of individual experiences, examples can be found that their HIV+ status was disclosed to others without their knowledge, mostly by healthcare workers. This has a direct impact on the treatment itself and is an introduction to discrimination against HIV+ patients within the healthcare system. Below are the experiences of people living with HIV/AIDS regarding the disclosure of their HIV+ status in the healthcare system.

*“But the healthcare system, the people who are supposed to know things. They don’t know... And I tell her nicely, yes, this fat can be increased in my blood, because of this retroviral therapy that I’m taking, because I’m HIV positive. The woman just about fainted. She began to shake, to tremble, ran out of her office, I did not know where she was going. She went to inform the nurse that she had and HIV positive person sitting in her office about to do ECG, and the nurse from ECG was my neighbour, whom I, of course, had not informed about my condition. I didn’t really go around the entire neighbourhood talking about it. And at that moment this nurse came into the office to supposedly count the medical records, to see how many patients were left to see the doctor. She couldn’t care less, of course, she just came to see who the HIV positive person was. So she came back, this alleged doctor, and asked me, she had no information on what was in front of her.... She ran away when she heard that I was HIV positive, I did not know where she went. She went to first inform the nurse, and then she came back, put on gloves to measure my blood pressure, trembling like a leaf..... In my report she wrote: HIV positive... Until I had left the office and saw the report, I didn’t know what she had written. I didn’t tell her not to write it, because it is discrimination. And then I filed a complaint against her”.*

*“I experienced recently, ehm, at the Pulmonary ward in Knez Danilova Street, when I was having a chest radiograph for my operation, that she said by telephone in a full waiting room, she told it to the person operating the radiograph, just - AIDS, hey, AIDS!!! I did not react at all ... because, in the end, what I have to react about?! I just think it’s...human vulgarity. It’s something in that woman. It’s not even a question of education, because I believe that by now they all have been very well educated, but it is simply some personal vulgarity. There you have it...”*

*“The first time she went out in the hall when I said that. Doctor, I can’t join you in the hall to tell you, I have to go into your office to tell you about my problem. She’s like, ‘so tell me here’, and I say ‘well, not in front of people’. She says, so what, say you’re HIV positive, I know about it...She says, well I know that you are HIV positive. I was like, excuse me Doctor, are you aware of how many there are here that just heard this?...”*

One of the most common practices of disclosing HIV positive status within the healthcare system is clear **marking of HIV+ status on the cover of patients' medical records**, and other medical documents (health insurance cards, therapy lists and referrals) as evidenced by numerous examples from the monitoring of individual experiences. Clearly indicated. Below are some of the experiences.

*"In general, when I first found out that I was HIV positive, mostly by having 'HIV positive' written on the cover of the medical record, which was traumatic, incomprehensible; as much as they were trying to explain that it must be so, I always asked: 'Why does it have to be so?' . Because what, will someone not take the record in their hands because it says HIV+, so it's like they need to know about it because of themselves personally? So I was like, what do you have to know, for you personally, when you're neither giving me a shot, nor do I need anything, so... That was one of the initial things, perhaps something that made me really fight that, this, this thing, disappears from the cover of my medical record... At that moment I felt miserable, how can I put it, branded, as they used to, uh, when they marked the Jews with the stars, the only difference was that I had no star, I had that one little plus, but I did not have to wear it on my sleeve. But I eventually I made peace with that, of course with the search for solutions, possibilities for how this could be deleted from the cover of my medical record..."*

*"Then I complained at... when I went to Novi Sad, about why they had written that on my health insurance card. I didn't know who to complain to, it's not like there was a special Institution for it there. And then this nurse took it and erased it. However, they later put it on the cover of the medical record. They even called me, when they wrote that on the health insurance card, they called me when I was at home to come to the clinic. And to bring my health insurance card with me. And when I have given them the health insurance card, the nurse wrote HIV+ and handed it back to me...."*

*"Well, at the institute, the institute where I once went to have complete blood test done and I was supposed to take it to Novi Sad, a medical technician, that is, a female medical technician, that drew my blood, there was an accident, as they say, and she was stung by, by my needle. Her reaction was stormy and she was scared, she did not know what to do and how, so they called me to come back and if possible to tell them about my HIV status, whether I was positive or not. I could not expect that something like that would happen to me in such a place and I will not say that I was tricked, but since my HIV status was nicely and clearly indicated on the referral, with a red marker pen, they knew. So I did not see then the point to confirm once again that yes I am HIV+ or not when it was clearly indicated on the referral..."*

During the last two years, incidents of entering HIV+ status to health records have not disappeared, but it is evident that people living with HIV/AIDS are more often encouraged to openly talk with doctors about it and that they are asking that the mark be deleted from their medical records and therapy lists.

*“So it was automatically written on the cover of the medical record in large red letters, ehm, ‘HIV+’, so to me, ehm, it was really shocking, but regarding that I had no choice, I couldn’t do anything, I mean, they are the ones who write and who keep those records with them, I could only, like, snatch the records from them to throw it away, burn it, whatever, but they would write another one again, I can’t, I mean, I couldn’t at that moment do anything about it... Through conversation, I heard that there were a few other people who had the same problem, but I, ehm, in the end, ehm, it took me a long time to tell them that it must be removed from the records, since the law provides that it must not be indicated visibly, that, ehm, this, uh, status, HIV, that you are HIV positive. Meaning, not even in your health insurance card, let alone on the cover of the medical records. So, ehm, eventually, they removed it, I mean, they brushed it over with white correction fluid, so it no longer says so on the cover of the medical record...”*

In January 2015, the Commissioner for Protection of Equality sent a recommendation to the Ministry of Health of the Republic of Serbia for taking measures to issue mandatory instructions to all healthcare institutions in Serbia, or to otherwise inform them that they must not enter information on the HIV status of patients outside of sections which are intended for entering such data in medical documentation. In addition, the Commissioner recommended that if of significance for medical treatment, the data on HIV status must be entered in a section of medical documentation intended for entering the diagnosis (or other diagnoses), with the same font and colour of the letters, which are normally used for writing diagnosis and conditions of importance for a medical procedure, using the Latin name and code of disease according to the International Classification of Diseases, Injuries and Causes of Death. The Ministry has acted upon this recommendation.

Unfortunately, despite this, the practice of entering HIV+ status in writing has not been fully revoked, and, at the time of preparation of this report, people living with HIV/AIDS are still faced with the same practice in the healthcare system. This is confirmed by the interview conducted with a person living with HIV/AIDS that was in intensive care in a medical institution in Belgrade some ten days ago.

*“I was in my bed in the ward and saw the patient across from me staring at my temperature chart. I did not know what it was about, so I got up to have a look. I was shocked when I saw “HIV+” written in huge red marker... I immediately reacted by talking to the nurse but she refused to erase it. Then I asked to speak with the chief, so they brushed it over with that white correction fluid afterwards. I couldn’t care less about these patients, but what if someone who doesn’t know I’m HIV+ comes to visit me?”*

### 2.3. Antiretroviral therapy and treatment

Since 1997, Antiretroviral therapy (concomitant administration of 3 or more ARVs) has been available in Serbia. All costs of treatment are borne by the National Health Insurance Fund for all people infected by HIV, who are in need of treatment. There were 1700 people in late July 2015 receiving combination therapy, compared to 330 people at the end of 2003. Since the introduction of ARV therapy in Serbia, there have been recorded half as much patients and three times fewer deaths from AIDS<sup>24</sup>.

Decentralization of this treatment was carried out in 2008, by opening three more regional centers in Niš, Novi Sad and Kragujevac (in 2009), as in the earlier period the treatment was only available at the Clinic for Infectious Diseases in Belgrade. However, the decision on decentralization was not made in consultation with people living with HIV, which caused many problems in its implementation. A certain number of patients from other cities changed their residence and continued to receive treatment in Belgrade, while others started treatment in other cities. According to people living with HIV/AIDS, there are currently only four patients receiving treatment in Kragujevac.

According to expert estimates, the drugs available in our country have long been out of use in other countries that now use the new generation of drugs that provide less adverse effects and are easier to use. In previous years, there have been breaks in the continuity of supply, which left many patients without drugs for several months. UNAIDS database indicates that, after Bosnian and Herzegovina, Serbia holds second places as a country in Eastern Europe and Central Asia with drastically high prices of HIV/AIDS drugs compared to other countries. On the other hand, at the global level, Serbia is among the first top two countries with the least resources, it only invested 250 euros in the treatment of patients.

The availability of treatment and medication therapy was improved in 2014 by putting 4 new second-generation drugs on the positive list (Prezista, Isentress, Viread and Celsentri), but it was provided only for 6% of patients who were resistant to existing therapies. However, these four drugs have long been obsolete in Western Europe where they are using the third, fourth and fifth generation of generic drugs, which are also the cheapest. It took as long as ten years to put new drugs on the positive list. National Guidelines for the treatment do not exist, but, according to experts in the field, the treatment practice is good and complies with European and adopted national recommendations for HIV infection treatment. Complying with these recommendations is most hindered by the unavailability of modern therapy.

In in-depth interviews, people living with HIV express clear dissatisfaction with available therapies, particularly those who have been in therapy for many years and in where there is a real chance that they will become resistant to all available drug combinations.

*“Well, with or without therapy, for the simple reason that these were fatal errors, and I mean fatal errors, cardinal mistakes were made when there was no, um, at that time, the treatment was on and off, the drugs were available for a while and then not, we all know that, for example, for three or four months they put you on one combination, and then there are three*

<sup>24</sup> <http://www.batut.org.rs/index.php?content=1325>



*months where you take nothing, and of course, there were a few combination that went to waste, since we have become, well, resistant to the them, and even one doctor asked me: "Well, you've almost used up all of it." I said "It wasn't by my mistake that it is used up, it was you who treat me that used it up, because I was held in therapy for three months, and then nothing for the next three months." They keep you on it for three months, then they change it, so there were quite a few, um, therapies, um, that failed. Combinations, I mean."*

*"... Our neighbours in Hungary, they have this test, I mean, automatically, when someone comes with the knowledge that they are positive, they run this test and get a drug that suits them best... And, let's say someone cannot handle a therapy, it does not suit them, so it means it is not always suitable; then there are people who can't handle it at all, they experience some incidental phenomena that simply do not work, so this means they need to change this therapy, that one has already gone to waste. So, there aren't a lot of combinations."*

It often happens that patients have to fend for themselves for the purchase of certain drugs that are not registered in Serbia or are not on the positive list.

The tests, reagents and devices for diagnosing and monitoring the progression of HIV infection and immune status are often unavailable and patients do not have the possibility to run the necessary analyses that are important for monitoring of infection and disease. Although the WHO has recommended that the analyses are performed three times a year, in Serbia they are done once a year or not even once. Monitoring of HIV infection is based on virological response to therapy (PCR), while the immune response is not monitored (CD4). Patients state that they have not been tested for two, three years (CD4). PCR is conducted twice a year for patients who have had worse test results from time to time, and in other patients even less frequently. Inability to perform resistance testing and the lack of CD4 and PCR tests jeopardizes the health and lives of patients and increases the cost of treatment of opportunistic infections.

This is recorded by numerous experiences of people living with HIV.

*"Well, the therapy more or less...but the tests and all that, I'm not satisfied because they did not have me do the tests for at least two years... The answer is always that they do not have the tests and those...reagents... I like, they do always get a little bit, but it's just for emergencies..."*

*"... Especially not to mention the tests, I mean, I haven't done CD4 for more than a year, aa, okay, I feel fine, they stick to the story that PCR is better than to measure CD4, because my last CD4 was when we the doctor said: "Oh my, it's better than mine." That I did not take, um, as a joke, or as something nice on her part, because I had just asked her. My comment on this was: 'So why don't you take these drugs, you would have a higher one'. That was my joke in the context of her answer because I did not feel good about it at all..."*

*“... We do not have enough tests, the state has not dealt with it sufficiently and we do not have what is most important for the treatment of patients, or for the treatment of patients with HIV, and that means having enough tests for PCR and enough tests, for, for, this, aaa, aaa, PCR and CD4. Only such tests can determine if we are resistant and if our PCR, i.e. the test which determines the number of viruses that if falls constantly then CD4 increases, and if the number of viruses increases per cubic millimeter of blood, then CD4 or immune system is on a decline. This means they are opposite each other, one decreases when the other increases and if there are no such tests, then we are actually convicted, and they do tests on us because of the lack of tests, according to the explanation, they run them very rarely and only for emergencies. I personally got it, but I know a bunch of patients are not being monitored because they do not have enough of these tests at the clinic, and not only there at the clinic, but in the whole of Serbia...”*

Lymphocyte phenotyping tests CD4 and CD8, HIV RNA quantitative tests, genotypic resistance tests, as well as viral tropism tests are not on the list of services financed by the National Health Insurance Fund. According to the experiences of patients in the department of Microbiology, Clinical Centre of Serbia (CCS), there is very often a lack of reagents for the tests, but this is not the biggest problem, because there is legal possibility to refund costs if the examination should be done in private practice when there are no reagents available.

In addition to being dissatisfied with the available therapies and tests, people living with HIV/AIDS are sometimes dissatisfied the treatment they receive at the Infectious Disease Clinics, excluding the Infectious Disease Clinic in Belgrade. Some of the Infectious Disease Clinics (in Novi Sad and Niš) work only once or twice a week, but what is often mentioned in in-depth interviews is that the quality of treatment, regardless of the available therapies, is rather bad and that their treatment was reduced to prescribing therapy (every two months). They point out that doctors do not talk with them about the therapy itself, the problems they have with it or other health issues. The following example indicates the difference in the quality of treatment.

*“... So, we always complained about something, it never, it could never go away, they just always told us: “And what's wrong with this?... So, even though I did not feel good with it and for example, at the last exam in Novi Sad there was a doctor, she was not an assistant, she was a doctor, who asked me: “What do you have to tell me?” So I thought to myself, why I even had to come to Novi Sad to have one doctor ask me: “What do you have to tell me?” No, I did not have this approach of these doctors, like in Belgrade. Although those in Belgrade were always crowded with um, patients, indeed, the Professor never had, um, how should I say, too much of a conversation with the patient, but if you asked something or if you wanted something, you never got the ‘I don't have time for that.’ Here in Novi Sad it's like you go, you enter, here are your receipts, you can leave. That's why I shouldn't go to Novi Sad. Well first, what I said, so Novi Sad should sit with itself and have a good talk to agree what they want to do.... I can say that, um, initially everything was great, wonderful and fabulous, but in the past, the past few years it somehow, um, I cannot say it's getting worse, but it's no longer what it used to be. What, what is the cause of all this, ...well, supposedly their excuse is, there are so few of us so they can't work every day and the other thing is that they are preoccupied*

*with other matters, obligations, such as universities and some other positions, and consequently, deprived in some way. Um, we literally we arrive there to jus say hello-hello, goodbye-goodbye. So nothing is ever done, no exams, nothing concrete, tests are less and less frequent. Plus, I do not like that someone, this, that the assistants, say, either work or replace professors and stuff like that. So, to me it is totally... Like, inconceivable, but what can we do..."(Subotica)*

The same person speaks in his interview about how the decentralization of treatment was made without consultation with people living with HIV/AIDS, and their inability to choose where they want to be treated.

*"Aaah, bad, because coincidentally I was just patient at an exam in Belgrade when these doctors arrived from Novi Sad that time, where they searched for our records, where the doctor said, ah, in Belgrade, so maybe they do not want to go, where we were told: "They are to go because they will have to." (Emphasis added). So I then asked: "Will we also have to go to your dentists because you so ordered?" Unfortunately, according to some government something we had to, unfortunately, leave Belgrade and go to Novi Sad, where for maybe the first year all was great, because it was like, work all day long, afternoons, so those who were employed were able to go without problems with a smile on their face and all. Of course, as the years passed, so that passed as well. Today, if I could make it happen that the government provides it, I would return to Belgrade. It doesn't matter that it is far away but, but, the kindness that I got in Belgrade, especially at the beginning, and afterwards in passing until the end, and whenever I had any kind of trouble, when I called, or maybe I was in Belgrade and maybe wanted to see the doctor, I would go to pick up therapy for an acquaintance, just to see the doctor, to talk with him a little, uh, he never omitted any of my acquaintances that, together with me, went from Subotica to Novi-, um, Belgrade... Ummm, so there's a world of difference between Novi Sad and Belgrade. I would go back to Belgrade this instant. (Subotica)..."*

Clinic for Infectious Diseases in Niš does not perform resistance test and PCR. In exceptional, urgent cases regarding the health condition of the patient, blood for analysis are sent to Belgrade, and the results sometimes take up to three months to arrive. Therefore, many patients have never done the PCR test, while the resistance test is inaccessible to most patients.

*"I think it is inadequate and tasteless, inappropriate... Totally. In my opinion. Yes, aaa, for us HIV patients the Clinic works once a week, from... When I come, I have to literally wait for the doctor, for like... It depends. Maybe sometimes I wait five minutes, and sometimes I wait for two hours. I may have some other things to do. I have a child who is eight years old. Maybe I'm supposed to take them to school, the child goes to school downtown..." Niš*

*"Every other month you must be present there, for what? Maybe they see you, maybe not. The last time I got my receipts in the hallway, and she said here are your receipts, and I said: "Well, thank you very much, I just do not know why I came back to Novi Sad again?" So, she*

*could just care less. According to me, a doctor should ask: how do you feel, do you have anything... In the last report I received, my finger had hurt, and she said, it said in the report: his finger hurts. So the general practitioner asked, "I which finger do you feel pain?". I said, "Why?". Well, he says, the report says, your finger hurts. That has nothing to do with HIV. Nonsense..."*

However, the majority of patients is satisfied with the services provided at the Clinic for Infectious Diseases in Belgrade, not only in the treatment of HIV but also the assistance of doctors from the Clinic for Infectious Diseases in exercising their right to treatment in other health institutions.

#### **2.4. Refusal to provide medical care and treatment**

Article 22 of the **Health Insurance Act**<sup>25</sup> provides that considered as insured persons shall also be persons who belong to the population group exposed to increased risk of disease, including (5) persons in relation to the treatment of HIV infection or other communicable diseases... Among the health services be funded by compulsory health insurance, Article 45 indicates examinations and treatment related to HIV infection and other communicable diseases for which the law stipulates the implementation of measures to prevent their spread. If required by the health condition of the insured person (Article 152), as well as the rationality in providing health care and on a proposal of the appropriate medical specialist treating the insured person, the selected doctor may delegate authority under Article 151 of this Act to that medical specialist, in issues regarding diagnosis and treatment, referral to inpatient treatment, including prescription of drugs that are dispensed by prescription for certain diseases (including tuberculosis and HIV).

Through in-depth interviews we learned that many people living with HIV/AIDS in Serbia, regardless of the legal provisions, cannot obtain equal treatment in access to healthcare services that go beyond the Infectious Disease Clinics where they are treated. People living with HIV/AIDS in Serbia often cannot even obtain services such as e.g. dental and minor surgical interventions, including surgery and postoperative treatment, if they indicate their HIV+ status or they usually obtain them with great difficulty. Examples from in-depth interviews speak about these situations.

*"So far I have always been provided health care, albeit with a slightly different treatment, for example, when I had knee reposition, they put me to the last place. I do not know, I came like in the morning at ten o'clock, and only about seven in the evening it was my turn. They put me as the last patient despite the fact that it was not open, no wounds or anything, my meniscus just had to be fixed and then there was anesthesia, and now they were afraid that contact, or the anesthesia with blood or something, all in all, they set me as the last patient, despite the fact that I was their colleague..."*

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<sup>25</sup> "Official Gazette of RS" No. 107/2005, 109/2005 - corr., 57/2011, 110/2012 - decision of the CC, 119/2012, 99/2014, 123/2014 and 126/2014 decision of the CC

*“Aa, the first case. Health centre. There, when she was supposed to give me, to put a bandage, she simply made this whole mess because I'm HIV positive and then she called... I don't know... Chief nurse with like five gloves. So just, it is our... Our mentality, more or less. I do not blame the people, they protect themselves, it's okay. But I think it's a little Tasteless...”*

*“Dental scaling... This was done by a doctor who was in a spacesuit, but literally in a spacesuit. Like, totally like a spaceman. I mean, again, I understand him because he probably knows what can happen and all. And another time I was supposed to go to him to have stuff done, that's when they kept me waiting for a long time, and then again the doctor who had done things before showed up and did everything the way he should...”*

*“Well, he did not want to pull my tooth, and then I said, so what do I do when I, I, I, I have a toothache. He says I can only send you to Novi Sad, and I was like 'so send me to Novi Sad', then he wrote the referral.... Well, apparently he didn't have the instruments or something, I do not know... that's what he told me...”*

*“Well, I was supposed to go to physical therapy... to the electricity and laser, and all that, like I went earlier. And I went like five times before, I don't know, this was the sixth time, and when she saw that I was HIV+ then she said, like, the first time when she approved therapy she wrote some other, not HIV+ but some other disease she wrote, like for these nurses and technicians to know, like, it is similarly transmitted, but she did not write HIV+ on the cover of the medical records, she put something, totally different, a code of some sort. And next time when I arrived there again, then she said, I consulted a colleague and he said that these technicians will not work with me, that they are afraid that somehow they will get infected, I don't know...”*

*“When after treatment in the Clinical Centre, when my pleura broke, and when I lost seventy percent of the left lung... In Ozren, where I... Where patients with pulmonary problems are sent to recover. When they saw the anamnesis, they emptied half of the room, and left me with a madman. Who also... A mental patient. Who also nobody cared about. If you understand me. The two of us alone, me and him in a room with twelve beds. A there they put additional... They transferred them, where there should be eight in the room, they threw in extra beds, they slept one on top of the other, to not be with me in the room. Specifically and directly. No one told me that, of course. But I saw exactly what was going on... - A mental patient, yes. A mental patient who gets up in the middle of the night and pees in the middle of the room, you know? So, direct endangering... Direct endangering of my health, as well, you know? He was full of germs, treated for tuberculosis, you know? They left me in the room with a man who was being treated for tuberculosis. You know? And we know well what pneumonia can do to me, let alone tuberculosis, God forbid...”*

There was one situation when was I supposed to do a test in private practice, I could not do it in a state hospital because there is no, and you can't get on the waiting list or I don't know, I needed one test and when I mentioned why, they said there was nothing available..."

*"Here no. Because pulmonologists will not receive HIV+ patients. The last time I got a referral to a pulmonologist, there was simply this young doctor that would not hear of it... She would hear of receiving me, but immediately gave me a referral to the sixth Department..."*

*"I hurt my hand. I hurt my hand, they did not know what it was, because I was unconscious and then they did analyses, and it took a day or two. However, I really do not know, I really do not remember for how long I was unconscious, I do not know how long it lasted. I remember that I woke up in Kovin... from VMA to Kovin, and the gate closes, and I read General Hospital Kovin. What am I doing here? I thought, that's for crazy people, I mean, that's for mentally ill people. And that's where they... the driver told me to be quiet, to be careful with what I said or else I would stay there. And when I went in three nurses, or three psychiatrists, I do not know what they were, probably some professionals. When they looked at my test results they asked me if I knew that I had HIV and I said yes. They examined me with that stethoscope, that's what it's called, is it?... They examined me and told me, approached the driver and said he's not for here, he's not for here, drive him elsewhere. Therefore ...they neither said where to drive me, nor have they sent me anywhere, nor gave me a referral to anywhere. When they bro.... The driver put me in the van and drove me to Pančevo, I sat there and I even spent the night, and in the end no one wanted to see me, and I threw all the papers and did not want to go to the doctor anymore..."*

*Well, at least she would not have acted, aura. You get a sense of inferiority. They are all little gods when you think of it. They are really, in the end they are the way they are. Me, first God and after him - me. But, when you come with this diagnosis, then they are like: what made you come to me. Why did you not go to your own doctor? Why did not you go to see your own doctor if the colleague explained her what this was about. That it was none of my fault, but they just scheduled my appointment in the wrong time. And she was rude enough to ask me something like that. So, they humiliate you in all possible ways. But you, at that moment, as much as you're angry and hurt, you do not know where to go. In this small town, where do I go? To the Protector of patients' rights? Well, they are all tight-knit, I know this woman. The last thing I need is for her to find out on top of all this..."*

In addition to the positive experiences with the doctors from the Clinic for Infectious Diseases, who often help in obtaining health services (through communication with doctors at other

clinics they know or referral to those doctors who they are sure would receive them), people living with HIV/AIDS have positive comments on their contacts with other physicians, mostly general practitioners.

*"Well, since I knew the doctor privately, she was genuinely sorry that this happened to me, well, that's just what she told me, and she took it quite normally, as well as any other illness. She never objected me, she never judged me on the basis of this and always asked me if I were feeling good and how I was and all. So I never had problems... (Niš)*

*"Surprisingly, I haven't had problems. I haven't. So, I am one of the few who has never had problems, I mean, even when I changed doctors at the Health Centre. Selected doctor. I had no bad experiences whatsoever. All the opposite..."*

Based on the experiences that people living with HIV/AIDS presented during the interviews, it is clear that there are many more of those that had their dignity and the principle of equality and non-discrimination violated in the healthcare system, than those who were not affected by this. It can be said that the exercise of rights in the health system is more of a problem that always has a solution rather than an unsolvable problem. People living with HIV/AIDS, usually do receive healthcare, with some difficulty, and often not in places where it is convenient for them, and where by law they are entitled to receive healthcare, but in places where healthcare staff is willing to provide them with care/services. Often through the interviews there were experiences of people living with HIV/AIDS, which suggest that it was "important who you happen to run into in the healthcare system", because some want and do not want to provide health services. Some examples talk about this:

*"Well, the treatment, umm, again, depends on who you happen to run into. I was once again at the emergency admission, that I said this, um, there was an emergency medicine intern, um, um, totally normal, his approach. He gave me all the help, he talked with me and, I mean totally normal, I mean, it was one doctor-patient relationship; even more so, perhaps at one point I was um, pleasantly surprised, I even felt embarrassed, I felt at that moment, because, um, I can't say it was pity, there was so much understanding, so much attention that I simply felt uncomfortable. So, I repeat, it's all just about who you happen to run into. Not everybody is the same..."*

*"Yes, I went to the clinic at Dr Subotic Street, to have treated...um, what's it called, gums, my problem with gums. And then when I told the doctor about my status, he said: "Please wait just a little bit", and he came dressed in protective uniform, like for protection against the worst...*

*White jumpsuit, green boots, hat on head, mask, totally dressed and said: "Now we're going to do it," and I said: "What is all this? I'm going to call the Chief" and I went to the Chief, and*

*he tells me: "I'm not going to do work on you now", and I said: "Well, then I'll go to the director now". And when I went to the director, he came with this protective uniform, he didn't even take off the tartar from my teeth, but just polished them, because he was afraid. But in the same healthcare, the same institution, I had a surgical intervention, the doctors did it without any problems, so we are all different..."*

*"Well, uh, the general practitioner is an extremely, extremely fair woman. I've really never had problems with her. Aa, she... Whenever I took a referral for, say, a neurologist or a scan, uh, umm, for EEG or MRI, or for anything else, she always helped me, she always directed me as to who I could go to. In that matter I have never had any problems. The only thing that can be, that I can say is a problem, it's the dentist. Going to the dentist..."*

People living with HIV/AIDS, members of other vulnerable groups, mainly intravenous drug users have particularly negative experiences with the provision of healthcare and the exercise of the right to dignity, non-discrimination and inclusion. Almost all research participants in this group had a negative experience in the healthcare system.

*"I was hospitalized, I had this operation when I was in Belgrade, then they saw, a brain tumor, on the cerebellum, and released me from Požarevac prison, but first they did not believe me that it was tumor. They thought that I wanted to get a sentence termination to get away, since the sentence was about four and a half years. However, at the end when they determined that it really was something serious, they let me go home, ended the sentence, and my mother took me to the hospital, town hospital, where a cleaner did not want to help me get up when I fell out of bed. He shouted down the hall: "Aidser, I will not help her", and at his insistence with the Chief, I got transferred to Belgrade, since he would not bring me breakfast, nothing, and alarmed the other patients. The patients started to fear me. Then I was moved to a separate room. And one day he made that fuss and the ambulance came, I was almost kicked to Belgrade, and I thank him for that, I got a strong doctor for surgery, really. And then drove me to Belgrade, and receive me at the Clinic for Infectious Diseases in Belgrade. It's like you're in a different country, both the doctors and the nurses; here the nurses won't move, there the nurses run to help. The doctors are different, completely, and their approach to the patient is the same as to other patients, no difference in whether you are HIV positive or not..."*

*"I select a doctor, he looks at the records. And with, like... He raised his head and said: I'm sorry, kid, I do not treat such patients. I asked: what kind? He said he didn't treat drug addicts, um, HIV positive, hepatitis... Please, go to... Another office, another doctor. To go to another doctor. I left without a word and, um, I went to another doctor and she received me, like, right away. That's as far as I can remember, which left an impression on me. It is... these are the two things about doctors that I..."*



## 2.5. Exercise of the rights of women living with HIV/AIDS in the healthcare system

Article 12 of the fundamental international document for women's rights protection, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)<sup>26</sup>, stipulates that Member States shall take appropriate measures to eliminate discrimination against women in the field of healthcare in order provide access, on the basis of equality of men and women, to health services, including those regarding family planning. The UN Committee on the Elimination of Discrimination against Women<sup>27</sup> pointed out in its general comments<sup>28</sup> the need to improve access to healthcare for women, and that it is necessary, in the programs for fight against AIDS, to pay special attention to the rights and needs of women and children, as well as factors related to the reproductive role of women and their subordinate position in some societies, which makes them particularly susceptible to HIV infection. The Committee, in its Concluding Observations on the second and third reports of the Republic of Serbia from July 2013<sup>29</sup>, expressed concern about the lack of access to antiretroviral second-generation treatment for women living with HIV/AIDS and the lack of information on the prevention of HIV transmission from mother to child and possible treatment. The Committee therefore requires that Serbia, as signatory states, take immediate measures to ensure women and girls living with HIV/AIDS have access to antiretroviral drugs of the second generation and other necessary medicines and services, as well as information on methods of prevention of HIV transmission from mother to child. The Committee expects Serbia to give answers to these questions in July 2017<sup>30</sup> to healthcare services, as well as access to adequate education and information, including in the field of sexual health and reproduction protection. Governments in particular need to provide funding for programs aimed at adolescents for the prevention and treatment of sexually transmitted diseases, including HIV infection.<sup>31</sup>

The *Strategy on HIV infection and AIDS*, on prevention of HIV infection in women, means the prevention of primary HIV infection among girls and women, prevention of unwanted pregnancies of women living with HIV, reduction of transmission of HIV from mother to child by treatment with antiretroviral drugs or prophylaxis, safer childbirth, counselling regarding the diet of infants, and providing care, treatment and support to women living with HIV/AIDS and their families.

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<sup>26</sup> Confirmed by the Law on Ratification of the Convention on the Elimination of All Forms of Discrimination against Women (Official Gazette of SFRY - International agreements, No. 11/81), text available at: <http://ravnopravnost.gov.rs/images/files/Konvencija%20o%20eliminisanju%20svih%20oblika%20diskriminacije%20zena%20UN.pdf>

<sup>27</sup> International expert body monitoring the implementation of CEDAW in the member states, established by Article 17 of CEDAW

<sup>28</sup> General comment No. 15 - Avoiding discrimination against women in national strategies for the control and prevention of Acquired Immune Deficiency Syndrome (AIDS), General comment No. 18 - On women with disabilities and General comment No. 19 - Violence against women

<sup>29</sup> Serbian translation of the document available at: <http://www.ljudskaprava.gov.rs/index.php/yu/ljudska-prava/konvencije/57-konvencija-o-eliminisanju-svih-oblika-diskriminacije-zena>

<sup>30</sup> The same as footnote 15

<sup>31</sup> In addition to the stated general recommendations, in the General Recommendation No. 27 on elderly women and protection of their human rights, the Committee notes that signatory parties should adopt special programs that are designed to meet the physical, mental, and emotional needs

The report of non-governmental organizations “Shadow over Serbia”, from 2013, points to the problems in realization of healthcare for women. In the total number of registered people with HIV/AIDS in Serbia, there is an insignificant share of cases in which the infection occurred through transfer from mother to child<sup>32</sup>, but there has been noted an increase in the number of infected women. HIV positive women in particular refrain from giving birth, for fear of vertical transmission of the disease and the lack of financial resources.

Experts believe that today, when highly active antiretroviral therapy is part of everyday clinical practice, for a large number of couples living with HIV/AIDS, life expectancy and quality of life are not only extended, but also the ambition to have children becomes a reality, and the birth of healthy and uninfected children of these couples is a significant and achievable goal.<sup>33</sup> There is no significant impact of pregnancy on the deterioration of the health of pregnant HIV-positive women. Conversely, HIV infection does not substantially compromise pregnancy. Safe pregnancy in HIV-positive pregnant women requires trust and cooperation between the patient and gynecologist and infectologist. The ultimate goal is the birth of a healthy and uninfected child, and the major measure is to prevent vertical transmission of the virus from mother to fetus.<sup>34</sup>

At the moment only the Centre for the treatment of HIV+ women at the Gynecology and Obstetrics Clinic<sup>35</sup> Narodni front in Belgrade offers the possibility of counselling for HIV+ pregnant women, as well as delivery (all HIV+ women give birth only there). The baby of the first HIV+ pregnant woman at the centre was born in 2004, and since then, according to the doctor<sup>36</sup>, another 22 healthy babies were born and there were 38 terminations of pregnancy. This is the only centre of its kind in the region and according to the doctor, its services are used by couples from neighbouring countries, as well.<sup>37</sup>

In the interviews we found several examples of HIV+ women who wanted to have children and did not or did give birth. Almost all of them had unpleasant experiences in contact with the healthcare system, from the lack of information about pregnancy, childbirth and breastfeeding babies, to discouragement from becoming pregnant.

*“I gave birth on .... I spent two days at the hospital, after that they let me go home. They kept the baby for seven days. The fifth, only on the fifth day running, I could see the child, in the*

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<sup>32</sup> The data of the National HIV/AIDS Office show that in the period 2002-2012 there were 12 HIV positive children born whose mothers did not know that they were HIV positive. This is a significant reduction in the number of infected children compared to data from the period 1992-2001, when 22 children were infected by vertical transmission, “Shadow over Serbia”, Report of non-governmental organizations for the 55th session of the CEDAW Committee 2013, p. 20

<sup>33</sup> “HIV and Options for Safe Pregnancy”, Dr Relja Lukić, available at:

<http://www.aidsresurs.rs/tretmani/%C5%BEene-i-hiv/hiv-i-mogu%C4%87nosti-za-bezbednu-trudno%C4%87u>

<sup>34</sup> “Pregnancy and Childbirth in Women Living with HIV”, Dr Relja Lukić, available at:

<http://www.aidsresurs.rs/tretmani/%C5%BEene-i-hiv/trudno%C4%87-i-poro%C4%91aj-%C5%BEene-koja-%C5%BEivi-sa-hiv-om>

<sup>35</sup> Gynecology and Obstetrics Clinic

<sup>36</sup> <http://www.blic.rs/vesti/drustvo/on-brine-o-hiv-trudnicama/1xtllg0>

<sup>37</sup> Ibid

*isolation cubicle, they put the child in the isolation cubicle. Only after, um, four days and fifth, they remove the child from the iso iso ... isolation cubicle, I began to stutter, I am, I cannot... If it weren't for one doctor (she specifies the name) I think they would keep her for 7 days, until the end I would not be able to take my child into my arms. I mean, it really doesn't make sense that I can't hold my child as if it were infected or if I was, I do not know... And when I came to visit to see the baby, the baby was crying, umm, and the doctor did not want to, actually the nurse did not want to take out the child. For fifteen minutes the child is crying, it went red and they did not even allow me to take it into my arms. When I said to take him out, she just turned around and left. Not a word she told me, just turned around and left the room...*

The following examples are about the attitude of some doctors regarding the desire of HIV+ women to become mothers.

*“Well, after a year I had a boyfriend. He wanted to have a child with me. However, it turned out that his neighbour where he lived, in Šabac, was the Chief of the Clinic for Infectious Diseases and he told him, of course, that I was HIV+. And I said, of course, that it was true and he still wanted to be with me even though the doctor, the Chief of the Clinic for Infectious Diseases actually told him and his mother and that, umm, what would he do with me, that I was sick, and why would... He wanted a baby with me. Of course, the Chief and his mother talked him out of it and he gave up. Aaaa, I don't know, I mean, what it is with the Chief going around... Telling stories about patients to others... To reveal... so that everybody knows, the serving staff and the whole Infectious Disease Department, about the patients...”*

*“Yes, last year I was pregnant, and I cannot say, I had finally found a doctor who accepted me for who I was, but until I came to him, I saw one doctor, then another doctor, then a third, I don't know... And there again I really heard some rather unpleasant comments: Why did you decide to be pregnant, do you know that you can transmit it to your child? And then I know, then, then... I thought if I should discuss it with them at all, to explain that doctor, that my doctors were familiar with all that and that I was taking this therapy, bla, bla, bla... But I gave up because it was an unsuccessful pregnancy after all... But there, I was disappointed... Afterwards, with one doctor, from here, from Niš, I spoke about what his colleagues were like and what was happening... And he told me that this was so, that was true, that there were still doctors who did not have a positive opinion about the fact that HIV+ women want to have children. And I had a situation at the laboratory, to hear comments from the nurse who takes blood, at the Health Centre...”*

*“... There, that was the only thing, so soon afterwards they transferred me to a small room, isolation, where there was only one girl who only had Hepatitis C. And there it was so nice, like I was in a suite... But I felt ... well, how I felt, when it was simply, uh, the whole room... We were eleven in the room. At Narodni Front, in Belgrade. Uh, the whole room found out and then, uh, they all hid, fled from me... How can you feel, depressed, like, down, uncomfortable, uh, um, uh, uh, I'm still in Belgrade...”*

## 2.6. How the media report on HIV in the context of healthcare

The largest number of articles analyzed in media monitoring dealt precisely with the subject of health, care and treatment in the context of HIV infection, with that the majority of the articles presented statistical data about the infection and ways of transmission of HIV, while only a part of the texts spoke directly about the health condition of people living with HIV/AIDS. In as many as 60 articles the subject is prevention (use of condoms and ways of transmission, and the source of information in almost half of the processed articles was the medical staff and exclusively the competent medical institutions, and the organizations of people living with HIV/AIDS only in cases if they were dissatisfied with the specific situation in this field or (in)activities of competent national institutions and organs. These organizations also speak out in cases where the reason for the publication of an article is World AIDS Day on 1 December or World Remembrance Day of AIDS Victims (observed in the third week of May).

HIV/AIDS is a mandatory subject, seen from a medical point of view, when writing about the diseases with the highest mortality rate. Here are a few examples.

*"It is a virus that attacks the immune system, making the body unable to defend itself of even the smallest infections. It is assumed that there are around 35 million people in the world today living with HIV. Every year around 1.5 million people die from the effects of the disease. HIV (Human Immunodeficiency Virus) is a virus which belongs to the group of retroviruses, whose actions caused the ultimate syndrome known as AIDS. HIV stands for Human Immunodeficiency Virus in English, which would characterize this virus as a cause of decline in the ability of the immune system of the organism. There are five body fluids that contain a sufficient concentration of the virus for a possible infection of people and these are blood, semen, pre-ejaculate fluid, vaginal secretions and breast milk. HIV can be transmitted via body fluids during anal, vaginal and oral sex, through blood transfusions, negligent use of needles in intravenous drug users, through the placenta (between mother and fetus), and breast-feeding a baby from mother to infant. HIV is originally from the area south of the Sahara in Africa, discovered during the second half of the 20th century."* Danas daily, from 11/3/2015.

In addition to data on the nature of the virus, mode of transmission, the development of the disease and mortality rate, there is not a single information on protection in the text. Another matter that is not pointed out is the fact that ARV therapy enables people living with HIV/AIDS to reach the average life expectancy, which is presented in some other articles with a medical approach. The focus on the drastic consequences of infection contributes to anxiety and social isolation of people living with HIV/AIDS. We are free to conclude that such articles have a "mask" of high concentration of data, and that they fall into the category of "interesting" with "catastrophic" overtones.

A far better measure of information was presented in the article titled "Forever labeled" from NIN weekly, which also points to the secondary infections in people living with HIV/AIDS but also to the possibility to avoid them.

*“Fighting is common, so the fact that my friend does not need norvir it's not a relief, even if there is no day that her drugs become scarce. Because, after ten years of application of highly active antiretroviral therapy, or HAART, one can expect anything, especially women. So powerful that in one month they rehabilitate the entire immune system, the drugs take their toll on the other side. So in the near or distant future she can expect the metabolic syndrome, hyperlipidemia, insulin resistance, accelerated development of atherosclerosis, osteoporosis and aging, chronic kidney disease, lipoatrophy, lipodystrophy... and other disorders whose name she still can't pronounce. Or it will all bypass her if the NHIF improves their policy” (and include in their program the more advanced generation of drugs, as stated in the second part of the text). This article briefly mentions the bed-ridden patients at the Clinic for Infectious and Tropical Diseases, therefore, those with symptoms of AIDS. “On the other hand, after thirty years, there are (too) often patients in the advanced stages of infection reporting to the clinic. And to hospital treatment only when they have nowhere else to go.*

*This ghostly place is gloomier even than the waiting room in Department VI. Those few patients are glued to the bed, and so is J. V. She is attached to the infusion, transfusion, and oxygen is also ready. She has been bleeding so much after surgery and cancer radiation that her body cannot make it up. Uterus cancer is, perhaps, the result of HIV, but the stage at which it was observed is a sign of negligence. “These are old habits”, she says, trying to smile, and somehow manages to. Now for the first time, she feels regret, she says, for the ‘wasted time and energy’.*

*Suddenly there was a roar coming, if it can be produced by a shadow-like woman: Give me cigarettes! Give me methadone! J. V. is rolling her eyes, because the shouting has been going on for days. She finds salvation in her tablet-computer, emptying what little Internet she had left. She will regret it in the evening already, because there is no wireless internet here. “We just recently received a printer for prescriptions, which is not yet switched on”, says a nurse, and on a monthly basis at least 1,000 people pass through this clinic. That is why errors occur due to which pharmacists at the Clinical Centre get angry, because their drugs are dispensed by prescription, and - since they are expensive - carefully recorded.”*

In most of the articles in the medical model, the “neutral” approach to reporting is dominating, with many figures, data on scientific discoveries, new achievements in medicine, etc. This indicates that for journalists, HIV is still a medical phenomenon. On the other hand, the medical model contributes to better inform the public about the virus, but it usually positions the infection into chronic, rather than “deadly” category.

Although there is a lot of talk about HIV testing in the media, covered during media monitoring, reporting on the practice of counselling and HIV testing is quite scarce. Media monitoring does not find articles that deal with this topic in the purpose that it has (HIV prevention), and what can be found in the media are announcements for free testing. Such articles may create confusion and cause negative emotions that can be unnecessarily linked with this practice. Thus, in the newspaper “24 sata”, there is an article from 3/12/2014, titled: “HIV test: five minutes as an eternity”. The article describes the experience of testing but does not address the practice of counseling and HIV testing, nor does it explain its purpose, which is particularly evident in the interview itself. In testing, one respondent says: “Well, I was not much afraid, I knew that I

*wasn't threatened because I hadn't been doing anything wrong."* The message for the majority of those who will read that is that the HIV test is only for those who are doing something wrong, and the title refers to a very unpleasant experience if the test does occur.

In the newspapers there can be found many articles that jeopardize the presentation of this practice as preventative much more seriously. So some newspapers write about the law in Russia and some other countries on mandatory HIV testing before marriage and before going into the army. Media monitors also find articles on the proposal for mandatory testing of pregnant women and persons belonging to the population of men who have sex with men.

Although health is the most common topic in the media, it seldom directly addresses the issue of ARV therapy and its availability. Journalists often report on the availability of ARV therapy, mostly at the initiative of associations which bring together people living with HIV/AIDS, mainly during the World AIDS Day and World Remembrance Day of AIDS Victims. Articles deal with this subject in a superficial manner and from a medical point of view, without linking this information with the rights of people living with HIV/AIDS to the health and quality healthcare.

*"World AIDS Day, 1 December, is now observed in Serbia through a campaign that carries the slogan "Filling in the gaps in knowledge, prevention and support of people living with HIV." Chief of the Center for HIV and AIDS at the Clinic for Infectious and Tropical Diseases of CCS, Prof. Dr Đorđe Jevtović, said on this occasion that patients in Serbia are treated effectively, that they have a good prognosis for survival, although drugs may be obsolete:  
- Drugs for HIV and AIDS are expensive, three are always used combined, and the most advanced treatment requires around 1,500 euros per month, while older drugs are almost two times less expensive."*

Only a few texts are an exception in that they are related to statements of people living with HIV/AIDS. Journalists focus on the presentation of a few people living with HIV/AIDS that speak openly about their HIV+ status. Unfortunately, not a single newspaper article deals in detail with bad experiences faced by people living with HIV/AIDS, within the healthcare system. It all remains at the level of statistical data. A person living with HIV/AIDS is still not a source of information for any other social issue or phenomenon for the journalist, except for their own illness and way of infection, regardless of their interests, business success, artistic merits, etc.

### 3. PRIVACY AND FAMILY LIFE OF PEOPLE LIVING WITH HIV/AIDS

The second most relevant topic when it comes to the exercise of human rights of people living with HIV/AIDS is privacy and family life.

Table 4 - Experiences in the area of privacy and family life

Privacy and family life		Number of people	Percentage	Number of experiences
Dignity	Dignity	9	9.6	11
	Lack of dignity	34	36.2	56
Non-discrimination and equality	Non-discrimination and equality	28	29.8	37
	Discrimination and inequality	28	29.8	44
Respect for diversity	Respect	28	29.8	34
	Lack of respect	20	21.3	26
Independence	Self-determination	18	19.1	24
	Lack of independence	16	17.0	29
Participation, inclusion and accessibility	Inclusion and accessibility	43	45.7	91
	Exclusion and lack of accessibility	22	23.4	35
<b>Total</b>		<b>84</b>	<b>89.4</b>	<b>378</b>

In introducing the five principles, 84 people reported cases in the field of participation, inclusion and accessibility, with that a larger number of people (but also a larger number of experiences) refers to the positive experiences. Negative experiences were reported by 22 people, but some of these experiences are drastic cases of exclusion from the circle of family and friends. The following are quotes from the interviews illustrating the negative experiences in situations where respondents were rejected or marked by their closest surroundings, family and friends.

*“My own sister tells me that, yes. Non-stop, there, like, aidser, um, you're this, you're that. So, I'm the worst”*

*“Well, I was at a birthday party, it... before I found out that I was HIV (kh), that is, when I found out at that time, since I didn't go anywhere. I was at a birthday party, however, my wise mother, as per usual, blurted out in front of everyone that I have HIV. They literally threw me out of the party and said: “Do not ever come. We do not know each other anymore...”*

*Vranje is a small town. Virtually everybody knows everybody. If not directly, then indirectly. So*

*probably someone would find out, and I suspect that one... One of my aunts found out, that she had seen drugs, that she googled it or something. So in the last week she has been very cold to me."*

*"...There are wonderful families, where, where, where it is handled in a much better way, but my family, just, may they be alive and well. But I think it's a problem of society that this sweeping under the carpet and suppressing inside ourselves, aa, does not contribute to the system. So, there is no communication in our families. About a problem of this nature, or any problem at all, you are expected to solve the problem on your own, to not burden, to, to, to, go through life on your own. At least it's like that for me, so... There isn't much I can do."*

*"Then, when he said that nobody should touch me because I was, after all, ill, I had my problems, then began the provocation, then my brother said at one point, he began to shout, and he said: "Come on, aidser, do not ever talk to me in your life, you do not exist for me, you're dead."*

*"However, whether she thinks or does not think that way, considers that this is part of her daily ritual that she performs, so that she does not think about it and say, for the first time when I had a friend come over, and um, since I have like five or six cushions on that sofa, I remember that, to me it was horrible, I even cried, even more so, we began to argue, when that friend left, the first thing she said was, 'I'll take from there those three cups that you have', that's one thing, and the other was when he left, and I followed him, and when I came back not one cushion was not on the sofa. She put them all on the clothesline to air them. I asked why she did that, and she was like, 'how should I know how it goes, it's all nice, is not transmitted this way, is not transmitted that way, there's a small child here', thinking of my nephew, and then we got into a fight there and we didn't even talk to each other for about two months, or three"*

*"It was like, you'll get better, you have more space, the whole house is yours now, we will renovate the rest as well, the other rooms. Aa, I think he was so happy when he was like: well, you no... You're a big boy now, and I was a big boy then. I was thirty years old... You... you need company, you need, like, a girl, you know. However, it was a disguise because of the HIV. As far as I know, and they confessed several times, my mother confessed and my brother confessed. Moreover, I avoided going upstairs, to them, but only my mother brought me food. I only went when I really needed something, and when it was slava. Our patron saint, St. Nicholas. I went for fifteen minutes, while the candle was lit, the bread, the prayer was said and that was it. Umm, I felt unwelcome."*

There are often cases of insulting people living with HIV/AIDS, their labeling, which among them causes a feeling of undesirability and impaired dignity.



*“From 6 October I’ve been in this relationship with this man with whom I am now breaking up, and he was first shocked when he heard from one of my, so-called friend, that I was an aidser and how the man who wants to be with me needs to put on three condoms. And he said that to my boyfriend, who passed it on to me. I had not, now I’m making a little jump in time, retroactively, going back to the beginning of the story. So, uh, I had not confessed him that I had HIV, I had planned to. However, already on the third, the fourth day, he jokingly started to call me Aidser. That was so terrible to me, it struck me so hard, that I then said to myself: “Ah, I do not want to, I will not even tell him yet, I will postpone it, let his emotions towards me grow a little, then I’ll admit it.”*”

In addition to stigma and discrimination, the topic of privacy and family life could potentially detect the finesses of sense of inferiority - auto stigma that people with HIV/AIDS experience in contact with people close to them.

Cases of disclosing HIV+ status of a person without their knowledge and consent, by relatives or friends, significantly undermines the principle of independence in the context of privacy and family life, because in this way people living with HIV/AIDS are denied the opportunity to decide for themselves whether and to whom they would reveal their HIV+ status, which is illustrated by the following examples.

*“Well, I basically was not even supposed to share it, unfortunately, um, as I say this, all these great friends, most of them, the one with the knife, uh, up the sleeve, have tried, um, to do much of the work, so, um, people found out very soon. Ummmm, but then, as I was in the hospital, my stepfather told my brother”*

Within the UN Guidelines on HIV and Human Rights<sup>38</sup>, there is defined the necessity of having clear criteria for healthcare workers on the basis of which they can disclose HIV+ status to sexual partners of their patients and what the procedure would be in these cases. In addition, it should be noted that the disclosure of HIV+ status to family members without the will and consent of the person living with HIV/AIDS also happens in the healthcare sector, which we addressed in more detail in the section on disclosing HIV+ status in the healthcare system.

The problem regarding invasion of privacy and free choice in disclosing HIV+ status applies to workers in the field of social protection, as evidenced by the following statements of respondents.

*“Other times, I asked them to give me social assistance. They approved and I went to pick up that money. Of course, there it says why I’m asking for it. The next day this same sister-in-law called me again, so the brother was again: “Well, you were at the Social Security Office.” “How do you know?” “Well, our neighbour works at the cash register”. And again. But this woman did not specify. She said only that I was very sick and so on. There he concluded that I*

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<sup>38</sup> Available at the following website: <http://www.ohchr.org/Documents/Publications/HIVAIDSGuidelinesen.pdf>

would die.”

*“Well, for example, this happened at the City Hall, yes, the City Hall. Not the City Hall, but this, center, Social, Social Security Office, yes. At the Social Security Office it happened to me that this guy told me, the older guy. You’re standing next to me, and you have HIV. You’re crazy to breathe the same air, you and me. Afterwards, well, I cannot remember...”*

*What do they say, what they say, what is the reason they close the door?”*

*“No, because we receive welfare, we have no right to immediate assistance. For books for children, anything we may need what not, but for drugs not. They do not have anything to talk about with aidsers.”*

*“How did they receive you at the Centre for Social Work?”*

*–“Badly. As soon as I go there, they look at the papers, immediately go to wash their hands, and you have nothing with it. It can’t happen, it does not belong to, they say do not come here anymore to talk to us.”*

Due to the lack of confidence in the system of social protection and possible risks that their HIV status will be discovered, people living with HIV/AIDS are reluctant to even apply for social assistance. This is evidenced by the following example.

*“I’m, I’m not registered at the National Employment Service anymore, but again I say, in my street I have lots of medical workers and people from the Employment Service and that where it needs to be, what’s it called, to seek social assistance, not someone else’s care and assistance but social, I have people from the street there, too. Now why would I go there to tell them my diagnosis, only for a little money to embarrass myself, not to embarrass, but to feel bad.”*

*“I feel humiliated they all those people now have to know. Those who need they know, they know. But nobody is thinking about my existence, what I live from, but, oh well.”*

### **3.1. Privacy and family life in the media**

When it comes to media monitoring, there is the impression that journalists are not too interested in everyday life of people living with HIV/AIDS. Social issues “do not sell newspapers”, but in the area of privacy and family life, the most important fact that is that in Serbia there are five people who speak publicly about their HIV+ status. Although this is a fact that by itself, albeit implicitly, talks about jeopardized human rights of people living with HIV/AIDS, journalists are not investigating this phenomenon. The media does not find it attractive to have the stories of these five people repeat, or to quote anonymous sources. Statements given under a

pseudonym, or without personal information are always followed by a hint of doubt as to the truthfulness by the audience. In the **“Alo”** daily, from 1/12/2014, on page 4, there is an article titled **“People were running away from me in fear”** that only partially deals with the subject of privacy and family life of people living with HIV. In this article, the author states the words of **“Vlada from a small inland town”**, under his full name.

*“I felt terrible, I did not know what to do with my life. For almost a month I could not accept it. I thought even to jump off a bridge, I nearly did... Then this was followed by disappointment, rejection, a million questions, worries about how we will continue to live normally, because my brother has a little daughter... People were running away from me in fear... Now they have accepted me, but there is always a concern, it just isn’t the same as before. I told my friends. Some rejected me immediately, some are still there. My partner is, of course, aware, and I don’t tell this to acquaintances because I would be stigmatizing myself if I did. Who is not in this, does not know what problems it carries.”*

The author of the text finds the approach of mercy sufficient, without going deeper into the causes of fear and despair that pervade the statement.

Somewhat more detailed is the article **“I wanted to kill me because they all left me”** of the daily **Kurir**, from 1/12/2014, by an author signed with initials.

*“I thought that my life was over. I was a young, beautiful, educated girl who had the whole world at her feet, and then I suddenly lost everything. My boyfriend immediately left me the next day!”- says this girl from Niš and adds: “Night after night I thought about killing myself. I locked myself in the room. Life was not worth living anymore.” Sandra took a long time to come to terms with the fact that she had HIV. “I did not want anyone to say that am infected, but I then realized that it was my duty. At the beginning there were many judgments, people turned away from me on the street. Not that it did not hurt, but now I know that this was just their fear and weakness” - points Sandra.*

*This brave girl today works at her family company, travels and socializes. She does check-ups...*

*- People are surprised because I look and behave quite normally. Nor did I do drugs, nor have I been promiscuous, it’s just - I wasn’t careful. The only thing that separates me from all others is that I do not have sex, but it is solely my decision - ends Sandra.”*

In this text the emphasis is on feelings of shame and pain as a result, while less space is devoted to the so-called normal life that this person leads. It would have been different had the reporter taken a statement from people who have accepted the interviewee.

**NIN** weekly, from 4/12/2014 brings more details about the various aspects of life of people living with HIV/AIDS, with the text **“Forever labelled”**.

*“Part of this gloomy atmosphere is produced by patients themselves (Clinic for Infectious and Tropical Diseases in Belgrade, author’s note). They are immersed in themselves, staring into blank space. It is evident that they are not afraid for their lives, almost all of them in good shape. I suspect that they feel shame that they are at the one place in the world where they can hardly deny “who” they are. “Of all the marks, the worst is the auto stigma, based on fear of rejection*

*and very present among us”, confirms S.S. one of the crowd in the waiting room, and the only one who laughs here. Other remain in grim silence.”*

*Based on the processed articles the public becomes aware that people living with HIV, “look” like everybody else, and that we cannot recognize them in the street. However, the articles do not provide insight into the social “mark” or “label” that follows these people.*

### **3.2. Criminal law and HIV transmission**

In an effort of ensuring the realization of human rights of people living with HIV/AIDS and de-stigmatization, the Centre for affirmation of positive living Q-club submitted to the competent committees of the National Assembly of the Republic of Serbia the initiative to amend Article 250 of the Penal Code of the Republic of Serbia as anachronistic and discriminatory, in view of decriminalization of unintentional HIV transmission.<sup>39</sup> Should this article be completely deleted, the intention of the legislator on criminal liability for the deliberate transmission of any communicable disease would be covered by Article 249 PCRS<sup>40</sup>. According to the current Penal Code, in relation to all other communicable diseases, the spread of HIV is punished separately, with twice the recommended sentence. In this form the provision of the Penal Code destimulates testing and stigmatizes people living with HIV.<sup>41</sup> According to information obtained by activists in the field of HIV, the main transmitters of infections are not people who know they are HIV+, since they go to therapy, which significantly reduces the risk of transmission. Also, this question, outside the cases of the deliberate spread of communicable diseases, should be regulated by the new law on the prevention of the spread of communicable diseases.

## **4. SOCIAL PARTICIPATION**

In the context of applying a holistic methodology for the monitoring of human rights, social participation means participation in a broader sense: cultural and political life, sports, recreation and leisure activities. The area of social participation speaks in the most direct manner about the attitudes that communities and society have towards people living with HIV/AIDS and it is important, from the standpoint of understanding the impact that these attitudes have on the decision of people living with HIV/AIDS, to speak openly about their HIV+ status.

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<sup>39</sup> *Ibid*, p. 50

<sup>40</sup>Transmission of communicable diseases: Whoever fails to comply with regulations, decisions or orders for the suppression or prevention of communicable diseases, and consequently there is transmission of communicable diseases,

shall be sentenced to three years in prison.

<sup>41</sup> <http://www.e-novine.com/intervju/intervju-drustvo/125222-Paragrafi-diskriminacije-zastraivanja.html>

#### 4.1. Social participation at the individual level

Table 5 - Experiences in the area of social participation

Social participation		Number of people	Percentage	Number of experiences
Dignity	Dignity	3	3.2	3
	Violation of dignity	34	36.2	59
Non-discrimination and equality	Equality and non-discrimination	8	8.5	8
	Inequality and discrimination	23	24.5	30
Respect for diversity	Respect	12	12.8	14
	Lack of respect	19	20.2	24
Independence	Self-determination	14	14.9	18
	Lack of independence	7	7.4	9
Participation, inclusion and accessibility	Inclusion and accessibility	40	42.6	64
	Exclusion and lack of accessibility	24	25.5	28
<b>Total</b>		<b>81</b>	<b>86.2</b>	<b>257</b>

81 people spoke about their experiences in the field of social participation with a total of 257 experiences. The most common principles in the field of social participation are participation, inclusion and accessibility (with a large number of positive experiences), inequality and discrimination and violation of dignity. As for social life, in general, it can be said that people living with HIV/AIDS have access to social life and most have positive experiences in this area, although one should not ignore the significant number of those who have negative experiences. The following are a few experiences in the area of

social participation

*“So in the beginning it was scary at first only to discover that I had HIV, but after that I was feeling awful, as if my whole world was sinking, you know? I now sometimes I’m not comfortable, you know, when someone who does not know enough like, recoils a little, and that, but all in all, I am used to living with that, and who accepts you really accept you with this, but who does not accept you, then they do not care about you, and you keep going, you don’t care, you know? And then I felt like I had Dango, the mark on the forehead. As if I were wearing it, you know, and everybody was turning around and I heard them many times. This one has AIDS. There’s no HIV there. They don’t make a difference there. They don’t differentiate AIDS and HIV, that’s the first thing, and number two is that stigma and discrimination are still very present in Serbia, especially in the southern parts. The northern parts have recovered, I’m telling you, but the South, terrible.”*

*Now I told something that happened a few years ago, but um, you know whenever I come exactly where I worked, I always get the feeling that they’re scanning me and talking behind my back: “That’s the one” or “How are you, you look great”, and then you come to the idea*

*that someone would like you to not look good, to fall, to this, to that, but everybody is like... you have the feeling that they're looking at you as a wonder... like, you're still alive ... and I don't know, in that sense."*

*"Well, I might mention one thing that was a bit funny, um, one of my tenants brought home a boy who was from a gay story, for coffee, where we are all together had coffee, talked and told jokes, and also later when he learned that I was HIV+, then there was a threat, you brought me to life-threatening situation. The friend asked: "Why?" He said: "You took me with a person who is HIV+ and I could have got infected." The friend asked: "Well, from what, from a cup of coffee?" Ummm, the boy's consciousness, umm, although in college, I consider it a zero, simply because if he had googled it, if he ha a little something to read, he remained shallow, I think. It was something so..."*

*"Not at all, afterwards the people were saying, when they see me on the street... you know how it got known in the city, it spread like a fire, because all are negative, then they would say: hey (NAME) has AIDS, (NAME) has HIV, and already a lot of people in town knew me."*

*"When it comes to the surroundings, I found, I usually said, that is, they found out that I was HIV+, the people who were next to me. And from them I did not feel any barrier. No barrier at all..."*

*"I have been training kickboxing, now as of about three months ago. And, umm, I made a deal with the coach, I met him on Facebook, he's my age and is very communicative and normal. He has a lot of gay friends among friends on Facebook, and then I told him that I had HIV. That I understand that it can happen to me to get hurt in training, that my nose will bleed or something. And I know that my bleeding nose would not be a danger to others. But again I have to say. And then he was a little taken aback, a little surprised, but I was expecting it for some reason. Um, he was taken aback, aa, and then he was like, he'll consult other coaches since he never had such a case. And then he said: Look, to me it's not a problem. He says, to me it's really not a problem. I can train you, but in a group, he says, in a group, for something to happen, I don't know, I mean, the tiniest option, 0.00000001 percent for you jeopardize any of them, that is my responsibility. And I simply cannot. And if I tell that to others, then there will be a problem or that, or they will look at you differently. And for me to treat you differently at training, for you have to wear a helmet to prevent injury, while others do not wear it, it brings imbalance to the group. You can have individual trainings, but, like, it is expensive. I said, let's do individual. And now I train with him once a week, since it is in the morning, and I cannot make it in the morning on work days, because I go to work, I work out once a week, and it is expensive. And we do this and now we do not have any problems, it's only him and me... But it's really ugly, towards me..."*

*That feeling when we go on a field trip and you know, like that, we start talking about drug addicts, homosexuals, he would have them all sent to a concentration camp. You know, when in a conversation like this he says that he would have them all sent to a concentration camp, what am I talking about with him..."*

*"Well, yes, they treated me differently by the fact that I was... I kind of felt that I would be isolated there. And it's a store where customers come and I thought it would eventually mean... Therefore, when she had already told the store owner that I was HIV+, I started to lose, there, I forgot to say, I come to lack of confidence, So, she crushed my confidence that she would tell a customer, that customers will stop coming to the store, that it's going to leak, that turnover would drop because they will, I don't know, start talking. I was not afraid they would begin to talk, I mean, they can talk, but consequently I felt isolated there. Meaning, yes. I decided that it was better to get away..."*

Certainly the most drastic example is an example of a family where both spouses are HIV+ and they live in a small town in the south of Serbia.

*"There's a hundred people standing, on Tuesdays it's the market, it's crowd like this, now two buses only run. We come, there is none. Children go to school, and when they come, they can't go to school. Aiders, here, there, and we have all certificates for children, that the children are healthy. The kids, they barely managed to finish school, to eighth grade... The teacher is wonderful to her, but parents are against it, they won't let their children... And so she sits in the corner, separated from all children. I once went to bring her a book and saw her in the corner of the room. I ask the teacher what happened, she says, now the situation has calmed down a little, she says, but this is what it is, we have to see something that is for the best. So it's not that woman's fault, the kids don't want to hang out, the parents would not let their children be with her... We don't even enter our local grocery store... The village wanted to beat us four or five times. We would go away a little, moved away but came back... When we call the police they don't want to come, they come the next day and blame it all on us, write charges against us... They smashed almost all the glass and it fell on my father-in-law's bed. The man was whimpering like a small child. And there is still no evidence of who did it... A man beat my son in the middle of the village while everyone watched, and they said nobody touched him. And the child was all in bruises... It used to be all normal, like we were all one family. When they found out, from that day on, no one even says hello. So, we live in this village just because we have to and because we have no other choice..."*

People living with HIV/AIDS also have positive experiences on the attitude of the community towards them.

*"*  
*So those who know never, no. So, they treat me the same as some other people. So, they don't make a difference... Yes, um,, do not touch this, or do not touch that, but, you know, we*

*are served drinks and snacks, we are received well, we sit next to each other, hang out... So, no such thing. But with other people, for example, I could not... sit and hang out."*

*"The priest had, was about to retire, he was 65-66 years old... I went to him and told him. I, it's my profession, I learned that I was HIV+, I thought it was the end of all things, and the man played an incredibly important role and to this day I remember this situation, where he said: "Stand up", meaning "it is a great sin, but God is great, and accepts such people, go to the people, be better, laugh, do not change in order to avoid someone noticing. Then when I asked: "How can parents this and that..." "They do not need to know, be a good man, and, let that be a turning point for you, not to get worse, but get better." "So I always encountered, understanding. Of course, with, with, information placement. I think that if I told that to some people I'd encounter misunderstanding, barriers, but somewhere, um, I filtered to whom I would say, but maybe there was little likelihood of misunderstanding. Simply, people who deserve to know, know..."*

More important than how the community reacts to people living with HIV/AIDS are the reactions of their friends and the relationships they have with them.

*Well, let's say it did not happen at work, but people, friends with whom I also hung out, had good relations with, I told a few of them, there, I thought, we knew each other for years, I've known some of them even from childhood. We also helped each other, they told me, I told them. In different ways, financially, out of need... I don't know... Cleaving wood, whatever it took... And I faced their indignation, so today I am just not in touch with these people. I do not want them to be friends with me, because they are afraid of my illness..."*

*"Um, friends, some know some do not know. Those who know are not as great friends as they once were, as I still consider them. Um, mostly they all act according to a pattern where one feels rejected. In, in terms of, when somebody completely tells their story when it comes to health. I don't know. Like I was lousy, I don't know how to explain it. I feel bad..."*

In in-depth interviews we encounter positive experiences in which people living with HIV/AIDS have support from friends.

*"... Absolutely no friend rejected me. No female or male freinds. Nobody turned their back on me. Everyone, everyone stood beside me. And to this day it means a lot to me."*

*"And my friends of course, do not separate the cups, drinking from the same thing when we get together, beer..."*



*“Yes, absolutely. Mostly everyone asks me, mostly everybody already knows, I have already explained to everyone what CD4 and PCR were, when there are drugs and when there are no drugs and why there are no reagents for this and that. And why we went to Novi Sad, that is once I went to Novi Sad to do the CD4...”*

*“Girlfriends have remained with me all these years”*

*Male friends not because they did not have, they had only the status quo: “There you go, you have it, what can you do. We do not mind, you're still our friend, everything is great.” Bla bla bla, and to this day it remains so. So, from the first to the last day they absolutely have not changed. I drink my pills in front of them without a problem. So, I have no problems hanging out, say, going to dinners, parties, all all all is great and everything is perfect because they know my status and there is no, there is no difference. We just do not mention that part and they do not see me like that...”*

Based on in-depth interviews, one can understand that people living with HIV/AIDS are cautious in making decisions about whom they will disclose their HIV+ status to and these are usually, in addition to family, close friends, people they trust. However, if their surroundings find out, the situation becomes more complicated and the number of negative experiences increases.

#### **4.2. The work of PLHIV (People Living with HIV/AIDS) organizations**

UNAIDS and the Office of the UN High Commissioner for Human Rights recommend participation of the community of people living with HIV/AIDS in the creation of programs and policies on HIV. In Serbia, there are nine PLHIV associations active, eight of which are associated into USOP (Union of PLHIV Organizations of Serbia). USOP is not aimed at the provision of personal social services, but at the representation of rights before state bodies and institutions, at lobbying for better policies and programs on HIV. Participation of representatives of the community of people with HIV/AIDS in the creation of programs and policies on HIV has been provided in the creation of the National HIV/AIDS Strategy, with the participation in the work of the National AIDS Committee and other bodies. This was carried out, and supported in part by the presence of the Global Fund to Fight AIDS, Tuberculosis and Malaria, whose departure significantly reduced the level of activity, or even terminated the work of these bodies. After the end of funding by the Global Fund, support to the associations was left to the individual efforts of these associations. Associations survived by applying for grants from different donors and different levels of government. These grants were associated with the subject of HIV in education, information and other fields. Some local governments (Pančevo and Subotica) support basic operating costs of these associations, including space for work, recognizing them as patients' organizations.

### 4.3. Media and social participation

Media monitoring showed that the processed articles about social participation are brief, without going into details, although relatively frequent. On the other hand, it remains unknown to the public whether there were examples of positive experience, and that kind of experience could be the way out of stigmatizing discourse. In the Serbian media, these are almost not recognized, with one exception, which we will analyze below.

However, the example of the article “Freedom in a cage” in Sandzak newspaper “Danas” (24/04/2015), on the promotion of the book by Srećko Gujunačić, the volunteers at “Philanthropy”, titled “Ten Positive Birds” confirms that, despite the abundance of the material offered on the subject of social participation of people living with HIV (with respect to the author's experience with people living with HIV/AIDS), journalists did not have the need to go deeper than his statements. Gujunačić “pointed out the stigmatization of the disease and the discrimination that those suffering from AIDS undergo in the society, which is mainly due to fear and ignorance of the community on the ways in which the HIV virus is transmitted, so they are unable to work and be socially engaged.” The focus of the article is to promote the book, but the article was not published in the category of culture, but placed under “Society”. This means that the journalist had the basis and space to deal more thoroughly with the details of stigmatization, through conversation with the author of the book, and he did not take the opportunity to do so. However, the text provides an explanation which leads to violations of human rights of people living with HIV/AIDS, so it can be set among the more “successful” articles on this subject.

The opportunity to better inform the public of violations of human rights of people living with HIV was neither used by the author of the interview (signed by initials) with Nevena Petrušić, Commissioner for Human Rights, on the occasion of the ending of Commissioner's five-year mandate, referred to in the article “We are far from a tolerant country,” published in “Kurir”.

*Question: Have we become a more tolerant society in the past five years? Where can the most discrimination be found today?*

*Answer: - Even in spite of a satisfactory legal framework, discrimination in Serbia is still widespread. Studies show that as much as two thirds of population think that discrimination is present in our country, that the most discriminated are women and the Roma population, followed by people with disabilities, the poor and the elderly. The greatest ethnic distance exists towards Albanians, Croatians, Bosniaks and the Roma population, while the greatest social distance exists towards LGBT population and people living with HIV. These are all indicators that we have a long way ahead in establishing a truly tolerant society.”*

*“We are far from a tolerant country”, “Kurir”, 14/04/2015.*

The participation of PLHIV organizations in the media landscape is there, but it is evident that more importance is given to confessions of people living with HIV/AIDS than to the work of the association and the importance of their activities for social participation of people living with HIV/AIDS.

## 5. PROVIDING INCOME AND SUPPORT SERVICES

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### 5.1. Realization of human rights of people living with HIV/AIDS in the area of social protection

Social protection of persons with HIV/AIDS in Serbia is guaranteed, as for all other citizens, in accordance with the **Law on Social Protection**. However, in the application of the law there are significant differences. Problems in exercising the right to social protection for people living with HIV/AIDS begin with the jurisdiction of the Centre for Social Work according to place of residence - people with HIV/AIDS often have different residence registration from their actual place of residence. Fear of disclosure of HIV+ status in smaller towns and better healthcare in larger cities are the main reasons for the formal switch of residence registration to an address where the person does not reside. For this reason, some people do not exercise the rights that they have under the law. Welfare recipients, and sometimes other vulnerable groups, also have rights to a reduction or write-off of utility bills. This right depends on the mentioned residence registration, because the bills must be addressed to the rights beneficiary.

Cash social benefits are reduced or eliminated for users who are capable of working, regardless of the fact that people with HIV/AIDS in reality do have difficulties to find work and cannot accept certain jobs, even if they are fit for work. This also applies to activities for which there is a health recommendation to be avoided, because they accelerate the course of the disease in the long term. There are no special instructions or regulations for dealing with beneficiaries who are persons with HIV/AIDS. One-time financial assistance in order to help meet the needs of treatment is no longer granted to persons with HIV/AIDS due to the chronic nature of the disease.

The law provides for the right of users to being informed about the data relevant to the determination of social needs, as well as on the manner in which these needs will be met (Article 34). However, in practice of the Centres for Social Work, the process is carried out by first having the user expose the problems for which they are asking for help and only then do they receive information about possible services. In the triage process, only after they disclose their HIV+ status to the competent adviser will they be informed that they are not eligible for some services. A file is opened for every beneficiary, which is confidential, according to the *Rules on Organization, Norms and Standards of the Centre for Social Work*. Access to these files is so broadly defined that there are no guarantees that this information will actually be confidential. Thus, the Rules allow access to files for persons employed in the Centres for Social Work, the supervisory authority, the judiciary and the police. With the approval of mentors, volunteers and students in practical training have access to data. In the series of data to be entered into the record, there is also medical documentation.

Accommodation in institutions of social protection is contingent on proof of absence of communicable disease, whereby the specificity of HIV infection transmission is not taken into account, and so the accommodation of people living with HIV/AIDS in social protection

institutions is not possible. This provision restricts access not only to accommodation, but also the living area and having meals in these institutions.

**Law on Pension and Disability Insurance**<sup>42</sup> regulates the pension rights of persons whose disease caused the total loss of working capacity. The process starts with a request of the insured and a recommendation of their selected doctor. The loss of working capacity is determined on the basis of medical records and the Rules on education and manner of operation of assessing authorities of the Pension and Disability Insurance Fund of the Republic of Serbia (PIO). The Rules provide that the minimum documentation to be delivered for communicable diseases includes the discharge summary of a competent medical institution, bacteriological findings proving the existence of pathogens during successive controls over a longer period of time and the opinion of the relevant health institution that the disease cannot be cured. Expertise is done in two steps and the findings, opinion and assessing authority evaluation include the assessment of working capacity. Mandatory inspection will not be determined for immunodeficiency diseases in advanced stages. The Rules do not specifically single out HIV/AIDS as the basis of disability, but rather the different conditions which may occur as a result of HIV and which affect the ability to work. Total loss of working capacity is a prerequisite for the realization of disability pension, and the necessary condition is also a previous length of pension insurance for a period of five years and one, two and three years for persons under the age of 20, 25 and 30 years of age, respectively.

The Law on Pension and Disability Insurance does not recognize the specificity of HIV, there is no sensitivity to varying degrees of impairment of work capacity and no flexibility mechanisms for the changes in the working capacity, which are typical for HIV. A small number of people are beneficiaries of family pensions, which they acquired as spouses of deceased old-age pension beneficiaries or as children of old-age pension beneficiaries, if their incapacity for work came in the age up to which the right to family pension is provided, in accordance with Article 31 of the Law.

### **Access to social protection services - experiences of people living with HIV/AIDS**

The Law on Social Protection provides for five basic types of services: assessment and planning services, daily community services, support services for independent living, advisory-therapeutic and social-educational services and accommodation services. People living with HIV/AIDS realize the right to these services not on the basis of HIV+ status, but the criteria that apply to all other citizens.

Table 6 - Number of persons according to the principles of human rights in the field of providing income and support services (social protection)

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<sup>42</sup> "Official Gazette of RS" No. 34/2003, 64/2004 - decision of the RSCC, 84/2004 - other law, 85/2005, 101/2005 - other law, 63/2006 - decision of the RSCC,, 5/2009, 107/2009, 101/2010, 93/2012, 62/2013, 108/2013, 75/2014 and 142/2014)

Providing income and support services (social protection)		Number of people	Percentage	Number of experiences
Dignity	Dignity	4	4.3	6
	Violation of dignity	11	11.7	12
Non-discrimination and equality	Equality and non-discrimination	10	10.6	11
	Inequality and discrimination	5	5.3	5
Respect for diversity	Respect	6	6.4	6
	Lack of respect	6	6.4	7
Independence	Self-determination	4	4.3	4
	Lack of independence	0	0	0
Participation, inclusion and accessibility	Inclusion and accessibility	38	40.4	86
	Exclusion and lack of accessibility	10	10.6	13
<b>Total</b>		<b>52</b>	<b>55.3</b>	<b>150</b>

In interviews, people living with HIV/AIDS usually talk about experiences in contact with the Centres for social work, social services, and services provided by organizations of people living with HIV/AIDS. Based on the experiences they were talking about in interviews, even when trying to obtain services in the field of social protection, they have experiences that are a violation of the principles of dignity, before the service is rejected for them due to HIV+ status. The following examples indicate some of the negative experiences and violations of dignity and inclusion and accessibility.

*“I just said the same thing. That is, I had the same unpleasant experience at the local community office by one woman, who was also supposed to complete some papers for HIV for me. It literally drove me out of the office. She told me: get outside. And, ‘I’m a grandmother, I have grandchildren, I have a daughter who is married and I must not be touching these papers,’ she threw the papers and threw me out of the local community office. She would not verify the medical papers related to social assistance. When she asked me why I needed her certification at the local community. I told her I needed social assistance because I was HIV +. And she kicked me out of the office. This was a year ago. Also a big inconvenience. Everything has been happening, it is commonplace. Only these things are a little bigger...”*

*“While I was pregnant, I could get refund for the travel expenses, but not all. So, I had to have special referrals, so, even though Narodni Front was all, I had to have one for the day hospital, one for counseling. These reports, they never recognized the travel expenses, then, because the referral was for the day hospital, and not for counseling. So, I get the same day to the day hospital and I have to go downstairs for counseling and they give me the report in counseling without a problem. No, they have not recognized it...”*

*“Oh, as soon as I go there, they look at me, and immediately tell me, you do not have anything to do with this. Goodbye. I went to complain there in soci..aaa, over there to the Ombudsman, I went to complain, two, three times there, and again there is nothing. No*

*nothing, this. I have no rights. Because like, my husband has land, but I have nothing to do with that. He told me, you live here until the child grows up, afterwards you go wherever you want..."*

Out of respondents who cited positive experiences, most of them relate to the exercise of a right to some compensation on the basis of HIV/AIDS, or disability, and in most cases, the care and assistance of another person

### **Support services from PLHIV organizations**

For people living with HIV/AIDS, the support and services they receive from PLHIV associations are very important. In Serbia there are currently eight such associations in Belgrade, Novi Sad, Subotica, Pančevo and Niš. The associations do not have continuous support, financial or any other. The associations provided a wide range of services: peer support, psychosocial support, self-help groups, peer education, practical help and daily assistance, social reintegration (organizing various gatherings, cultural and other events), telephone counseling, informal gatherings, etc. The most important feature of these services is that they were created and developed in accordance with the needs of people living with HIV/AIDS and that they are mainly provided by people living with HIV/AIDS.

We present some of the positive examples relating to associations that provide support for people living with HIV/AIDS.

*"And to me, for example, it meant a lot when you took me to Čovekoljublje and then soon afterwards several organizations were formed. We had nice gatherings and education everywhere. Not to mention all the places we travelled to and I really felt good. I wish, regardless of travel, to do it again here in the city, only those facilities like your offices were..."*

*"Yes, it could be with you in the AID+. I had support from Aleksandra from Čovekoljublje. I could obtain some information that I needed. And regarding Dr Šer, and in relation to the ophthalmology department where you went. No, I'd just here, that's what comes to mind, I only had the opportunity to meet you at the start, and you had a vision problem, and two more people, not to name them now, so I was very scared that I would lose my sight. Then I figured out that the CD must be under 50 to set off some happenings..."*

*"This person and I still have an excellent relationship, I am immensely grateful to him. I have often wondered how to return this appreciation, but I think he feels it. I am immensely grateful because of what he did, I thought that I was non-existent then, that there was no life, no hope, no sense, but that person, through a two-hour meeting, did something even psychologists were unable to do. So, I am immensely grateful, but this person has been for many years in that, how should I say, story, an HIV+ person, but they are a noble person and a good person, informed, um, so in that person, umm, in one place, you have whatever you need. When I want to rewind or to stabilize once when I am going through a hard patch. That is my role model, my role model..."*

## 5.2. Providing income and support services in the media

Within media monitoring, the support services are mainly discussed in texts whose main subject is HIV, most often on the World Remembrance Day of AIDS Victims and 1 December - World AIDS Day. Greater representation of the subject is present in the local media which are not directed at sensationalism, and have more space for the presentation of local organizations. The withdrawal of the Global Fund triggered the call for the need to provide support to people living with HIV, so the text titled **“People were running away from me in fear”** from **“Alo”** daily says the following:

*“AIDS is not a bogey, and not a death sentence! Unless you live in Serbia! People with HIV are still discriminated in every sense, people run away from them, they lose their jobs, and the quality of treatment and psychological support is horrible! To make matters worse, from 1 July the only source of funding for the fight against this serious disease, the Global Fund withdrew from Serbia, where they spent 10 years, and in the state budget there is no money for these purposes! There is a growing number of patients, which we only remember on this day - World AIDS/HIV Day. Djurica Stankov, Director of AS Centre for Support to People with HIV, said for “Alo!” daily that the future of prevention and treatment of HIV is uncertain because most services should have been transferred to the state system, while the Global Fund was still there. It did not happen. Since January of this year the number of HIV-infected crossed the 3,000 mark. The situation is alarming because the state budget does not provide funds, but experience shows that in all countries, from which this Fund withdrew, recorded a significant increase in the number of infected people - he says. “Alo”, from 1/12/2014.*

An article from **Subotičke novine**, **“Preventive work with young people”**

*“The Association Stav+ confirms these devastating facts, but also highlights the problem of the “departure” of the Global Fund whose resources financed numerous services that were offered to people who have HIV or AIDS. - Our association covers about twenty users from Subotica, but also around 60 from the rest of Serbia. We have preventive programs with young people, and our volunteers are peer educators for HIV and AIDS. What particularly worries us and what we do not stop to emphasize is that the departure of the Global Fund will very quickly be felt in the whole of Serbia and this story. As Association we have already felt that because practically all services that we provided to patients with AIDS and those living with HIV are almost non-existent, so the only thing we have left are the projects where we work with young people. Our doors are still open to everything in our power, but we are no longer able to pay for the services of psychologists who worked with these people and so on - stressed Boris Kovačić, president of the Association Stav+. Subotičke novine, from 22/5/2015.*

## 6. AREA OF LABOUR AND EMPLOYMENT

Article 18 of the **Labour Law** prohibits direct and indirect discrimination of persons seeking employment, as well as employees, with regard to their gender, birth, language, race, skin colour, age, pregnancy, health condition or disability, national origin, religion, marital status, family obligations, sexual orientation, political or other opinion, social origin, property, membership in political organizations, trade unions or any other personal characteristic. Although HIV is not mentioned specifically in the Labour Law, the prohibition of discrimination based on health status includes this category of the population.

Table 7 - Experiences in the area of labour and employment

Labour and employment		Number of people	Percentage	Number of experiences
Dignity	Dignity	4	4.3	4
	Violation of dignity	12	12.8	14
Non-discrimination and equality	Non-discrimination and equality	3	3.2	3
	Discrimination and inequality	14	14.9	20
Respect for diversity	Respect	3	3.2	3
	Lack of respect	5	5.3	6
Independence	Self-determination	6	6.4	7
	Lack of independence	7	7.4	7
Participation, inclusion and accessibility	Inclusion and accessibility	22	23.4	27
	Exclusion and lack of accessibility	18	19.1	25
<b>Total</b>		<b>50</b>	<b>53.2</b>	<b>116</b>

As for the other areas of life, people living with HIV/AIDS have access to labour and employment, up to the moment when people learn about their HIV+ status. Then they mostly come to the situation of getting fired.

*“...Five years ago... when I started working in a boutique.... one of my neighbours from the street... I did not know she worked at a kiosk next to me... when she came in to buy something for her daughter, probably some clothes or whatever, I have no idea, and the landlady was there. And when she saw me... she was friends with the landlady, she asked what I was doing here. She said that I was the worker. I immediately got fired the next day.”*

*“Here, when I was in Belgrade, something happened to me at the moment when I was working that when I found out I was on a three-months contract and was on sick leave for more than 20 days and when I returned, I brought the report, I worked the remaining 7 days to the expiration of the contract and immediately got fired. And just when I asked what the reason was, it was like .... company policy...”*



*... By a coincidence it turned out one of my superiors at work knew I was hospitalized at the clinic and I was positive, and luckily he did not spread the story further, but the matter was brought before me as a fait accompli and I was forced to leave the company. So I was fired, and we agreed that I leave peacefully..."*

*"...Well, I felt miserable. First of all you're working for them for years and finally when they find out you're sick, what you're sick from, they just start to threaten that they will fire you, you cannot take sick leave often. Until then nobody found out, I do not know which way, how, what,... since at our company you are required to submit your test analyses if you are often on long sick leave, of what, that reads, here, there, and when they find out in the end we do not need you any more..."*

In these examples there are situations that describe disrespect for diversity.

*"It's not. I told a friend who's ... who owns a company... and I asked him, he knew the situation... and promised me, promised me ... and finally he said, you know what, I cannot, this .. I cannot hire you, you are infected, people are afraid, I'm afraid I have a family, this, that, I'm sorry, this, that. If you need any help, let me know. However, I never even said hello, because I realized that I did not need help, I needed a job, not help and charity..."*

*"I said: I am HIV positive, I need help. Um, I cannot go and look for a job, because they ask you, um, for some documents from your doctor, um to certify whether you're sick or not. And now if I go to the hospital, I cannot give it to a doctor, this. With the paper. The one that says that I'm HIV positive..."*

Only three texts dealt with the subject of labour and employment for people living with HIV/AIDS. These were mainly agency news, which is to say that the information is superficial, offered at press conferences, and that the media failed to do research on the news that had been "served" to them. An example of such reporting is the article "**Discrimination continues to rage in Serbia**" on the **Euractiv.rs** website of 17/3/2015 in which it informs the public of data on the basis of the annual report of the Commissioner for Protection of Equality:

*"According to the opinion poll, the greatest social distancing also exists towards people living with HIV/AIDS. 'These people are exposed to discrimination and stigma in almost all fields, from treatment in healthcare centers, through the reaction of the surroundings and the family, to the field of labour and employment'".*

The report of the Commissioner got no reaction from journalists, in terms of sub-questions, nor are they initiated by official statements for further research. In the media there is no questioning, let alone an answer as to why this violation of human rights of people living with HIV/AIDS exists, in any sphere, including the field of labour and employment, and there are no breakthroughs in the form of suggestions on how to eliminate this attitude.

## 7. ACCESS TO JUSTICE AND REPORTING CASES OF HUMAN RIGHTS VIOLATIONS

Access to justice refers to justice in the broader sense, including status under the law, access to justice system, freedom and protection from abuse and other forms of degrading treatment as well as information and physical accessibility of public institutions where citizens exercise some of their guaranteed rights.

In Serbia, PLHIV organizations specialize in working with users in the form of advisory work, social services and “peer” support. In order to have professional legal support and protection of human rights in proceedings before state authorities it is necessary to hire additional lawyers, and this requires substantial financial resources. In the previous period, free legal aid was formally offered by a large number of organizations and institutions, but in practice, this was usually advising on specific areas of law, for certain categories of citizens, only occasionally assuming representation before the courts.

Legal aid can also be provided by educational institutions. Faculty of Law, Union University launched the opening of the Legal Clinic for the medical, labour, family and children's law. Work with clients is aligned with the dynamics of the university operations and examination periods. Denial or violation of rights in the field of healthcare, damage or deterioration of health condition due to improper treatment and violation of rights in the field of health insurance are the areas for which citizens will be able to ask for assistance. For people with HIV/AIDS this potentially covers a large number of cases of human rights violations because it basically works on discrimination based on health status, the way discrimination against people living with HIV/AIDS is defined by the National Council for Combatting Discrimination.

A special form of free legal aid is information and procedures for protecting the rights before independent state bodies for the protection of human rights. In this report, we have already mentioned the extent of importance and the areas where the role of the three independent bodies is significant: Commissioner for Protection of Equality, Commissioner for Information of Public Importance and Personal Data Protection and Ombudsman

Monitoring individual experiences showed that a certain number of people living with HIV/AIDS have experience of discrimination and exclusion when it comes to access to justice.

Table 8 - Access to justice

Access to justice		Number of people	Percentage	Number of experiences
Dignity	Dignity	0	0.0	0
	Lack of dignity	4	4.3	4
Non-discrimination and equality	Non-discrimination and equality	2	2.1	2
	Discrimination and inequality	11	11.7	15
Respect for diversity	Respect	1	1.1	1
	Lack of respect	2	2.1	3
Independence	Self-determination	3	3.2	3

	Lack of independence	3	3.2	6
Participation, inclusion and accessibility	Inclusion and accessibility	6	6.4	8
	Exclusion and lack of accessibility	9	9.6	14
<b>Total</b>		<b>24</b>	<b>25.5</b>	<b>56</b>

Based on the experiences it is evident that people living with HIV/AIDS, because of the stigma and discrimination they experience, do not have confidence in the institutions that protect their rights, so they rarely dare to take legal action.

“Well, now you've got the Protector of patients' rights. They can also come help when it comes to such events.”

*“They can come help, but they help the one who broke their leg, got their head bashed and so, you know, people with pneumonia or, God forbid, cancer... They find that it's nothing, it's not a terrible disease, but for us to show up, I mean, an HIV+ person, or someone with hepatitis C or so, they show distance. Or they're afraid, they just get scared at one point. So they will talk to me for half an hour and they will tell you everything in half an hour and there is no: 'come the next day'. That's not happening...”*

A common problem is the lack of legal assistance and information necessary for the initiation of legal proceedings.

*“...Well, I would also have a choice to go...to..to inquire whether she's right or I'm right. What are my rights and what are their rights... And I think we all have the same rights. So, no matter what we are like, so we have the same rights to be received and treated in the same way as others...”*

Due to the financial and legislative barriers, people living with HIV/AIDS are unable to hold legal action until the end, because they feel that they cannot rely on all the links of the system that is supposed to protect them from discrimination and inequality.

*“... So when I get carded by the police I have a problem with them if, um, I let them know about my status, and I like doing it just for the sake of knowing what they think about us and how. So, they start spraying with disinfectant, all sorts of chemicals, rubbing their hands, oh my god identity card, oh my god this, oh my god that, etc. etc. How do you work in the hospitality sector? And then they start with this big slamming of the attitude of HIV people. Their opinion is that only in Serbia we can have HIV+ status and work in the hospitality sector...”*

Table 9 - Reasons for not reporting or the type of reaction

Reasons for not reporting or the type of reaction	People	Percentage	Experiences
Fear	45	47.9	88

Alienation	32	34.0	43
Nothing would have happened	25	26.6	30
Lack of access	21	22.3	25
Charges or lawsuit	16	17.0	18
Insistence	12	12.8	17
Corruption	8	8.5	13
Sense of guilt	7	7.4	10
Lack of finances	4	4.3	5
Other	21	22.3	27
<b>Total</b>	<b>75</b>	<b>79.8</b>	<b>276</b>

The biggest stumbling block in certain respondents' reactions to the violation of human rights is fear, which is usually related to disclosure of HIV+ status and exposure to possible negative experiences because of it. A significant response in cases of human rights violations for people living with HIV/AIDS is distancing: people usually want to get away from the situation they lived through.

*"...It's maybe mostly about some anxiety. I mean, in the sense of...mmm, say, uh, about the, about the status. I mean, for example, when I'm travelling, so when I have my medication in the bag, well then..uhm, I do not know, maybe, maybe there's something written on some piece of paper. I mean, I do not know, it's just, I don't know what to associate with what, but I always have something in my head, uhm, something that gets me into thinking..."*

"... Do you want to simply start the issue of behaviour, of how that doctor treated you?"

*"I can't. In Palanka I can't. Everybody would know that I'm HIV positive"*

And have you reported it to an institution, a non-governmental organization, not just a government institution, some case at the doctor's that you spoke about?"

*"Never, I have never officially reported, because I think that there is no sense, that that's fighting windmills, crows are smart enough not to peck out each other's eyes, at least it has been like that so far. If something changes now, and God willing, something will change for the better in Serbia as well, and at least for that, to move a little, to get out of the status quo, because this does not lead anywhere, really, for a doctor to think that they can infect an entire floor from a single patient who needs catheter inserted in their vein... It is both sad and funny at the same time..."*

Most of the analyzed articles that deal with access to justice, refer to Article 250 of the Penal Code of the Republic of Serbia. Article 250 is disputable according to the representatives of human rights organizations because it separates HIV from other transmitted infections. However, while a part of the media treats this subject in a somewhat sensationalist manner, the **E-novine** web portal brings a complex text, in the form of an interview with the executive director of "Q-club". This is perhaps the best example of media attitudes towards people living with HIV/AIDS, but it is not about random interest of journalists. It is the project "**HIV among us: people like everyone else**", conducted by **E-novine** in partnership with the "AS Center for the Empowerment of Young People Living with HIV and AIDS", and financed by the Ministry of Culture and Information of the Republic of Serbia. Among other useful information, the text says as follows:

*"UNAIDS, for example, states that criminalizing unintentional HIV transmission has done more harm than good in terms of the impact on public health and human rights. Here, it is only about the damage because there is no use, there was no reply, it is about a norm that is used only for intimidation and stigmatization of people living with HIV. At risk are those people who are found to be HIV positive, people are afraid even to shake hands with HIV positive people. And large sentences are foreseen, up to 12 years in prison. The basic form of a criminal offense is 'endangering'. What does this mean in practice, that HIV positive people must not have sex? Because if they use a condom, there is a risk that the condom breaks. As there is the risk of millions of other sexual infections, some of which may be deadly, more dangerous than HIV, such as hepatitis C, for example. But, HIV is punishable because of the stigma and fear that comes from the eighties."*

The article was professionally made, it even informs readers that according to the Ombudsman there is no basis to amend the controversial article of the Penal Code because the legislator had in mind the prevention of the spread of infections and, therefore, it is not about the discrimination of people living with HIV/AIDS. So, the problem is viewed from various angles.

Recently, according to the findings of media report author, there has started the first case at a national court on the basis of an alleged violation of Article 250 of the Penal Code. However, due to privacy of the person living with HIV/AIDS against whom legal proceedings have been initiated, journalists did not have access to the trial. The defendant was represented by JUKOM and was acquitted of the charges.

In the context of this project, E-novine has been reporting on organizations of people living with HIV (Belgrade: AID + (More than help), Žena +, Q klub, AS, Pančevo: Nova +, Subotica: Stav +, Novi Sad: Crvena linija, Niš: Sunce) that provide users with free legal aid. The articles are not about what kind of legal aid it is, whether it is about solving social problems or human rights violations.

## 8. MODELS OF MEDIA COVERAGE OF HIV/AIDS

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Media monitoring has not only given insights into the way of reporting on HIV/AIDS, but also indirectly into what the community attitudes in this area are. If we analyze the manner and place in the papers where they present issues of people living with HIV/AIDS, it is easy to conclude that this category of population occupies a marginal place in the media because the largest number of articles is published in the “Other” section.

An analysis of texts by types of population that are mentioned in the texts shows that key populations are not mentioned in the majority of cases (90%). Vulnerable groups such as children, pregnant women, women, prisoners, persons with disabilities and others, rarely or almost never stand out, which shows that the media is not concerned for their vulnerability. A bit more attention is paid to young people, usually only as participants in peer education. Mentioned more often are people who inject drugs, mostly in a negative context, as well as members of the population of men who have sex with men, which, typically, double discriminates them.

As their sources of information newspapers mostly indicated institutions of the system - various ministries, healthcare institutions, funds and others.

The so-called political correctness is the tendency that has been present in the Serbian media as well, in the last decade or two. It is noted that in the media some politically correct terms are adopted. However, in everyday communication, even in the media, when there is talk of the methods of transmission of HIV in injecting drug users or sex workers, the terms “drug addicts” or “prostitutes” are still there, and they are a literal, but an inadequate description of the situation. It is obvious that the proper and politically correct terminology is used in the texts in which the source of information are people living with HIV/AIDS or their organizations.

This methodology identifies five models of writing about HIV: medical, criminalization model, the model of mercy and victimization, the model of human rights and the model where HIV is mentioned only in passing. Although the medical model is the most prevalent one in the analyzed articles, only a very small number of articles deal with these issues in detail. These are mostly information about the number of infected people, advice for prevention, information about scientific discoveries and the like, while the rare exceptions speak about the real problems, always when confession of the infected is mentioned.

As for the prospect of criminalization, it is noticeable that during the 11 months that were the focus of this monitoring, there were only several articles where the public “pointed a finger” at someone who “spread the infection”, while in the past these incidents were more frequent in the media. Instead, incriminating writings are more often directed at those who “deliberately infect themselves”. Various types of criminalization are “reserved” for populist media which have no real significance, but have a greater impact on the general public. The fact that there is no “hate speech” in them, not explicit, at least, is encouraging in terms of a certain deflection in the coverage of HIV/AIDS compared to, for example, political issues.

The perspective of human rights is the second most frequent issue in the analyzed articles. The media treat the human rights of people living with HIV/AIDS in a superficial manner, at the level of served information. This approach dominates the public statements of the Ombudsman, the Commissioner for Protection of Equality, or other state officials or institutions, and it more so represents the desire of journalists to publish something that is topical, than to point out how important it is to people living with HIV/AIDS. Reports from these press conferences are broadcast and published in many media. However, it is always limited, with only a few sentences that do not go into the causes of discrimination. They do not go beyond the statement that research shows that social distancing is most present in contact with people with HIV (and some other populations).

## **9. SITUATION TESTING**

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Situation testing of discrimination was conducted in the field of availability of healthcare and services. According to the results of the analysis of individual experiences, this is the area with the highest number of cases of discrimination. There has been a total of 54 testings in four towns: Niš, Subotica, Novi Sad and Belgrade. Testing was conducted by telephone by trained testers, and included 12 state and 42 private medical offices/clinics. Five cases of discrimination have been reported (all five in private practice) and complaints were submitted to the Commissioner for Equality. The test result is very good, but the question remains what would the conduct be like during an examination or intervention.

## 10. CONCLUSION

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Monitoring of rights of people living with HIV/AIDS has shown gaps that exist between the prescribed laws, policies and practices on the one hand and experiences of people living with HIV/AIDS in exercising their rights, on the other. Although it seems that the legal framework that regulates the issue of human rights of people living with HIV/AIDS in Serbia is sufficient, it is clear that it has not been designed taking into account the reality of HIV or its interpretation as a matter of human rights. People living with HIV/AIDS are only explicitly mentioned in the Law Against Discrimination.

The new National HIV/AIDS Strategy was not passed after the old one expired in December 2015 (there is talk about HIV being included in the National Strategy for Public Health), the new National HIV/AIDS Board has not been established, and the activities of the National HIV Office have been taken over by the Department for Sexually Transmitted Diseases, Viral Hepatitis and HIV within the Institute of Public Health of Serbia Dr Milan Jovanović Batut.” During 2015, there was public debate on two laws (passed in early 2016) that are important for the field of HIV: the Law on Protection of Population from Infectious Diseases and the Law on Public Health. Amendments to the laws have not brought the changes that were expected and which were related to facilitating HIV prevention and respect for human rights of people living with HIV/AIDS, despite the significant participation of PLHIV organizations in the public debate. The situation is not much better when it comes to the National Protocol for HIV Infection Treatment. Although the practice of treating people living with HIV/AIDS complies with the recommendations of the World Health Organization and European guidelines for the treatment of HIV infection, infectologists, too, make strenuous efforts to provide the best possible treatment, in accordance with available resources.

The available drugs are outdated and the availability of tests for monitoring infection unpredictable. HIV counseling and testing is carried out in institutes of public health, but there has been a decrease in the number of tested people compared to the previous years, due to the unavailability of tests. At the same time, at the time of writing this report, the National Institute of Public Health published the results of testing for HIV in 2015, which indicate over 37% more of HIV positive people compared to 2014. More specifically, over the past year, 378 people discovered their HIV+ status, which is the largest number since 1987 (45 tested people were HIV+ during the last two months of 2015). More than a third are young people aged 15 to 29. These data are discouraging, especially if you take into account that prevention programs among the population at increased risk of HIV infection almost disappeared after the completion of GFATM project.

The areas of life which have the highest recorded case of violation of human rights of people living with HIV/AIDS are healthcare, privacy and family life and social participation. Nevertheless, most of the negative experiences of people living with HIV/AIDS come from the field of healthcare: clear labelling of HIV+ status on health documentation, disclosure of HIV+ status in the healthcare system, but also refusal to provide health care. However, there were positive experiences recorded in the healthcare system, mainly at the Clinics for Infectious Diseases and in contact with the selected doctors in health centers or in other places, so it



cannot be said that the violation of the right to healthcare is systematic, but rather left to the individual level, and individual healthcare workers. Still, this is about the lack of systematic care in the healthcare system regarding the termination of the practice that violates the rights of people living with HIV/AIDS.

Violation of the right to privacy of people living with HIV/AIDS is evident in almost all areas. It often happens that the information about a person's HIV+ status is transferred without any understanding of the impact that such practices may have on the lives of people living with HIV/AIDS. It is therefore not surprising that people living with HIV/AIDS decide to disclose their HIV+ status only to those with whom they feel safe.

Social protection services that are available to people living with HIV/AIDS are not always tailored for their needs nor do they take into account the reality of living with HIV. In this area there are experiences of violations of the right to dignity and non-discrimination as well as positive experiences, which only means here as well there is a lack of systematic struggle for the rights of people living with HIV/AIDS.

It is not uncommon for persons living with HIV/AIDS to lose their jobs after the employer learns of their HIV+ status, and in some workplaces, due to the fact that HIV is one of the communicable diseases, they cannot even get employment. Many realized the right to a disability pension back when it was possible. An increasing number of young people who discover their HIV positive status, if nothing changes in this area, will remain without work, or will not be able to find a job.

Having the government ignore the importance of rights of people living with HIV/AIDS reinforces the stigma and discrimination which they face in accessing care and support systems. Stigma prevents them from complaining when their rights are violated. This way, they enter the circle which is difficult to get out of: the more the stigma, the less the people are willing to report violations of their rights, which is why there is the general impression that there are no such violations.

The media still report about HIV as about a medical phenomenon, and they usually present data on the number of infected and those affected by the disease. Half of the articles is totally irrelevant. A smaller portion of the analyzed articles gives a real contribution to public awareness about the disease, and only a fraction of them is related to the rights of people living with HIV/AIDS, while there is almost never talk about examples of violations of their rights, especially by state institutions. Progress has been noted in the areas of criminalization and media speech, but also in the knowledge of the general population on the manners of the spread of infection, as well as preventive measures.

All social actors should include people living with HIV/AIDS in their activities. Their experience is the most important source of knowledge about the problems they face and their specific needs. Positive examples of coping with HIV infection can encourage people living with HIV/AIDS but also make people from their surroundings accept them and respond to their needs.