

## 12. The role of public organizations and non-governmental organizations (NGOs) in addressing and supporting people with HIV

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### *Introduction*

The Joint International Social Work Agreement defines social work as follows: 'Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledges, social work engages people and structures to address life challenges and enhance wellbeing' (International Federation of Social Workers [IFSW] 2024).

Non-governmental organisation (NGOs) and other civil society institutions play an important role in a democratic state by increasing the socio-political and socio-economic potential of the country.

Uzbekistan has long struggled with the need for an effective social protection system and qualified social workers to help those in need. Despite efforts to restructure ministries and address these gaps, the country still lacks a cohesive professional social work system. Recent plans led by President Shavkat Mirziyoyev aim to address these shortcomings by establishing the National Social Protection Agency. This agency, which will operate independently, is tasked with overhauling social services, creating a robust support network for various vulnerable groups, and implementing advanced international standards in social protection. The agency's objectives include training programmes for social workers, improving support for people with disabilities, expanding social insurance coverage and promoting social partnership initiatives with civil society organisations. By setting clear timelines and targets, Uzbekistan aims to reform its social protection landscape and create a more inclusive and supportive environment for its citizens.

## *Government Measures to Combat the Spread of HIV in Uzbekistan*

By a resolution dated 20<sup>th</sup> January 2023, President of Uzbekistan Shavkat Mirziyoyev approved the Program of Comprehensive Measures to Increase the Efficiency of Combating the Spread of HIV Infection among the population for 2023–2027 (LexUZ 2023a).

The document was adopted in accordance with the political declaration ‘95–95–95’, approved by UN member states in the summer of 2021 (The Joint United Nations Programme on HIV/AIDS [UNAIDS] 2021a). It calls on all states to ensure that 95% of the people living with HIV (PLHV) know their HIV status, 95% of the people who know their status receive HIV treatment, and 95% of the people on HIV treatment achieve suppressed viral load (meaning that the level of viral load in the blood is reduced to undetectable). The government is planning to allocate 120 billion soums and 54 million US dollars for the implementation of this strategy throughout 2023–2027 at the state budget’s expense, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), borrowed funds from the Asian Development Bank and the Asian Infrastructure Investment Bank (The President Republic of Uzbekistan 2023).

The Government of Uzbekistan is committed to strengthening support for essential HIV services and interventions. This commitment is demonstrated by increased government leadership and the fact that the government has increased the share of funding allocated for the HIV response. For example, the government is increasing its share in financing the purchase of antiretroviral therapy (ART) drugs to 75%. This increased commitment to the HIV response is essential to developing a new strategy that will bring services closer to people and ensures increased funding for the HIV response (World Health Organization [WHO] 2023).

The coordinating body for all activities to combat the spread of HIV infection is the Republican Commission for Coordination of Activities to Combat the Spread of HIV Infection in the Republic of Uzbekistan. At least once a quarter, the Republican Commission holds meetings that include the heads of key ministries and departments, local governments, and civil society. In order to raise the system of measures to counter the spread of HIV infection to a modern and high-quality level, the Resolution of the President of the Republic of Uzbekistan No. PP-3800 dated 22<sup>nd</sup> June 2018 ‘On additional measures to counter the spread of the disease caused by the human immunodeficiency virus and the prevention of nosocomial infections’ (LexUZ 2018) was adopted. ‘On measures to further strengthen the

system for countering the disease caused by the human immunodeficiency virus' was adopted, which approved the Programme of Comprehensive Measures to Increase the Efficiency of Countermeasures against the spread of HIV infection among the population for 2023–2027 (LexUZ 2023a).

In order to further enhance the role of NGOs as active participants and partners in the reforms carried out in Uzbekistan, strengthen the protection of their rights and legitimate interests, expand the scale of state support, and create favourable conditions for them, the Resolution of the President of the Republic of Uzbekistan No. PP-5012 was approved in March 2021, entitled 'On additional measures for state support of non-governmental organizations, ensuring freedom of their activities, protection of rights and legitimate interests' (SoyuzPravoInform 2021).

This resolution of the President also defines the conditions for social partnership and state social order. This is also intended to improve the legislation in terms of introducing administrative liability for interference by government bodies and their officials in the legitimate activities of NGOs.

The resolution defines measures for the financial support of NGOs, including the provision of premises for hosting NGOs without charging rent and the introduction of social partnership and state social order. It also provides for the improvement of legislation in terms of introducing administrative responsibility for the intervention of government bodies and their officials in the legitimate activities of NGOs.

A state social order is a state assignment to carry out work or activities for the implementation of socially and publicly significant projects by concluding an agreement between a state body and an NGO or other civil society institution (Institution in the form of a non-governmental non-profit organization "Madad" 2019). The provision of state social orders is carried out through the Public Fund under the Oliy Majlis (Parliament), Public Funds for the support of NGOs and other civil society institutions under the Jokargy Kenes of the Republic of Karakalpakstan, the Kengashes of people's deputies of the regions and the city of Tashkent, as well as government bodies.

Within the framework of the social partnership provided for by this Law, state bodies shall determine the priority areas of their activities. If state bodies need the participation of NGOs and other civil society institutions to carry out their activities, they shall submit applications for the implementation of the state social order for the next fiscal year to the Public Fund under the Oliy Majlis or to the Public Support Fund for NGOs and other civil society institutions under the Jokargy Kenes of the Republic of

Karakalpakstan, the Kengashes of People's Deputies of the regions and the City of Tashkent. The application of the government body that submits the order indicates the priority areas of activity of this government body. This body also indicates the goals, objectives and conditions of the order to carry out work or carry out activities (ibid).

A parliamentary or public commission, having considered the documents submitted by the Public Support Fund under the Oliy Majlis, public foundations, NGOs and other institutions, associations under the Jokarg Kenes of the Republic of Karakalpakstan, and the Kengashes of People's Deputies of the regions of the Republic and the city of Tashkent, makes a decision on incentives in the prescribed manner; The procedure for the provision of social orders by the state and their volumes are published in the media, the list of officials and the types of state activities for which these funds are allocated, including specialized associations (including on the fight against HIV/AIDS), create equal legal rights for them and the opportunity to participate in the defence (Article 58 of the Constitution of the Republic of Uzbekistan) (ibid). These provisions are specified in the laws of the Republic of Uzbekistan 'On public associations', 'On NGOs', 'On public funds', 'On guarantees for the activities of NGOs', 'On the openness of the activities of public authorities and management', 'On social partnership', 'On environmental control', 'On public control', etc. Dissolution, prohibition, or restriction of the activities of public associations can only take place on the basis of court decisions (Article 62 of the Constitution of the Republic of Uzbekistan) (ibid). NGOs and other civil society institutions develop projects of state social orders and submit them for consideration to the Parliamentary Commissions and public commissions.

When providing a state social order, an agreement is concluded between the state body that sent the application for the provision of a state social order and an NGO or other civil society institutions. State bodies can co-finance projects of state social orders supported by the Parliamentary Commission and public commissions at the expense of extra-budgetary funds. In this case, the amount of co-financing should not exceed 20% of the total amount of financing (ibid).

In addition, the state protects the rights and legitimate interests of public associations (including those related to the fight against HIV/AIDS). For example, on 3<sup>rd</sup> March 2021, the President of Uzbekistan issued a Decree 'On additional measures of state support for NGOs in ensuring the freedom of their activities, protection of rights and legitimate interests' (O'zbekiston Milliy Axborot Agentligi [UzA] 2021), which introduced a

number of changes aimed at improving the legal environment of NGOs. For example, the order increased the total amount of foreign funding that NGOs can receive annually; the period for re-registration of an NGO, as well as state registration of its symbols, has been reduced from one month to 15 days; ordered the development of a bill introducing administrative liability for interference by government bodies and other officials in the legitimate activities of NGOs (the draft was developed in 2021, but has not yet been adopted) and other important initiatives that would enhance the activities of NGOs (International Center for Not-For-Profit Law [ICNL] n.d.). The dissolution, prohibition or restriction of the activity of public associations shall take place only on the basis of a court decision (Article 70 of the Constitution of the Republic of Uzbekistan, LexUZ 2023b).

The state creates equal legal opportunities for women and men to participate in public and state life (Article 58 of the Constitution of the Republic of Uzbekistan, LexUZ 2023b). Discrimination is the establishment of any direct or indirect restrictions belonging to public associations, as well as other circumstances not related to the business qualities of employees and the results of their work (NORMA Information and legal portal 2022).

### *Prevention Services for Key Populations and Other Groups*

Prevention services are provided through 137 Trust Rooms located in medical institutions, where services are provided mainly for persons who inject drugs (PWID); through one republican and a number of regional NGOs that provide services to sex workers, their clients and men who have sex with men (MSM); through 15 Friendly Rooms that conduct anonymous interviews with representatives of all key population groups and offer syndromic treatment of sexually transmitted infections (STIs) and a number of other services (testing, distribution of condoms, referral to other specialists, counselling on HIV and STIs); and through anonymous offices located in AIDS centres and other medical institutions. Trust rooms and friendly rooms are integrated into the healthcare system and are maintained at the healthcare budget's expense. Prevention work is funded by the Global Fund under its Behaviour Change and Prevention Services component for key populations. The Global Fund grant supports the salaries of 140 assistants and 300 outreach workers at 137 drop-in points. The Global Fund also supports the provision of services, including the distribution of needles, syringes, alcohol swabs, male condoms, printed tuberculosis (TB) screen-

ing questionnaires and rapid testing of oral fluid samples for HIV (WHO 2023).

Following the completion of the pilot project in 2006–2009, the opioid substitution therapy (OST) programme was not continued, despite promising results. During the discussions, it was assessed by the drug treatment service and was discontinued due to unfavourable results. Various stakeholders within the country viewed the programme positively, but the prospect of its implementation was considered highly unlikely. Arguments in favour of its termination included drug treatment specialists misunderstanding the goals of the programme, a lack of political support, including from key stakeholders, major changes in the drug addiction situation, and a reduction in the number of opioid injecting drug users (IDUs) (*ibid*). By May 2009, the working group decided that it was inappropriate to carry out OST in the country. A month later, the Ministry of Health circulated a letter to international organizations informing them of the working group's decision and the official completion of the project. On 25<sup>th</sup> June 2009, patients stopped taking replacement medications, having previously reduced their daily doses for a month. During the consultation meeting “Drug Control Policy and Public health”, organized by the United Nations Office on Drugs and Crime (UNODC) on 18<sup>th</sup> August 2009 in Tashkent, the participants of this event asked representatives of the Ministry of Health to share the report of the working group, which made recommendations on the cessation of substitution therapy in Tashkent in order to familiarize themselves with the assessment methodology and on the conclusions that were made. This would have allowed them to compare the approaches used with those adopted in international practice standards. Unfortunately, the request was denied “due to the report being in the nature of a document for official use” (Latypov et al. 2010). In connection with the closure of the program, the Eurasian Harm Reduction Network conducted an international campaign to advocate for OST in Uzbekistan. An open letter was sent to the President and Minister of Health of Uzbekistan signed by 77 OST specialists and activists from Eastern Europe and Central Asia, the USA, Canada, France, Great Britain and other countries. But the program has not been resumed (Fedorova/Chingin 2014).

The coverage of prevention activities for two key population groups – PWID and women engaged in sex work (also known as female sex workers [FSW]) – has been assessed as relatively high (more than 50%). This seems significant, given the complexities of the environment and the way in which related services are provided. There is a trend towards expanding

the coverage of prevention activities for key populations. However, coverage among MSM remains low (less than 11%), which may be due to the high degree of stigmatisation of this group, even by medical personnel (ibid).

Progress has been made in reaching MSM, but it is still insufficient to have a significant impact on the spread of HIV. However, coverage of PWID has increased significantly from 58.5% in 2018 to 77% in 2020–2021. It should be noted that anecdotal evidence suggests that coverage of women who inject drugs remains below 50%.

The NGO 'Intilish' project has been working with PWID for a long time and has successfully integrated this work into medical institutions. However, the majority of clients are regular participants in the programme; only 1.9% seeks help just once a year. Research shows that current coverage of PWID mainly depends on old programme clients, including former prisoners who were previously registered with drug treatment services.

The state programme to combat the spread of HIV infection in the Republic of Uzbekistan introduced the following approaches to expand the coverage of key population groups with preventive measures: HIV testing (through mobile testing units, including rapid testing), support for Friendly Rooms for syndromic treatment of STIs in representatives of key population groups, development of a comprehensive information and educational programme, and the creation of a special fund for the development of information and communication components of HIV prevention. NGOs were brought in to monitor these activities. Prevention services were provided to traditionally key population groups: FSW, MSM, and PWID. In addition, migrant workers are considered to be an important target group. The primary goal of the prevention programme among vulnerable populations is to ensure access to services aimed at reducing the risk of HIV transmission, as well as ensuring access to HIV testing and linkage to follow-up ART and other health services (WHO 2023).

All measures to combat HIV infection are carried out on the basis of the Law of the Republic of Uzbekistan No. ZRU-353 of 23<sup>rd</sup> September 2013 'On countering the spread of the disease caused by the human immunodeficiency virus (HIV infection)' (LexUZ 2013a). The most significant measures are outlined below.

*Law of the Republic of Uzbekistan No. ZRU-353 of 23rd September 2013, 'On countering the spread of the disease caused by the human immunodeficiency virus (HIV infection)'*

The purpose of this Law is to regulate relations in the field of combating a common disease caused by the human immunodeficiency virus (HIV infection). Below are excerpts from this law.

Article 5 of this law states that public administration in the field of combating the spread of HIV infection is carried out by: the Cabinet of Ministers of the Republic of Uzbekistan; Ministry of Health of the Republic of Uzbekistan; Ministry of Internal Affairs of the Republic of Uzbekistan; local authorities. Actions to counter the spread of HIV infection can be carried out by other institutions in accordance with the law.

### Medical Examination for HIV

Medical examination for HIV (Chapter 3 'Measures to counter the spread of HIV infection. Providing medical care to HIV-infected people', LexUZ 2013a) is a study and assessment of the health status of the person being examined, which establishes the presence or absence of HIV. Medical examination for HIV can be carried out in all treatment and prevention institutions in accordance with the norms and rules established by the Ministry of Health of the Republic of Uzbekistan, on a voluntary or compulsory basis. During a medical examination for HIV, the person being examined receives both a preliminary and a follow-up consultation. Medical examination for HIV of minors and persons recognised as incompetent or partially capable is carried out with the consent of their legal representatives. At the request of the person being examined, the results of examinations conducted by laboratories of the state healthcare system to determine the presence or absence of HIV are issued at the treatment and prevention institution that conducted the preliminary consultation. For minors and persons recognised as incompetent or partially capable, the results are issued to their legal representatives. If HIV is detected in the person being examined, a follow-up consultation is carried out and the person is registered at a dispensary. This person is warned in writing about criminal liability for infecting other persons with HIV infection (Article 113 'Spread of sexually transmitted diseases or HIV/AIDS' of the Criminal Code of the Republic of Uzbekistan, LexUZ n.d.). That is, when HIV is detected, the person being



examined signs a document stating criminal liability for infecting another person with HIV.

### Mandatory Medical Examination for HIV

The following are subject to mandatory medical examination for HIV: donors of blood and biological fluids (Article 15 ‘On countering the spread of the disease caused by the human immunodeficiency virus [HIV infection]’, LexUZ 2013a); persons marrying under the age of fifty (author’s note: fertile age) (ibid); pregnant women; persons suspected of using drugs by injection; children born by HIV-positive mothers; medical workers who come into contact with human blood, biological fluids, organs and tissues in their activities; and persons whose sexual partner has been diagnosed with HIV.

### Providing Medical Care to PLWH

The provision of medical care to PLWH is carried out after they are registered at the dispensary in AIDS centres and in treatment and preventive institutions in their place of residence. Providing medical care to PLWH includes specific treatment of HIV infection, as well as prevention of the development, diagnosis, and treatment of diseases associated with HIV infection. Free specific treatment for PLWH is prescribed based on the conclusion of a medical commission, depending on the stage of the disease, in AIDS centres and in departments for HIV-infected medical institutions. Providing medical care to HIV-infected people to prevent the development, diagnosis, and treatment of diseases associated with HIV infection is carried out by AIDS centres, together with other treatment and preventive institutions (Article 17 ‘On countering the spread of the disease caused by the human immunodeficiency virus [HIV infection]’, LexUZ 2013a).

### Social Protection of Medical Workers at Risk of Contracting HIV Infection While Performing Their Official Duties

The spreading of HIV infection among medical workers while performing their official duties is classified as an occupational disease. Medical work-

ers providing specialised medical care for the diagnosis and treatment of PLWH, as well as ensuring the implementation of preventive and anti-epidemic measures, receive benefits provided for by law (Article 18 ‘Social protection of medical workers at risk of contracting HIV infection during the performance of their official duties’ of the Law of the Republic of Uzbekistan ‘On countering the spread of the disease caused by the human immunodeficiency virus [HIV infection]’, LexUZ 2013a).

## Rights and Responsibilities of PLWH

PLWH have the right to: receive the results of medical examinations for HIV and recommendations for preventing the spread of HIV; obtain information about their rights, the nature of the diseases they have, and the methods of medical care used; be treated humanely; and receive psychological support and assistance (Article 19 ‘Rights and obligations of HIV-infected people’ of the Law of the Republic of Uzbekistan ‘On countering the spread of the disease caused by the human immunodeficiency virus [HIV infection]’, LexUZ 2013a).

## Obligations of PLWH

PLWH are obliged to: carry out measures recommended by medical workers to prevent the spread of HIV infection; take precautions when in contact with healthy persons; and inform their sexual partner about their illness, as well as medical workers and service workers who use piercing and cutting devices in procedures that violate the integrity of the skin and mucous membranes. PLWH may have other rights and bear other responsibilities in accordance with the law (*ibid*).

## Social Protection of PLWH

PLWH are provided with free, specific treatment. PLWH under eighteen years of age have the right to receive a monthly social benefit, regardless of the stage of the disease, and benefits for children with disabilities are established by law (Article 4 ‘Main directions of state policy in the field of combating the spread of HIV infection’ and Article 20 ‘Social protection

of HIV-infected people' of the Law of the Republic of Uzbekistan 'On countering the spread of the disease caused by the human immunodeficiency virus [HIV infection]', LexUZ 2013a) or a life-threatening and chronically developing rare (orphan) disease, and persons over 18 years of age with disabilities from childhood' of the Cabinet of Ministers of the Republic of Uzbekistan Decision (LexUZ 2011). Parents of HIV-infected children or persons in loco parentis have the right to stay together with their children in a treatment and prevention institution in a stationary setting, with temporary release from work and payment of temporary disability benefits in the manner prescribed by law (Article 20 'Social protection of HIV-infected people' of the Law of the Republic of Uzbekistan 'On countering the spread of the disease caused by the human immunodeficiency virus [HIV infection]', LexUZ 2013a). Legislation might also establish other measures of social protection for HIV-infected people and members of their families in the future. *ibid*). Legislation might also establish other measures of social protection for PLWH and members of their families in the future.

### Financing Activities to Combat the Spread of HIV Infection

The financing of activities to combat the spread of HIV infection is carried out from the State Budget of the Republic of Uzbekistan, as well as from other sources not prohibited by law.

### Compensation for Harm Caused to the Health of a Person Infected with HIV

Compensation for harm caused to the health of a person living with HIV as a result of failure to perform or the improper performance of their professional duties by medical workers and service workers is rewarded in the manner prescribed by law. Compensation for harm does not relieve the perpetrators from liability in accordance with the law (Article 23 'Rights and obligations of HIV-infected people', LexUZ 2013a).

'On countering the spread of the disease caused by the human immunodeficiency virus (HIV infection)' of the Law of Uzbekistan, Article 12 Participation of self-government bodies of citizens and NGOs in the field of combating the spread of HIV infection.

“Self-government bodies of citizens and NGOs can participate:

in carrying out activities to counter the spread of HIV infection, in the implementation and protection of the rights, freedoms and legitimate interests of PLWH;

in providing legal, methodological, informational and other assistance to PLWH or their legal representatives within the limits of their powers;

in organizing and conducting awareness-raising work among the population on issues of HIV prevention based on local customs and traditions.

Citizens’ self-government bodies and NGOs can participate in other activities to combat the spread of HIV infection” (LexUZ 2013a).

### *The Law of the Republic of Uzbekistan on Social Partnership*

This law was adopted by the Legislative Chamber on 18<sup>th</sup> June 2014 and approved by the Senate on 28<sup>th</sup> August 2014. The purpose of this law is to regulate relations in the field of social partnership. Social partnership is the interaction of government bodies with NGOs and other civil society institutions in the development and implementation of programmes for the socio-economic development of the country, including sectoral and territorial programmes, as well as regulations and other decisions affecting the rights and legitimate interests of citizens (LexUZ 2014).

### *State Support for Social Partnership*

The Parliamentary Commission or Public Commissions, having studied the documents submitted respectively by the Public Fund under the Oliy Majlis, public funds for the support of NGOs and other civil society institutions under the Jokargy Kenes of the Republic of Karakalpakstan, the Kengashes of people’s deputies of the regions and the city of Tashkent, decide on the advisability of providing state social orders and theirscopes, publish in the media a list of government customers and areas of activity to which these funds are planned to be allocated to public organisations and NGOs (including on issues of combating HIV/AIDS), and create equal legal opportunities for public organisations and NGOs to participate in public life (Article 58 of the Constitution of the Republic of Uzbekistan, LexUZ 2023b). These provisions are specified in the laws of the Republic of Uzbekistan ‘On public associations’, ‘On NGOs’, ‘On public funds’, ‘On

guarantees for the activities of NGOs', 'On the openness of the activities of public authorities and management', 'On social partnership', 'On environmental control', 'On public control', etc. The dissolution, prohibition, or restriction of the activities of public associations can only take place on the basis of a court decision (Article 62 of the Constitution of the Republic of Uzbekistan, LexUZ 2023b).

### *A Critical Look at the Situation of NGOs*

In May 2018, a decree of President Shavkat Mirziyoyev was adopted, 'On measures to radically increase the role of civil society institutions in the process of democratic renewal of the country' (LexUZ 2018b). The decree highlighted excessive bureaucratic hurdles and barriers in registering NGOs, citing outdated legislation that doesn't align with contemporary standards as a significant issue.

The development of public organizations and NGOs is hampered by various bureaucratic obstacles, a complex registration process, low legal literacy and lack of legal support, combined with illegal 'expertise' rules.

There is a reluctance to weaken control over the non-governmental sector, control over the financing and distribution of funds of NGOs, the creation of additional commissions that decide how to distribute funds from public organizations, and the adoption of important decisions behind closed doors create obstacles to the development of a free society and public organizations.

Despite the laws on NGOs, which state that the introduction of new proposals and innovations in public administration can be achieved through joint decisions, this remains the prerogative of the government. Citizens, NGOs and other factors are not sufficiently involved in this process.

This presidential decree adopted in May 2018 emphasised the inadequacy of state funds to sufficiently support expansive projects by civil society institutions. Consequently, the decree aimed to create specific public funds, funded locally, to increase assistance for NGOs and other civil society bodies from 2019 onwards. Although these public funds have been established and formally recognised in all regions of the country, their effective operation faces substantial limitations. The funds haven't been allocated, and the staff required to run these funds haven't been recruited. For instance, the Fergana regional branch of the Association of Disabled People of Uzbekistan has faced challenges securing grants and subsidies

from the regional public fund meant to aid NGOs due to the fund's lack of financial resources and personnel. Similar difficulties persist across various other regions nationwide.

As per the legislation encompassing 'On NGOs' and 'On public associations', NGOs are legally entitled to obtain grants and financial support from foreign donors. However, due to constrained financial resources allocated by the state, various restrictions persist concerning the utilisation of foreign funding for NGO activities. A recent press release from the Uzbekistan Ministry of Justice highlighted that the utilisation of funds and assets acquired by NGOs from foreign states and international and foreign organisations is permitted without hindrance, provided these receipts of funds and assets are reported to the registration authority prior to their reception (LexUZ 2013b).

For NGOs, the process of obtaining grants still involves navigating bureaucratic procedures, reminiscent of what was previously referred to as the 'grant commission'. Even though this commission was not officially documented, it functioned in practice. Previously, NGOs had to open a dedicated account exclusively in branches of the National Bank for Foreign Economic Affairs of the Republic of Uzbekistan or the state-owned, joint-stock commercial bank Asaka. However, according to the Ministry of Justice, there has been a shift: now, 'grant funds are deposited into specially designated accounts of NGOs in any banking institution' (ICNL n.d.b).

Resolution of the Cabinet of Ministers No. 858 of 9<sup>th</sup> October 2019 on the procedure for NGOs to receive funds and property from international donors received by NGOs, and No. 328 of 13<sup>th</sup> June 2022 on the procedure for the interaction of NGOs with government agencies when implementing international grant projects, became invalid on 5<sup>th</sup> October 2023. The initiative group of NGOs made a collective appeal to cancel Resolution No. 328 of 13<sup>th</sup> June 2022 due to the fact that it contradicts national legislation and international standards ensuring the freedom of activity of NGOs. After a meeting of the initiative group with the leadership of the Ministry of Justice, a mutual decision was made to finalize this resolution, taking into account the proposals of representatives of civil society. However, an analysis of comments from representatives of NGOs on the portal for discussing draft regulatory legal acts shows that the draft resolution requires improvement. Experts from the International Center for Non-Commercial Law (ICNL) came to a similar conclusion, which identified a number of conceptual problems that raise reasonable concerns about Uzbekistan's compliance with international standards and national

legislation. We hope that the Ministry of Justice will take into account these constructive proposals and recommendations when further editing the draft resolution of the Cabinet of Ministers (Yusupov 2023).

On 4<sup>th</sup> October, the Government of Uzbekistan adopted a resolution (No. 527) regarding the social partnership of NGOs with government agencies as part of the implementation of projects financed by international grants (LexUZ 2023c).

To this resolution, Appendix No. 527 dated 4<sup>th</sup> October 2023 was approved: Regulations on the procedure for coordinating the receipt of funds and property by non-state commercial organizations from external sources and the procedure for implementing projects in the territory of the Republic of Uzbekistan financed from external sources (LexUZ 2023c).

The new procedure to some extent simplifies the procedure for receiving funds and property from external sources and cooperation between NGOs and government agencies when implementing international grant projects.

The ICNL welcomed the adoption of the resolution, noting that it was the result of a successful advocacy campaign by Uzbek NGOs and “the first success of its kind in the last 25 years in the history of Uzbekistan”. The expert organization noted that the government and the Ministry of Justice held active consultations with NGOs. The draft resolution was published for public discussion, and the Ministry of Justice organized several meetings with representatives of NGOs. Based on these consultations, a number of important recommendations from civil society were reflected in the resolution (Yusupov 2023).

### *Stigmatization*

HIV-related discrimination – and stigma when it leads to rights violations – is a human rights issue. People have the right to protection from the church and to a life of dignity where stigmatizing attitudes do not reach others’ enjoyment of their rights, including the right to education, health care, employment, access to justice, privacy, family, bodily autonomy and other rights (UNAIDS 2021b).

47 countries still have travel restrictions for PLWH (ibid). According to official information, in 25 of the 36 countries, more than 50% of people aged 15 to 49 years share discriminatory attitudes towards PLWH (UNAIDS 2020). 40% of PLWH report being forced to undergo certain medical procedures. HIV treatment depended on taking birth control pills funds (ibid).

Representatives of key populations face high levels of stigma, discrimination and violence (ibid).

More and more people in the world believe that the unstable emotional state of a person is caused by both social insecurity and the turbulent situation in the world and in the country. People who seek psychological and social services experience fear and anxiety for a variety of reasons. HIV infection is seen by society as a discreditable, inappropriate, dangerous characteristic of an infected person, i.e. it becomes a shameful stigma. People perceive PLWH as a threat to their personal safety, treat them with hostility and seek to protect themselves in a variety of ways, including outright discrimination and even isolation.

Psychosocial work is needed in segments of the population exposed to stress and depression. Public NGOs support vulnerable segments of the population. Orphans and disadvantaged segments of the population, the disabled, and those suffering from infectious or other diseases that worsen the quality of life are closely monitored by society and public organisations.

Vulnerable segments of society include those PLWH and those who engage in risky behaviour, such as sex workers who use injecting drugs, as well as MSM.

The Article 113 of the Criminal Code penalises the intentional transmission of HIV/AIDS with up to eight years in prison (LexUZ n.d.). This article constitutes a serious barrier for HIV prevention if HIV/AIDS was to be criminalised in Uzbekistan. This law has been used to target and prosecute people living with HIV, even when there is no evidence of intentional transmission. Sexual work is subject to administrative sanctions, while clients have no penalty, and men having sex with men is still considered a criminal act in Uzbekistan according to Article 120 of the current criminal code (LexUZ n.d.): ‘satisfying the sexual needs of a man with a man without violence is punishable by restriction of freedom from one year to three years or imprisonment for up to three years’. These laws create a climate of stigma and discrimination, making it difficult for key populations to access the prevention and care services they need.

The Joint United Nations Program on HIV/AIDS (UNAIDS) considers gay men and other MSM, sex workers, transgender people, PWID and prisoners and other incarcerated people as the five main key population groups that are particularly vulnerable to HIV and frequently lack adequate access to services (UNAIDS 2023). At the same time, other groups, such as migrants and young people, are not part of key populations but still participate in HIV programmes and awareness-raising because of their



risk behavior. According to UNAIDS' latest estimation, in Uzbekistan there are 105 needles and syringes issued per person who injects drugs, HIV prevalence among sex workers is 3.2%, and HIV prevalence among MSM is 3.7% (UNAIDS 2022).

Sexual relations between men remain illegal in Uzbekistan, despite past promises by authorities to repeal the discriminatory law. This follows on from the draft of the new Criminal Code of the Republic, published by the Prosecutor General's Office for public discussion. In Uzbekistan, voluntary sex between men is currently punishable by a prison term of one to three years in accordance with Article 120 Criminal Code (LexUZ n.d.). In the new edition of this law, the punishment for men who have sex with men only changed in terms of the article number: the wording of the new Article 154 is identical to that of its predecessor, Article 120. The position of this article within the document has also changed: where in the old article, sodomy, or 'besoqolbozlik' (Eurasian Coalition on Health, Rights, Gender and Sexual Diversity [ECOM] 2021), referred to crimes against sexual freedom, in the draft of the new document it refers to crimes 'against family, youth and morality' (ibid). Over five years (2016–2020), 44 people were prosecuted on charges of sodomy in Uzbekistan, as reported by Qalampir (2021). The persecution of MSM makes it more difficult to provide care to PLHV.

The scope of the package of services for PWID is limited and includes the distribution of 25 disposable syringes per month, 1–2 alcohol wipes for each syringe, condoms, information and educational materials, HIV testing, and a questionnaire to identify TB symptoms. In addition, legal assistance and referral to a specialist may be provided as part of the package of services. The service package does not include naloxone or other materials (UNAIDS 2022).

Condoms are provided to all target groups, to both women and men. There were no specific complaints about the quality of the condoms. Lubricants were not provided. The group of MSM and FSWs emphasised the need to provide lubricants and even suggested using them to increase the motivation of new clients to participate in the programme and get tested for HIV.

All new programme clients are clinically screened using a TB questionnaire and, if symptoms are detected, it is easy to obtain follow-up TB diagnostic services. Testing of oral fluid samples for HIV has been available since May 2022 and is considered a useful addition to the range of services provided.

## NGOs Working with PLHV in Uzbekistan

There are currently 11,303 registered NGOs in Uzbekistan (Ministry of Justice of the Republic of Uzbekistan n.d.). Out of those, the following NGOs work with vulnerable segments of the population such as HIV-infected people: 'ISHONCH VA HAYOT' (since 2003), 'ISTIQBOLLI AVLOD' (since 2001), the Republican Information and Educational Center 'INTILISH' (since 2001), and the Anti-Cancer Society of Uzbekistan.

Also, Uzbekistan has specific laws governing NGOs, including 'On NGOs' and 'On public associations'. These laws outline the legal framework within which NGOs operate.

Civil Society Development: efforts have been made to encourage the development of civil society in Uzbekistan. However, the effectiveness of these efforts may vary, and NGOs, especially those in all regions of Uzbekistan, may face unique challenges in terms of resources and support.

However, NGOs make a significant contribution to the prevention of HIV infection. Communities living with and affected by HIV, including key populations, support programme development and implementation, expansion of coverage, and improvement in the quality of health services. In all regions of the country, there is a system of approach and social partnership between the government and NGOs for the prevention of HIV infection. Through the joint efforts of regional AIDS centres and NGOs in all 14 administrative regions of the Republic, preventive measures are carried out among sex workers and MSM and psychological and social support for PLHV.

*Republican NGO in the Form of a Public Association in Support of People Living with HIV/AIDS and Their Loved Ones 'Ishonch va Hayot' ('Faith and Life') (Ishonch Va Hayot n.d.)*

The organization carries out its activities in accordance with the Constitution of the Republic of Uzbekistan, the Law of the Republic of Uzbekistan 'On NGOs' and on the basis of laws on other public organizations. The organization is a self-governed created by individuals and (or) legal entities on a voluntary basis, not pursuing as its own the main goal of generating income (profit) and not distributing the received income (profit) among its participants (members). The organization was created and operates on

the basis of voluntariness, equality of its members, self-government, legality and transparency.

Mission of the organization is unifying and comprehensive support PLHV, specially affected populations (SPAs), and their loved ones, improving the quality and dignity of their lives, fighting against stigma and discrimination, and actively participating in overcoming the development and spread of the HIV/AIDS epidemic in the Republic of Uzbekistan. Over the past 20 years, since the registration of the NGO 'Ishonch va Hayot', the organisation has provided assistance and support to more than 35,000 PLHV and their loved ones in Uzbekistan, in the form of crisis counselling, social support, and support on issues related to living with HIV infection.

In collaboration with the AIDS centres, with direct participation and involvement in various projects and programmes in the context of HIV infection, the organisation helps and supports PLHV:

- when their HIV status is confirmed;
- when they are adapting to the diagnosis;
- when it comes to complying with ART regimen;
- by providing care and support at home during the terminal stages of HIV infection (the AIDS stage);
- by expanding the access of PLHV and Maternal and Child Health (MCH) to prevention, treatment, and care; by providing support through peer counselling;
- by finding healthcare specialists who can help;
- by offering referrals to specialised institutions;
- and by providing social support and support in all areas of life.

Together with the AIDS centers and within the framework of projects funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria, the NGO 'Ishonch va Hayo' organised the first multi-disciplinary teams (MDTs) in the Republic of Uzbekistan who provide medical and psychosocial support, preparation for ART, and treatment, care, and support for PLHV.

The Republican NGO 'Ishonch va Hayot' annually organizes and hosts events dedicated to International AIDS Day (1<sup>st</sup> December), World Tuberculosis Day (24<sup>th</sup> March), World AIDS Day of Remembrance (the third Sunday of May), International Day against Drug Abuse and Illicit Drugs drug trafficking (26<sup>th</sup> June).

*The Republican Social Information Center 'Istiqbolli Avlod' (established in 2001)*

The activities of the 'Istiqbolli Avlod' Information and Educational Center and a number of regional NGOs aim to reduce the risk of HIV infection particularly among vulnerable segments of the population by strengthening outreach work.

The aim is to strengthen activities to achieve the '95-95-95' goal and 'Stop-TB partnership' (2019) (hosted by United Nations Office for Project Services [UNOPS]) in the Republic of Uzbekistan, focusing especially on vulnerable population groups through financial support from the Office of the Global Fund to Fight AIDS, Tuberculosis and Malaria and the Republican Center for the Fight against AIDS.

Goals of the organization are strengthening and expanding outreach activities among vulnerable groups of the population to reduce the risk of HIV infection in Uzbekistan.

The Global Fund Sub-Project is designed to promote the following: innovative solutions; new services and tools for the prevention of HIV/AIDS and STIs among key populations through outreach work; and healthy lifestyles and changing risk behaviour by providing free counselling and testing for HIV/STIs and TB screening among beneficiaries in eleven regions of Uzbekistan (the regions of Tashkent, Andijan, Bukhara, Namangan, Navoi, Syrdarya, Fergana, Samarkand, Khorezm, Republic of Karakalpakstan, and Tashkent City).

**Beneficiaries: Key Vulnerable Population Groups (Sex Workers, MSM)**

- 16,920 representatives of a key vulnerable group (sex workers, MSM) received information through outreach workers on the prevention of HIV/AIDS and STIs, as well as on healthy lifestyles and changing risk behaviour
- 115 representatives of a key vulnerable groups (sex workers, MSM) were provided with testing, HIV diagnosis, and registration. Because test is necessary to receive ART
- 16,906 information materials were distributed to key vulnerable groups
- 79,834 mini sessions were conducted by outreach workers on four different topics: 'HIV/AIDS', 'STIs', 'About a healthy lifestyle', and 'Testing for HIV'

- 5,760 representatives of key vulnerable groups were accompanied for tuberculosis screening

*The Republican Information and Educational Center ‘INTILISH’  
(established in 2001) (Intilish n.d.)*

The organisation promotes the following: the implementation of government programmes; the implementation of programmes of NGOs and associations (both foreign and international) that focus on improving the cultural and educational level of the population and certain key groups, preventing drug addiction, and preventing the spread of HIV/AIDS and tuberculosis; the social adaptation of people who have stopped using drugs; and psychosocial support for PLHV in prisons, released PLHV, and other key groups.

The Republican Information and Educational Center ‘Intilish’ is an NGO operating in all 14 administrative territories of the Republic of Uzbekistan in the field of public health and social protection. NGO ‘Intilish’ provides support with the implementation of programmes on twelve topics. The NGO has an educational programme for executive leaders, Australian workers, and volunteers, which is conducted in the form of monthly webinars in two languages (Russian and Uzbek). It also leads the work within the harm reduction programme, preparing methodological materials on topics such as ART, Voluntary Counselling and Testing (VCT), outreach to key populations (mainly PWID), overdose prevention, safe injections, STIs, hepatitis, and tuberculosis.

The NGO ‘Intilish’ project has been working with PWID for a long time and has successfully integrated this work into medical institutions. However, the majority of clients are regular participants in the program; only 1.9% of clients seek help once during the year. Research shows that current coverage of PWID mainly depends on old program clients, including former prisoners who were previously registered with drug treatment services (WHO 2023).

Goals: The goals of the NGO ‘Intilish’ project are: improving the quality of life of the population and its vulnerable groups by maintaining health, increasing cultural and educational levels, and increasing social adaptation. Vulnerable groups include, but are not limited to, people at risk of or affected by infectious, endemic, psychiatric, drug addiction, and any other

diseases, people who find themselves in difficult life situations, and people who are in prison.

The tasks of the NGO are: the implementation and management of activities that help to effectively achieve the statutory goal of the Center, promoting the development and strengthening of cooperation with state and non-state, local, foreign, and international structures interested in achieving the statutory goal of the Center, and the development of the material and technical base, personnel, and administrative potential of the Center to increase the effectiveness of the implementation of the statutory goal of the Center.

The organisation's experience is represented by working with such groups as injection drug users, people (women, men, adolescents) serving sentences in prison and those released after serving their sentences, PLHV, youth (organised, un-organised, with a high behavioural risk), professionals (senior and paramedical personnel, law enforcement officers, representatives of partner public organisations), and decision makers. Moreover, the organisation prepares and evaluates the activities of trainers of educational programmes.

### *NGO 'Anti-Cancer Society of Uzbekistan'*

In 2013, MDTs began operating in the country, the work of which was initiated jointly by the NGO 'Anti-Cancer Society of Uzbekistan' (n.d.) and the AIDS centers. Multidisciplinary teams provide social-psychological support to PLHV when entering the clinical observation programme and when initiating antiretroviral therapy, and also provide assistance in resolving social and everyday issues. MDTs are the link between AIDS service organisations and healthcare institutions. This ensures continuity in the provision of the medical and social-psychological services provided by organisations of various levels and profiles.

### *Project grants and partners*

The Global Fund has one core grant currently operating in Uzbekistan: the HIV and TB Joint Grant, which aims to strengthening the country's HIV response, especially for key populations, improve TB treatment, and address the high drug burden-resistant tuberculosis in the country (The

Global Fund 2022). A joint HIV and TB grant of up to 44.1 million USD is being implemented in Uzbekistan throughout 2021–2024. Our investment supports the country's goal of delivering an impactful, efficient and sustainable HIV and TB response. For HIV, the grant is aligned with the national HIV strategy and mainly focuses on providing prevention services to key populations as well as quality antiretroviral therapy, care and support. For TB, the grant focuses on diagnostics and treatment of drug-resistant TB, counseling and psychosocial support for people with TB, treatment monitoring, health information systems and monitoring and evaluation, as well as strengthening Uzbekistan's laboratory systems (ibid). The national economy of Uzbekistan constitutes the major portion of funding for the HIV response, covering roughly 72% of the AIDS budget in 2018. A projected investment of 36.6 million USD was outlined for the period spanning 2019–2022, as stated in Presidential Decree PP-3800 (LexUZ 2018a). While these funds primarily support medical care, treatment, and program management initiatives (PP-3493, 2018), significant attention is devoted to holistic development efforts, notably directed towards enhancing hospital infrastructures and broadening laboratory networks.

UNAIDS is a programme of ten UN organisations created to facilitate a comprehensive, coordinated response to the global HIV/AIDS epidemic. A country office of the UNAIDS has opened in Uzbekistan. In addition, Uzbekistan adopted a programme of additional measures to combat the spread of HIV infection for 2018–2022 worth about 50 million USD (Sputnik Uzbekistan 2019).

The Russian government and UNAIDS donated a mobile clinic worth 300 thousand USD to Uzbekistan. This was reported by the Information Department of the Sanitary and Epidemiological Service.

The UN Resident Coordinator in Uzbekistan, Helena Fraser noted that the mobile diagnostic complex is designed for rapid response and preliminary examination of patients, especially in remote regions where access to care and treatment is difficult to find (Uznews.uz 2021).

The UNAIDS Secretariat supports activities for the implementation of the Program of Assistance to EECA Countries in the field of prevention, control and surveillance of HIV/AIDS and other infectious diseases (WHO 2019).

United Nations Office on Drugs and Crime (UNODC) provides support to the Government of Uzbekistan by promoting modern international approaches and standards in the field of HIV prevention and treatment, ensuring access for people who use drugs in terms of necessary medical care

based on comprehensive, evidence-based programmes, while respecting the human rights, reducing stigma and discrimination. UNODC helps to build the capacity of health and social service workers who work directly with PWID. Thus, in 2012, together with World Health Organisation (WHO) and UNAIDS, UNODC released an updated version of the technical guidance for countries to develop targets within the framework of the concept of ensuring universal access to HIV prevention, treatment, and care among IDUs (UNODC 2023), and in 2017 released practical guidance for joint efforts to implement comprehensive HIV and AIDS programmes for PWID (UNODC 2017), which can be considered as international standards on the problem (UNODC 2023).

In turn, from May to August 2018, the Monitoring and Evaluation (M&E) group of the Inter-agency Expert Council (IEC) with the support of UNODC, conducted annual monitoring of the provision of services to people with HIV infection in almost all regions of Uzbekistan. During the inspection, the M&E group visited trust rooms, regional AIDS centres, tuberculosis clinics, and NGOs providing support to PLHV and vulnerable population groups. The M&E group conducts monitoring to determine the effectiveness and quality of HIV prevention services, including harm reduction programmes (exchange of injection equipment), pre- and post-test consultation, and antiretroviral therapy (ibid).

The United Nations Children's Fund (UNICEF) is working to strengthen the capacity of Uzbekistan's health system to prevent mother-to-child transmission of HIV (PMTCT) and provide paediatric and psychosocial care to HIV-positive children.

The international non-governmental organisation Doctors without Borders, in close cooperation with the Ministry of Health, is working on the basis of the Tashkent City AIDS Center, through which it provides technical assistance in carrying out specific treatment for PLWH.

A new strategy is in the process of being developed and approved by the president of the country, which recognises the importance of ensuring access to prevention measures, treatment services, and support for PLWH.

A network of HIV/AIDS centres ensures that people across the country have access to the care and resources they need to treat the disease. With centres located in major cities and rural areas, people in every part of the country can access health services. When it comes to dispensing medications, coordination between AIDS centres and primary healthcare facilities is a valuable strategy for increasing access to healthcare. This network of centres does not experience staff shortages or problems retaining staff.



The provision of services in healthcare settings remains the norm in many settings, despite high levels of stigma and discrimination, including the criminalisation of these communities. Outreach efforts are needed to promote the need for services in communities to ensure access for the most vulnerable.

## *Conclusion*

A comprehensive examination of Uzbekistan's legal framework and social landscape of NGOs, social partnership and the fight against HIV/AIDS provides a multifaceted picture of both progress and challenges. The legal structures governing NGOs and social partnerships show a clear intention to promote cooperation between civil society and the government to address socio-economic issues, including HIV prevention. However, the practical implementation of HIV prevention programmes faces many barriers in Uzbekistan, as illustrated by bureaucratic obstacles to NGO registration and the complex process of obtaining grants, particularly from foreign donors.

The article presents a critical assessment of HIV prevention policies in Uzbekistan, based on the information provided by experts and HIV activists. The study highlights some key concerns. Issues such as bureaucratic hurdles, lack of funding and limitations in government support schemes hamper the effectiveness of NGOs and affect their ability to provide comprehensive services to vulnerable populations, including those affected by HIV/AIDS. Stigma remains a major barrier to HIV prevention, affecting marginalised groups such as MSM and sex workers and preventing them from accessing essential treatment and prevention services. The legal environment, including laws that criminalise certain behaviours, contributes to a climate of fear and discrimination that hampers efforts to respond effectively to HIV/AIDS.

Despite these challenges, NGOs remain key actors in HIV prevention efforts in Uzbekistan. They play a pivotal role in advocacy, programme development and support services to vulnerable groups. Their collaboration with government agencies demonstrates promising advances in inter-sectoral partnerships for HIV prevention and support. Overall, the article provides a nuanced understanding of the complex landscape surrounding NGOs, social partnerships and the fight against HIV/AIDS in Uzbekistan. It highlights the need for streamlined bureaucratic processes, increased

financial support, legal reforms to combat stigma, and an enabling environment for NGOs to operate effectively and drive impactful change in HIV prevention and care.

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## *12. The role of public organizations and non-governmental organizations (NGOs)*

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