Human Rights of Women Living with HIV in Ukraine
INTRODUCTION

The charitable organization “Positive Women” represents the national community of women living with HIV, bringing together participants from all regions of Ukraine who advocate for the observance of the rights of women in Ukraine, primarily those living with HIV and vulnerable to HIV. CO “Positive Women” promotes the empowerment of women as well as comprehensive support and development for them.

Positive Women implemented measures to monitor the observance of the rights of women living with HIV by conducting a survey of 502 women from ten regions in Ukraine, out of them: 86% are in reproductive age (18-45 years old); 49% live in big towns or cities, 15% live in villages; 39% learned about their HIV status during pregnancy; 47% have been living with HIV for fewer than five years; 13% had/have tuberculosis, 30% had/have hepatitis C; 37% have experience of drug use, 10% are sex workers; 14% have a disability; and 20% of respondents were in detention or in prison. The objectives of the study were as follows: to identify the main barriers to the observance of the human rights of women living with HIV, with a special focus on the right to health.

Data Sources and Methodology:

A survey of 502 women living with HIV, in the form of a semi-structured questionnaire, was carried out during July-November 2018 in ten Oblasts of Ukraine.

Documentation of the offenses against women living with HIV in ten Oblasts of Ukraine by regional representatives of the CO “Positive Women” and women at HIV-service NGOs. This occurred primarily during 2017-2018.

Official requests to the regional departments of health and the Ministry of Health of Ukraine.

Desk review of the relevant laws of Ukraine, pertaining to the rights of women living with HIV.

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Abbreviations:

ARV-prophylaxis - Antiretroviral Prophylaxis
ART - Antiretroviral Therapy
CO "Positive Women" - Charitable Organization "Positive Women"
SPSU - State Penitentiary Service of Ukraine
AsRT - Assisted reproductive technology
IVF - In vitro fertilization
OST - Opioid substitution therapy
PLHIV - People living with HIV
MoH - Ministry of Health
NGOs - Non-Governmental Organizations
CPH Ukraine - Center of Public Health of the Ministry of Health of Ukraine
Statistical Information

As of January 1st, 2018, the number of HIV-positive women under medical surveillance was 65,755, of which 42,093 or 64%, had received ART. As of 01.07.2018, 45,215 women had received ART. The total number of new HIV cases among women in the first half of 2018 was 3,549 (40.2% of the total number of new cases of HIV).

A disaggregation by the number of women patients who use drugs, sex workers, women who are coinfected with HIV and viral hepatitis C, HIV and tuberculosis is not provided in official statistics of CPH Ukraine. In Ukraine, in 2017, there were 1,165 new cases of HIV among pregnant women. This represents 44.7% of the total number of HIV-positive pregnant women (2,606 women) and 21.9% of new cases of HIV among women who are 15-49 years old (5,328 women).

In 2017, pregnancy ended with childbirth for 2,544 HIV-positive women in Ukraine\(^2\). During 2017, 95.7% HIV-positive pregnant women were covered by ARV prophylaxis/ART. In 2017, the proportion of HIV-positive pregnant women who continue to receive ART after childbirth increased to 88.2\(^3\).

As of January 1st, 2018, 296 women have received ART in SPSU institutions. As of July 1st, 2018 - 231 women. There is no official statistical disaggregation by sex of PLHIV who are currently in prisons.

As of July 1st, 2018, 10,635 people have received OST in Ukraine, among them 1,894 were women, which is 17.8% of the total. 4,347 OST participants have an HIV-positive status, of whom 3,644 patients receive ART (83.8%). There is no statistical disaggregation by sex among those who receive OST and are HIV positive.
HUMAN RIGHTS OF HIV-POSITIVE WOMEN IN THE HEALTH CARE SYSTEM

Social stereotypes that affect the overall picture of gender relations in Ukraine are not conducive for women to exercise their rights and correspondingly double the pressure on women living with HIV. This forces women to adopt life practices that impact their relations with family and with public facilities (hospitals, state-run institutions, and law enforcement agencies) and their willingness to protect their rights: they keep their contacts with such institutions to a minimum and try to avoid any actions that could lead to disclosure of their status.

From a legislative standpoint, Ukraine guarantees accessibility and quality of medical examination, monitoring, psychosocial, legal, and medical consultations, medical assistance and provision of medications, social and legal protection, and prevention of any forms of HIV related discrimination. In practice, the models of provision of medical, social, legal and other services fail to account for entrenched gender norms and stigmatization in the society and by service providers

According to a study conducted in ten regions throughout Ukraine, approximately every tenth respondent (9.1%)\(^4\) is convinced that in case of a violation of her rights as a woman living with HIV, she will not receive the necessary legal protection, and 23.8% of women do not know if they can count on legal support. 41% of respondents do not know their rights and do not know where to file their complaints against actions of health workers if their rights are violated in medical institutions.

Almost one in five women living with HIV (19%) do not believe that health care workers do not disclose their HIV status or any other details without their consent, and another 22% do not know if this is happening.

During 2018, 182 women living with HIV\(^5\) ask for help from the Ukrainian Helsinki Group for Human Rights receptions in the Dnipro, Kiev, Kropyvnytskyi, Lviv, Rivne, Sumy, Kharkiv, Kherson, Khmelnitsky and Chernigov, and of them, 181 reached out again.
Case One:

... Upon return [from the hospital] home, everybody knew about the status of a woman and her child. It turned out that the head of the village summoned the village nurse to see her, and in the presence of the secretary began to scold and accuse the health worker because a mother and her daughter were “dying” of AIDS right before her eyes, but she was not doing anything. The next day, the whole village knew the HIV status of the mother and daughter, including people at the daughter’s school. ... The consequences of this disclosure of HIV status became very apparent in the daughter’s life. Her classmates are afraid to talk to her. This child is experiencing psychological trauma in addition to her existing health problems. The mother is also on the verge of a psychological breakdown.

Kherson Oblast, July 2018

Case Two:

An HIV + woman gave birth at Sumy Oblast’s Maternity Hospital №2. A nurse, her friend who works in this hospital, called the doctor who facilitated the delivery and inquired about the health of her friend ... During this conversation, the doctor shared the HIV status of the woman. ... After further conversation, this woman quickly realized that her nurse friend was told about her HIV status. After some time, the circle of common acquaintances of this woman and her nurse friend — girlfriends, godfathers, neighbors, etc.— began to cease both direct and telephone communication with her. Almost all of their mutual friends stopped communication with her. Some of these mutual acquaintances who had come in contact with this woman showed pity and sympathy in their conversations with her.

Subsequently, this woman’s HIV status became known to family friends and workmates of her husband. Now, this woman has a severe distrust for doctors. She avoids communicating with them and only reaches out in extreme or critical cases. She is pregnant a second time and expects to give birth in the same hospital. These painful memories from the hospital have left her upset and brought her to tears many times.

Sumy Oblast, May 2017

Case Three:

An HIV positive woman, with a history of active tuberculosis, came to see a TB doctor after experiencing side effects. She was experiencing issues with her musculoskeletal system, so she came to the appointment with her mother. At the appointment, the TB doctor informed the mother of her daughter’s HIV status, that until this point, the daughter had chosen to keep from her mother. After becoming aware, the mother of the woman caused a scandal and, after returning home, spoke about the daughter’s status to her neighbors, relatives and friends. To avoid further stigmatization, the woman moved to a new home. She has become depressed, lacks support and any kind of communication with relatives and friends, including her mother.

Rivne, April 2018
Case Four:

After returning home from the hospital, an HIV positive woman and her one-year-old child who also has a positive HIV status, faced complaints and accusations from her brother. He berated her that she was infected, and that together with her son she had disgraced her family in front of her neighbors, which could even lead to additional infections. When she asked her brother how he knew about her status, he responded that a doctor at a local hospital had given him this information. Following these insults and accusations, the woman was suffered a psychological breakdown. She and her three younger children had to move to a new place of residence. As a result of all of these events, this woman is forced to rent housing, no longer feeling safe to go home.

Kherson Oblast, August 2018

The aforementioned actions of health care workers violated the right of women living with HIV to preserve the confidentiality of their diagnosis and for respect for the privacy and the protection of their personal data, which are declared in regulatory and legal acts:

- The Constitution of Ukraine, Article 32 (the right to respect for personal and family life);
- The Civil Code of Ukraine, Article 286 (the right to secrecy about the state of health);
- Law of Ukraine “Fundamentals of the Legislation of Ukraine on Health Care”, Article 391 (the right to secrecy about the state of health);
- Law of Ukraine “On Combating the Spread of Diseases Caused by the Human Immunodeficiency Virus (HIV) and the Legal and Social Protection of People Living with HIV”, Article 13 (protection of information about HIV positive status from disclosure and disclosure to third parties);

According to the Criminal Code of Ukraine, Article 132, for disclosure by healthcare worker of information about conducting a medical examination to detect HIV or other incurable infectious disease and its results, there must be criminal liability (from a fine of up to 1,700 hryvna, to restriction of liberty for up to three years with the deprivation of the right to hold occupation).

Case Five:

As this woman’s health began to deteriorate, she was sent to an OBGYN for a gynecological examination and for making a diagnosis at the gynecological department of the KLPU “City Oncology Center of Kramatorsk”. Before the examination, the doctor asked about her HIV status. After she informed the doctor that she has HIV, the doctor raised his voice and shouted at and insulted this woman. The doctor justified this behavior by the fact that he needed to utilize special protective equipment to inspect the “aids infested” ones, that he risks that blood from her vagina splashing into his eyes, and how good he has glasses. At the same time that this took place, in the office there was also a nurse and another employee working. The doctor’s elevated voice could be heard outside the door, where there were a number of patients waiting to be seen. The doctor conducted a superficial examination, and despite the fact that the woman had previously consulted with a gynecologist, sent her to the gynecological department (and threw the social worker a medical card with instructions to treat the underlying disease (HIV infection). Treatment with a gynecologic oncologist is not prescribed, and the diagnosis, due to the refusal of the doctor, was not established. As a result, this woman became very depressed, feels generally bad, and her health is deteriorating.

Kramatorsk, August 2018
**Case Six**: Tatiana has repeatedly appealed to medical institutions in both the city of Dnipro and within the Dnipropetrovsk Oblast to receive an endoprosthetic (replacement) of the knee joint. State municipal institutions in the Dnipropetrovsk Oblast do not provide this service. It is only provided through private clinics. A clinician of modern orthopedics: Academician A. E. Loskutova "MedinUA", based in Dnipro, refused to provide this service on the basis of an internal position posted on their official website - Contraindications to endoprosthesis: "Chronic and severe diseases (heart or kidney failure, infections, mental disorders, endocrine system diseases, hip defects, etc.)."

Thought it was a difficult path, this woman eventually received medical care in Kiev.

Dnipro, July 2018

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**Case Seven**: Woman asked for medical help from the gynecologist designated to her place of residence. This gynecologist refused to provide medical services after she learned about this potential patient’s HIV status, referring to the fact that “such people” are better suited to specialized institutions. This woman received the appropriate gynecological care at the regional AIDS center, which is located 30 km from her home.

Cherkasy Oblast, June 2018

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Denial of health services because of HIV status violates the right to health care, which includes, among other things, qualified health care, including free choice of a doctor, choice of treatment according to their recommendations and health care facilities to provide such treatments. Moreover, such situations may indicate discrimination on the basis of HIV, which is expressly prohibited by current legislation:

- The Constitution of Ukraine, article 24 (equality of citizens);
- The International Covenant on Economic, Social and Cultural Rights, article 12 (the right to the highest attainable standard of health) and article 2 (prohibition of discrimination);
- Law of Ukraine “Fundamentals of Health Care Legislation”, article 6 (right to health protection);
- Law “On Combating the Spread of Diseases Caused by the Human Immunodeficiency Virus (HIV) and Legal and Social Protection of People Living with HIV”, article 14 (equality before the law and prohibition of discrimination against people living with HIV)
REPRODUCTIVE HEALTH AND THE RIGHT TO MOTHERHOOD OF HIV-POSITIVE WOMEN

Despite universal access to ARV treatment and prevention of vertical transmission of HIV, around a quarter of women with HIV from the selected ten regions have a fear of infecting their unborn child. Just 17% of women do not see obstacles when making decisions about giving birth to children. Examples of said obstacles:

"I could die early and the child would be left alone."

"There were many very bad attitudes toward me during my pregnancy and child delivery in 2007. I was afraid this bad attitude from medical staff would affect my children."

"I learned about HIV during pregnancy, and until I can stop worrying about the risk, I will not consider another pregnancy."

"I need IVF to become pregnant. It is an expensive treatment and remains inaccessible to HIV-positive women because of their HIV status."

"My desire to have children was great, but the obstacle was that IVF is very expensive and I was not able to afford it."

"Denial of IVF treatments!! In all clinics."

"I am afraid to tell my husband that I’m positive and will have a child."

"I have a lack of information about how to safely give birth to a healthy child."

Access to Assisted Reproductive Technologies

In Ukraine, PLHIV do not have access to reproductive technologies. Despite the fact that: (1) the Law of Ukraine “On Combating the Spread of Diseases Caused by the Human Immunodeficiency Virus (HIV) and the Legal and Social Protection of People Living With HIV” defines that, "People living with HIV have the right to participate in assisted reproductive technologies, provided that the transmission of HIV from parents to the future child is prevented"; (2) the national social HIV program for 2014-2018 has to provide access of PLHIV to assisted reproductive technologies in preventing the transmission of HIV from parent to child, and, starting from 2014, at least three state assisted reproductive technology centers should be able to provide such services; none of the existing centers provide such services, as there are regulatory obstacles from orders by the MoH.

The issue of ensuring the realization of the reproductive function should be a fundamental human right. HIV is not an obstacle to pregnancy and childbirth, while provided the proper health of the couple (adherence to ART), which protects the child from HIV. The issue of access to safe fertilization and the birth of a biological child is also extremely relevant for couples affected by the HIV epidemic. After all, according to experts, about 0.8% of the adult population of Ukraine is affected by HIV. About 70% of them are citizens of reproductive age, and the majority new cases of HIV fall within in the age group of 25 to 49. Women and men with HIV should have the same sexual and reproductive rights as those who are not infected with HIV. For example, the right to decide about the birth of children, number of children, and the time interval between birth as well as other considerations. The sexual and reproductive health of people living with HIV is an important component of their personal well-being, as well as that of their partners and children.

Private clinics are practicing excessive payment for services because of HIV status.
**Case Eight**:  

A woman living with HIV, after 10 years of unsuccessful attempts to get pregnant and carry a child, together with her husband (an HIV-negative partner) decided to use IVF services through a private medical clinic. Doctors were notified by the patient that she is on a dispensary surveillance through the city’s AIDS center. The private clinic, abusing the barriers in the legislation on this service for PLHIV, undertook the procedure and conduct of IVF for a substantially increased payment. The total amount of the procedure cost around 100,000 UAH.

Kyiv, 2017

The CPH Ukraine, together with “Positive Women”, developed a draft of the order of the MOH - an initiative aimed at removing barriers to the use of AsRT for HIV-infected women. The draft order of the MOH proposes to amend the following orders of the MoH: 29.11.2004 № 579 “On Approval of the Procedure for Referring Women for the First Course of Treatment of Infertility by AsRT Methods for Absolute Indications for Budgetary Funds” (hereinafter - order № 579) and 09.09.2013 № 787 “On Approval of the Procedure for the Use of ART in Ukraine” (hereinafter – order № 787).

The essence of the changes is to bring into line the orders to the AIDS Law of Ukraine and coordinate with the Unified Clinical Protocol of primary, secondary (specialized), and tertiary (highly specialized) medical care “Prevention of Mother-to-Child Transmission of HIV”. This order was supported by the Program Committee of the National TB and HIV Council, the Center for Harmonization of Human Rights Research Institute of IP, the National Academy of Legal Sciences of Ukraine, the Committee of Medical and Pharmaceutical Law and Bioethics, the National Bar Association of Ukraine, as well as specialists of the medical company “AA Partners”, and charitable organization “Hope and Trust”.

The AIDS Law of Ukraine establishes that people living with HIV have the right to participate in AsRT, provided that the transmission of HIV from parents to the future child is prevented (Article 10 of the aforementioned law). To implement the Law, the order of the MoH approved a Unified Clinical Protocol, which in paragraphs 2.2.1, 2.2.3, 3.1.11, defines the procedure for the management of pregnancy that occurred concurrently with ART in an HIV-infected woman or a woman whose partner is HIV-positive. The Protocol describes approaches for the prevention of mother-to-child HIV transmission during pregnancy, regardless of whether it has resulted from the use of IVF or naturally.

Thus, by order of the MoH, the guarantee, defined in Article 10 of the AIDS Law, for preventing the HIV transmission from an HIV-infected woman, whose pregnancy resulted from AsRT, is already partially implemented. At the same time, other orders of the MoH are not consistent with either the law or the Unified Clinical Protocol, namely order No. 579 and order No. 787. Thus, order No. 579 states that HIV-infection or AIDS is a contraindication for female infertility treatment. Order No. 787 determined the list of mandatory and additional examinations before making a decision on the use of AsRT, and it was determined that in the case of detection of diseases, if there are indications for AsRT, the identified pathology is treated accordingly.
In response to a request from non-governmental organizations, the director of the Health Department of the Poltava Regional State Administration referred specifically to the order No. 579:

“... With regards to women living with HIV, we hereby inform that according to the list of medical contraindications for the treatment of female infertility using AsRT methods (diseases in which pregnancy is contraindicated) based on the relevant order from the MoH, HIV infection or AIDS are contraindications to treatment funded by state budget using these methods.”

At the same time, the chairman of the commission on reorganization (the head physician) of the Rivne Regional Clinical Treatment and Diagnostic Center - named after V. Polishchuk - reported the following:

“... in the absence of contraindications for conducting AsRT programs, and being subject to the appropriate procedure, doctors’ recommendations are that women with HIV-positive status can benefit from in vitro fertilization ...”

I live with HIV. I explored in detail the AIDS Law of Ukraine. According to Article 10, people living with HIV have the right to use of assisted reproductive technologies, if they take a measures to prevent the transmission of HIV from parents to a future child.

That is why I am upholding the right of HIV-positive women to in vitro fertilization procedure, and demanding amendment in obsolete and discriminatory orders of the Ministry of Health that violate the reproductive rights of women with HIV.

Olena Stryzhak, Cherkasy

Photo of Rights flashmob #МоїПраваВажливі (My Rights are Important), CO "Positive Women", campaign "No excuses for violence". Olena Stryzhak, Chair of the Board CO "Positive Women".
Access to Sexual and Reproductive Health Services

73.3\% of respondents were consulted on safe conception (which makes it impossible to infect a partner). At the same time, 31.4\% of women tested for HIV during pregnancy did not consider it voluntary. 66.4\% received the necessary consultation before and after HIV testing (28.4\% did not receive it). Only 15.6\% of women have (40.2\% do not know whether or not they have, 44.2\% do not) access to free or affordable abortion and just 11.1\% have access to quality medical care after such procedures and assistance with regard to miscarriage.

62.5\% of women who gave birth in 2016-2018 independently determined exactly where they wanted to give birth, but every fifth woman (21.5\%) was not able to make such a choice.

**COUNSELLING OF HIV-POSITIVE WOMEN**

- 73.3\% have been given/can get advice about safe conception (getting pregnant without putting partner at risk of transmission of HIV)
- 31.4\% don’t consider they were voluntarily tested for HIV during pregnancy
- 66.4\% given necessary counselling before and after HIV test

**ABORTION**

- 15.6\% have access to free or affordable abortion
- 11.1\% have access to quality post-abortion and miscarriage care
The UN Committee on the Elimination of Discrimination against Women considered the eighth periodic report of Ukraine at its 1472th and 1473rd meetings, on 14 February 2017. In the concluding observations to the eighth periodic report of Ukraine, the Committee noted its concerns about the increase in the number of cases of breast cancer, which is the main cause of death in women of working age, and the lack of diagnostic services, prevention and mammography. Women with HIV are at higher risk of cervical cancer and the development of invasive cancer than are HIV-negative women. Invasive cervical cancer is an AIDS-indicative condition. Therefore, screening done for HIV-positive women is vitally important. It can prevent up to 80% of cervical cancers.

Only half of HIV-positive women from the selected ten regions of Ukraine reported the availability of cervical cytology; and only a third of respondents reported the service of a mammologist. At the same time, “Positive Women” requested the number of cases among HIV-positive women in 2017 and the first half of 2018, where cervical cancer screening was conducted, free abortions were provided, and contraceptives and the use of assisted reproductive technologies, including IVF, PHC responded that the provision of such statistical information is outside the competence of the Center.

62% of women living with HIV indicated that they receive the services of a gynecologist at the antenatal clinic where they live, 46% - at the AIDS center. Almost one in five women (18%) receives the services of a gynecologist outside their place of residence and connects this with the absence of a gynecologist (55%), a desire to maintain confidentiality (to avoid meeting friends, acquaintances, colleagues) (20%), a desire to change the doctor (there was a conflict/I didn't like the doctor’s qualifications/I had more confidence in another doctor) (13%). 4% of women consider that it was forced decision (since they were denied services at their place of residence, etc).

“There is no qualified gynecologist who is available for HIV-positive clients.”

“Their attitude is incorrect and humiliating.”

“They are disinfecting room without finishing the appointment.”

I live with HIV. I explored the Convention on the Elimination of All Forms of Discrimination against Women. I feel more confident in protecting my rights and the rights of other women.

In accordance with the Convention, Member States, including Ukraine, should include in their reports information on the impact of HIV on the situation of women and the steps they taken to meet the needs of HIV-positive women, and to prevent them from being discriminated in the AIDS response.

Svitlana Moroz, Brovary

Photo of Rights flashmob #МоїПраваВажливі (My Rights are Important), CO "Positive Women", campaign "No excuses for violence". Svitlana Moroz, CO "Positive Women", Chair of the Board Eurasian Women’s Network on AIDS.
Preventing Vertical HIV Transmission

The survey included 144 HIV-positive women who gave birth during the years 2016-2018. They answered the question about the prevention of vertical transmission of HIV, and in particular, 67% took ARV drugs throughout pregnancy, 5% took ARV prophylaxis only during childbirth, 66% were provided with artificial mixtures (breastmilk substitutes) at a children's clinic or AIDS center, 69% of women indicated that the child underwent PCR for up to two months after childbirth (4.2% do not know the answer to this question). The provision of breast milk substitutes to children born to HIV-positive women is regulated by the Law of Ukraine of October 20, 2014 No. 1708-VII "On Approval of the National Target Social HIV Program for 2014-2018". Reporting on the number of issued courses of breast milk substitutes is, as of now, unavailable.

Ukraine does not apply the latest WHO recommendations on breastfeeding for women living with HIV. They say that HIV-positive mothers are recommended to breastfeed for at least 12 months and should continue breastfeeding in accordance with the recommendations for the general population, that is, up to two years or more, while providing women with all necessary support for continuing ART. According to the Unified Clinical Protocol of the Ministry of Health "Prevention of HIV Transmission From Mother to Child", in Ukraine, all children born to HIV-infected women are prescribed artificial feeding.

I live with HIV. The AIDS Law of Ukraine emphasizes that the state guarantees the provision of free access to services for the prevention of HIV transmission from HIV-positive pregnant women to their newborns. That is why I actively participate in the process of validation by Ukraine of the elimination of vertical HIV transmission.

Vira Varyga, Kyiv

Photo of Rights flashmob #МоїПраваВажливі (My Rights are Important), CO "Positive Women", campaign "No excuses for violence". Vira Varyga, member of board CO "Positive Women", founder of the self-help group "Kiyanka+".
**Parental Rights of Women Living with HIV**

According to the Order of the MoH of Ukraine No. 479 of August 20, 2008, which exists within the framework of the state measures put forth to protect the rights and legitimate interests of children, women who are living with HIV are prohibited from being guardians or adopting a child. “The disease that causes HIV”, with the clinical classification of HIV infection B20-B24, is included in this norm as contraindications, and this qualifies that all HIV-positive people cannot adopt children or be guardians. This directly contradicts Part 3 of Article 14 of the AIDS Law of Ukraine: “Discrimination based on the presence of HIV infection and the fact that a person belonging to high-risk groups, is prohibited.”

In addition, there were cases when women living with HIV were deprived of parental rights in relation to their biological children due to their HIV-positive status.

On February 3, 2017 the MOH of Ukraine, in the draft order “On Amendments to the Order of the Ministry of Health of August 20, 2008 № 479”, proposed to reduce the list of diseases in the presence of which the adoption of children in Ukraine is forbidden. The agency removed transgenderism, transsexualism, other sexual identity disorders, Alzheimer’s disease, epilepsy, epileptic condition, schizophrenia, and HIV infection from the list, granting the right to such people to adopt children. The explanatory note to the draft notes that the existing list of diseases is discriminatory and does not comply with the “UN Convention on Human Rights and the Law of Ukraine on Principles of Prevention and Combating Discrimination in Ukraine”. Under pressure from deputies and various religious organizations, this draft order did not pass public discussion.

38.4% of respondents to our survey believe that they cannot adopt a child and 48.3% do not know whether they can or not.

**Case Nine:**

...After discharge from hospital, her husband tried in every possible way to limit Victoria’s communication with her children, explaining that she is dangerous to them because of her HIV status and TB. One day, the husband took the children to his parents and forbade them to allow her to visit. If this woman dared to approach the house, he beat her. The husband announced that Vicki had developed mental disorders following the appearance of the disease and demanded an examination by a psychiatrist. A neurologist unfamiliar to the woman, simply at the request of her husband and without the woman’s consent, gave the husband a referral to a psychiatrist, which indicated her diagnosis (HIV) and he provided this referral to the guardianship council. The council is not helping Victoria to reunite with her children, but willing to find out where she acquired HIV. .. She is forced to live with her sister, as she is not allowed into her own home.

Dnipro, April 2018
Case Ten:

Woman has been deprived of her parental rights since 2010. Custody of her child was determined by her mother, who prevents the woman from communicating with her daughter when the woman does not live with her. This woman was discharged from a drug registry in 2016. She's officially working. She has positive references from her place of work and place of residence. She filed an application to the court with a request to officially set the days and hours for visitation with her daughter. Her daughter's guardian has filed a counterclaim and is trying to use her HIV status to ban her from seeing her child.

Poltava Oblast, August 2018

Case Eleven:

Following the consideration of Albina’s application, the Children's Affairs Service of the Odessa City Council refused the plaintiff to appoint a guardian over the minor Eugene, referring to the application of the provisions of the MoH Order, noting: “[Child] cannot be arranged into the families of people suffering from diseases the list of which is approved by the Ministry of Health regarding the persons who can not be adoptive parents and guardians. The list of diseases, in the presence of which a person cannot be an adoptive parent and guardian, and according to the conclusion about the state of health of a citizen dated 04.09.2017. and related health problems (tenth revision) B20, so there is no reason to appoint you as a guardian.

Odesa, March 2018

I live with HIV. My status does not prevent me from loving my daughter and being a caring mother. That is why I defend my parental rights in court.

Olena Khoroshulya, Poltava

Photo of Rights flashmob #МоїПраваВажливі (My Rights are Important), CO “Positive Women”, campaign "No excuses for violence". Olena Khoroshulya, woman which protects their parental rights (case ten).
ACCESS TO HIV TREATMENT SERVICES

The vast majority of HIV-positive women (95%) are aware of the ARV treatment options that exist in their area/country. 89.2% of women indicated that they could receive free and quality ARV treatment and information when they needed it. 87% of women given all the information they need to make a decision about initiation or proceeding with a treatment, without feeling any pressure from the service provider.

HIV-positive women are quite careful about visits to the infectious diseases doctor: 26.3% - visit the doctor monthly, 55.6% - quarterly, 11.8% - at least once every six months.

88% of the surveyed women have an office of a doctor of infectious diseases at their location of residence, 72.4% of women receive these services at their place of residence.

Among women receiving the services of an infectious disease doctor outside the place of residence (27.6%), the reasons were as follows: lack of an office (50%), the desire to maintain confidentiality (29.5%), the desire to change physicians (10.3%).

The majority of women (60.2%) spend less than an hour to get to the place where the doctor of infectious diseases provides services, a third of women (32.4%) -1-2 hours. However, 7% of women spend more than three hours to get somewhere for appropriate HIV care. 69% of respondents noted that their infectious disease doctor operates five days a week, for eight hours a day.

22% of HIV-positive women from ten regions of Ukraine do not know their immunological indicators. 8% have strongly suppressed immunity (CD4 cells level below 200), 30% of women - above 500 cells. 27.2% of women noted that immunological examinations are carried out five days a week for eight hours, 41.1% - three to four days a week for eight hours.

A third of women who answered the question about reasons for not taking ARV drugs referred to good health and/or not being prescribed drugs by a doctor. A quarter of women referred to the side effects - “Drugs were taken previous, but I was not satisfied with their side effects”. Lifestyle, which does not allow to take drugs strictly on time, prevents 18% of women. Among other reasons (a small percentage, single answers) - depression, fear of side effects, “my family is against the use of drugs”, “taking drugs is contrary to my beliefs”, “I was afraid that my husband would become suspicious”.

56.2% noted that the issuance of ARV drugs is carried out five days a week for eight hours, 28.4% - three to four days a week for eight hours. 23.9% of women noted that diagnosis of VL is carried out five days a week for eight hours, 43.6% - three to four days a week for eight hours.

Indicators of the last viral load (which determines the success of treatment) (51% have checked within last 3 months, 29.3% - within last 3-6 months, 3.5% - more than 1 year ago, 1.6% - never):

![Viral Load Indicators Chart]

More than half of women with HIV believe that they have no problem having an undetectable viral load. About 10% referred to side effects. Others do not know or indicated the following reasons: a break in treatment intake, drug use, change in therapy, “I forget to take them”, low adherence, and constant moving.
Aspects that have a major impact on women living with HIV in ensuring their access to quality health and social services and well-being are as follows:

- Cost of services in the places at point of delivery - 61.5%
- Cost of travel to access services - 55.0%
- Lack of family support - 41.0%
- Economic dependence on partner(s)/family members - 26.4%
- HIV-related stigma and discrimination in the workplace – 21.0%
- The cost of pre-school education, babysitter, and kindergarten – 21.0%
- Cost and burden of care for other family members – 17.0%
- Divorce, widowhood, or separation - 15.2%
- Discrimination in the workplace due to sex, age or the presence (absence) of children – 13.0%
- Unequal inheritance and property Rights - 9.3%

Among other things, these women noted: the presence of a small child, the lack of provision of services for HIV positive women in private and public clinics, problems with adoption, denial of medical services due to HIV status, marking on a child's medical card, no access to IVF, an inconvenient location of the regional AIDS center, a negligent attitude of doctors, and the lack of issuance of ARV therapy on weekends were all barriers to treatment and health care.

**MULTIPLE DISCRIMINATION**

Despite the absence of a definition for “multiple discrimination” within Ukrainian legislation\(^39\), UNAIDS international documents\(^40\) note that multiple or complex stigmatization and discrimination - that is, stigmatization and discrimination based on multiple factors - further exacerbates the problem of access to health services. Such discrimination, and other human rights violations, are widespread in health-care settings and have a negative impact on the health of marginalized groups of women.

Under international law, states are obliged to take the appropriate measures to eliminate all forms of discrimination, including the right to access to health care on a non-discriminatory basis. The UN Committee on Economic, Social and Cultural Rights noted that all health facilities should be accessible to all without discrimination. This includes ensuring physical and economic accessibility for the most vulnerable groups\(^41\).

In 2018, UN Women in Ukraine\(^42\) and the Ukrainian Lawyers Association “JurFem”\(^43\) actualized the theme of multiple discrimination, and in particular, for HIV-positive women.

Quite often, HIV-positive women suffer from multiple discrimination related to drug addiction or drug use.

**Case Twelve\(^44\):**

*Due to the fact that I had been injecting in the groin area, my legs had become very swollen. I went to see the doctor – the surgeon from our district. Of course, I explained that I used drugs and about my [HIV] diagnosis. I was amazed at how the surgeon abruptly walked away from me, so that if I sneezed on him, he would just become unconscious and die. Not only did he not touch me, he put on two pairs of gloves and moved far away from me, squeezed up against the wall. He directed me, using his finger, that I should turn and lift my trouser, as he looked from a distance of around two meters... I left the office, then came back, because I forgot my bag and heard them discussing: “she's a junkie, coming here, and she’s not ashamed to come here...”*  
Odessa, February 2018
**Case Thirteen**

This incident occurred in the Department of Pulmonology of the Severodonetsk Multidisciplinary Hospital, when the patient was being treated for pneumonia. Upon admission, the patient informed the doctors orally about her HIV status. When, two days later, the doctors found out that she was also a client of the substitution therapy program and received HIV while taking drugs, she was immediately transferred to a separate area of the infectious diseases department. She was left in complete isolation, where she remained until the end of treatment. 

... Buying intravenous drugs was a waste of money for this patient because she had an issue with her veins, but she was refused a subclavian catheter and was only given intramuscular injections.

As a result, the patient did not receive full treatment. For the entire period of her stay in the hospital, this patient never met with the doctor. She was only seen by nurses, who came in to administer intramuscular injections. The patient was discharged ahead of schedule, without having received a full course of treatment.

Severodonetsk, Lugansk region, 2016

**Case Fourteen**

... In the same hospital, the patient went to the Department of Purulent Surgery with a diagnosis of purulent hidradenitis ... After repeated unsuccessful attempts to take blood, the client refused to have her blood taken. The doctor began to insist that the client produce a blood sample independently. When she refused, the doctor began to scream (with strangers waiting in the reception area) ... repeating the phrase: “it cannot be that a ‘drug addict’ could not take blood on their own.” ... after being humiliated and insulted in the presence of nurses and other patients of the hospital, called a “drug addict”, and having had psychological pressure exerted on her... the doctor threatened to write in the statement that the patient refused treatment or would be discharged for violation of regime in the medical institution. ...

Severodonetsk, Luhansk region, summer 2017

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I live with HIV and drug dependence. In accordance with AIDS Law of Ukraine, our state guarantees the provision of opioid substitution therapy (OST) for people who suffer from drug dependence. I personally know about its effectiveness. That is why I uphold the right of women to access quality OST treatment.

Yuliya Kogan, Odesa

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Photo of Rights flashmob #МоїПраваВажливі (My Rights are Important), CO “Positive Women”, campaign “No excuses for violence”.

Yuliya Kogan, activist, member of Eurasian Women’s Network on AIDS.
MAIN RECOMENDATIONS

1. **Provide effective mechanisms to protect the personal data of women living with HIV**.

2. **Remove or resolve existing contradictions in the MOH regulations that violate the human rights of HIV-positive women - the right to motherhood, reproductive rights, the right to adopt a child and the right to protection against discrimination**.

3. **Ensure the application of modern WHO guidelines on the sexual and reproductive health of women living with HIV and the recommendations of the Committee on the Elimination of Discrimination Against Women, in particular, in the context of breastfeeding, prevention of breast cancer, and cervical cancer. Ensure appropriate collection of statistical information.**

4. **Provide effective mechanisms for women living with HIV to have access to justice in the event of denial of health services, neglect, overpriced services, referral to “specialized” institutions, etc.**

5. **Develop and implement mechanisms to ensure the public monitoring of the rights of women living with HIV by involving women themselves in relevant councils, advisory bodies, committees, etc.**

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*Maintaining confidentiality, namely the secrecy of the diagnosis by health workers, remains an important issue for HIV-positive women. There is an urgent need for further resolution of the issue of anonymity and confidentiality of data. Disclosure of the secrecy of the diagnosis and stigmatizing attitude of health workers leads to serious problems related to mental health, loss of trust to the health care system, unwillingness to seek medical care at all, and has serious social consequences, such as the loss of family ties and forced change of residency.*

**It’s important to note that the introduction of changes and the practice of using AsRT for people living with HIV does not require the creation of separate conditions for infection control, as the order of the MoH “On Approval of Legal Acts on Protection from HIV Infection in the Performance of Professional Duties” approved:**

1) the list and standards of use of personal protective equipment by employees who conduct diagnostic tests for HIV infection, provide medical care and social services to people living with HIV, or frequently are in contact with human blood or biological materials, contaminated tools, and equipment or items that are relevant;

2) a model instruction on the use of personal protective equipment by employees who conduct diagnostic tests for HIV infection, provide medical care and social services to people living with HIV, or frequently are in contact with human blood or biological materials, contaminated instruments, equipment or other objects.

The need for change for Order No. 579 is also due to the need for updates of outdated links and inaccurate definitions, in particular: the Order states that “pharmacological and clinical diagnostic provision of the first course of infertility treatment by the methods of assisted reproduction to women, is provided by the MoH of Ukraine in the State budget for the implementation of comprehensive measures to promote fertility for 2002-2007 as part of the budget program “Provision of Medical Measures of Individual State Programs and Complex Measures of a Program Nature”, in the amount according to the budget program”; in accordance with the name of the order, its effect extends to medical institutions using AsRT for budgetary funds, while a significant number of patients receive AsRT services in private medical institutions at the expense of the patient.

Currently, the draft amendments to the order № 579 are under public discussion in the Ministry of Health.
# ANNEXES

## Annex 1. Experience with health care services

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>I experience the same service as any other women, when I go for sexual and reproductive health services</td>
<td>159</td>
<td>225</td>
<td>70</td>
<td>7</td>
<td>25</td>
<td>486</td>
</tr>
<tr>
<td>I am aware of the ARV treatment that exists in my area/country</td>
<td>243</td>
<td>221</td>
<td>15</td>
<td>0</td>
<td>7</td>
<td>486</td>
</tr>
<tr>
<td>I can get free and high-quality ARV treatment and information about it when I need it</td>
<td>237</td>
<td>197</td>
<td>30</td>
<td>3</td>
<td>19</td>
<td>486</td>
</tr>
<tr>
<td>I have been provided with all the necessary information, without pressure, from a health worker, in order to make a decision on the initiation or continuation of my treatment.</td>
<td>212</td>
<td>209</td>
<td>45</td>
<td>2</td>
<td>16</td>
<td>484</td>
</tr>
<tr>
<td>Healthcare workers do not disclose my HIV status or any other details about me without my permission</td>
<td>142</td>
<td>147</td>
<td>64</td>
<td>29</td>
<td>104</td>
<td>486</td>
</tr>
<tr>
<td>I know my rights, and if I experience a rights violation within the health service, I know where I can go to make a complaint</td>
<td>133</td>
<td>149</td>
<td>43</td>
<td>6</td>
<td>155</td>
<td>486</td>
</tr>
<tr>
<td>If my rights as women with HIV are violated, I know who to ask for legal protection</td>
<td>161</td>
<td>162</td>
<td>42</td>
<td>4</td>
<td>116</td>
<td>485</td>
</tr>
</tbody>
</table>

## Annex 2. Experience of Sexual and Reproductive Health

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
<th>Not applicable</th>
<th>Don’t know</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have been given/can get advice about safe conception (getting pregnant without putting my partner at risk of transmission of HIV or other sexually transmitted infections)</td>
<td>302</td>
<td>48</td>
<td>69</td>
<td>62</td>
<td>481</td>
</tr>
<tr>
<td>I have been/am able to free access fertility treatment if I need it (for example, IVF)</td>
<td>42</td>
<td>117</td>
<td>143</td>
<td>180</td>
<td>482</td>
</tr>
<tr>
<td>I was voluntarily tested for HIV during pregnancy</td>
<td>207</td>
<td>97</td>
<td>166</td>
<td>5</td>
<td>475</td>
</tr>
<tr>
<td>I was given necessary counseling before and after HIV test</td>
<td>214</td>
<td>92</td>
<td>22</td>
<td>17</td>
<td>345</td>
</tr>
<tr>
<td>I have access to safe and affordable abortion, if I need it</td>
<td>61</td>
<td>173</td>
<td>88</td>
<td>157</td>
<td>479</td>
</tr>
<tr>
<td>I have access to post-abortion /miscarriage care, if I need it</td>
<td>43</td>
<td>171</td>
<td>95</td>
<td>173</td>
<td>482</td>
</tr>
<tr>
<td>I have been able to make choices about where I want to deliver my baby (those who gave birth in 2016-2018)</td>
<td>90</td>
<td>31</td>
<td>128</td>
<td>22</td>
<td>271</td>
</tr>
<tr>
<td>I can adopt a child if I want</td>
<td>50</td>
<td>144</td>
<td>104</td>
<td>181</td>
<td>479</td>
</tr>
<tr>
<td>I can access pre-exposure HIV prophylaxis if I need it for my partner</td>
<td>205</td>
<td>47</td>
<td>38</td>
<td>192</td>
<td>482</td>
</tr>
<tr>
<td>I can access post-exposure HIV prophylaxis if I need it for my partner</td>
<td>242</td>
<td>22</td>
<td>39</td>
<td>179</td>
<td>482</td>
</tr>
<tr>
<td>I have access to free preventive examinations, and I can undergo cytology smears for early diagnosis of cervical cancer</td>
<td>233</td>
<td>94</td>
<td>15</td>
<td>140</td>
<td>482</td>
</tr>
<tr>
<td>I have access to the services of a mammologist</td>
<td>154</td>
<td>159</td>
<td>13</td>
<td>152</td>
<td>478</td>
</tr>
</tbody>
</table>
Annex 3. Prevention of vertical transmission of HIV

<table>
<thead>
<tr>
<th>Women who gave birth in 2016 – 2018</th>
<th>Yes</th>
<th>No</th>
<th>Not applicable</th>
<th>Don’t know</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was on ARV treatment at the time of conception</td>
<td>66</td>
<td>58</td>
<td>20</td>
<td>0</td>
<td>144</td>
</tr>
<tr>
<td>I started taking ARV drugs as a prophylaxis during pregnancy</td>
<td>69</td>
<td>50</td>
<td>25</td>
<td>0</td>
<td>144</td>
</tr>
<tr>
<td>I took ARV drugs throughout my pregnancy</td>
<td>96</td>
<td>25</td>
<td>23</td>
<td>0</td>
<td>144</td>
</tr>
<tr>
<td>I only took prophylaxis at the time of childbirth</td>
<td>7</td>
<td>97</td>
<td>38</td>
<td>1</td>
<td>143</td>
</tr>
<tr>
<td>My child took the syrup in the first days of life</td>
<td>110</td>
<td>7</td>
<td>26</td>
<td>1</td>
<td>144</td>
</tr>
<tr>
<td>The polyclinic/AIDS center provides me with breast milk substitute</td>
<td>95</td>
<td>19</td>
<td>28</td>
<td>1</td>
<td>143</td>
</tr>
<tr>
<td>My child did a PCR test up until two months of life</td>
<td>99</td>
<td>12</td>
<td>26</td>
<td>6</td>
<td>143</td>
</tr>
</tbody>
</table>

Annex 4.
На Ваш запит за вих. № 8 від 06.08.2018 року повідомляємо Вас про наступне, що у відповідності до Порядку застосування допоміжних репродуктивних технологій в Україні, затвердженим наказом Міністерства охорони здоров’я України № 787 від 09.09.2013 року цивільні жінки та/або чоловіки мають право за медичними показаннями на проведення лікувальних програм ДРТ, тобто за відсутності і протиокремань на проведення лікувальних програм ДРТ та за умови дотримання відповідної процедури, рекомендацій лікарів жінки, які мають ВІЛ-позитивний статус можуть скористатись послугами екстр корпоративного запізнення.

При цьому, виконання кожної лікувальної програми ДРТ проводиться з обов’язковим клінічним моніторингом та контролем загального стану пацієнтки.
References to sources:

1. Dnipropetrovska, Donetska, Luganska, Odeska, Poltavska, Rivnenska, Sumksa, Cherkaska, Khersonska oblasts and the city of Kiev.

2. According to the results of report № 63, the coverage rate of ART for HIV-positive, pregnant women to prevent vertical transmission of HIV is calculated among the number of HIV-positive women who have given birth to a child in the reporting year.

3. 74.2% in 2016, 54.8% in 2015.


5. The project “Development of the legal aid network for people living with HIV/AIDS, vulnerable to HIV infection and people with tuberculosis” with financial support from the CO “100% LIFE”.

6. Documented by the regional coordinator of Positive Women in the Kherson Oblast, 02.08.2018.


8. Documented by the regional coordinator of Positive Women in the Rivne Oblast, 09.28.2018

9. Documented by the regional coordinator of Positive Women in the Kherson Oblast, 08.02.2018.


11. Documented by the regional coordinator of Positive Women in the Dnipropetrovsk Oblast, 06.10.2018.


13. The indicator improved in comparison with the national survey of 2016 (30%).

14. In total, 206 women answered, with the exception of 3, for whom this question is not relevant. The indicator improved in comparison with the national survey of 2016 (27%).

15. Documented by the regional coordinator of “Positive Women” in the city of Kyiv. 28.09.2018.

16. Dated 16.05.2016 № 449, as amended by the order of MoH dated 02.07.2016 № 655.

17. AIDS Law of Ukraine.

18. Unified clinical protocol of primary, secondary (specialized) and tertiary (highly specialized) medical care “Prevention of mother-to-child transmission of HIV” dated 16.05.2016 No. 449, as amended by the order of MoH dated 02.07.2016 № 655

https://www.unicef.org/ukraine/ukr/Protocol_2016_YKPMD_167x238mm_WEB.pdf


21. Among the 412 women for whom this issue is relevant.


23. Among the 309 women for whom this issue is relevant.

24. Among the 324 women for whom this issue is relevant.

25. Among the 391 women for whom this issue is relevant.

26. Among the 387 women for whom this issue is relevant.

27. Totally - 144 women.

28. Approved by the Committee at its sixty-sixth meeting on February 13 - March 3, 2017

http://www2.unwomen.org/-/media/field%20office%20eca/attachments/publications/country/ukraine/cedaw%20concluding%20observations%20ukr.pdf?la=en&vs=1036


23 - p.2 1.6. Organization of medical care for children born to HIV-infected mothers, Unified clinical protocol of primary, secondary (specialized) and tertiary (highly specialized) medical care “Prevention of mother-to-child transmission of HIV” dated 16. 05.2016 №449, as amended by the order of 02.07. 2016 №655 (in Ukrainian)
https://www.unicef.org/ukraine/ukr/Protocol_2016_YKPMD_167x238mm_WEB.pdf

33 - Among the 375 women for whom this issue is relevant.

34 - Documented by the regional coordinator of Positive Women in the Dnipropetrovsk oblast. 06.10.2018.

35 - Documented by the regional coordinator of Positive Women in the Poltava oblast. 02.08.2018.

36 - Documented by the regional coordinator of Positive Women in the Odesa oblast. 04.10.2018.

37 - Totally - 44 answers.

38 - «When did you check your viral load last time?». The total number of responses - 493.


40 - Eliminating discrimination in health care. Stepping stone towards ending the AIDS epidemic. UNAIDS. 2016


43 - https://www.radiosvoboda.org/a/ja-zakhyshchaju-ji/29532299.html

44 - Interview with HIV+ woman from Odesa http://www.ewna.org/ya-poluchila-sviyu-gorst-tabletok-cherez-tyuremnoe-okoshko/


47 - От 05.11.2013 №955, зарегистрированный в Минюсте 20.11.2013 №1980/24512.

48 - Changes in Annex 1 to the Order of Referring Women for the First Course of Treatment of Infertility by AsRT Methods for Absolute Indications for Budgetary Funds* http://moz.gov.ua/uploads/1/8930-pro_20181205_1.pdf#page=3

Products published in the framework of projects:
(1) “Capacity building of the community of women living with HIV” with the financial support of the charitable organization “All-Ukrainian Network of People Living with HIV/AIDS” as part of the project “Investing in Impact on Tuberculosis and HIV” supported by the Global Fund to fight AIDS, Tuberculosis and Malaria, and
(2) Campaign "No excuse for Violence!" with the financial support of the Eurasian Women's Network on AIDS in the framework of the project “Women Living with HIV: Frontline Influence & Impact”, supported by the Robert Carr Civil Society Networks Fund.

The stated views and points of view are the views and points of view of the CO "Positive Women", and cannot be viewed as the views or points of view of the Global Fund to Fight AIDS, Tuberculosis and Malaria, the All-Ukrainian Network of People Living with HIV/AIDS, Eurasian Women's Network on AIDS, Robert Carr Fund.

Design: Alina Yaroslavska