GLOBAL PARTNERSHIP FOR ACTION TO ELIMINATE ALL FORMS OF HIV-RELATED STIGMA AND DISCRIMINATION

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ANALYSIS OF BARRIERS TO ACCESS TO SOCIAL AND MEDICAL SERVICES FOR WOMEN LIVING WITH AND VULNERABLE TO HIV IN UKRAINE

POLICY BRIEF

KYIV, UKRAINE, 2023

EXECUTIVE SUMMARY

The full-scale war launched by russia in the whole territory of Ukraine has resulted in women living with and vulnerable to HIV ending up in a severe crisis situation – displaced, with no money and roof over their heads. Within the project “Emergency response for people living with and vulnerable to HIV in Ukraine and neighboring countries”, the CO “Positive Women” has set up the centres for information and humanitarian assistance in Dnipropetrovsk, Odesa, Poltava and Zaporizhzhia oblasts of Ukraine. This policy brief focuses on identifying the barriers and trends in women’s impeded access to social and medical services while living in the selected oblasts amid the war, as well as providing recommendations to scale up access to the most needed interventions, especially HIV-related.

The women living with and affected by HIV regularly face systems- and context-level (e.g.: long distances to medical facilities, unemployment and job loss, lack of affordable housing, stigma and discrimination) and personal level (e.g.: self-stigma, lack of money and documentation, presence of comorbidities, poor psychological well-being), as well as legal and institutional barriers in accessing social and health care services in Ukraine. 39,2% of all interviewed women across project oblasts claim to have no or limited access to medical services, and 71% – to social services.

The key trend revealed is that women living with and vulnerable to HIV acutely feel the lack of food, hygiene items and baby products (83,1% of women across four project oblasts). Making sure that women have adequate and non-stop access to food, in the first place, would reduce their vulnerability to HIV and preserve their adherence to ARV treatment. Once this basic need is met, women would as well prioritize their health, including sexual and reproductive, and well-being.

The displaced women living with and vulnerable to HIV report numerous barriers to getting the expected social benefits and humanitarian assistance due to their IDP status, as well as the need in information counselling, financial and other kind of support to access medical services in the new place of residence. But, in times of war, there is also another side of the coin. Unfortunately, there is a tendency towards discrimination of people living with HIV who decide to stick to their homes. Unlike IDPs, they do not receive any welfare payments; their employers, if any, do not get compensation for employing them (thus, IDPs are preferred); and there is no compensation for utility fees (as in case of individuals and communities that host IDPs). Moreover, there are fewer, if any, funds and projects that provide local women with humanitarian aid, as compared to IDP support programmes. But just as IDPs, they lose their jobs, partners and health.

The need for psychosocial support has been significant and directly asked for by 7,9% of women living with and affected by HIV amid all the challenges faced both in and without connection to the hostilities.

The funding for psychological care will be relevant for a long time even after the war ends and should now on be prioritized by international donors. Elimination of stigma and discrimination towards people living with and vulnerable to HIV in all types of settings (individual, household and community; workplace; health care; justice; education; emergency and humanitarian) would certainly lead to greater access to health care and social support for women living with HIV and, consequently, less incidents of AIDS mortality and HIV transmission.

Protracted non-satisfaction of basic needs will most certainly lead to the lack of concern to one's physical, mental, sexual and reproductive health, and, consequently, low level of adherence to HIV treatment and increased mother-to-child transmission. Thus, the war is gradually ruining the progress achieved by Ukraine in terms of countering HIV and decisive actions should be taken jointly and individually by governments, civil society, regional and international organisations in this regard.

INTRODUCTION
BACKGROUND AND RATIONALE

On February 24, 2022, russia launched a full-scale invasion of Ukraine, which was preceded by annexation of Crimea and a continuous armed conflict in Donetsk and Luhansk oblasts since 2014. In the first month of the war, **3.6 million people fled Ukraine**, and around 6.5 million Ukrainians left their permanent place of residence and moved within the country. As of December 2022, according to **the International Organisation for Migration data**, there are 5.9 million internally displaced persons (hereinafter – IDPs) in Ukraine. Most of the IDPs are originally from eastern and southern oblasts – which make up the epicenter of the ongoing hostilities. On February 24, 2022, the President of Ukraine signed the **Decree imposing martial law in Ukraine**, which enacted the restrictions of cross-border travel for specific categories of citizens (under martial law, men between 18-60 years of age are prohibited from departing). Thus, taking this into account, most of those who moved abroad as well as were forcibly displaced within Ukraine, are women and children.

The war has caused not only the largest movement of people in Europe since World War II, but also one of the severest humanitarian crises in the world. With their partners mobilized to the Armed Forces of Ukraine, **women have taken over full responsibility for their children and elderly relatives**. Quickly running down their savings and having no adequate employment opportunities, they have found themselves

in need of humanitarian assistance to cover at least basic needs in food, clothing, medicines and accommodation. The women's situation has been aggravated not only by family separation and lack of financial resources, but also by psychological trauma, chronic diseases, loss of identity documents and personal property. It has been further worsening with the onset of cold weather and permanent power outages across Ukraine due to a barrage of russian strikes. The need for such winter items as blankets, heaters and thermal underwear has been in especially high demand. In addition, when there is a constant threat of a direct attack on health care facilities or when the latter are destroyed due to shelling, **sexual and reproductive health is endangered** – pregnant women cannot get medication and care on a daily basis and complications with pregnancy occur more often.

Women living with and vulnerable to HIV face additional challenges. Apart from not being able to meet their basic needs, they feel neither financial opportunity nor psychological desire to adhere to antiretroviral medicines and treatment of comorbidities. Due to their HIV status, they are not always welcome in communal shelters and are often excluded from available state support. They increasingly feel the **burden of mental health distress**. Pregnant women living with HIV often **encounter negative stigmatizing attitude** on the part of society, including health care personnel, and are being told what (not) to do with their health, e.g. not to get married or to have an abortion. Afterwards, they self-discriminate, deciding not to apply for a job, not to have children, and even isolate themselves. Besides, access to the life-saving aid like ARV treatment and opioid substitution therapy turned out to be very challenging because of, among others, constant rocket shelling and security concerns, disruption of logistic chains, mass displacement and inaccessibility of health care facilities and personnel. The interviews of the women living with HIV and from key populations (women who use drugs) about the life in the conditions of the armed conflict in Donbas after 2014 in the **documentary "Looking for the Dawn. Women of Donbass"** by Svitanok Club NGO prove the above-mentioned challenges, which still remain relevant for women across all the territory of Ukraine.

Though Ukraine has already had an experience of dealing with internal displacement because of war and much of the groundwork for humanitarian response has already been done by state authorities and civil society organisations, the humanitarian challenges this time have got strongly aggravated. The legal and institutional framework turned out to be imperfect and unable to respond to the worst humanitarian crisis in the modern history of Ukraine. The efforts to respond to the humanitarian challenges are also very costly. Taking into account the protracted nature of the crisis, Ukraine is in a constant need of western funding.

Since the start of the full-scale war of russia against Ukraine, the CO "Positive Women" has been receiving numerous requests from women living with and vulnerable to HIV – mostly they were related to help with purchasing food, clothing and medicines,

often psychological and legal support. The Organisation started looking for emergency funding opportunities at the international level in order to urgently mobilize all possible resources to help women living with HIV who suffered. In particular, this work has been planned and implemented as part of the project “Emergency response for people living with and vulnerable to HIV in Ukraine and neighboring countries” (hereinafter – the Project) supported by Stichting Aidsfonds – Soa Aids Nederland (hereinafter – Aidsfonds) with the financial support of the Dutch organisation De Samenwerkende Hulporganisaties (hereinafter - Giro 555) and technical assistance of the Eurasian Harm Reduction Association (hereinafter – EHRA). The project started on June 1, 2022 and will be completed in March 2023. Looking ahead, this work has proved to be a successful combination of humanitarian assistance and counselling services, which have helped women living with and vulnerable to HIV survive and cope with day-to-day challenges complicated during war. It is also worth mentioning the flexibility of EHRA, Aidsfonds and Giro 555 in the process of agreeing the project activities and changes thereto caused by the emergency.

GOAL AND OBJECTIVES

The goal of this analysis is to develop an overview of the barriers faced by women living with HIV and from key populations when trying to meet their basic needs in social services and access medical services, including HIV-related, in the times of the russian military aggression in the territory of Ukraine.

The objectives of the analysis are:

1. to identify the key trends in women’s impeded access to social and medical services;
2. to reflect on the needs of women living with and vulnerable to HIV, including in the conditions of war, and
3. to develop a set of recommendations for decision-makers, civil society organisations and international donors with the view of covering the needs of women and preventing further challenges in accessing services and information for women living with and vulnerable to HIV. The special attention in the paper is paid to the barriers causing non-adherence to ARV treatment and to the challenges faced by internally displaced women living with and vulnerable to HIV.

METHODOLOGY

This overview is based on and limited by the data provided within implementation of the Project throughout the period from June up to and including November 2022.

Centres for information and humanitarian assistance

The work of the Project has been organised on the basis of the centres for information and humanitarian assistance led by local project coordinators. The centres have been set up for the purpose of providing women living with HIV or from key populations with a humanitarian assistance (food, essential non-specific medicines, etc.) depending on their needs (on average, not exceeding a 1100 UAH voucher/certificate and a set of thermal underwear), psychological help, social support and, if needed, referral to legal aid. The centres for information and humanitarian assistance are located in four oblasts of Ukraine: Dnipropetrovsk, Odesa, Poltava and Zaporizhzhia. Due to their geographical proximity to the areas of active hostilities, these oblasts serve as hubs for IDPs. In addition, the Project has aimed to include the territories of Ukraine not covered by other donors and funds.

Documentation tool

To record the applications and the assistance provided, the local project coordinators use a documentation tool. It has been developed by local project coordinators with the assistance of the Focal Point at CO “Positive women” and further agreed by EHRA in order to ensure the unified work in all four project oblasts. Precisely, the tool includes sections aimed to document (1) the barriers for women living with or vulnerable to HIV to access to social, medical and other services, (2) the description of their needs, and (3) the assistance provided, including counselling and humanitarian assistance in the form of the thermal underwear and/or certificate to purchase food and/or hygiene supplies in the Ukrainian chain of grocery stores Silpo.

Data collection and entry

All data are collected using a documentation tool via in person interviews held by local project coordinators assigned to each project oblast (one coordinator/documenter per oblast) among the official representatives and trusted members of the CO “Positive Women”. The data are entered into the documentation tool by local project coordinators. As of the beginning of December 2022, 449 applications in total were received, of which 94 applications in Poltava oblast, 102 – in Dnipropetrovsk oblast, 109 – in Odesa oblast and 144 – in Zaporizhzhia oblast.

The local project coordinators are directly addressed by the women in need. They are trusted by women living with and vulnerable to HIV, cooperate with the medical institutions (oblast AIDS Centres and / or Public Health Centres) and the City Aid Centres (centres to provide assistance to IDPs), and have more than 10 years of experience in the social work and a significant work experience in the field of HIV. The coordinators regularly provide humanitarian assistance, information consulting, crisis counselling, social support and paralegal services to women living with and vulnerable to HIV, as well as represent them in health facilities and state authorities. Thus, their contacts are being disseminated within the community of women living with HIV, via charitable and partner organisations, in the shelters and centres for IDPs, by the doctors from the AIDS Centres, via social media, by police, etc.

The local project coordinators have entered the data concerning every application into the documentation tool. The protection of personal data of the applicants has been partly ensured. The names of the applicants are encoded using the following scheme: first letters of the full name (surname, name and patronymic name) and year of birth, e.g: ABC1990. There is a separate column where the phone number of the applicant is indicated, which is needed, in particular, to pass the voucher if the applicant temporarily moved abroad or is located in the occupied territory. Apart from documenting the barriers, the needs and the assistance provided, the tool asks to mention whether the applying woman living with HIV belongs to the key population (sex workers, women who use drugs, LBTQI, trans* women) and whether any additional criterion is present (internal displacement, pregnancy, many children, TB, low income, disability, low mobility, unemployment, HIV-positive children, etc.).

Data limitations

The data is of the limited geographical scope (Dnipropetrovsk, Odesa, Poltava and Zaporizhzhia oblasts) and covers women living with and vulnerable to HIV. Provision of assistance did not discriminate based on age, abilities, race/ethnicity, or nationality. Any woman living with HIV who was seeking humanitarian and / or information assistance received the needed support. Though, at the same time, the data is limited only to those women living with and vulnerable to HIV who knew about the existence of the centres for information and humanitarian assistance, sought assistance and could come to the centre in person. Therefore, the analysis is not representative of all women living with and vulnerable to HIV. Local project coordinators collected data at different locations (project oblasts), over extended periods of time, during various levels of intensification of hostilities. Therefore, data collection errors and regional variability may be present.

Further, all data collected are prone to biases due to the lack of the unified approach among local project coordinators to the data documentation. In particular, the documentation tool has three open, among other, questions (on the description

of application, needs and obtained assistance), where the coordinators have no standardized options of responses and are free to provide as much detail as it is possible. It has resulted in the differences in details across four project oblasts.
Also, the data collected is limited to 449 cases of humanitarian assistance and information support (including 404 unique cases; some women applied several times) across all project oblasts.

In spite of these limitations, a strength of the work done is in provision of emergency humanitarian assistance and information support to women living with HIV and suffering from multiple factors in the times of the war. These data can be further utilized to introduce nationwide interventions, improve national policies and programmes, as well as to attract foreign funding.

Profile of women seeking help

From June to November 2022, women living with or vulnerable to HIV (women who use drugs, sex workers, transgender women, LBTIQ women) applied for help or were referred by the AIDS Centre doctors in view of the barriers to access to social, medical and other services, including those related to HIV care and treatment, which exacerbated amid the war.

Across four oblasts, the sample was as follows:
449 women living with HIV in total, where

- 102 – **in Dnipropetrovsk oblast**, of whom 2 women who use drugs and 5 women who have TB;
- 109 – **in Odesa oblast**, of whom 31 women who use drugs, 11 sex workers, 2 women who have TB and 1 LBTQI woman;
- 94 – **in Poltava oblast**, of whom 8 women who use drugs, 3 sex workers and 3 women who have TB;
- 144 – **in Zaporizhzhia oblast**, of whom 4 women who use drugs and 2 LBTQI women.

A great number of applicants reported to be IDPs, mostly fleeing from hostilities in Donetsk, Kharkiv, Kherson and Luhansk oblasts. Among women living with or vulnerable to HIV, there were also pregnant women, mothers of many children, women who have children with HIV, low-income women, unemployed women, women with disabilities, women who have tuberculosis, women with other chronic diseases, women

in discordant partnerships. The access to social and healthcare services for women living with or vulnerable to HIV has become more complicated due to such social determinants as poverty, unemployment, lack of housing, chronic diseases, caregiving, lack of family support, etc.

OVERVIEW OF BARRIERS TO ACCESS TO SOCIAL AND MEDICAL SERVICES FOR WOMEN LIVING WITH HIV AND VULNERABLE TO HIV

The equitable access to the highest attainable standard of treatment for HIV, which is implied in the right to health for people living with HIV, is directly dependent on the provision of access to basic social and health care services. Under **Art. 25 of the UDHR**, “everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. Motherhood and childhood are entitled to special care and assistance”. Although the original text of the Declaration involves the generic use of man and he, the scope of the meaning refers to women as well. In fact, it is the women who face the most impeded access to services that are vital for their health and well-being.

Women living with HIV and belonging to key populations daily face numerous barriers to accessing social and medical services, which got only aggravated in times of war. Based on the documented data, the most prevalent barriers are the following.

SYSTEMS- AND CONTEXT-LEVEL BARRIERS TO ACCESSING SOCIAL AND MEDICAL SERVICES

Long distances to medical facilities

The women mentioned the difficulties in receiving health care and getting social services due to their residing in the remote locations (villages or other settlements) outside the oblast centre. Long distances to medical facilities are also closely related

to such obstacles as the lack of transportation and high (unaffordable) travel price. In order to get to the medical facility, women need to save or borrow money, find time to get there in-between working or taking care of their loved ones, order special transportation in case of mobility issues, etc. The war has made it even harder to get to the medical centres since not all of them function and the fare has risen. Unfortunately, women face a choice of whether to pay for a ride to the medical facility to get treatment or to buy groceries for their children and themselves. Indeed, inaccessibility of medical facilities / personnel is one of the major barriers to HIV treatment adherence.

Documented cases

In Poltava, the woman who resides in the rural location reported that in order to pay 1000 UAH for a ride to the health care facility, where she undergoes routine examinations, she has to save this money for more than one month. This woman is low-income, unemployed and cares for a 4-year-old HIV-positive son.

There have been several cases where women reported that the medical facilities in their villages were closed due to the war and lack of personnel. Getting to the medical facility in other village/city turned out to be unbearable for women.

Lack of adequate / affordable housing

Stability, quality and affordability of housing strongly influence the health and well-being of women living with and vulnerable to HIV. Almost all reported cases show that the households are cost-burdened for women living with and vulnerable to HIV – the need for help with a rent was often stated. The war has even intensified the housing needs and, unfortunately, worsened the existing housing options. The women seeking help either had to leave their homes in the occupied territories and then ask for apartments for rent in the safe areas or they no longer had a financial opportunity to rent an apartment, or they live in unsuitable home conditions and / or overcrowded places. The places, where IDPs are settled, lack bathroom, shower and heating – due to russia's shelling of Ukrainian critical infrastructure, the room temperature has cooled to around 12-14 degrees C, which is especially unbearable for those having health issues. The women living with HIV who suffered intimate partner violence are denied accommodation in shelters / dormitories, because all vacant places are occupied by IDPs.

Documented cases

Due to the large number of IDPs in Zaporizhzhia oblast, there is not enough room in places of compact placement. Thus, people are settled there for a limited time. Afterwards, they are forced to rent a flat or, if they have no resources, become homeless. Though it wasn't directly reported, most probably, the situation is identical in other project oblasts.

In Poltava, one woman commented that she had lost her apartment because of fraudulent schemes and other woman said that her house had burnt down and all family resources had been spent to reconstruct it, to the detriment of their basic needs like health care, clothing and food.

Unemployment and job loss

These barriers prevent women from taking medicine and meeting their basic needs. Being unemployed officially over the last 6 months leads to the impossibility to obtain social assistance. The job loss due to the war was repeatedly mentioned. Some women reported that it is difficult to get a job in their locality, since the employers prioritize hiring IDPs. Another common reason relates to the need to care for children as kindergartens and schools do not operate on an ongoing basis during war and countless alarm sirens or because their partners were drafted into the army. Further, since the start of war it is not allowed to enter a state-sponsored daycare if both parents are not officially employed, which poses a real barrier for a great number of people living with and vulnerable to HIV. Also, during the war the possibility to ask for a government-issued nanny is not available and women have to take care of their children while they are on a distance learning.

Documented cases

A great number of women reported being unemployed due to various reasons, e.g.: health-related concerns (prolapsed uterus, trophic ulcer, sore feet, mental disorder, arthrosis, sore joints, liver cirrhosis, hearing loss, disability issues, rehabilitation after myocardial infarction, undergone operations, etc.) and outpatient treatment, fear of discrimination in the workplace because of the HIV status and fear of disclosure, the need to care for their (grand)children or ill relatives, lack of employment opportunities in their settlement, loss of identity documents, etc.

In Dnipro, the woman was denied employment because of being on opioid substitution therapy.

Inadequate work conditions

Inadequate work conditions include non-payment of wages over several months, unstable / low salary, part-time employment or temporary earnings, which generally prevent women living with or vulnerable to HIV from meeting their basic needs and those of their families. Women who are IDPs are frequently being denied formal employment. Living near or below the poverty line, women are afraid to complain about or to give up on out-of-pocket salary or low-paid work, especially if they are the sole breadwinners for their families. Inadequate work conditions are also closely connected to the lack of supportive / understanding work environments.

Documented cases

In Dnipro, the woman reported that she was forced to stop taking ARV treatment – she could not afford standing in lines in the medical facility as she would get a fine for being late for work.

Stigma and discrimination

Women living with and vulnerable to HIV face a lot of manifestations of stigma and discrimination towards them, which is mostly reflected in declines to provide direct care and assistance in health care settings and social service. Frequently, women living with HIV do not seek help or do not exercise their right to access to social, medical or other services because of the fear of being stigmatized and discriminated. To a great extent, the fear of stigma and discrimination is experienced by newly diagnosed with HIV.

Women living with HIV were refused to be mobilized to the army – they made the voluntary decision to serve – because of being HIV positive (such cases were documented in Odesa oblast).

Documented cases

Declines to provide direct care and assistance in health care settings – in Poltava, woman living with HIV was denied surgery on the uterus because of her HIV status; in Zaporizhzhia, woman living with HIV was denied to sign a declaration with a family doctor in the medical facility at the place of actual residence.

Declines to provide social service – in Poltava, woman living with HIV and mother of 3 children was denied social assistance without stating reasons; in Poltava, single mother of many children who lives with HIV was denied registration as a mother of many children; in Poltava, shelter administration refused to settle the woman who uses drugs and has mobility issues – as a consequence, she ended up in the streets having no access to social and medical services, her health and life being at serious risk. This is not a single case reported.

In Zaporizhzhia, children of the 55-year-old woman living with HIV stopped any contact with their mother because of her HIV status.

In Zaporizhzhia, an IDP woman living with HIV was denied help at the private clinic, which positioned itself as the one offering free medical care to IDPs, without any justification.

Lack of documentation

Without paper, i.e. identity and related documents, we are nobody, but with a piece of paper – a person. That is how a system of service provision functions. Lack of documentation has caused difficulties in getting officially employed – women reportedly shared their stories of not being able to find a job because of the lack of an identity document or individual tax number; receive a disability group, get other social benefits like the status of the mother-heroine, and be accommodated within compact settlements. Without documents it is also impossible to sign a declaration with a family doctor to get free health care services, and the doctors are reluctant to provide them for free, without declaration (as they are not being paid for such clients by the state).

There have been a lot of cases where a loss or a failure to obtain some documents were primarily for the reason of war and being forced to immediately leave one's place of residence. In that respect, lack of documentation has made it impossible to apply for

humanitarian assistance (women are denied humanitarian assistance due to the lack of an IDP certificate), move abroad, etc. All the women were provided with legal advice on the restoration or obtaining of documents. Though, even being aware of the procedure, the document restoration costs money, which the women cannot afford.

Documented cases

One woman from Sloviansk started to receive a disability group in her locality though because of hostilities was forced to leave the city forgetting her documents.

In Zaporizhzhia, a woman living with HIV who is a mother of 7 children does not want to undergo the process of receiving the status of the mother-heroine, since she has no belief in the government assistance.

In Zaporizhzhia, one woman said that she wanted to flee abroad with her 14-year-old son for the period of war, but she did not have a foreign passport.

PERSONAL-LEVEL BARRIERS TO ACCESSING SOCIAL AND MEDICAL SERVICES

Lack of HIV-related knowledge and information on services-related issues

Generally, women lack information on how to receive social and medical services, e.g.: how to make an appointment with a doctor and get free medical services, and how to protect their rights in case of violation and whom to address. The request for information is one of the most common. Additional barriers for women living with HIV have been created by the war. Being IDPs, women reported of not being aware of where to get contact information on the medical facilities to conclude an agreement with a family doctor; how to change the place of registration as an IDP to get a targeted assistance at the place of actual stay; how to obtain a foreign passport to move abroad; where to get contact information of charitable funds, which provide assistance to women living with

HIV, IDPs (shelters, warm clothes, food, medicines, etc.); how to cross the border with medicines, etc.

There is also a considerable lack of HIV-related knowledge on the part of women living with and vulnerable to HIV. They have indicated not being aware of the importance of adhering to ARV treatment, the modes of HIV transmission, and asked about the impact of ARV treatment on the fetus and where to get ARV both within Ukraine and abroad. Some women shared their fear of stigma and discrimination by the medical personnel, especially during delivery.

A great bulk of issues relate to childcare and motherhood concerns. Thus, pregnant women were not aware of how to register for a prenatal care and what check-ups, tests and scans are required during pregnancy, labor, postpartum period and child care (analyses, vaccinations and routine check-ups). The demand of childbearing was named as one of the greatest barriers to self-care for women living with and vulnerable to HIV. Unfortunately, it is often reinforced by the lack of trained and competent health care personnel who, e.g.: persuade pregnant women living with HIV to get an abortion to avoid vertical transmission (see case (1) below).

Documented cases

In Dnipro, a 31-year-old woman was being persuaded to terminate her pregnancy because of the inciting risk of giving birth to an HIV-positive child. The woman needed information on the modes of HIV transmission.

In Poltava, a 35-year-old woman living with HIV asked for a consultation for her partner on HIV pre-exposure prophylaxis algorithm. The woman was provided with a consultation on the relationships in discordant couples.

Also, there have been a number of cases on providing consultations on the consequences of the self-termination of the treatment course, manifestations of opportunistic infections, and the risks of developing TB.

In most cases, it has been difficult to determine whether women were unaware of certain information and / or how and where to get it, or whether they needed assistance with obtaining a certain service. For instance, women sought help with receiving a disability group, but it was unclear whether they were unaware of what institution to address to or had no resources (time, money) to arrive at that institution. Thus, lack of knowledge is closely connected here to the need for client management and / or financial support.

Lack of financial resources

There was hardly a woman among the applicants who could not be identified as low-income, or in need of money. Almost every documented case proves that women lack financial resources to purchase groceries, clothing, hygiene supplies, diapers, milk substitutes and other baby goods; to hire a private carrier to get their ARV treatment at the AIDS centre; to continue treatment, including HIV and comorbidities; to pay for medical treatment of their children; to pay the state fee to restore the lost identity document needed to receive a disability group; to pay a flat rent, etc. In fact, lack of financial resources has highly affected the prioritization of needs on the part of women – they would rather spend their savings on food, rent and baby goods than on treatment-related needs.

Every woman who applied for humanitarian assistance got a certificate to purchase food and/or hygiene supplies in the Ukrainian chain of grocery stores Silpo. The food vouchers have been regarded as the best solution to provide humanitarian aid since women have been given a choice what to buy (with alcohol and tobacco ban).
It is also important to note that unlike internally displaced women living with HIV, local women do not have access to any kind of humanitarian aid, though they similarly lose their jobs, husbands, sources of income, health, etc.

Documented cases

In Dnipro, one woman, asking for humanitarian assistance, said that she had so little money to cover all expenses that she would rather buy her child some milk than use available money for treatment-related needs.

In Poltava, several pregnant women who claimed to be at risk of poverty asked humanitarian assistance to buy milk substitutes (they are not state-funded and are expensive) and diapers for their children.

In Odesa, one woman said that she had no money at all to purchase food (not to mention other needs) and thus she felt mentally depressed. Such a case is not unique across all oblasts.

Poor psychological well-being

Not being able to buy groceries and hygiene supplies strongly affected the women's mental health, which in turn led to challenges in perceiving information and memory issues. Women reportedly asked for psychological help because of the self-stigmatization due to their HIV, fear of status disclosure or because they felt tired of taking the therapy.

War and fear for one's security and integrity have further aggravated the psychological well-being of women living with and vulnerable to HIV. Frequently, they leave no chance for adhering to the continuous ARV treatment. Being IDPs and thus having scarce or no knowledge at all about local medical facilities / personnel where they can get a dispensary registration or charitable funds providing humanitarian and other assistance to IDPs, women feel anxiety and discontinue their treatment. Based on the analysis of the assistance provided to the women, psychological support was among the most urgently needed. Also, women were invited to join mutual support groups.

Documented cases

In Poltava, one woman mentioned that her partner had been taken prisoner and, thus, fear for him and their future undermined her physical and mental health. This is not a single case reported.

In Dnipro, a 32-year-old woman reported recently being released from captivity in Tahanroh and requiring urgent psychological support.

Presence of comorbidities

Not feeling well - because of comorbidities – to attend visits to the medical facility to get therapy has been named as one of the barriers to accessing care among HIV-positive women. On one hand, the presence of comorbidities makes women spend all their money to treat those diseases, e.g.: undergo chemotherapy in case of cancer or hormonal examination in case of thyroid disorders. On the other hand, being aware of the comorbidities, women cannot treat them properly at all because of financial issues – e.g.: among the seekers for help were women living with HIV who needed eye surgery, chemotherapy to treat cervical cancer, hepatitis C treatment, arthroplasty,

consultations of a neurologist and, fairly common, a gynecologist, etc. In most cases, women have not been aware of the possibility of being medically examined for free – they paid significant amounts of money and there was nothing left to buy essential goods.

A number of women who fled abroad because of the hostilities ceased to take ARV treatment, which, in turn, worsened their state of health and exposed their comorbidities.

Documented cases

In Poltava, a woman who is currently on the maintenance therapy after heart attack spends about 3 000 UAH monthly to buy necessary medicines (that is practically all her salary).

In Poltava, one mother of seven children reported having been saving money and not meeting the basic needs of her family and herself because of the illness of her 2-month-old child who requires expensive diagnostics

Also, there are a lot of cases of women living with HIV who take care of their HIV-positive children, children with disabilities or comorbidities.

Intimate partner violence

Women IDPs are at greater risk of violence, exploitation and abuse both at the hands of strangers and the partners involved in armed conflict. Displaced women living with HIV disproportionately experience violence on the part of their partners who having lost their jobs, economic freedom and status in their communities, resort to drinking, physical, emotional and psychological abuse, as well as sexual violence. Besides, due to the fear of HIV-related stigma, discrimination and criminalisation, women prefer not to go to the police and, thus, deal with mental breakdown and physical disorders on their own. Unfortunately, due to the war, local women living with HIV who suffered intimate partner violence are frequently refused to be admitted to the shelters, because all the places are being filled in by the whole families of IDPs.

Documented cases

There have been a number of cases where women were prevented from accessing health care services by their partners. The latter used violence (physical and psychological), burned documents, took away phones and / or locked up women at home not to let them report it to the police. Unfortunately, there are also cases where police refuse to open a criminal investigation – the reason was not always clearly stated.

LEGAL AND REGULATORY BARRIERS TO ACCESSING SOCIAL AND MEDICAL SERVICES

Unlike systems- and context-level, and personal-level barriers to accessing social and health care services that were directly mentioned by women living with and vulnerable to HIV, legal and regulatory barriers were not always obvious and hardly indicated by the applicants. Coupled with little trust in public institutions, the Ukrainian legal and institutional framework strongly impacts the women's access to social and medical services. Bearing in mind the vast array of legal and institutional obstacles that could arise when exercising the right of access to services, the analysis is limited to the barriers stemming from the needs indicated by women living with and vulnerable to HIV, and they are the following:

A to get state support and social benefits provided for the IDPs, one should be registered as an IDP and have a valid IDP certificate. According to the **Order on Registration and Issuance of a Certificate of Registration as an Internally Displaced Person** approved by the Resolution of the Cabinet of Ministers of Ukraine No. 509 of October 01, 2014 (as amended of October 14, 2022), to issue an IDP certificate, which is needed to get state support and social benefits, a person should present documents certifying identity and registration in the territory that was temporarily occupied territory or where hostilities take place. Lack of documentation is directly stated in para. 8 of the above-mentioned Order as a reason to deny an issuance of an IDP certificate. And it was repeatedly stated by the women as a barrier to access to social services.

B

at the same time, in the event of lacking the hardcopy, the laws of Ukraine make it possible to present the image of the identity document from Diia application, eDocument or a certificate on the submission of documents for the issuance of a citizen's passport. Regarded as a step forward, this provision is not always a relief for women, as it is sometimes not observed in reality and often hardcopy is requested. Re-issuing an identity document is costly, and, frequently, unaffordable. Thus, there were cases where women living with and vulnerable to HIV sought financial help to cover these expenses (state fees). Though, more commonly, women asked for social support with document renewal.

C

according to the **Law of Ukraine "On State Financial Guarantees of Medical Services to the Population" No. 2168-VIII of October 19, 2017**, free medical services, except for emergency medical assistance, are not accessible to foreigners and stateless persons. There was one case documented in Zaporizhzhia, where a woman could not access free medical and social services, since she is a stateless person.
The same relates to the disability group. The service is only accessible to citizens of Ukraine. Also, one case in this regard was documented in Zaporizhzhia.

D

in order to be provided with free medical assistance, it is necessary to sign a declaration with one's family physician. Under the **Medical Guarantee Programme**, the state covers a basic package of health care services and medical tests. But to get these services, the patient's personal data based on his or her identity documents should be entered into the electronic system and the declaration should be signed. The National Health Service of Ukraine pays to the physician for the services provided only on the basis of the declaration and electronic referrals. Thus, no documents means that a person cannot sign a declaration to get medical services free of charge.
Unfortunately, internally displaced women living with and vulnerable to HIV (e.g., women who use drugs), even having a declaration signed with a physician in their locality, faced another kind of challenges in accessing services in their new place of stay. For example, a local project coordinator in Dnipropetrovsk oblast mentioned that there were cases where doctors could refuse to treat women living with HIV / women who use drugs who were homeless saying that they already got a full list of patients and there was no place left. As a result, women addressed several physicians, got similar responses and gave up on trying to access the services.

E

there were several cases of the failure to get a disability group because of the lack of declaration with a family doctor. Indeed, in order to proceed with a disability group, it is necessary first to go to one's family doctor in order to get a referral to the medical advisory committee. Though, under martial law, the health care personnel have no right to demand the IDPs to re-sign the declaration at their actual stay – it is possible to remotely contact one's doctor and arrange all needed documents.

F

according to the **Order on keeping records of people living with HIV and carrying out medical supervision of them** approved by the Order of the Ministry of Health of Ukraine No. 585 of July 10, 2013, people living with HIV are deregistered in the event of changing their place of residence (place of stay), death. There were several cases where women were deregistered after moving abroad due to the threat posed by the hostilities and upon their return, they faced challenges in restoring their dispensary registration (due to ignorance, loss of documents, bureaucracy, etc.). In case of people living with HIV and, especially, during the war, it is vital to ensure permanent HIV-related treatment, care and support, which cannot be implemented without registration in health care facilities.

G

there were 12 cases reported in Dnipro, where women could not get ARV treatment since they were at inpatient rehabilitation centres and were prohibited from leaving the premises. Such centres are not state-funded, they are either private or belong to religious organisations (e.g., New Generation church). When being admitted to the rehabilitation centre, women sign an agreement which prevents them from leaving the premises of such an institution. Some centres have their social workers who can get an ARV treatment for HIV-positive women, though there are cases when women are left without treatment for the whole period of being within the rehabilitation centre, and, moreover, their personal mobile phones are being taken away. Women have no choice but to comply with the internal rules.

H

under the **Order of the Ministry of Defense of Ukraine** dated August 14, 2008 No. 402 (as amended) "On approving the Regulation on military medical examination in the Armed Forces of Ukraine", when being drafted for military service, candidates undergo a mandatory HIV examination. People with HIV at the time of enlistment are considered unfit for military service. There were cases of women who reported their desire to serve, though, based on legislation, they were denied to.

Apart from legal barriers, the women living with and vulnerable to HIV, who are registered as IDPs, reportedly mentioned delays in social payments, which frequently turn out to be their only means to pay for food, medicines and baby stuff. According to the clarifications provided by the Ministry of Reintegration of Temporarily Occupied Territories, the delays are individual and caused by technical reasons.

A separate attention was paid by local project coordinators to the shortcomings of the public procurement of medicines and motherhood-related items– there is no state funding for TORCH screen, treatment for suppression of lactation, and formula. Women have no resources to cover them themselves.

The identification and overview of barriers to accessing social services and health care for women living with and vulnerable to HIV will help indicate the types of initiatives needed to improve women's health and well-being and to include them in HIV programming.

KEY FINDINGS

Women living with HIV and from key populations experience limited or no access to social and medical services caused by systems- and context-level, personal-level, legal and regulatory barriers.

More specifically, 39.2% of all women reported having no or limited access to medical services, which includes but is not limited to: inaccessibility of health care facilities and personnel, inaccessibility of ARV treatment, unaffordability of treatment or travel cost to health care institutions, burdensome legal requirements. In the regional context, the lack of access to medical services is felt by 11% of women in Odesa oblast, 28,5% in Zaporizhzhia oblast, 34% in Poltava oblast, and 89,2% in Dnipropetrovsk oblast. The burden of comorbidities was prevalent in the responses of 94,5% of women in Odesa oblast, compared to 27,5% in Dnipropetrovsk oblast, 21,3% in Poltava oblast, and 20% in Zaporizhzhia oblast. The women mentioned not feeling well, both physically and psychologically as a reason of having comorbidities, to attend visits to the doctor or to the AIDS centre to take ARV treatment. Several women in each oblast said that they had received refusals of care and support in health care settings and refusals of free medical assistance (both medical examinations and medicines).

71% of all women reported having no or limited access to social services, which

includes but is not limited to: inaccessibility of housing and education, inadequacy and inaccessibility of employment opportunities, inaccessibility of social benefits based on disability group, IDP status or being a mother-heroine. In the regional context, the lack of access to social services is felt by 89% of women in Odesa oblast, 71,5% in Zaporizhzhia oblast, 66% in Poltava oblast, and 56% in Dnipropetrovsk oblast.

83,1% of the seekers for help reported the need for foodstuff and hygiene supplies. 93,6% of women in Poltava oblast, 88,2% in Dnipropetrovsk oblast, 77,8% in Zaporizhzhia oblast and 76,1% in Odesa oblast said that they were on the verge of poverty, with no means for existence and could not afford buying conventional products, childcare goods, baby formula, not to mention medicines to treat their comorbidities and those of their children and other family members. Prioritizing meeting basic needs in food, warm clothing and baby goods to the detriment of one's own health was common for women from all over covered oblasts.

The access to social and medical services for women living with and vulnerable to HIV most commonly was impeded by the lack of financial resources, knowledge and documentation (often – combination of these three barriers). The lack of money was directly caused, among others, by the lack of employment or inadequate working conditions – experienced by 30% of women living with HIV across four oblasts. In particular, 41,5% of women in Poltava oblast, 38,9% of women in Zaporizhzhia oblast, 28,4% of women in Dnipropetrovsk oblast and 11% in Odesa oblast directly mentioned being unemployed due to various reasons (mostly, because of war, the need to care for children and/or ill relatives, lack of employment opportunities in their localities or health-related concerns). The data may differ from reality, since not all the applicants referred to their employment as a barrier to access to social and medical services and this was not documented by local project coordinators. Though, based on the responses, it became clear that the lack of financial resources directly affected women's capability to restore the lost or unavailable documents (further needed to get employed or receive state support), to pay for medical treatment, analyses, travel fee to visit the doctor/get ARV treatment and/or pass medical examinations, etc.

The lack of documentation turned out to be more common among women living with and vulnerable to HIV in Zaporizhzhia oblast. 10,5% of the seekers for help mentioned that they cannot access the needed services because of the lack of documents (identity document or individual tax number) – 40% out of these women said that, as a result, were not able to find a job, 40% – to receive a disability group and/or other social benefits and 20% – to access other social and medical services. 27% of the women in Zaporizhzhia oblast who reported the lack of documentation as a barrier to access the services said that it was caused by internal displacement and hostilities. Generally, it appeared to be a challenge to get registered in the medical facility and sign a declaration with a family doctor without documents or copies thereof. This legal barrier

was especially felt by displaced women since they had to re-sign a declaration in their actual place of residence. In addition, lack of documentation made it impossible to get settled in a state-funded shelter.
Unfortunately, the lack of documentation and the lack of money are interdependent barriers since no documents means no access to humanitarian assistance and no money means no capability to restore the documents in case they are lost. Women get trapped and cannot access the services they need to enjoy their human rights.

The war has made it more difficult for women living with and vulnerable to HIV to care for their health and well-being. It caused more psychological distress and fear of stigmatization and discrimination. For instance, women in Odesa oblast reported being afraid (due to constant shelling) of just going through the territory of the oblast to attend the medical facility. There were also cases of intimate partner violence reported by women living with and vulnerable to HIV. The shelters for IDPs are insecure for women too. Moreover, they lack places for women who are not regarded as IDPs. Fear for one's life and favoring one's security to the detriment of one's health was clearly manifested. The need for psychological assistance in the given circumstances was directly mentioned by 8.5% of women in Poltava oblast, 8.3% in Odesa oblast, 7.8% in Dnipropetrovsk oblast and 6.9% in Zaporizhzhia oblast. Although, the poor psychological well-being itself was reported by far more women.

The onset of war has also severely disrupted women's access to health information, in particular where and how to get the ARV treatment in the location where they moved to. The lack of HIV-related knowledge (including how to get registered in the medical facility) was mostly felt by women in Dnipropetrovsk oblast (51% of all women) compared to surprisingly low in other oblasts of Ukraine – 19% in Poltava oblast, 11% in Odesa oblast and 1,4% in Zaporizhzhia oblast. The information counselling was documented to have been provided by local project coordinators in almost every case, the social support was offered little less often, but still common.

The project activities have proved to be very necessary and provided women living with and vulnerable to HIV with valuable guidance and highly needed humanitarian assistance. Although, the support has to be followed within other projects and organisations.

KEY RECOMMENDATIONS

Below are the recommendations to decision-makers, civil society organisations and international donors in terms of both supporting already existing and designing new

interventions to provide women living with and vulnerable to HIV with a full and necessary access to health care and social services, especially in the times of war. The timing of interventions is of great importance and cannot be postponed till the end of the hostilities due to the vulnerability of women living with HIV and belonging to key populations. Women should be put first in all possible policy making processes.

For decision-makers

Under **CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)**, the State shall ensure the access to health facilities, goods and services to everyone without discrimination, and by accessibility we mean that they should be accessible to all, especially the most vulnerable and marginalised sections of the population (non-discrimination); be within safe physical reach for all sections of the population, especially vulnerable or marginalised groups, such as, among others, persons with HIV/AIDS (physical accessibility); be affordable for all, including socially disadvantaged groups (economic accessibility); and the right to seek, receive and impart information and ideas concerning health issues shall be ensured (information accessibility). States are therefore obliged to ensure that women as part of the broad community of people living with and vulnerable to HIV have equal, timely and sustainable access to health care services. The following interventions are recommended to address to decision-makers in the field of health care and social services.

1. *Engage the communities of women living with HIV and belonging to key populations into decision-making processes so that their needs and priorities are adequately reflected in humanitarian response.*
2. *Ensure that the needs of women living with and vulnerable to HIV are prioritised in national strategic plans, programmes and other policies.*
3. *Provide regular audit and monitoring of valid legal environment on the gaps in ensuring the HIV prevention, treatment, care and support, and the rights and freedoms of women living and vulnerable to HIV as part of the broad community.*
4. *Amend the legislation, in terms of providing the right to serve in the armed forces for women living with HIV.*
5. *Amend the legislation, in terms of simplifying the access to free medical services in the event of the absence of identity documents.*
6. *Monitor the timely provision of social payments to IDPs.*

7 *Facilitate access of women living with HIV to free legal advice and representation. Ensure regular training of the Free Legal Aid system staff on the rights of people living with HIV, including women living with HIV.*

8 *Support legal awareness raising programmes implemented by CSOs and international organisations.*

9 *Ensure that women living with and vulnerable to HIV are provided with income-generating opportunities and reasonable accommodations in the workplace.*

10 *Design interventions aimed at eliminating HIV discrimination in the workplace. Ensure non-screening for the purpose of employment.*

11 *Design and support housing-focused interventions (rental assistance, case management and follow-up services) as cost-effective strategies for HIV response.*

12 *Support, including financially, the stable functioning of shelters for internally displaced women and their children, inter alia, on the basis of women's and HIV care and support organisations. Increase the number of compact settlements.*

13 *Hold regular monitoring and evaluation of the functioning of shelters for internally displaced women and their children in terms of accommodation, conditions of stay, documents needed to get settled and other prerequisites specifically related to women living with and vulnerable to HIV. Any segregation, exclusion or another manifestation of stigma and discrimination based on HIV status should be tackled.*

14 *Ensure that women living with HIV are protected against violence within and outside home, especially in places with high concentration of armed men, at IDP centres and along the contact line.*

15 *Ensure the public procurement of baby formula, as well as TORCH screen, treatment to suppress lactation and other medicines, which are indispensable for women living with and vulnerable to HIV.*

16 *Prioritise the development of programmes that aim to reduce the effects of traumatization caused by hostilities. Including a special focus to the needs of people living with and vulnerable to HIV.*

17 *Develop telemedicine to address emerging needs of women living with HIV in health care advice when real-life interaction with the doctor is impossible.*

For civil society

Civil society organisations should gain more and more access to national and global decision-making fora to demand more attention to the needs of people living with HIV and more funding to meet those needs. In the emergency setting, CSOs play the role of the lifeline for people living with and vulnerable to HIV, especially women, since their needs have to be addressed as early as possible to avoid life-threatening conditions. The following recommendations are the ones of many to use in the advocacy and other types of interventions to make the voices of women living with and vulnerable to HIV heard, and their needs met.

1. *Conduct advocacy interventions with relevant state authorities to ensure that national strategic plans mainstream gendered human rights.*

2. *Involve the mass media in highlighting strategic cases. Provide training sessions to mass media representatives on non-stigmatizing language.*

3. *Empower women living with and affected by HIV with knowledge about their legal and human rights, on how to negotiate their relationships and build their capacity so that they are able to take action when their rights are violated.*

4. *Raise awareness of women living with HIV on the need to adhere to ARV treatment and on issues related to their sexual and reproductive health.*

5. *Develop the network of paralegals to timely address the increasing needs of women living with and vulnerable to HIV. Train paralegals on newly adopted laws and bylaws on HIV- and IDP-related issues.*

6. *Organise help centres (hotlines) that provide humanitarian assistance, consultation on issues of primary health care, accommodation support, financial support and employment support for women living with and vulnerable to HIV. These help centres should take into consideration the existing infrastructure and respect for the needs of women in war-affected territories.*

7. *Support and promote cooperation between women living with and vulnerable to HIV and providers of HIV-related services.*

8. *Keep on carrying out vulnerability assessments to determine links between armed conflict, displacement and gender. Cooperate with governments to document these vulnerabilities and guide appropriate response.*

For international donors.

In the emergency setting, international funding is more needed than ever. The donors are urged to fund a long list of interventions to support people living with and vulnerable to HIV, and to get the HIV response back on track.

1. *Increase the level of support to activists and communities of women living with HIV and belonging to key populations that provide assistance in the times of war. Ensure that community activists and leaders are trained to provide assistance in the emergency setting and have enough tools to address emerging challenges and complicated issues.*

2. *Increase programme funding to meet the needs for humanitarian assistance and information counselling. It is critical to ensure that such assistance addresses the varying needs of women in vulnerable situations and from different key populations.*

3. *Allocate funding namely to women-led and women-based organisations. Ensure flexibility in using funds taking into account constant changes in interventions that require funding.*

4. *Support interventions aimed at providing psychosocial help to women living with and vulnerable to HIV.*

5. *Provide funding for suppression lactation treatment, milk substitutes and other pregnancy and motherhood-related items.*

6. *Support interventions aimed at increasing access of women living with and vulnerable to HIV to sexual and reproductive health.*

The document was developed by Nataliia Gerasymchuk, Human Rights Expert, Consultant of the Global Network of People living with HIV.

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