



# TO FIGHT DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS IN SERBIA ?



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# **HOW TO FIGHT DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS IN SERBIA**



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# COMMUNITY-BASED PSYCHO-SOCIAL SUPPORT TO PEOPLE LIVING WITH HIV/AIDS

## THE MOST IMPORTANT PROBLEMS OF PEOPLE LIVING WITH HIV/AIDS AND IMPORTANCE OF WHOLESOME COMMUNITY-BASED SUPPORT

**H**IV infection affects all dimensions of life: physical, psychological, social and spiritual. Apart from disturbed physical health, the knowledge of the infection existence, due to stigmatisation and fear, often results in loss of socioeconomic status, employment and secure income sources, social isolation, to depression and aggravation of mental health. From the outbreak of HIV/AIDS until the present day a lot has changed. Contemporary medicine and availability of adequate therapy have significantly improved the quality of life of people living with HIV/AIDS. Today, with adequate therapy, PLHIV can live and work normally, if they are permitted to do so by those around them. In that context HIV is less a health problem (in the sense of treatment), but more a social problem devastating for the individual, family, business environment and the community as a whole. One of the most important current problems of PLHIV is their re-socialisation into their surroundings. Different types of support can help PLHIV and their close ones to confront the infection, illness, fears and stigmatisation in a considerably more efficient way and to improve their quality of life.

Continued and mostly widely understood psycho-social support to PLHIV population and members of their closest social surroundings, their families in the first place, is as important as adequate health care. Psycho-social support implies numerous kinds of help and support: psychological, social, legal, cognitive, instrumental. There is a wide range of services: from individual and group counselling, education, information dissemination, social engagement support, support in protection of various rights, support in preservation of economic stability and independence, help in alleviating consequences of economic deprivation or poverty, psychological, social and moral empowerment of people living with HIV/AIDS and members of their families to confront with and overcome difficulties brought by the infection, to informal instrumental help and support in performing daily activities.

Psycho-social support to PLHIV is different in content, and its resources are numerous and diversified, from individuals (friends, family members, volunteers, experts), groups (informal associations of citizens, unions, therapeutic groups, business environment), to public institutions of health care and social welfare, educational and cultural institutions, media and wide public. Community-based psycho-social support encompasses all aforementioned contents and resources, i.e. sources. Different contents and resources are mobilised in different phases, i.e. life cycles of PLHIV. Psycho-social support must be continuous and adapted to different life needs. Psycho-social support needs to be adjusted to needs of the following situations in PLHIV lives:

**I Period of crisis** – Discovery of infection. This is probably one of the most difficult periods of crisis for a person living with HIV/AIDS, as well for her/his family members. Adequate psychological support in the period just after HIV/AIDS diagnosis is of utmost importance, in order to reduce stress which can be a trigger for further complication of situation, in order to ease fear and the sense of rejection, and prepare the person at the same time for treatment and adjustment of life habits to the course of illness. In period of crisis psycho-social support is mostly provided by experts, i.e. professionals working with HIV/AIDS. On the level of community, these are carriers of health care and social welfare services and specialised counselling centres for HIV/AIDS, as well as organisations specialised in HIV/AIDS issues.

The local community can and must support constant improvement of institutional and human resources of psycho-social support to people with HIV/AIDS in situations of crisis. Support pro-



grammes should be developed in accordance with experiences of PLHIV population and contemporary support standards, and individual approaches should be especially favoured, respecting cultural and social identity of the individual, as well as her/his personal integrity.

**II Accepting and adapting.** The period right after finding out about the existence of HIV infection and awakening after the first shock. This is the time of confrontation with numerous fears, social and health – related, the period when the person is adapting to the new situation, the time to change attitudes and life habits, and the time when the family is adapting. In this period expert and community groups and associations should play an important role in securing psycho-social support, but especially important sources of support are support groups. Psycho-social support in this phase should empower PLHIV to create positive changes.

Local community should support formation and empowerment of PLHIV self-support groups, with strong participation of PLHIV themselves. In order to improve the work of the existing organisations dealing with support work and development of new ones, material assistance is necessary, as well as transparency in resources allocation and control. It is also important to establish more intensive coordination among support groups and institutions of health care and social welfare.

**III Process of re-socialisation.** Once the infection, i.e. disease has been stabilised and under medical control, PLHIV can work and enjoy all aspects of daily life – cultural, economic and social, without any disturbances. Social community in this phase is extremely responsible in supporting full re-integration of PLHIV into the social and working environment. All segments of the community should participate in this phase: decision makers, creators of policies and strategic development documents, public institutions, civil society, private sector, media and wide public. The essence of social action is de-stigmatisation of the disease and PLHIV and acceptance of these people with full respect for their privacy, integrity and dignity.

Community has three key tasks in this phase:

- To influence change of public opinion on HIV/AIDS and support and promote acceptance of these people as equal members of community, to influence clarification of expert public about HIV infection, rights and needs of PLHIV, and to raise awareness on harmful implications of discrimination. Community should support various campaigns, education, informing actions and other similar activities, advocating for acceptance of PLHIV as equal community members and preservation of their overall quality of life.
- Monitoring implementation of legislative mechanisms in order to prevent discrimination. This implies various kinds of legal support to PLHIV, and establishment of additional mechanisms of control for implementation of legislative acts, in order to promote rights of people living with HIV/AIDS.
- Development and strengthening of capacities of organisations directly providing different services to PLHIV, such as counselling, legal support, psychological support, volunteers' support, support to gain self-assistance skills, palliative care support. By licensing or accreditation of organisations providing direct services to PLHIV, the community can set and control standards of such services, secure transparency in their work and raise the quality of available services.

Community based psycho-social support for social re-integration of PLHIV is based on fight against discrimination against PLHIV. Carriers of such support are equally decision makers and creators



of policies on the level of local community and other segments of the community. Establishment of coordination among different sectors, especially the public and the civil society one, is of utmost importance, as well as their joint action pointed at development of a more tolerant social environment for the needs and problems of PLHIV. Wider social action, aimed at supporting social integration, sends a meaningful message to people living with HIV/AIDS to mobilise their psycho-social and physical capacities to the maximum in directly participate in their re-integration into their community.

**IV Psycho-social support within palliative care.** The community should be capable to provide special psycho-social support to the patient and her/his family members in terminal phases of the disease i.e. within palliative care. As palliative care is still not wholly established in Serbia, nor developed as an integral part of the health care system, despite the Strategy on Palliative Care being adopted, the support to PLHIV in terminal phases is unplanned and left to “good will” of the few civil society organisations.

On the Balkans as a whole and in the Eastern Europe in general, the position of people living with HIV/AIDS is difficult. Study trips, organised mostly within Global Fund projects, have convinced activists that in all countries of the region there are activities being undertaken to solve the problems of people living with HIV/AIDS, but their security is often jeopardised. In all countries, especially EU members, there are laws against discrimination, but processing the cases involving this kind of discrimination is practically impossible because of the fear that discrimination victims have. The best examples of legislation in this field are Poland and Romania, but even with the laws existing in these countries, brought mostly under pressure of CSOs and international institutions, PLHIV are neither properly having access to medications (ARV) nor are they tested as necessary. Prevention and treatment functions well in Poland, but PLHIV are not fully protected, for their scarce associations are under direct patronage of the state and often do not want to recognise examples of direct and indirect discrimination.

#### **SITUATION IN SERBIA AND ATTEMPTS TO IMPROVE IT – EXPERIENCES FROM THE REGION, FACTUAL STATE AND PROBLEMS, NORMATIVE FRAMEWORK AND KEY ACTORS**

When the current situation in Serbia is compared with the one from ten years ago, an advancement concerning the security of people living with HIV can be seen. Thanks to number of projects which are giving results regarding treatment, care and support, laws have been passed to regulate and prevent discrimination of people living with HIV. Defect of laws sanctioning discriminatory behaviour is lack of explicit mentioning of HIV, while in the Criminal Law of Serbia there is disputable Article 250, which predicts imprisonment for behaviour of people living with HIV. Although, apart from acts of intentional HIV transmission (which are regulated by other acts of the Criminal Law – rape, inflicting injury etc), in cases of wilful engagement in unprotected sexual activities both or more people must be held equally responsible, the Criminal Law openly sanctions people living with HIV, while at the same time there is no law to directly protect these people, so they can refer only to other laws which basically protect their rights (Constitution, Law against Discrimination, etc).

To begin a process against any type of discrimination, no matter how serious it is, it is necessary for the discriminated party to address the authorities with full name and surname (Commissioner for Protection of Equality, Ombudsman on all levels, Patient’s Advocate, etc), but a small number of discriminated people is ready to talk in public about life with HIV and give personal data, so often cases of discrimination pass unregistered. In that context, one cannot talk of safety of people

living with HIV, who often even decline using basic existing services (treatment, psycho-social support, etc) because they fear reactions from their environment if they are recognised as people living with HIV/AIDS. According to the Ministry of Health run research in 2010, a certain number of registered people living with HIV do not receive treatment, while services of psycho-social support in various CSOs are used only by 24% of the registered.

People living with HIV/AIDS in Serbia, who have regulated health insurance, can count on treatment in primary, secondary and, what is most important, in tertiary health institutions. Clinics for HIV/AIDS are within university clinic centres, the tertiary health institutions, in Belgrade, Novi Sad, Nis and Kragujevac, where around 1.000 infected people were treated in 2011, and the trend is around 100 new cases diagnosed every year. A significant number of the infected is still out of the reach of the health system, either because they refuse treatment, or because they are unaware of their HIV status. According to WHO estimations, there are around 4-6 thousand people infected with HIV in Serbia. Those among them without health insurance can obtain it if they are infected with HIV virus, as treatment of contagious diseases in Serbia is always covered by the Republic Institute for Health Insurance. Most of the HIV infected in Serbia are unemployed and they obtain health insurance otherwise. On average, social and economic status of people living with HIV/AIDS in Serbia is bad, due to low education, unemployment, poverty, unsolved basic life issues, as well as because of neuro-psychiatric complications of the disease, stigmatisation and discrimination.

Because of a relatively small number of qualified counselling centres for HIV/AIDS, where voluntary, confidential counselling and HIV testing (VCCT) are being organised, and because of fear from finding out about HIV status, stigmatisation and discrimination, many people, although aware of the risk that they might have acquired HIV, avoid testing. As a result, usage of screening tests for HIV antibodies in Serbia is the lowest in Europe. Due to this tendency, more than 50% of newly discovered cases of HIV infection are in late stadium of infection (AIDS). Late diagnosis often implies prolonged hospital treatment of fatal opportunistic infections and tumours, with an uncertain outcome. Insufficiently educated health workers sometimes contribute to late diagnosis, not recognising HIV clinical manifestations in their everyday practice. Early diagnosis of HIV infection and therapy are essential for longevity of people living with HIV, and in developed countries it is estimated that PLHIV have life span similar to general population. In developing countries, where Serbia belongs to, there is a slight possibility that the attitude and education of health workers will change soon, which have been pointed in recent research on attitudes and knowledge of health workers concerning HIV/AIDS, as well as the relation of PLHIV unaware of that fact, towards their risk and importance of an early diagnosis. It is, therefore, most probable that the coming decade will also have a significant increase of late diagnosed patients.

There are associations of PLHIV in Serbia, which function mostly thanks to projects of the Global Fund and the European Union. Within these associations certain services have been formed which are currently at stage of empowerment, definition of minimum package of services and accreditation, and they are mostly led by educated persons from PLHIV population, therefore on this level expert help is not being offered, but mostly peer help. During conversations with beneficiaries of services provided by these associations, a devastating fact was found that a small number of beneficiaries, around 40% have support of their families, around 50% do not inform their families of their status, and 10% were banished from their families upon revelation of their status and suffered discrimination within their families.

In the National Strategy for Fight against HIV/AIDS 2011-2015, local communities have been recognised as important factor in prevention, treatment, care, help and support for people living



with HIV, but their role in this field has not become active almost anywhere in Serbia. Best examples can be found in Serbian north province of Vojvodina, while in other parts of Serbia there is minimal or no cooperation on the local community level. Adequate services are available to people living with HIV only in bigger towns, mostly ones where there are centres for treatment. Services are concentrated in Nis, Belgrade, Novi Sad and Subotica. In other places there are public institutions which officially provide services of psycho-social support, but research made among PLHIV has shown that they do not use these services up to satisfying level (only 17% of them use the services of centres for social work).

The essence of organising adequate social welfare is development of a layered system of complementary types of support that answer the needs of various social groups. The Law on Social Welfare has set the development of networks within the community as one of its fundamental goals, which encompasses identification of needs and definition of territorially and functionally available services for various vulnerable groups within the community. Centres for social work are basic units of social welfare on a local self-government level. Activities of centres for social work consist of social welfare, social work and family-legal protection. The social welfare system in Serbia consists of a network of 136 centres, and the Belgrade City Centre for social work with 17 municipal centres. Centres offer specialised services regulated by law and bylaws. Local self-governments are obliged to provide certain kinds of specialised services and level of social welfare needed at their territory (e.g. accommodation centres for homeless, or day-care centres for certain groups as specialised services). The law allows local self-governments to take financial assets from their budgets in order to secure subventions to certain vulnerable groups (help for poor children, subvention of utility expense, etc). Local self-governments are also authorised by law to introduce new social services in accordance with needs of the local population, which are provided by competent, authorised persons monitored by competent departments.

The basic principles of social welfare, according to the new Law, are: the best interest of beneficiaries, the least restrictive environment, prohibition of discrimination, efficiency, development of services networks within the community, timeliness and wholesomeness of social welfare, publicity of work, availability and individualisation of social welfare (the beneficiary is provided with an individualised approach and competent worker in charge of a concrete case – case leader). Development of services network within the community means development of social welfare services on local level that should answer specific needs of beneficiaries in their natural environment. This trend of services' development on local level, when it comes to PLHIV, is followed by the Strategy adopted in 2011, which recognised the importance and role of local community and its inclusion in implementation of specific programmes. The Strategy foresees, among other things, expansion of programme activities through improvement of gender sensitive and other specific programmes, as well as introduction of "positive" prevention programmes. Emphasis is put on respect for human rights, both of PLHIV and members of marginalised population groups who are under increased risk and vulnerable to HIV. The role of local community in response to HIV infection is given as one of very important components of the Strategy.

Support of family and community is a primary foundation, which is often not present, although it should be understood. Due to common stigmatisation, people living with HIV/AIDS and their families rarely answer calls to participate in common activities at any level. The process of inclusion can be started by members of the local community or some "outside" group (CSOs), but in both cases the aim is to support the sense of togetherness and increase chances for the support to continue even after individual initiatives end. The aim of alliance is to help a vulnerable group until they recover, and the word "support" is emphasised, because the community is an active participant in this process. Family support is recognised as the most significant type of support,



and therefore comes the conclusion that people living with HIV/AIDS are mostly oriented towards their own families and they are not able to realise a higher level of independence. Often, there are totally opposite situations, where the most misunderstanding comes from the family, which completely rejects the person living with HIV/AIDS.

Part of the changes happening in the social welfare sector must come from the community, firstly through activities of CSOs. CSOs providing certain social services are recognised as actors who can significantly influence the structure of social services offered, by their participation in the social welfare planning process and by pressurising local and central authorities. According to the data of the Serbian Business Registers Agency, more than 10,000 CSOs were organised in Serbia. Few of them have specialised on local level when it comes to people living with HIV/AIDS.

There is a difference between CSOs which have full-time employees or associates who are expert, competent, licensed for helping vulnerable groups and those which represent a group of citizens gathered around a common problem, and who have social services beneficiaries as members, aware that only if they associate and activate they can expand their rights. Advantages of CSOs as service providers are that they are more flexible, faster to react; they are less burdened by bureaucratic procedures in their work; they can more easily introduce novelties in their work and adapt to the needs of beneficiaries. The problem with CSOs is that they too will have to comply with a list of requests in order to become licensed providers of certain social services. Although the number of organisations dealing with problems of people living with HIV/AIDS is growing, most of them are not visible enough within the community, and another problem is that the culture of activism is underdeveloped among citizens. Furthermore, there are not enough organised programmes for volunteers, whose work would strengthen the support for people living with HIV/AIDS and their families (a positive example in that sense is Philanthropy).

Although civil society is actively participating in providing support for people living with HIV/AIDS, its role is undervalued in comparison with other service providers. Contents of services are not known enough both to the service givers and beneficiaries. However, apart from the growing number of activities of the CSOs, service providers are mostly public institutions. Social inclusion of people living with HIV/AIDS is low. Reasons for their social marginalisation are rejection, prejudices in the environment, low standard and insufficient number of services, and passivity of PLHIV themselves. The principle of participation of PLHIV in creating policies of protection and services is almost inexistent neither on the local level, nor in local communities.

Although there is a legal framework, and in spite of activities of CSOs and the Ministry of Health, the response to HIV infection in Serbia is not equal on its whole territory, and the most activities are being undertaken in Belgrade and other bigger towns. Some local authorities have the capacity to undertake actions in response to HIV infection through city secretariats for health, municipal councils, and centres for social work, youth offices, etc, but they have not assessed local needs and priorities, and are lacking material resources as well.

Based on all aforementioned facts, the following system faults can be identified:

- Insufficient safety and participation of people living with HIV/AIDS in usage of fundamental services offered by state or civil society (treatment, psycho-social support, legal protection and social welfare);
- There are no laws to properly protect the interests and right of people living with HIV/AIDS;
- PLHIV are insufficiently informed on their own rights and fear often prevents them to practice their rights;
- Few PLHIV have the full support of their families;
- Local communities do not recognise the needs of people living with HIV/AIDS in their action plans;
- Services provided to people living with HIV/AIDS are concentrated on bigger towns, while in rural areas these services are nonexistent;
- There is a lack of regulated support system of local community and state, which will have grave consequences after the Global Fund projects end.



## RECOMMENDATIONS

In order to improve community-based psycho-social support to PLHIV, local self-governments/communities and other relevant actors should direct their efforts at implementation of following actions and measures:

- Change the existing legislation and adopt bylaws to regulate the rights and obligations of PLHIV more closely;
- Regulate the way of registering discrimination cases (optional disclosure of basic data by PLHIV);
- Promotion and dissemination of information regarding human rights and patients' rights in media, by flyers and posters, starting with service providers on primary level (VCCT);
- Give space, through amendments to existing legislation, to empowerment of people living with HIV to speak openly and in public about their problems, discrimination and needs;
- Inclusion of families into the associations' work, with the fundamental precondition of wide and compulsory education of population on HIV prevention, without excluding PLHIV as important factor in dissolving prejudices, decrease of stigma and discrimination, in order to diminish the resistance most families have towards PLHIV;
- Consistent implementation of the National Strategy of the Republic of Serbia in fight against HIV and work on sensitisation of local communities through education, adoption of recommendations and bringing of action plans where support and help for PLHIV would be recognised, with local communities committing themselves to provide real assistance and support;
- Accreditation and standardisation of services which are now being provided mostly through CSOs, with indispensable help of the state and inclusion of experts into provision of services;
- Maximal and continuous empowerment of existing capacities of peer counselling through public support and constant education;
- Constant pressure on local communities and state to consistently practice guaranteed rights, such as the right to adequate treatment. Stronger and more constant reactions from the civil society, primarily through the existing USOP, with preservation of its functions and constant monitoring of the field situation;
- Equality in treatment and availability of help and support for all people living with HIV/AIDS in Serbia;
- Consistent implementation of GIPA principles in the field of prevention and empowerment of people living with HIV/AIDS for inclusion into the National response to HIV pandemic;
- Amendment and implementation of regulations and standards in fields of health care and social welfare relating to health education, rehabilitation, social care and palliative care of people living with HIV/AIDS;



- Strengthening of institutional capacities in order to support formation of specialised institutional units, counselling centres and support centres for PLHIV within the public system of health care and social welfare;
- Provision of additional education and expert trainings of professional health care and social welfare workers for work with PLHIV and their families;
- Strong support to establishment of cooperation among different participants in the process of social care for people living with HIV/AIDS, primarily between health care and social welfare on the local community level;
- Informing public on HIV infection and problems of PLHIV, primarily actors in education, culture, security, etc;
- Development of psycho-social support programmes based on experience of PLHIV, i.e. active involvement of the infected and diseased in programme creation or support services provided by public institutions;
- Establishment of more intensive cooperation between the public and the civil society, i.e. among state institutions and CSOs which focus their work at supporting PLHIV;
- Strengthening the capacities of CSOs which exclusively help and support PLHIV, those employing people living with HIV/AIDS, from supporting implementation of specific projects, to securing continuous financial support;
- Support to development and institutionalisation of support groups;
- Securing sustainability of organisations and agencies providing various services important for preservation of life quality of PLHIV, by licensing or accreditation of such organisations' programmes and through financial support;
- Organisation and enforcement of public campaigns, aiming to increase the public awareness about HIV infection, in order to reduce and eliminate stigmatisation of PLHIV.

In accordance with conditions in Serbia, politic authorities and competent institutions should provide more efficient division of economic resources to follow the process of decentralisation of services into local levels, so that both more efficient and less developed communities in the country could respond adequately to the needs of PLHIV.



## LEGAL PROTECTION OF PLHIV (PEOPLE LIVING WITH HIV/AIDS)

**H**IV epidemic has opened sensitive issues worldwide, issues related to harmonising the need for efficient measures to combat HIV/AIDS and the equally important need of respecting human rights, both of people living with HIV/AIDS and other people whose rights may be at risk because of specific prevention measures and treatment of these people. As in cases of other grave diseases with distinguished social implications, the consequences of HIV infection are not limited only to people directly struck by the illness – their whole psycho-social environment is at risk: family, professional and working environment, other people with whom they socially interact in formal and informal social groups, cultural or sports activities.

Contemporary tendencies in protecting fundamental human rights and freedoms are striving to secure equal rights for all population groups. In the past two decades, practice and work of international organizations, as well as in legislation of all UN member states, expressed great importance to standards of labour and social rights, the realisation and practicing of which is extremely significant for life and dignity of people.

Having in mind concrete consequences of measures from the domain of respect for human and civil rights that certain countries have been undertaking in order to combat HIV infection more efficiently, and international obligations that member states within the organisation had assumed, the UN Commission on Human Rights determined in 1996 that in the classical definition of prohibited discrimination the term “or on any other ground”, which legally determines that discrimination is prohibited on any personal characteristic, relates also on people infected by HIV virus. The Commission simultaneously listed the following human rights to have fundamental importance for combating HIV with examples of their breach:

- The principle of non-discrimination and equality before the law, and especially combat against discrimination in the fields of health care, employment, education, immigration, issue of travel documents, housing and social welfare;
- Availability of health services to everyone, especially particularly vulnerable, with lower social status;
- Respect of privacy and confidentiality of personal data, e.g. securing confidentiality of HIV virus tests results;
- Provision of educational and informative contents on prevention and treatment of AIDS in languages of ethnic minorities which are at higher risk;
- Securing independence and personal freedoms of PLHIV;
- Freedom of participation in political and cultural life, and especially participation of people with HIV/AIDS in formulation and implementation of measures in fight against HIV infection;
- Prohibition of discrimination in practicing rights to marriage and equality in family relations, e.g. prohibition of compulsory HIV testing before entering into marriage, prohibition of forced abortion or sterilisation.



In spite of the existence of a number of legal and strategic acts and practical policies, even today, thirty years after first registered cases of infection appeared, we cannot speak of complete implementation of all documents guaranteeing legal protection for PLHIV, both worldwide and in Serbia. Legal protection of PLHIV must be seen from various angles: prevention programmes (determination of HIV positive status), health care for PLHIV, privacy protection, HIV transmission, and stigma and discrimination that are accompanying lives of PLHIV.

Legal protection of PLHIV population in these fields in Serbia is not regulated by separate legal documents, but it is an integral part of various laws, i.e. normative regulations which lay down the mentioned fields. In that context, people living with HIV/AIDS practice their rights as all other citizens. Public unawareness about HIV infection and stigmatisation of PLHIV population result in discrimination of these people in many aspects of daily life, which leads to violation of their fundamental human rights. Because of these reasons the existing normative regulations lack more sensitiveness to specific needs of PLHIV population in practicing fundamental human rights in various fields.

## **1. Determination of HIV positive status**

The law orders consensual testing, after conferring information on the testing and the testing itself, otherwise it is considered that freedom and privacy of the person in question are directly violated. Functioning of VCCT (Voluntary Confidential Counseling and Testing) centers in Serbia mostly depends on the region they are in, and despite recommendations of UNAIDS and WHO from 2006, these centers in Vojvodina, central and southern Serbia have a significantly different approach and method of operation, according to testimonials of PLHIV and other tested. According to aforementioned recommendations, compulsory testing should not exist, but it still occurs, for example, as pre-condition for surgery, which can be interpreted as violation of right to freedom of choice and privacy. After HIV status determination, anonymity, voluntariness, even confidentiality are often lost. According to the Law on Protecting the Population from Contagious Diseases in force, registration of an illness to the adequate regional Institute for Public Health is mandatory, where given data are forwarded to the unique register of patients suffering from contagious diseases in the Institute of Public Health of Serbia.

## **2. Health care of PLHIV**

In international recommendations on PLHIV human rights it is said that countries are obliged to alter and reform their legislation in part relating to health care linked to HIV/AIDS. In the basis of these recommendations is the intention to stop putting HIV infection and communicable contagious disease into the same context. According to these recommendations, a wide spectrum of services for prevention and treatment of HIV/AIDS should exist, including education, VCCT centres, programmes of damage reduction, availability of condoms for the population under higher risk of HIV infection, etc.

In Serbia, most of these programmes on national level are being supported by the Global Fund, which will be present in the country until 2014, according to current plans. None of these programmes (except partly VCCT and methadone centres) has been recognised by the state as sustainable and necessary, and the question of their continuation and sustainability after GF leaves Serbia remains open.

Treatment of patients living with HIV/AIDS has been seriously brought into question in the past because of lack of basic tests for monitoring therapy success and illness progression, which directly makes antiretroviral therapy senseless and jeopardises patients' lives. PLHIV associations reacted on this immense problem several times.

All citizens of Serbia have the right to health insurance and health care. People treated for contagious diseases and HIV belong to a group of specially protected insured persons according to the Law on Health Insurance and they have guaranteed health insurance even in cases of owing health insurance contributions. Treatment of PLHIV is performed in special health institutions for hospital treatment of contagious diseases patients, according to the Law on Protecting the Population from Contagious Diseases. The Law does not foresee isolation and quarantine measures for PLHIV. Unfortunately, according to filed reports, if PLHIV need treatment for a different disease, not directly connected to HIV, i.e. in another health institution, those patients are hospitalised in separate rooms; they have a different treatment thus bringing the treatment's success into question. Often times, patients are sent into specialised institutions for treatment of HIV/AIDS when they suffer from an additional disease, although there is no real need for this, and as AIDS is classified as a contagious disease, they are prevented from using spas, recreational centres and accommodation in social care institutions, since beneficiaries of these services are required to be healthy from any contagious diseases. In treatment of HIV/AIDS patients, the most significant role is played by antiretroviral drugs, which are deficient in Serbia, and around 10% of patients are resistant on existing drugs.

### **3. Privacy protection**

The right to privacy is guaranteed by the Article 9 of the Universal Declaration on Human Rights, Article 17 of the International Covenant on Civil and Political Rights, Article 8 of the European Convention on Human Rights, Article 6 of the Council of Europe Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data and the Declaration on Commitment on HIV and AIDS. Although Serbia verified all of these declarations and conventions, these rights are violated mostly because of ignorance about their existence. The most common are violations of these rights in health care (because of pronounced need of patients for health care), then in social welfare (cases of exposing HIV status even on documents), and in employment.

In case of revelation of data relating to someone's HIV status by an individual, on public gatherings or in media, thus jeopardizing the honour and respect of the person whose status is in question, Article 172 of Criminal Law stipulates criminal liability. According to Law on health care, during health care, every patient has the right to confidentiality of data disclosed to a health worker, as well as the right to protection of privacy. The Constitution of Serbia does not guarantee the right to privacy as such, but the Article 42 of the Constitution does contain a general provision that guarantees protection of personal data, and stipulates that collecting, keeping, processing and use of personal data will be regulated by law. The Law on Data Protection from 2008 stipulates that the intention for collecting, processing and use of personal data must not only be lawful, but also clearly determined even before data collecting begins. This Law also stipulates that data referring to a person's health is considered especially sensitive and can be processed only with the person's consent, if not otherwise regulated by the Law.

Perceived problems in this field are in treatment by medical staff and other state employees, as well as treatment of medical and other documentation from which it can be conferred that it is a person living with HIV/AIDS in question and from which someone's identity can be revealed



(engagement in PLHIV associations, according to requests of donors and National HIV/AIDS office implies use of codes containing certain data for every beneficiary, and only deeper analysis of codes could reveal true identity).

According to the professional ethics code of the Medical Chamber of Serbia and provisions of the Ethical Code of Doctors and Dentists protection of patients' privacy is guaranteed. Health staff has the obligation to reveal information without the patient's consent only if there is grave and real danger for third persons and if in their professional opinion revelation of this data would lead to reduction or elimination of this danger. Health staff refers to this part of the Ethical code when they print the patient's HIV status in red letters on their health records. PLHIV associations are striving to point out how unnecessary this is, if all measures foreseen by law concerning accidents at work are obeyed. Because of this action the patient's status is visible to anyone with access to health records and following documentation, which violates the right to data confidentiality, as well as the right to privacy and freedom.

#### **4. HIV transmission**

International association GNP+ in its report form 2005 says that 36 out of 45 states comprised in the research think that HIV transmission or risk of HIV transmission may represent a felony. UNAIDS report "Criminalisation of HIV Infection Transmission" (2006) refers to the same problem – there is no data confirming the justifiability of the Criminal Law application in regard to HIV infection expansion, neither from the justice aspect nor from the HIV prevention aspect.

Since 2005, apart from keeping transmission of a contagious disease a felony (Art. 249) another article was added into the Criminal Law (Art. 250, Par. 2 and 3) which punishes HIV infection transmission in Serbia,. Strict imprisonment is foreseen even for bringing into danger of infection, without conditions if transmission occurred or not. The Law is not clear if people infected with HIV can be criminally liable in cases of infection transmission by negligence (in place of work) and in case of conscious bringing of another person in danger of infection transmission (theoretically with a kiss). There is no court practice to show how courts would interpret and apply this regulation, which offered theoretic possibilities to begin a criminal procedure in various situations, even when a person did not know she/he was living with HIV/AIDS.

People living with HIV, in meetings with the formed inter-parliament group which gathered representatives of the governing and opposition parties and with the Parliament President, had to opportunity to present current living conditions of PLHIV in Serbia, including medical treatment, care and support. These discussions contributed to creation of amendments on the existing Law on Health Care and amendments of the Criminal Law of the Republic of Serbia, which is waiting for the change of current Law to come to the agenda.

Although USOP is aware that a complete revision of Criminal Law of the Republic of Serbia in the part which talks of HIV criminalisation is impossible, it is the wish of this organisation to try to humanise this part of the Criminal Law of the Republic of Serbia with securing the respect of an individual's rights by amendments and petitions.

## **5. Stigma and discrimination**

According to definition, discrimination implies events that most often follow PLHIV in environments not sensitised or educated for coexistence. The Universal Declaration on human rights (Article 7) and European Convention on Human Rights (additional protocol 12 from 2000.) which were signed by all countries in Europe, imply absolute prohibition of discrimination on all issues.

The Constitution and Criminal Law of the Republic of Serbia prohibit discrimination, including discrimination of PLHIV. The Law on Prohibition of Discrimination does not encompass specifically discrimination cases based on HIV positive status, although the question why they were not emphasised was raised several times, since this is the case in the Criminal Law of the Republic of Serbia, and the explanation given said that thus PLHIV would be additionally stigmatised, which was not the intention of this Law. People living with HIV can refer onto this law from Articles 15-27. Article 27 clearly prohibits discrimination based on health condition and it widely encompasses discrimination based on HIV positive status.

Field situation is significantly different and today there are a lot of PLHIV discrimination cases which are not registered, nor even recognised. Philanthropy issued a leaflet which was distributed across Serbia, especially on clinics for HIV/AIDS (Belgrade, Novi Sad, Nis), in which human rights were listed, with the aim to educate PLHIV in Serbia in order to be able to recognise stigma or discrimination, as well as the possibility to report it to the authorities.

Today PLHIV rarely decide to make this step, mostly out of fear, and therefore there are no recent processed cases of discrimination based on HIV positive status. Part of the problem is probably the fact that most PLHIV organisations in Serbia do not have a clearly defined legal protection service. USOP members organizations received the possibility to meet and talk to representatives of various sectors who can directly influence the possibility of recognition and raising the awareness of necessity to prevent discrimination among PLHIV themselves (for example Commissioner for equality) thanks to the Philanthropy's EU funded project.

## **6. The right to work and employment**

One of fundamental human rights is the right to work, which implies the possibility of every person to find employment without any pre-conditions, except fulfilling necessary qualifications for a certain post. The Labour Law prohibits any discrimination in employment and work. People living with HIV/AIDS, as other employees have the right to adequate wage, safety and public health at work, health care, personal integrity protection and other rights in case of illness, decrease or loss of working ability or old age, as well as material remuneration for the time of temporary unemployment.

People living with HIV/AIDS in Serbia, in order to remain employed, often do not reveal their HIV positive status to anyone. In cases when employers find out the real or even assumed information on HIV positive status of employees, these people are usually dismissed or degraded to positions requiring less qualification than they have. In some cases employees were kept formally at work, but with instructions not to come and a promise to receive some sort of remuneration nevertheless. Some PLHIV associations made proposal of regulations regarding PLHIV employment and work, in cases when the information on HIV positive status has been voluntarily delivered to the employer.



In cases of loss of working ability and insufficient number of years in employment for early retirement due to disability, people who lose their jobs usually remain left on their own. PLHIV who are retired based on their HIV status (which is enabled by the definition of HIV in the Law on Contagious Diseases) do not have the same rights to realise benefits foreseen for pensioners with disability, since currently HIV is not implying any subventions on the issue of disability. One may conclude that these people are withdrawn from their working environments with minimal remuneration, not to represent a threat in their place of work.

## **7. The right to education and social welfare**

Protection of PLHIV population's interests in the field of education is similar to the situation in the field of labour. Existing laws prohibit discrimination and guarantee every individual the right to education, as to work. Legislation in Serbia in the field of education contains no specific regulations relating to special rights of people living with HIV/AIDS.

Rights in the field of social welfare are regulated by the Law on Social Welfare. People living with HIV/AIDS have no rights to special social income according to current regulations. PLHIV population is often a candidate for various services from the social welfare system, due to the nature of the disease and their health condition, and due to social prejudices which unable their access to paid employment. Experience has shown that in practice PLHIV have difficult access to social rights although their need for them is high.

## CONCLUSION AND RECOMMENDATIONS:

From aforementioned data it is clear that the existing state of rights and position of PLHIV in Serbia is troublesome. The following recommendations would definitely improve the implementation of existing laws, as well as their amendments in parts which are currently allowing additional discrimination and punishment of PLHIV without a reasonable foundation, which calls for their adjustment to contemporary knowledge of HIV:

- A separate legal act and other necessary regulations should be passed in order to regulate most issues relating to HIV and AIDS (now there are a sequence of norms in different laws, without clear provisions on issues related to HIV);
- Certain rights of PLHIV should be guaranteed by an adequate social policy, binding for authorities;
- Public awareness on the importance of prevention and timely HIV testing should be raised, with recognition of the role of PLHIV themselves (activists, associations), giving them a more significant role in the process;
- It is necessary to separate HIV from other easily transmitted diseases, by special provisions or a law, due to specificity of this infection;
- It is necessary to secure stronger guarantees for respect and protection of PLHIV, by application of legislative regulations and professional ethical codes, with special attention on actions of health workers and medical documentation treatment;
- Efforts to reduce the degree of HIV transmission criminalisation should be continued, with simultaneous work on positive prevention application. Existing amendments should be updated and good cooperation with the highest decision makers should be continued;
- Greater inclusion of PLHIV into all activities relating to HIV should be insisted on, in order to increase their social visibility;
- Creation of clear laws and provisions preventing employers from demanding revelation of HIV positive status from applicants for employment or persons realising their rights to remuneration should be influenced by lobbying and advocating;
- Processing PLHIV to treatment should be facilitated, especially when they originate from places without clinics for treatment of the HIV positive;
- Number of centres for voluntary counselling and HIV testing should be increased;
- Definition of HIV in the Laws on Contagious Diseases should be altered, so that AIDS is characterised as a chronic disease with which one can live, if revealed on time, instead of a terminal disease;
- Competent ministries and other public institutions should be influenced in order to provide support for PLHIV associations, as for other patients' associations, from the republic, regional and local budgets;
- It is indispensable to secure free access to education for children living with HIV/AIDS, by creating a more tolerant environment caring for health protection of all children. Furthermore, with the help of curricula, it is necessary to improve knowledge of schoolchildren on HIV/AIDS infection and nature of the disease, in order to combat prejudices;

- The state should prevent children, youth and adults living with HIV to be deprived of the right to education, including access to schools and universities, possibility of receiving scholarships or participation in international education – only because they are living with HIV/AIDS;
- Isolation and special treatment for schoolchildren or children living with HIV/AIDS, living in centres for children without parental care should be prohibited;
- Laws clearly regulating free access to all health, social and other services should be secured for people living with HIV/AIDS, and they should be offered greater amount of social and psychological support programmes;
- Bylaws or special books of regulations on local self-government level should define more precisely the rights of PLHIV population in the field of social provisions, and people living with HIV/AIDS in need of social assistance should have social welfare system services made accessible on the level of local self-government;
- Measures of positive discrimination (affirmative action) should be introduced in favour of PLHIV, in order to equalise them with other members of society;
- Legislative regulations should specially define the rights of people living with HIV/AIDS to palliative care, since epidemiological data show that 30% of newly registered PLHIV in 2009 learned of their status only in terminal stadium of infection.





## MAPPING OF SOCIAL PARTNERS FOR PLHIV (PEOPLE LIVING WITH HIV/AIDS)

## POSITION OF PEOPLE LIVING WITH HIV/AIDS IN SERBIA

**M**apping of needs and services is a basic method and instrument for establishing a system of integral social welfare on local level, as well as for an estimate of circumstances and projection of needs for services within the social welfare system of the local community. Maps are a fundamental methodological framework for recognition, registration, estimation and evaluation of basic services and programmes of services defined on the basis of priority rights and needs, together with strategies for meeting the needs and realisation of rights of beneficiaries in the local community. Maps are based on social rights (right to live in a natural environment, right to use capacities and develop all potentials of beneficiaries and right to integration into social environment) that should be respected by creating an adequate system of social welfare that protects them. The aforementioned rights have been set as a general framework to recognise the corpus of needs and certain strategies for meeting them.

The most important social resources of support and assistance for people living with HIV/AIDS (PLHIV) can be divided into those relating to their health care (availability and possibility of early infection diagnosis, adequate, comprehensive and quality health care, as well as available palliative care in terminal phases of illness) and resources that can save and improve life quality of these people in other fields – prevention of social marginalisation, preservation and improvement of social integration into wide and narrow social environment, psychosocial and legal support. Social partners in this area are considered to be the following: local community, public health and social welfare institutions and educational institutions, civil and private sector on local and higher levels, competent policy and programme creators and decision makers on all levels, municipality managements, city administration secretariats, competent ministries, the Republic Institute for Public Health, potential donors and other potential partners as well.

Capacities of local communities for response to HIV have not neither been sufficiently developed nor properly used in the previous period. Official data on registered cases of HIV infections which show that the highest number is registered in big cities, especially in Belgrade, and that certain municipalities have no registered cases, have influenced the creation of opinion that HIV infection is a problem of big communities and certain vulnerable population groups. Such an opinion of not only a general public, but of a part of expert public as well, influenced a lack of response and inclusion of all segments into HIV prevention, as well as a lack of organising specific help and support for PLHIV on local level. In that context it can be noticed that there are no specific kinds of assistance, i.e. welfare expenditures and other kinds of support directed especially at population living with HIV.

The influence of HIV infection on a person's social status depends mostly on the size of the local community in which the person lives. In bigger cities this influence is less than in smaller places. Cases of open discrimination have been rare, but in small communities there is a greater fear of stigmatisation, and therefore there is notable migration towards bigger cities. There are no reliable data as to how much HIV status influences the possibility of employment in various local communities. Anyway, due to latent discrimination, stigmatisation and numerous prejudices, this population is facing intensive exclusion from distribution of almost all social resources.

Although the social status of people living with HIV is generally bad, they approach social welfare centres more rarely than before (according to a research conducted in 2010, only 280 PLHIV in Belgrade and Novi Sad). It is supposed that reasons for this might be fear of discrimination, as well as lack of understanding the procedures for use of some services provided by these centres due to inaccessibility of information on rights and kinds of available assistance, support, or social welfare expenditures.



Patients living with HIV infection and AIDS are occasionally treated in hospitals, apart from ambulatory care, due to complications requiring tests and therapy that cannot be given in ambulatory circumstances. They also often need palliative care. Hospitalisation often lasts longer than necessary, as there is no continuity of health care on local level, which demands a well organised network of health, social and informal services that would address complex needs of these patients. Not often there is a lack of support from family members and wider social network.

Hospitalised individuals who have no family or accommodation pose a specific problem. As cooperation and coordination between health care and social welfare services is insufficient, and the network of social support services and social services in local communities is nonexistent, these patients remain in hospitals for months, since they have nowhere else to go. Life quality of these people is extremely low and they feel abandoned and unwanted. The Centre for HIV/AIDS of the Clinical Centre of Serbia has no position for a social worker, so health care workers and their patients cannot count on expert help of that kind.

Inexistent constant material income further aggravates the situation. There are few institutions for collective accommodation of the homeless and they are often inadmissible for people with HIV infection. Both adults and children are in this difficult situation linked to accommodation and care for PLHIV without families.

Palliative care for PLHIV is currently possible only on clinics for infectious disease, but training of infectologists and their nurses for palliative care provision has not started yet, and it is being provided by insufficiently trained health workers. Palliative home care is mostly unavailable for people in terminal stages of AIDS.

According to the Strategy of Social Welfare Development, the position of citizens and beneficiaries in the system of social welfare is extremely passive and the network of social services is insufficiently developed. Social welfare services organised by civil society are not developed and used enough, and the system of public social-protective institutions and services is centralised, burdened by bureaucracy, paternalistic, and insufficiently economical and efficient.

Problems occur especially when it comes to accommodation in social welfare institutions which is conditioned by a confirmation of inexistence of a contagious disease, where the specific way of HIV transmission and wide possibilities for safe social contacts of PLHIV are not taken into account.

## **LEGAL FRAMEWORK**

Legislation in Serbia does not contain regulations on issues linked to PLHIV. The existing regulations relating to wider issues in connection with health and its protection are applicable mostly in an indirect way, while certain fields remain unregulated and left to practice and professional and ethical codes. Health care of PLHIV is regulated by the Law on Health Care and the Law on Health Insurance.

All services on levels of primary, secondary and tertiary health care are available to people living with HIV/AIDS in the same scope and content as to other population categories. However, increased social care is shown by securing specific health care for population groups who are more vulnerable to developing a disease, in the sense of prevention, control, early discovery and treatment of illnesses of greater social-medical importance. In that context, these people enter into a specially protected insured group, and have guaranteed health insurance even in case of lacking contributions for health care.



The Law on Health Care defined community care for health both on the level of provinces and the local level. This care involves monitoring population health, care to implement priorities set before, creation of conditions for availability and equality of primary health care usage, coordination, encouragement, organisation and direction of health care implementation which is realised by activities of local self-government units, citizens, companies, social, educational and other institutions and organisations, as well as cooperation with humanitarian and other expert organisations, unions and associations and on the tasks of health care development.

In accordance with the Law on Self-Government, local self-government is the founder of primary health care institutions, and experts in primary health care can be employed in municipal management. Unfortunately, foreseen competences, i.e. founding rights are partial and as such they often disable local self-governments from creating and implementing special health care programmes for certain vulnerable population groups. Millennium goals adopted in 2006 by the Government of Serbia foresee that prevention centres should be founded in all health centres until 2010, but this has been done only in some health centres.

Social welfare in the Republic of Serbia is regulated by the Law on Social Welfare and Social Security of Citizens. In order to practice rights provided in the welfare system, potential beneficiaries address Centres for social work on the territory of their residence. Social welfare is provided to citizens incapable of work, those who have no means of subsistence, as well as to citizens and families who cannot provide minimum resources to meet their basic needs by their work or in other ways.

## **FIELDS OF ACTION IN ORDER TO IMPROVE THE POSITION OF PEOPLE LIVING WITH HIV/AIDS**

Services directed at prevention of marginalisation of needs and discrimination of PLHIV and support to preserving their social integration into community encompass organisation of various campaigns dedicated to informing, education and sensitisation of professional and wider public about the needs of people with HIV/AIDS. Carriers of these services are educational institutions, public institutions of health care and social welfare and culture, media, civil society and companies. Civil society and media representatives have used their capacities mostly for such organisation and implementation and provided the largest contribution to improvement of PLHIV rights.

However, the whole community is responsible for providing and organisation of psycho-social and legal support, necessary for preservation of social integration and participation in distribution of all social resources. Carriers of these kinds of services should be firstly counselling centres in preventative health care institutions, counselling centres in centres for social work and independent counselling centres of associations of PLHIV or other CSOs. Psycho-social support for these people as a specific service is not provided and there is a lack of accredited training programmes for those interested in working with PLHIV.

In prevention of discrimination of PLHIV in all segments of life (education, health, work, etc.) clear legislation is of utmost importance, which has been formed in Serbia by adoption of the Law on the Prohibition of Discrimination. Insufficiently recognisable and defined mechanisms for implementation and control of legislation implementation can pose a drawback. The legislation must secure that all cases of HIV/AIDS, registered by the authorities due to epidemiological reasons, are treated in a way that provides personal data protection and confidentiality.

In order to fully protect the privacy of PLHIV complementary application of provisions from the Law on Health Care and professional codes is necessary. It is necessary to introduce stronger guarantees for respect and protection of privacy of PLHIV in accordance with regulations and professional codes of honour – especially those ones referring to behaviour of medical staff and medical documentation treatment.

People living with HIV/AIDS can be candidates for social welfare services, as to the nature of their illness and health condition, as well as to social prejudices that disable them from receiving a paid employment. However, in practice, they experience strong difficulties in exercising their social rights, although that is of additional importance in their case.



## INTERNATIONAL REGULATIONS

On its last session, in June 2010, convened in order to prepare a Convention to be adopted in the following two years, the International Labour Organization (ILO) adopted the Recommendation which refers to the rights of workers infected by HIV virus, i.e. workers diseased from AIDS. This Recommendation was adopted with only eight votes against, and by it ILO addresses governments of all UN member countries, and asks them that:

- They perceive protection of labour and social rights of PLHIV as an inseparable part of enjoying basic human rights and freedoms;
- Associations of employers and workers treat issues linked to the rights of this group of workers in the same way as all other issues linked to the rights of workers;
- There should not be any discrimination or negative preconception linked to workers that have any connection to their health condition;
- PLHIV should be actively involved in all union activities and all activities of importance for improvement of rights of workers;
- PLHIV workers and their families and persons they support should enjoy special rights in the domain of data protection and information confidentiality about workers' health condition – in accordance with the Convention on Protection of Fundamental Human Rights and Freedoms;
- Measures to address HIV/AIDS should be part of national policies and programmes, which would equally treat issues related to labour, education, social welfare and health;
- Workers in professions with greater risk of HIV transmission should enjoy specific protection;
- Governments of all countries should organise specific campaigns to raise the general population's awareness on issues related to HIV/AIDS;
- Real or perceived workers' HIV/AIDS status must not be a reason for employment termination;
- Temporary absence from work due to illness or care-giving duties related to a family member living with HIV/AIDS should be treated in the same way as absence for any other medical reason, taking into account the general provisions of ILO Convention no. 158 on reasons for employment termination;
- PLHIV workers should not be prevented from transferring onto other suitable position, or attending necessary trainings and instructions;
- Strategies for HIV/AIDS prevention should be adapted to needs specific for every country according to type of employment, economical, social and cultural heritage;
- Health safety measures at a workplace should be adequate and efficient;
- UN member states should start a public campaign in media in order to promote continuance of employment of workers living with HIV/AIDS as well as the need to employ such people;
- HIV/AIDS status must not endanger career advancement of individual workers;

- Testing on HIV/AIDS must not be set as condition for employment;
- UN member states should ensure efficient solving of labour disputes in this domain;
- Member states should incite and improve international cooperation in this field;
- Member states should make all necessary changes in their legislation in the next five-year period in order to ensure efficient realisation of labour and social rights of this category of workers;
- Within already existing ILO Convention no. 111 on prohibition of discrimination in employment and choice of profession, specific measures should be taken to prevent discrimination based on real or perceived HIV/AIDS status;
- When existing measures for prevention of discrimination at work place based on HIV/AIDS status prove insufficient or inadequate, all UN member states should change and adapt them in a way necessary to stop potential discrimination on this basis.



## COMPARATIVE EXPERIENCES AND FORMER ATTEMPTS OF IMPROVING THE POSITION OF PEOPLE LIVING WITH HIV/AIDS

In the European Union countries, which were the first to become involved in response to HIV in the world, thanks to continuous work on population education, there are almost no more registered cases of HIV transmission from mother to child. Through well thought and implemented services, each person living with HIV/AIDS is given an equal possibility of employment, treatment, and dignified dying (hospices, which are not recognised in our country, neither in health care nor legal frameworks).

From countries around Serbia, Romania provided means for subsistence for every person living with HIV/AIDS, as well as well solved medical services, through organisation of more than 15 centres for treatment and prevention of HIV. Through cooperation with civil society organisations, these services exist as “safe houses” or residences for youth.

An example of good practice, both in Serbia and abroad, is associating organisations from different sectors that work in this field, in order to offer organised support and assistance to PLHIV. This happened in Serbia in 2009, when the Union of PLHIV organisations (USOP) was established. USOP is supported by resources from several donors, and is becoming affirmed as a relevant partner in our country and abroad.

Still insufficiently recognised by the state, services within CSOs, psycho-social ones in the first place, have been developed in the past few years. In total eight CSOs provide psycho-social services exclusively to PLHIV people. Few more, including Philanthropy, also provide assistance for PLHIV in different ways.

Through implementation of the Global Fund supported project “Strengthening of the National Response to HIV/AIDS by Decentralisation of Key Health Services”, the importance of local communities in response to HIV was recognised. It was clearly shown that in local communities where education on HIV issues was organised and where there were activities connected to HIV prevention and support to PLHIV people, especially in big cities, approach and communication with them were significantly better than in other areas.

Long and difficult procedures of attending medical controls on monthly basis have seen somewhat eased by the possibility of receiving referrals to physicians issued every six months, where all authorisations are transferred from general practitioners to infectologists.

The Institute for Public Health offers identity protection to all tested. There is a Counselling centre for HIV and sexually transmitted diseases in this institution, accessible for all those who wish to be tested.

## RECOMMENDATIONS

- USOP capacity should be strengthened and all relevant actors and social partners in this field should be further connected, with recognition of the role of specialised CSOs, especially in areas not covered by public services;
- Implementation of policies of health care and social welfare should be more intensively decentralised, and the role of local self-governments in organisation and implementation of special programmes to protect PLHIV should be strengthened, in accordance with local needs;
- Health care and social welfare services should be more intensively decentralised and made more accessible, especially in less developed communities;
- Capacities of public health care institutions should be strengthened in order to provide wholesome and adequate services to PLHIV, including increasing the availability of early diagnostic tests, possibility of testing in more health care institutions, availability of medicines, training of professional staff for working with this kind of patients, establishment and development of continuous health care within the community, improvement of palliative care in social environment etc;
- Capacities of public social welfare institutions should be strengthened, in order to provide services to population living with HIV/AIDS, system of priorities in provision of various services should be defined, special social income should be provided for socially endangered people living with HIV/AIDS, services of psycho-social support to PLHIV and their families should be developed, professional training for staff in social welfare system working with this population should be organised, discrimination during long-term institutionalisation in social welfare institutions should be eradicated;
- Special local programmes of continuous and long-term care for patients living with HIV/AIDS should be made and integrated protection services should be developed, including more intense cooperation of all local level service providers (public, private, civil society sector; institutions of health care and social welfare, professional and informal service providers). Such programmes should depend on clearly defined protocols of cooperation among all service providers – health care centres, hospitals, centres for social work, CSOs that offer other kinds of support and help, associations for support to patients and family members, etc;
- Networks of informal support and assistance should be further developed, through local self-government supporting civil society organisations, informal support groups, special centres for self-support qualification, licensing of special agencies for health care provision (which would demand changing the legislation), all aiming to improve quality of life of PLHIV in their natural social environment;
- Counselling centres for PLHIV on primary health care level should be improved;
- More support should be secured for the Institute for Students' Health in the domain of its competences;
- Prevention activities should be strengthened through regular education of children and youth in educational institutions;
- Regular educational contents on HIV/AIDS prevention and the disease itself should be introduced in curricula of all school children;



- Educational campaigns in working environments should be organised in order to diminish discrimination and raise knowledge and awareness on HIV/AIDS in the wider public;
- Better coordination among different social actors on the level of local community should be secured, in order to identify needs and implement measures to protect, help and support people living with HIV/AIDS;
- Accreditation of educational programmes for dealing with people living with HIV/AIDS in the system of health care, social welfare and education should be supported;
- Local self-government authorities should become more involved in implementation of national programmes and strategies related to fight against HIV/AIDS;
- A position for a social worker should be opened at the Institute for Infective and Tropical Diseases of the Clinical Centre of Serbia;
- Media and cultural workers should be mobilised to a higher extent to be engaged in the fight for preservation and improvement of rights and quality of life of people living with HIV/AIDS.



# ДИСКРИМИНАЦИЈА ОСОБА КОЈЕ ЖИВЕ СА ХИВ/СИДОМ



## DISCRIMINATION AGAINST PEOPLE LIVING WITH HIV/AIDS

**D**iscrimination (Lat. *discriminare* – separate, differentiate) most widely denotes different treatment of certain individuals or groups based on one fact that makes them different from the majority. In that sense, being discriminated means being excluded. A victim of discrimination may be any person, an individual or member of a group that suffers discrimination, even members of her/his family or any close persons. Equality of all people, as one of principles of modern society, implies non-discrimination. Contemporary law inviolably protects the principle of non-discrimination, which prohibits creation and implementation of policies causing obstacles or damage to individuals or groups because of their racial, national and religious affiliation, disability, social, marital or health status. Unfortunately, discrimination on various bases is present in all segments of society and daily life aspects: in policies and programmes of social and economic development, in health policy, culture and education. Consequences of discrimination can be basically divided into two kinds:

- **Social:** neglect of one group as an important human resource of every social community, which is against the Constitution, and economically unjustifiable and inhumane;
- **Individual:** violation of fundamental human rights, social segregation and isolation, violation of social and health security, which jeopardises an individual's health and life. On individual level, experience of discrimination permanently damage the sense of one's worth and dignity, increase suffering, diminish the sense of control over one's life and increase chances for development of mental health disturbances.

Simultaneously with the apparition of a new disease, AIDS, in 1981, the epidemic of strong discrimination also began. High levels of intolerance, prejudices, stigma and discrimination against PLHIV were registered. This discrimination epidemic evolved much more rapidly than the disease itself, thanks to initial ignorance of the disease etymology, irrational fear of the virus and labelling only specific social groups as prone to the disease. Due to intolerant media contents and as some authorities and part of experts let the new disease be talked of and taught about in an inadequate way, soon a specific atmosphere was created, which is unfortunately still present today, although slightly more benign. In such an atmosphere people facing the disease had no adequate response to stigma and discrimination they had been exposed to. Cruel reality of high patients' mortality, lack of medicaments at the time and badly conducted campaigns, brought to expansion and strengthening of stigmatisation and discrimination of people living with HIV/AIDS (PLHIV).

Family members of PLHIV, as well as other people close to them, mostly endure equal discrimination as PLHIV themselves: they are denied enrolment into schools, employment and medical care, they are excluded from social environment, publicly humiliated, etc. Causes of discrimination of PLHIV most often can be found in negative social climate within the community, determined by insufficient awareness, prejudices on HIV infection and AIDS, as well as fear of the unknown. Due to ignorance, people often perceive HIV and AIDS as a lethal disease with unknown ways of transmission and insecure means of protection, which results in enormous fear and feeling of being personally threatened. A natural response to such fear is isolation and exclusion of infected or ill people. Lack of education within expert public on HIV infection and ways of transmission are the most common causes of discrimination within systems of health care and social welfare, and education as well.

People living with HIV/AIDS are prone to self-stigmatisation, which reflects in avoidance of social contacts, leaving their partners, early retirement, etc. Research conducted in both non-developed and developed countries have shown that progress in HIV infection treatment and prolongation of the infected people's lives up to normal life expectancy are not always directly proportionate to decrease of stigmatisation, including self-stigmatisation. On the other hand, discoveries of successful ARV (antiretroviral) therapy, which is expensive and life-long, and for many people worldwide, especially inhabitants of the "third world" also inaccessible due to poverty, lead into new types of discrimination. Where this modern therapy is accessible, there is often an attitude present, that people living with HIV/AIDS have no right to spend resources from health insurance funds, which is an additional source for discrimination.

In spite of the fact that there are no cases of discrimination against people living with HIV/AIDS processed in Serbia, all research conducted on national level, reports of civil society organisations working directly with PLHIV and archived discrimination cases clearly show a high degree of stigma and discrimination of PLHIV. There can be no word of general and widely accepted discrimination, but often there are individual cases, more pronounced in the south of Serbia, and a little less in Vojvodina. This can be explained by regional differences in attitudes and population mentality, the degree of tolerance towards differences from generally accepted views, which are very difficult to change. Ignoring problem, significant unawareness of the public and lack of education about HIV infection, with prejudices and stigmatisation against PLHIV, not only offend human dignity of people living with HIV/AIDS and their families, but also create environment of high risk for HIV transmission. Therefore, fight against discrimination of PLHIV is not only a fight to preserve their human rights and improve the quality of their lives, but simultaneously it represents a fight for HIV/AIDS prevention. These goals make the fight against discrimination of PLHIV complex, and this task requires a systematic approach in facing problems and their solution.

## **1. Forms and levels of discrimination of people living with HIV/AIDS**

Immediate or direct discrimination is a typical form of discrimination. It is immediately or directly visible, as authors of discriminatory actions do not hide their action, but they often defend them in public. Mediate or indirect discrimination is different, as it is hidden – authors of discrimination do not want their discriminatory actions to be visible, and they hide behind seemingly equal treatment, although their actions are motivated by discriminatory intentions. Mediate discrimination is, for example, often in surgical wards. Surgical intervention is not officially denied, but is refused or delayed because of various reasons (waiting lists, priorities, inadequate conditions), while real reasons are connected to HIV status and belonging to a so-called "high-risk group". Cases of multiple discrimination, i.e. discrimination based on multiple reasons (e.g. woman – Roma – HIV infected), are common in our practice.

Analyses point at multitude, diversity, unpredictability and unexpectedness of forms and social levels where discrimination is manifested. These are direct and indirect violations or refusals of rights in daily life, labour, education, health care and social welfare; furthermore, there is humiliation, labelling and privacy violation, rejection, social segregation and social isolation, up to direct psychological and physical harassment and violence. Generally, PLHIV can experience discrimination on three levels:



**On individual level** – direct and immediate discrimination by closest family members, friends, colleagues. Such discrimination most often implies partial or total rejection and physical avoidance, social and/or emotional isolation of PLHIV by family members and friends. Conflicts arise and even rejection and total break of all social links among a person living with HIV/AIDS and her/his closest ones occur due to fear of infection and unclear consequences of a family member becoming ill, often joined with fear from condemnation by social environment and social isolation, as well as due to ignorance and unawareness in confrontation with the new situation. Discrimination on individual level implies neglect and refusal of basic needs for love and belonging as consequences, which represents the most serious risk for mental health and psychological wellbeing. The biggest burden of HIV infection is linked to discrimination and stigmatisation. Fear of discrimination, condemnation of the environment and rejection causes PLHIV to feel insecurity and immense fear. It is not rare in such cases that people run away into self-isolation and bring themselves into risk from mental and general health disturbance.

**On community level** – in all daily situations (in the street, in a park, in a post office, in public institutions, in shops, cinema, restaurants, schools, at work, etc). Widely spoken, from avoidance of direct or indirect contact, through direct or indirect verbal harassment and violation of personal integrity and dignity, to refusal of the right to using service in public facilities and on public ground, conditioning in realisation of various rights in front of authorities, refusal of right to education and various forms of social segregation in educational institutions, refusal of right to work, equal working conditions and further training at work, as well as violation of number of rights connected to labour.

Social pressures of schoolchildren parents and teachers caused by fear from infection, as well as unfavourable general social climate based on number of prejudices, ignorance and not knowing the problem, have as consequence social segregation and isolation of children and youth living with HIV/AIDS. The situation is similar on labour market, i.e. in business environment. The difference is that employers feel free to find various excuses for refusing PLHIV their right to work and other labour rights. Hidden forms of discrimination are most present in these situations and they are the most difficult to prove.

**On institutional level** – different forms of discrimination, neglect and refusal of needs and rights of PLHIV in systems of health care, social welfare and education. PLHIV often do not have necessary documentation which would enable them entrance into the health care system, they do not have financial possibilities to pay for these services, they have negative prior experience in health care institutions, but they also lack a right relationship to their own health, which is a segment implying their own responsibility. Even if they realise an equal approach into a health institution, they often meet an unequal treatment. Doctors are often insufficiently informed of different forms of risky behaviour and advice to avoid it, or of possibilities of prevention and treatment. Cases of refusing to provide health care to PLHIV have been known, by sending them from one to another institution, as well as refusing contact with these patients without special medical reasons. Families of these persons are also exposed to numerous unpleasant situations, as companions of the diseased. Every open or hidden form of discrimination in health care is potentially more dangerous than others, because of the position in power, which is implied by the social role doctor have. PLHIV users of health services are exposed to significant stress in contact with health institutions. Testimonials of insecurity and uncertainty in relation to reactions, communication quality and acceptance by doctors indicate this stressfulness. Article 27 of the Law on the Prohibition of Discrimination prohibits discrimination of a person or a group of persons based on their health condition, as well as discrimination of their families, and especially refusal to provide health services, setting special, medically unjustifiable conditions to provide health services, refusal to produce a diagnosis and withholding information on current health condition, measures undertaken or intended

to be undertaken in treatment or rehabilitation, as well as harassment, insulting and scorn during a person's stay in a health institution.

Doctors and nurses often do not refuse to accept a patient openly, but they invent excuses linked to instruments or being busy, they hand over PLHIV to colleagues in order to avoid examining them, or otherwise they treat them more roughly than other patients. One of the most common forms of discrimination is violation of the patient's rights to medical data confidentiality, which is often not respected in Serbia, although it is guaranteed by law. There are many examples of data confidentiality violations, including marking medical records of patients living with HIV/AIDS. Experience and revelations show that discrimination within the health care system represents a greater source of worry for many people living with HIV/AIDS than an insecure medical prognosis of the disease itself. People living with HIV/AIDS are confronting problems in approaches to health care in primary health care institutions, in dentistry, surgery and gynaecology. The situation is the same in the social welfare system and experience has shown that hidden, indirect forms of discrimination of PLHIV are still widely present, in the sense of service provision evasion, labelling and violation of the right to data confidentiality, conditioning acceptance into social welfare institutions by testing, etc.

In spite of a number of laws and provisions that PLHIV could refer to in cases of discrimination, these people most often decide against this step. Their complaints mostly remain archived in organisations that work with them, as processing a case requires filing a complaint in full name and surname. Thus the circle of discrimination is closed, and no one is punished or reprimanded. Fear of deterioration of the situation connected to use of certain services in case of reporting discrimination is an additional reason for PLHIV to tacitly tolerate visible discrimination. Ignorance of their own fundamental human rights and unawareness of a part of PLHIV of what represents various forms of discrimination has also been noted, and therefore discrimination is often not even recognised.

Often times, children living with HIV/AIDS are not allowed to go to school regularly, and their parents are advised to find private tutors. There is an example of a boy living with HIV/AIDS who had numerous problems to attend regular classes in school. When his HIV status was revealed to other children's parents, they complained and he was not allowed to attend classes with their children, which was against the law. After numerous sensationalist titles in the media, the Ministry of Education came up with a solution which suggested individual classes for the boy, with a teacher who "agreed" to work with him. The boy's parents were satisfied that a solution was found, although the solution itself was discriminatory.

## **2. Reach of former attempts to solve and alleviate the problem**

Discoveries and revelations from 1980s connected to the virus and the disease itself, as well as the growing number of people infected, brought the possibility for PLHIV to get associated and send clear messages to the population, governments and world organisations concerning their position and relation towards them, which marked the beginning of fight against discrimination on various fields. In numerous international documents and national strategies regarding the position of PLHIV, actions to decrease stigma and discrimination are listed as one of fundamental goals. Development of anti-discriminatory policies and legislation, as well as inclusive programmes within the communities both on institutional and individual levels stand as premises that every country must have in its strategy for fight against HIV/AIDS. Although certain improvement of PLHIV position has been marked in Serbia in the last couple of years, the situation is far from ideal. Preconditions for further improvement of PLHIV position have been created by passing the Law on Prohibition of Discrimination and establishing the institution of Commissioner for protection of equality.



## 2.1 Changes in regulations

Regulations prohibiting different treatment of individuals according to their personal characteristics are scattered around the whole Serbian legal system – from constitutional texts, over specific laws referring to discrimination, to general laws containing specific anti-discriminatory regulations (laws in the fields of labour, employment, family and hereditary relations, informing the public, criminal-legal regulations etc). Of course, all these regulations include those from international documents related to human rights, as well as those made during their implementation, e.g. regulations contained in decisions of the European Court for Human Rights applying the European Convention on Human Rights. There is a unique legal regime prohibiting discrimination in Serbia today, which can wholly respond to all relevant legal issues regarding any individual discrimination case.

The Constitution prohibits discrimination (both direct and indirect, based on any reason, and especially based on race, gender, birth, language, culture, social origin, nationality, etc), therefore it prohibits discrimination against PLHIV as well. In Criminal Law of the Republic of Serbia, equality of its citizens is protected in a similar way (Article 128). In laws and legal acts prohibiting discrimination on any basis, prohibition of discrimination against PLHIV is nowhere explicitly mentioned, and its closest definition is given in the Law on Prohibition of Discrimination from 2009, in Article 27 where it is stated that discrimination towards a person or group of persons based on health condition is strictly prohibited. There is a number of other laws and books of regulations, e.g. Law on Prevention of Discrimination against People with Disability from 2006. It is a fact that none of these acts have been fully implemented in Serbia so far, as such cases are non-existent in judicial practice. Therefore we can speak only of a possibility to use existing articles of already passed laws as there is a lack of regulations concretely relating to HIV/AIDS as specific issues.

Discriminated persons can seek protection by filing a complaint. Apart from final protection, a complaint might also seek temporary protection, secured by a temporary measure even before the proceedings are ended, even before the complaint is filed. Apart from the protection which would prevent the realisation of impending discrimination (preventive protection), which is required by a complaint for failure to act, there also exists protection from already realised discrimination (reactive protection), based on a complaint for elimination, complaint for identification and complaint for reimbursement of damage. Apart from these forms, representing types of elementary protection, there also exist forms of additional protection, which amend elementary protection – pronouncing judiciary penalty and publishing the sentence.

The Law on Prohibition of Discrimination has also foreseen penalties for misdemeanour for persons whose actions are discriminatory. The point in punishing in the field of fight against discrimination is to socially reprimand the perpetrator for performed discriminatory action which was qualified as misdemeanour, i.e. to influence her/him and all other persons not to perform misdemeanours of this kind in the future. A request to start proceedings is filed in written form to the Court for minor offences, exceptionally orally, with minutes to be taken. A person against who the proceedings are being started should be stated, as well as the time and place of the offence made, and evidence to prove these statements. The request should be clear in order to be processed. For specific cases of discrimination the court in proceedings for misdemeanour pronounces fines for legal entity, responsible person and individual.

Experience in Serbia has shown that a tendency of direct discrimination of PLHIV by health workers to decreases. Reasons for this positive trend are in the fact that open discrimination in institutional framework can be identified and sanctioned most easily as laws defined protection of human rights more precisely. Unfortunately, indirect i.e. mediate and hidden forms of discrimination,

neglect of needs and refusal of service to people living with HIV/AIDS is impossible to eradicate by changing regulations. An important legal source in this field is represented by domestic judicial practice and decisions made by other state organs.

## **2.2 Changes in judicial practice**

In spite of the fact that prohibition of discrimination, the right to privacy and the right to work are not absolute rights, because of which exceptions from them are possible, the practice of the European Court for Human Rights (ECHR) in Strasbourg is that every action without an objective or reasonable justification concerning the goal and consequences of the action is considered to be discriminatory, i.e. if there is no proportion between the means and the goal. By adoption of the Additional Protocol no.12 from 2000, with the existing European Convention on Human Rights, discrimination was absolutely prohibited in Europe.

On 13 March 2007, ECHR brought the sentence against the Republic of Serbia, which binds it to pay the reimbursement of EUR 15,000 due to intangible damages to the injured party together with court expenses of EUR 4,350. This sentence refers to the duration and unfair procedure for divorce and custody over a child from the marriage, which prevented the mother to see her child for eight years because she was infected with HIV. This represented a violation of the European Convention for the Protection of Human Rights and Fundamental Freedoms, which was ratified by the Republic of Serbia in 2004, concretely a violation of Articles 6 and 13 (the right to fair trial and effective legal remedy). This sentence proved that one of the biggest problems of PLHIV is huge stigma and discrimination in the society, among individuals and in state institutions. The significance of such a decision from the European Court for Human Rights is not only the solution of this individual case, since it influences improvement in the practice of courts and social welfare centres, in deciding on custody of a child regarding a HIV positive status, which has often been taken as a basis for unequal treatment so far. Furthermore, this sentence can inspire others with similar problems and influence the decrease of stigma towards people living with HIV/AIDS.

## **2.3 Institutional changes**

The Law on prohibition of discrimination established the Commissioner for Protection of Equality, an independent organ which takes care of the implementation of the law and fight against all forms of discrimination. A person who thinks she/he had suffered discrimination can file a complaint to the Commissioner. The complaint is filed in written form, exceptionally orally with minutes to be taken. Apart from the person who suffered discrimination, in her/his name and her/his agreement a complaint may be filed by an organisation dealing with human rights protection or another person. The Commissioner delivers the complaint to the person against whom it was filed within 15 days from the date of filing. The Commissioner acts upon the complaint unless proceedings in court have already been started or ended concerning the very same matter. Before undertaking any other actions, the Commissioner initiates reconciliation, according to mediation regulations, if the participants agree. The Commissioner issues an opinion if provisions of the Law on Prohibition of Discrimination have been violated and informs the person against whom the complaint was filed of this opinion. The Commissioner can also act as prosecutor in court proceedings, with written agreement of the person who suffered discriminatory actions, and in that role can start a complaint against any person who performed discriminatory actions.



## 2.4 Specific projects

Significant positive changes have been achieved, due to activism of people living with HIV/AIDS, who began their own empowerment in order to prevent discrimination and position themselves within individual projects, and unselfish support of many other actors. Good practice examples are projects of the Global Fund, as well as of Philanthropy, with the support of the Delegation of the European Union in the Republic of Serbia. Thanks to number of Philanthropy's projects, within which flyers with listed human rights of PLHIV were distributed in clinics for treatment of people living with HIV/AIDS, a huge step was made to educate this population of their own rights and enable them to recognise cases of discrimination. However, because of fear, ignorance and unawareness, there is no real registry of types and number of cases of PLHIV discrimination in Serbia.

## 3. Fight against discrimination – conclusions and recommendations

As discrimination is carried out on various social levels, the fight against it should also be performed on more levels, as follows:

### 3.1 On community level (carriers are society actors, the state, political authorities, expert public, wide public, civil society organisations, media, family...)

3.1.1 Legal protection, i.e. protection by law is the fundamental component of the social response to various forms of human rights violations and discrimination on various bases. As legal protection of PLHIV is not regulated by specific legal documents, but is an integral part of different legal acts which regulate different aspects of daily life, distribution and intensity of various forms of discrimination prove that existing normative regulations lack more sensitivity to special needs of PLHIV in practicing their fundamental human rights.

In that context the state should act on improving normative regulations to sensitise legal measures for recognising and sanctioning direct, and especially indirect forms of discrimination of PLHIV in realisation of their rights and meeting their needs, as well as on creation of special mechanisms for implementation and control of laws. Affirmative action measures (positive discrimination) are definitely efficient means to improve social position of marginalised groups. Therefore, employment of people with known HIV positive status should bring certain benefits, including those for employers. A kind of code of behaviour in employing PLHIV should be adopted, with lobbying associations of employers. Drafts of such code have already been created by some civil society organisations.

Existing legal solutions should be improved, in the context of changing existing definitions of diseases, which instigate fear (e.g. the formulation "lethal contagious disease" should be changed into "chronic contagious disease with which one can live"). Definition of HIV as an easily transmissible virus should also be changed, as it is definitely not such a virus, and classify it in the group of viruses more difficult to transmit. Thus various rights and benefits currently refused for PLHIV could be achieved.

The necessity to bring a national strategy in fight against discrimination should be emphasised and PLHIV representatives must be involved in its creation.

3.1.2      3Legislation should be followed by fight in community to change public attitudes and behaviour. A more wholesome approach is needed in systematic programme to combat discrimination; one which would go above legal protection, in order to influence changes is the whole social climate. In that context, the fight against discrimination on community level should encompass the following:

- Activities to increase public awareness on the phenomenon of discrimination on different foundations and the necessity to protect human rights, with promotion of acceptance and tolerance for differences. The responsibility for this task lies on all community segments, from state and political authorities, churches and religious communities, over public educational institutions, culture, economy, private sector, civil society organisations, families and individuals. The ultimate goal is to change the values of society, where tolerance and social acceptance of differences would be deeply rooted, which is a process that requires time.
- Activities aimed to increase knowledge of the wide public about HIV infection itself, ways of transmission, disease prognosis, and treatment, risky types of behaviour, prevention and PLHIV needs. The responsibility for this task lies on the expert public, professionals, policy creators and participants in education and upbringing of children and the young, civil society sector, family and media. The importance of organising and realising systematic education of children and youth about HIV infection in ways acceptable and understandable for them should be particularly emphasised, with interactive methods of learning. It is necessary to support realisation of creative peer education in order to disseminate knowledge of HIV/AIDS and people living with HIV/AIDS.
- Activities to increase community awareness on the necessity to fight against discrimination of PLHIV and fight for HIV/AIDS prevention, through organisation and realisation of media campaigns. Within this task it is indispensable to invest joint efforts of social actors into education of media themselves, including:
  - o Education about the need to change HIV presentation in the media, as the majority of media still fail to present a wider frame of the epidemic, but prefer the "it's happening to someone else" approach, focusing their attention on risky behaviour of specific groups. The "HIV could happen to anyone" approach can raise awareness and convince people that it is risky behaviour that should be talked about, not risky groups.
- Presentation of true stories people living with HIV/AIDS experience, in order to personalise and humanise educational campaigns
  - Education of media representatives on good models and programmes for de-stigmatisation, as well as of their role in the fight against stigma and discrimination.
  - Mobilization and strengthening of civil society capacities in the fight against discrimination of PLHIV. Civil society in Serbia is the carrier of the largest number of activities in fighting discrimination of people living with HIV/AIDS, activities in HIV prevention as well as activities of support to PLHIV. Their fight is ongoing on all levels, from the community to an individual. The state and Serbian society should recognise the importance of civil society in this fight and help and support to PLHIV so far and provide support in realisation of successful activities.
- Inclusion of people living with HIV/AIDS into education and programme implementation in fighting against discrimination of PLHIV. All social actors should include people living with HIV/AIDS more intensively within various activities. Their experience is the most signifi-



cant source of knowledge of challenges and problems they face, their needs, and positive examples of confronting the infection and/or the disease that can inspire people living with HIV/AIDS to “fight for life” and their surroundings to accept them and respond to their needs.

### **3.2 On the institutional level (carriers are relevant state and political authorities and public health care and social welfare institutions)**

The fight against discrimination of PLHIV on the institutional level in the widest sense should encompass the organisation and realisation of:

- 3.1.3 Activities aimed at increasing social awareness of professionals working in health care on hidden forms of discrimination of people living with HIV/AIDS, legal measures, as well as consequences and difficulties PLHIV are facing because of direct and indirect discrimination;
- 3.1.4. Activities of continuous education of professionals within the health care and social welfare system about HIV infection itself and ways of its transmission, as well as the needs of people living with HIV/AIDS, in order to create a more tolerant and humane approach in service provision process. It is necessary to emphasise articles in the legislation which prohibit differentiating individuals based on their characteristics during service provision;
- 3.1.5. Activities to secure continuous further expert training of professionals specifically dealing with people living with HIV/AIDS. The discovery that a person suffers from HIV is often not followed by adequate, wholesome and efficient information given by the doctor or other expert workers about the newest achievements in treatment. Therefore, it is necessary to increase the number and availability of experts specialised for HIV/AIDS, who would be able to provide genuine information on the infection, clinical course of the disease, prognoses, therapy, services and networks that can provide support and help;
- 3.1.6. Activities to educate staff engaged in mental health, counsellors in the voluntary counselling and testing process, and general practitioners about the PLHIV needs, in order to decrease inner stigma and its consequences;
- 3.1.7. Activities to secure consistent and total respect for the privacy of medical and other personal data, and to inform professionals on the importance of data privacy protection and effects of confidentiality violation;
- 3.1.8. Activities to secure consistent and full respect (by informing, education, intern books of regulations and legal acts) of the equal rights and obligations principle in all institutions.

Apart from educational measures, the necessity to establish hospices and safe houses for PLHIV who become homeless upon revelation of their status should be pointed out at the institutional level, and efforts should be made for the state to recognise hospices as a permanent solution of the problem which people in need of such a type of accommodation are facing.

### **3.2 On the individual level (carriers are expert services, specialised counselling points, informal groups, family)**

On the individual level, fight against discrimination in the first place encompasses securing support and help for people living with HIV/AIDS in the process of facing inner stigmatisation, i.e. in the process of coping with numerous fears that follow the positive status and most often lead into social isolation and withdrawal from usual business and social-cultural life. The fight against discrimination on the individual level should encompass the following:

- 3.2.1 Strengthening of self-support groups of people living with HIV/AIDS,
- 3.2.2 Capacity building of people living with HIV/AIDS and their family members confronting inner stigmatisation, building of skills to overcome and decrease it, as well as skills of social reintegration;
- 3.2.3 Increase of information availability to PLHIV about their fundamental human rights and ways to protect them. In the first place they should be informed that in case of recognising certain form of discrimination, they have real protection only if they decide to start a process, but they also receive help to bring this process to an end with maximal protection of private data.











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