

REPORT ON THE PROJECT OF SOCIAL AND LEGAL SUPPORT IN ST. PETERSBURG, RUSSIA 2017-2020 • DECEMBER 2020

HUMAN RIGHTS AND SUPPORT IN HEALTH CARE

IMPROVING OUTCOMES ALONG
THE HIV CASCADE FOR PEOPLE
WHO INJECT DRUGS



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The HIV Legal Network promotes the human rights of people living with, at risk of, or affected by HIV or AIDS, in Canada and internationally, through research and analysis, litigation and other advocacy, public education and community mobilization.

The Legal Network acknowledges that the land on which we live and work is traditionally known as Turtle Island and home to the Haudenosaunee, the Wendat and the Anishinaabe, including the Mississaugas of the Credit First Nation. We are all Treaty People. As settlers and as human rights advocates working for health and justice, we are called to honour the Calls to Action of the Truth and Reconciliation Commission in our work. We must do our part to address the ongoing injustices and resulting health inequities faced by Indigenous Peoples, which contribute to the disproportionate impact of the HIV epidemic on Indigenous communities. We are actively committed to this effort, working in collaboration with our Indigenous colleagues and others.

List of abbreviations

AC	AIDS Centre
ART, ARV therapy	Antiretroviral therapy
CC RF	Correctional Code of the Russian Federation
CRC RF	Criminal Code of the Russian Federation
CCSSP	Comprehensive center of social services for the population
CF	Charitable foundations
CS	Corrective Service
DFMS	Department of the Federal Migration Service
ECHR	European Court of Human Rights
FC RF	Family Code of the Russian Federation
HBV	Hepatitis B virus
HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
IE	Individual entrepreneur
INN	International Non-proprietary Names
MDR-TB	Multidrug-resistant TB
NGO	Non-governmental organization
PAS	Psychoactive substance
PLHIV	People living with HIV
PWUD	People who use drugs
SL	Street lawyer
SSO	Social Security Office
STI	Sexually transmitted infection
TB	Tuberculosis
TBD	TB dispensary
VL	Viral load
XDR-TB	Extensively drug-resistant tuberculosis

Summary, conclusions, and recommendations

From April 2017 to May 2020, with the support of the Elton John AIDS Foundation, a pilot project of social and legal support for people who inject drugs was carried out in St. Petersburg in order to improve health outcomes, specifically along the HIV testing, treatment, and care cascade (hereinafter referred to as the “HIV cascade”). The results of the project are presented in this report.

In just three years, the project, implemented by five full-time social workers with the support of part-time lawyers, reached 968 people, 615 of whom received antiretroviral therapy (ART) and 288 of whom achieved a stable, undetectable viral load.

The project resulted in more than \$127,920 USD per year in savings by preventing treatment interruptions or changes to treatment regimens, demonstrating that the costs of developing and implementing social and legal support services can be recouped within 1.5 years. Longer projects will show even greater efficacy, as many clients need long-term support to start ART and adhere to treatment.

The project illustrates the importance of including a component of social and legal support in work done with key populations to prevent and treat HIV infection. Social and legal support, with the participation of non-governmental organizations (NGOs), is recommended as one of the key components for implementing the National HIV Strategy in the Russian Federation.



The case for social and legal support as a tool to improve outcomes along the HIV cascade

HIV infection is a chronic disease that can be controlled with the timely detection and with lifelong anti-retroviral therapy (ART). Epidemiological data show that people who inject drugs are one of the groups most vulnerable to HIV infection.¹ Their vulnerability is largely driven by the existence of legal barriers to accessing HIV cascade services. Assisting members of this group to overcome such legal barriers improves health outcomes along the treatment cascade. This approach is in line with national and international standards.

The term “HIV cascade” refers to the chain of significant events that are involved from the moment a person is diagnosed with HIV until their viral load is suppressed to, and maintained at, undetectable levels. For a more detailed definition of the HIV treatment cascade, see the 2015 UNAIDS Terminology Guidelines.²

In 2016, the Russian Federation, along with other UN Member States, committed to:

- achieving the “90-90-90”³ targets for HIV treatment;
- using strategies for community-based testing, post-test referrals and follow-up to facilitate links to care, support, and treatment services, including viral load monitoring; and
- addressing socioeconomic and regulatory barriers to diagnosis and treatment.⁴

In the implementation of international obligations, the following strategic documents reflecting the 90-90-90 targets were adopted by the Russian Federation in 2016 and 2017:

- “National strategy to fight the spread of HIV infection in Russia for the period up to 2020 and beyond”;⁵
- “Action plan for implementing the National strategy to fight the spread of HIV infection in the Russian Federation for the period up to 2020 and beyond”;⁶
- “Instructional guidelines on the ‘Development of a typical interdepartmental program on HIV prevention in key populations.’”;⁷ and
- “Methodological recommendations for ensuring access of socially oriented non-profit organizations to services under the Russian Federation state program “Healthcare Development” in relation to “Prevention of HIV infection, viral hepatitis B and C” and implementation of regional health development programs.”⁸

These strategic documents make it possible to structure the work on HIV prevention, treatment, and care within the monitoring system of simple and interdependent indicators of progressive achievement of the public health goals both at the national level (“90-90-90”) and at the individual level.

Acting to improve outcomes along the HIV cascade is fully consistent with the interrelated concepts provided for in Russia’s primary health statute: “health protection,” defined as a system of broad-based measures with the participation of a wide range of people, and “medical care,” defined as a set of measures performed by medical workers.⁹

Together, health protection and medical care measures are targeted at:

- preserving and strengthening health;
- recognizing conditions or establishing the presence or absence of diseases; and
- eliminating or relieving patients’ symptoms, restoring or improving their health, employability, and quality of life.



Consolidated strategic information guidelines for HIV in the health sector, 2015.¹⁰

Health sector services in the cascade encompass prevention, treatment, and care interventions. The term “cascade” emphasizes that a sequence of services is needed to achieve desired impacts. The “cascade” concept also informs tracking of patients from one service to the next and highlights the gradual attrition of coverage of the eligible population over the steps of the sequence. Monitoring the cascade of services requires a consolidated set of indicators covering the entire sequence.

The terms **social and legal support** refer to activities aimed at meeting the legal and social needs of patients, including members of “key populations,” allowing them to overcome difficulties, including legal barriers, and thereby gain access to, and benefit from, needed health care and social services. By increasing access to diagnosis and treatment, and supporting the achievement of viral suppression, the ultimate result is an improvement in the quality of life of people living with HIV and a contribution toward realizing the human right to the highest attainable standard of health.¹¹



A project team based in a community-centred NGO platform

The project started with a team of 10 social workers. The community-based organization “Humanitarian Action” in St. Petersburg was chosen as the pilot site. During the project’s first year, social workers worked part-time, but to permit them to focus exclusively on the project, a decision was made to reduce the team to five social workers working full-time. As a result, they began to progress more quickly toward the declared targets.

The project showed that what clients need most is not the motivation, development, and maintenance of an ART regimen. Often, they need legal support in order to adhere to the medication regimen. This is due, in part, to the fact that many clients are also facing criminal charges.

Not all clients are able or have the opportunity to change their behaviour quickly. Given their active addiction, they often encounter barriers when moving along the cascade, including: criminal prosecution, administrative arrests, and deprivation of parental rights. At these stages, the social worker who works with the client on adhering to treatment turns out to be the closest and most trusted specialist. Therefore, basic legal training, the ability and skills to represent the client’s interests in court, along with knowledge of the regional legal specifics, are essential for social workers working to improve clients’ health outcomes along the cascade.



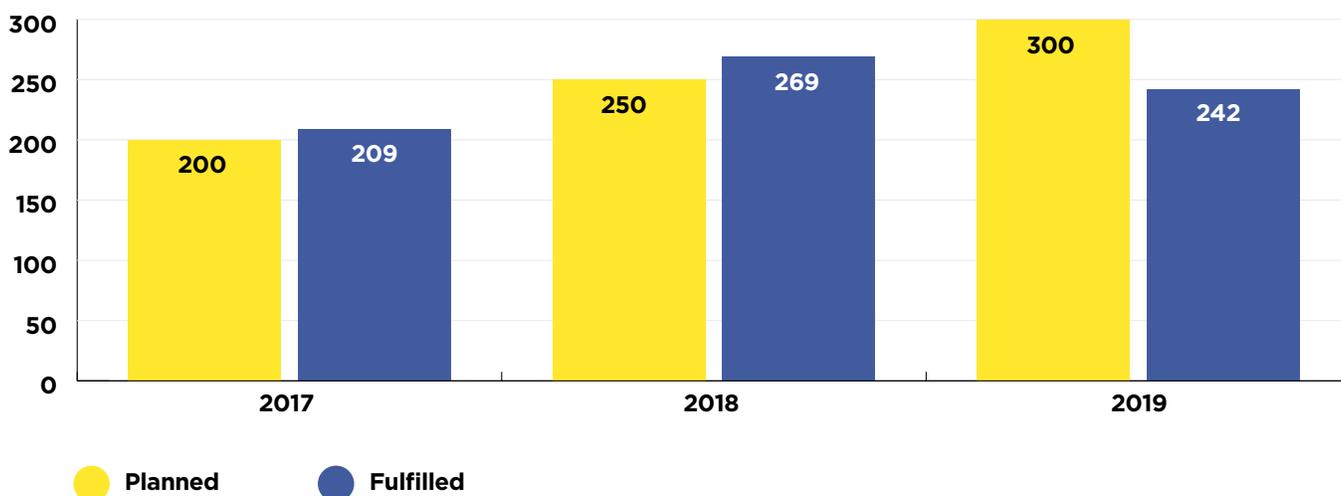
Project clients and social workers at the mobile point of prevention and medical care for PWID of the “Humanitarian Action” Foundation

Declared project indicators and targets

Year	Number of HIV+ clients who registered at the AIDS Centre (AC)	Number of HIV+ clients who received ART	Number of HIV+ clients who were brought to the AC and received services at AC for more than 12 months
2017	200 of 350 clients 	150 of 350 clients 	170 clients NB: This figure is the sum of the number of retained clients who were admitted for ART during Y1 and Y2 (47% of 150 clients admitted for ART during Year I, plus 50% of 200 clients admitted for ART in Year II). We could not measure this output for Y3 clients as the period for measuring retention in treatment extended beyond the project timeframe.
2018	250 of 350 clients 	200 of 350 clients 	
2019	300 of 350 clients 	250 of 350 clients 	

Overall, the project’s actual results over three years exceeded the targets agreed upon at the outset. In just three years (May 2017 – April 30, 2020), the project served 968 people, 288 of whom had been receiving services in the AIDS Centre for 12 months or more.

Number of HIV+ clients who registered with the AC

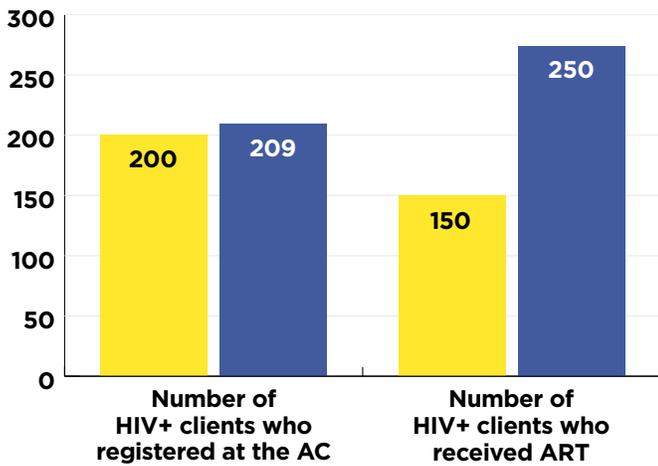


Achieved project indicators, 2017-2020

Year	Total number of clients accepted for support	Number of HIV+ clients who registered with the AC	Number of HIV+ clients who received ART	Number of HIV+ clients who were brought to the AC and received services at AC for more than 12 months
2017	279	209 of 279 clients 	174 of 279 clients 	288 of 404 clients (71% received ART in 2017-2018) 
2018	379	269 of 379 clients 	230 of 379 clients 	
2019	310	242 of 310 clients 	211 of 310 clients 	
Total	968	720 of 968 clients 	615 of 968 clients 	

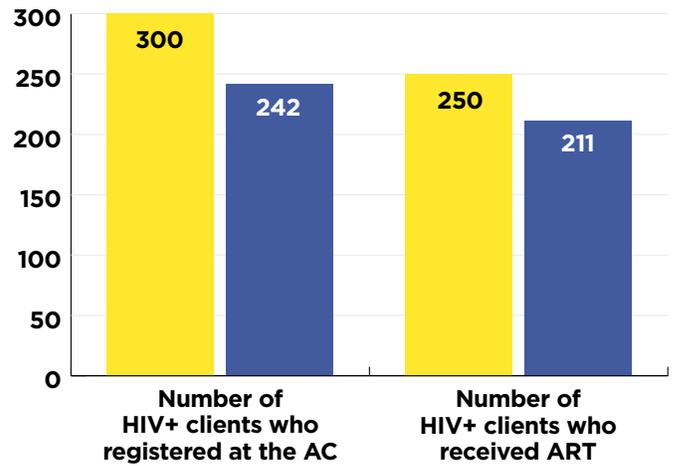


Results of the first year of the project



● Planned ● Achieved

Results of the third year of the project



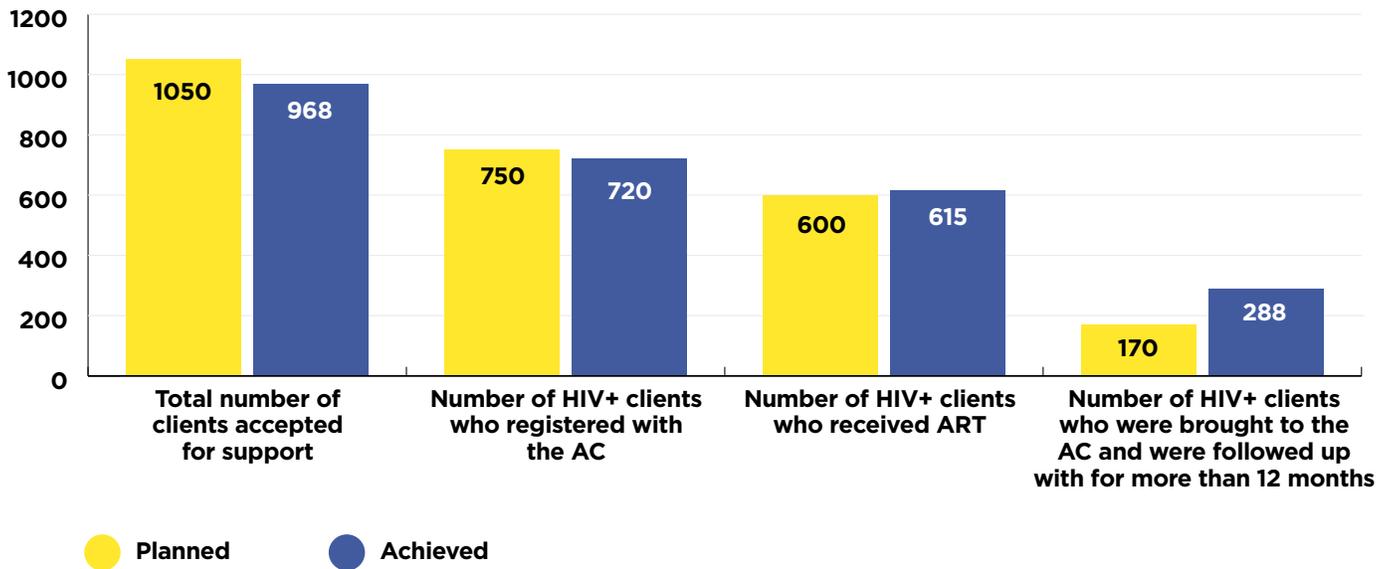
● Planned ● Achieved

This diagram shows the results of the final year of the project, during which qualitative and quantitative indicators were mainly achieved. The insignificant deviation between the planned and achieved performance and benchmark indicators for the “Number of HIV+ clients who came to the AC” (242 against 300 planned) and for the “Number of HIV+ clients who received ART” (211 against 250 planned) is explained by the fact that the organization simultaneously launched a new large-scale social support project, which attracted some lower-need clients. The clients who faced the most difficult legal barriers stayed with this pre-existing project.

The most significant indicator of the effectiveness of the project is that a total of 288 clients (71% of the 404 clients who received ART in the first and second years of the project) have achieved and maintained an undetectable viral load for more than a year.



Total number of clients at the cascade stages over three years



This diagram shows the overall quantitative indicators over three years.

This project was started with a cost of \$250,000 USD over three years. As a result, 968 clients were helped, 615 of whom started moving along the cascade and have received ART. These outcomes represent a good return on investment.

The following criteria were considered during project implementation and adjusting strategy where warranted:

- the effectiveness of the team of social workers in meeting the project objectives;
- the effectiveness of the proposed educational activities for the project staff; and
- the cost of implementing the project in relation to potential savings.

A review of the project, arrived at the following conclusions:

- The most effective team is the one in which each employee is 100% involved. Five full-time employees are more efficient than 10 half-time employees.
- The most effective tool for training and professional development is the study visits of the community legal workers to different projects in Russia and abroad to learn about best practices in social and legal support.
- Hiring personnel directly by the Legal Network rather than a grant making through an additional large Russian NGOs is more cost effective. Lower administrative costs save money for enabling great coverage by project activities.

An economic assessment was not the focus of the evaluation of the project, but some conclusions can be drawn.

Project costs can be divided into two large categories: the **costs of the project support and development** and the **costs of social and legal support**.

Project support and development

- Taxes
- Mandatory government payments and bank charges
- Training sessions and working meetings
- Salaries of administrative staff

Social and legal support

- Salaries of social workers and lawyers
- Reimbursement of costs for prompt reissuance of documents
- Procurement of take-away materials (syringes, condoms, ointments, etc.)

Cumulatively, the direct cost of supporting clients was about \$150,000 USD (the total cost of the project minus the cost of the project support and development). In general, this is about 60% of the total funding.

An average of \$150 USD was spent on support for each client, including the salaries of social workers. Of all clients, 615 people received ART and 288 clients achieved stable undetectable viral load.

Clients who received first-line ART medications were able to prevent the development of drug resistance, health decline, and complications, meaning that the cost of the project was offset by savings in the cost of patient treatment.

The cost of standard first-line ART ranges from \$182 USD (11,753 RUB) to \$2,032 USD (131,383 RUB) per patient per year. In 2019, the most common first-line treatment regimen (lamivudine 300 mg + tenofovir 300 mg + efavirenz 600 mg), cost 11,753 RUB (approximately \$182 USD) per year. The cost of the most common second-line ART regimen in 2019 ranged from \$390 USD (25,200 RUB) to \$1,567 USD (101,335 RUB) per patient per year.¹²

In the implementation of this project, \$111,930 USD was spent on support for 615 people, who were prescribed first-line ART at the minimum cost of \$182 USD for a one-year course. If they were subsequently prescribed a second-line regimen, in the case of non-compliance with the initial drug regimen or interruption of treatment (e.g. because of legal barriers), their treatment would cost at least \$390 USD (25,200 RUB) per patient per year, or \$239,850 USD for 615 patients.

In fact, due to the project's interventions, which prevented changes or interruptions in treatment, the project saved more than \$127,920 USD a year, illustrating how the costs of developing such social and legal support services can be recovered. Investments in the project will be fully recouped within a year and a half, after which the project will generate net savings of federal and regional funds. It should be noted that many clients require long-term follow-up; sustaining support to keep them retained on ART and virally suppressed will continue to pay off with further savings by preventing changes or interruptions in treatment.

At the same time, in cases where a client had dual diagnoses of HIV and TB, the project created favourable conditions in which such clients adhered to TB treatment without interruption and successfully completed it without developing drug resistance.

Treatment of drug-sensitive TB takes six months and is fairly inexpensive, in terms of the cost of the drugs. However, some of project clients have already attempted TB treatment and carry a drug-resistant form of the disease, which requires treatment for a year or more, including in-patient treatment, significantly increasing treatment costs. The table below compares the costs of treatment for drug-sensitive versus drug-resistant TB. The cost is calculated for multidrug-resistant TB (MDR-TB) and extensively drug-resistant TB (XDR-TB) using an average of 20 months of treatment; individual treatment times can vary depending on the specific needs of the patient.

The project has supported at least 200 clients with HIV-TB coinfection, who started ART and had to maintain adherence to this treatment as well as to TB treatment. Most of them had a standard (drug-sensitive) form of TB disease. Thanks to the project, these clients did not stop TB treatment and did not develop drug resistance, which would require switching to more aggressive and expensive drugs.

Average cost of TB treatment in the Russian Federation, per course of treatment¹³

Type of TB	Duration of treatment	Drug names	Course cost in rubles
Sensitive	6 months	isoniazid, rifampicin, pyrazinamide, ethambutol	2,460
MDR XDR	18-24 months	pyrazinamide, kanamycin, levofloxacin, cycloserine, prothionamide	91,000
MDR XDR	18-24 months	kanamycin, levofloxacin, bedaquiline, cycloserine, linezolid	719,000

As we can see, the potential saving was 88,640 RUB (\$1,130 USD) for each patient who received first-line therapy and did not switch to second-line therapy. By keeping patients on second-line therapy and avoiding switching to third-line therapy, the project potentially saved at least \$100,000 USD on drugs only, excluding the cost of in-patient treatment, doctors' work, and additional procedures.



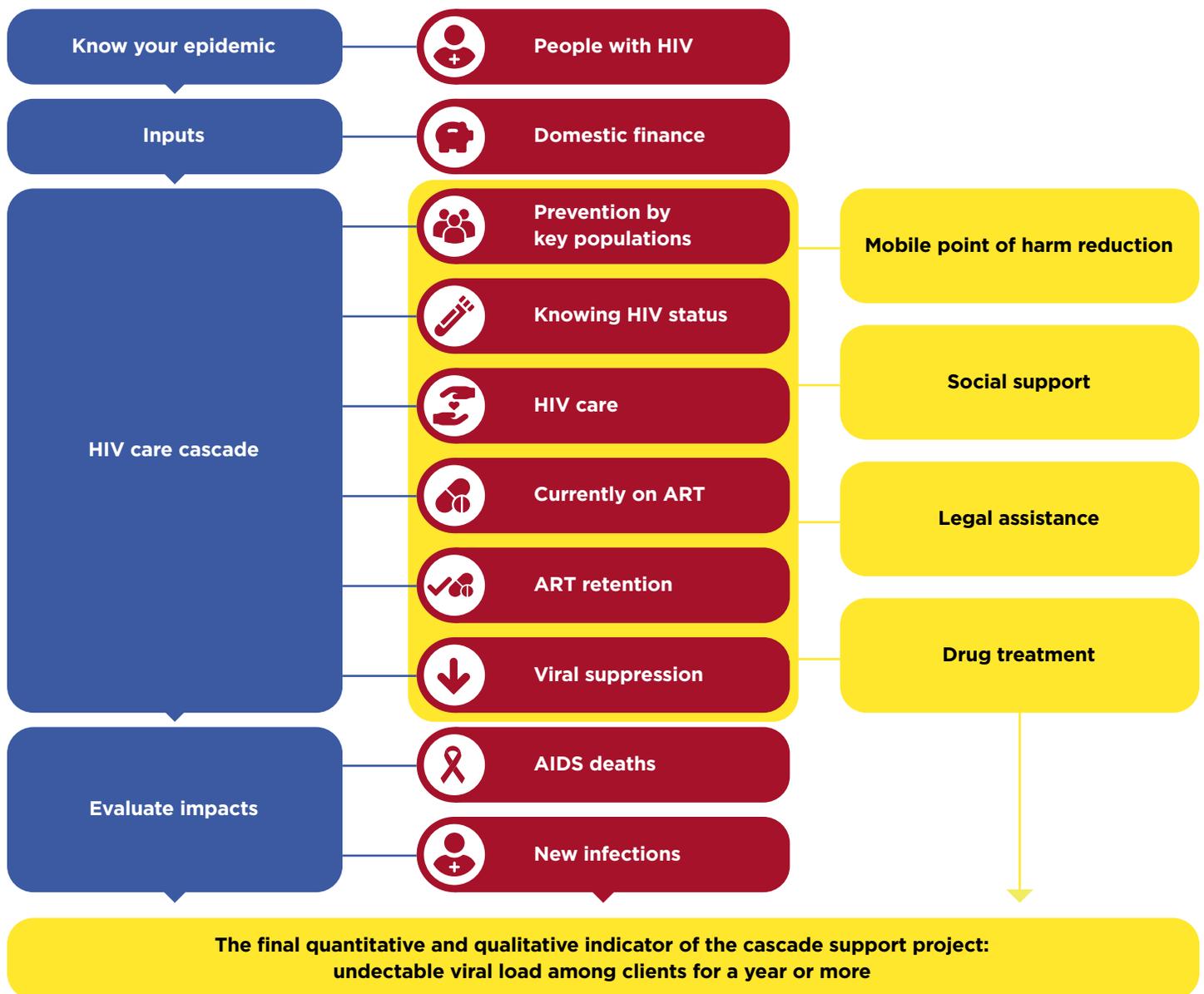
Counselling clients, documenting cases

Social and legal support scheme for improving the indicators along the HIV cascade

Figure 1 sets out the theory of change for the project: social and legal support enables clients to improve outcomes along the HIV cascade by overcoming the social and legal barriers that clients commonly face related to unjustified criminalization of drug use and discrimination against people who use drugs.

The project starts client engagement by providing access to low-threshold services. Once in a safe and comfortable environment, clients get the opportunity to take an HIV test, which starts them moving along the cascade. With the social and legal support provided by the project, they can reduce or remove a range of barriers to getting and adhering to ART, and ultimately achieve an undetectable viral load. Clients' adherence to ART for more than a year, as confirmed by their continued undetectable viral load, is the final point for monitoring clients within the project.

Figure 1: Theory of change



Client support within or along a cascade of services consists of activities to help clients overcome hardships they face that may interrupt their treatment. These hardships may relate to their health or psychological condition or be associated with a violation of their rights.

Social support does not exclude legal assistance, but the legal component is limited to simple activities that do not require special skills, such as assistance in registering with medical institutions or assistance in obtaining necessary documents required to access health care or other services.

One must understand that clients' problems in this context are mainly associated with the loss or lack of skills to fulfill their social needs independently. For example, a client may not know where to apply for a letter of verification of their residence or identity. In this case, the social worker can suggest where to go or accompany the client.

Social and legal support implies an emphasis on restoring or realizing the client's rights, including through representation in court or acting on behalf of the client vis-à-vis public authorities when necessary. This support can also come in the form of development and implementation of certain standard procedures for providing legal assistance with commonly encountered problems; in some instances, this requires some degree of special legal knowledge and skills, which can only be developed through additional training or education.

Legal support includes establishing a client's identity in court in cases when the client did not have a passport or other government ID before or arranging the defence in proceedings on drug offences when it is necessary to show the court that the client's rehabilitation is possible without incarceration. In general, if the main barriers to the client's movement along the cascade are legal, a case manager with experience in legal support and the appropriate skills is required, and therefore, a **specialist in social and legal support** should work with the client.

At the same time, if the barriers that a client faces are domestic or family issues, or the absence of motivation for treatment and associated health problems affecting their social activity, then this calls for typical **social support**.



Stages of support

In the project, social and legal support was divided into four stages:

1. Providing access to HIV testing
2. Registration at the AIDS Centre upon confirmation of the positive diagnosis
3. Receiving treatment
4. Achieving undetectable viral load and making sure that patient adheres to treatment

The first stage is ensuring low-threshold (widely available, affordable, and safe) HIV testing of all population groups, which helps to identify those who need HIV treatment. At this stage, those who need treatment should receive high-quality pre- and post-test counselling, including clear and up-to-date information about HIV, and should have access to social services (social workers) that can provide motivational counselling to help the patients move along the cascade, including supporting them in registering at a specialized medical facility for treatment.



Low-threshold access to testing (Photo: Artem Leshko)

The second stage is ensuring easy and timely access to high-quality health care services, namely, by registering the client in the AIDS Centre with an official diagnosis and ensuring they get an examination to assess their condition and the extent of disease. At this stage, noticeable legal barriers within key populations begin to arise. In Russia, people can receive HIV medicines and health care only in the region in which they are registered (temporarily or permanently). Many people in key populations do not have such registration, thus cannot access services.

In Russia, there exist both the Federal Register of Persons Infected with Human Immunodeficiency Virus and the Federal Register of Persons with Tuberculosis, which are regulated by government.¹⁴ However, these registers are still not fully operational due to the lack of a unified system for the coordination of public procurement of ART and TB medications. In 2020, the Ministry of Health will be purchasing ART based on the register data, in accordance with government regulation “Regulation on the organization of provision of persons infected with the human immunodeficiency virus, including coinfection with hepatitis B and C viruses, with antiviral drugs for medical use.”¹⁵

Due to significant internal migration in Russia, many people do not have access to treatment if unregistered in the region where they seek treatment. This problem is especially pressing for more socio-economically marginal PWUD, since their lifestyle, and the criminalization, can make it difficult to keep personal documentation in order, and often makes it impossible for a person actively using drugs to access ART.

The third stage is receiving treatment. The clinical guidelines of the Ministry of Health recommend that ART be given to all patients diagnosed with HIV, and urgently if the CD4 count is less than 200 cells/uL.¹⁶ In Russia, the cost of ART is covered by the national budget for all citizens. However, there are interruptions in the drug supply in the country.



According to the International Treatment Preparedness Coalition (ITPCru)¹⁷, as of March 2020, interruptions were predicted for the following medications:

As of March 1, 2020, the website of the Unified Procurement Information System contains information about 61 procurement competitions for 20 international non-proprietary name medications in various forms and dosages for a total amount of 24,306,828,256 RUB. As in previous years, pharmaceutical companies did not participate in the competition because the price for medications wanted by the government was too low and/or the other competition conditions were too hard to fulfill. By the application submission deadline, not a single application had been submitted for:

- Fosamprenavir oral suspension 225 ml (pediatric form), 201 packs in the amount of 562,283.48 RUB.
- Abacavir tablets 300 mg, 114 863 packs at a cost of 68,504,332.96 RUB.
- Raltegravir chewable tablets 25 mg (pediatric form), 695 packs at a cost of 1,345,110.41 RUB.

There are also numerous medical and administrative barriers that officially limit access to treatment. In addition to treating HIV, treatment for HIV-related comorbidities and other diseases is often required. For patients with multiple diagnoses, including dependence on psychoactive substances, treatment may be impossible or very difficult because their need to use will not allow them to comply with medical indications, and narcological treatment is not fully available in infectious diseases hospitals. Given the lack of opioid substitution therapy in the Russian Federation, the services available to PWUD are insufficient to provide many patients who use drugs with conditions for sustained adherence to HIV and/or TB treatment.

The fourth stage is keeping the patient adherent to treatment with an undetectable viral load. This is one of the key outcomes and measures of the HIV cascade. It reflects, on the one hand, the patient's adherence to the treatment regimen and, on the other hand, the availability and consistency of services supporting retention in care.

At this stage, the mechanisms of keeping the client "on the project's radar" are important, since when the main problems are fixed, the client can disappear until new hardships arise.

The consistency of harm reduction services is a perfect tool for interacting with and keeping in touch with the client at the fourth stage to support treatment adherence and viral suppression. The whole range of services in projects that work with a cascade, as well as the infrastructure of third-party services and the principles of interaction with clients and partners, is complex because the system exists in a constantly changing environment. It is influenced by trends in grantmaking by donors, the political and legal environment, the epidemiological situation in a particular region, and the level of partnerships with government services.

There are many barriers that clients face at all points along the cascade. These are the risks and difficulties that must be considered when planning client support, including:

- acute drug withdrawal symptoms;
- long support period;
- remoteness of medical institutions;
- lack of drug treatment during the in-patient TB treatment;
- inappropriate assessment of one's own health;
- low adherence to treatment for HIV and/or TB;
- difficult financial situation;
- self-stigmatization and discrimination;
- lack of rehabilitation centers for women with children;
- fear of deprivation of parental rights when seeking help from public social services; and
- problems with law enforcement and penal authorities, including police harassment, criminal charges and prosecutions, administrative arrests and sanctions.

Overcoming legal and social barriers

The federal government's Instructional Guidelines on "Development of a typical interdepartmental program on HIV prevention in key populations"¹⁸ define **social support** as a process during which the health care and social needs of key populations are met, and members of these populations receive assistance in accessing the necessary social and health care services. The result is an improved quality of life for clients.

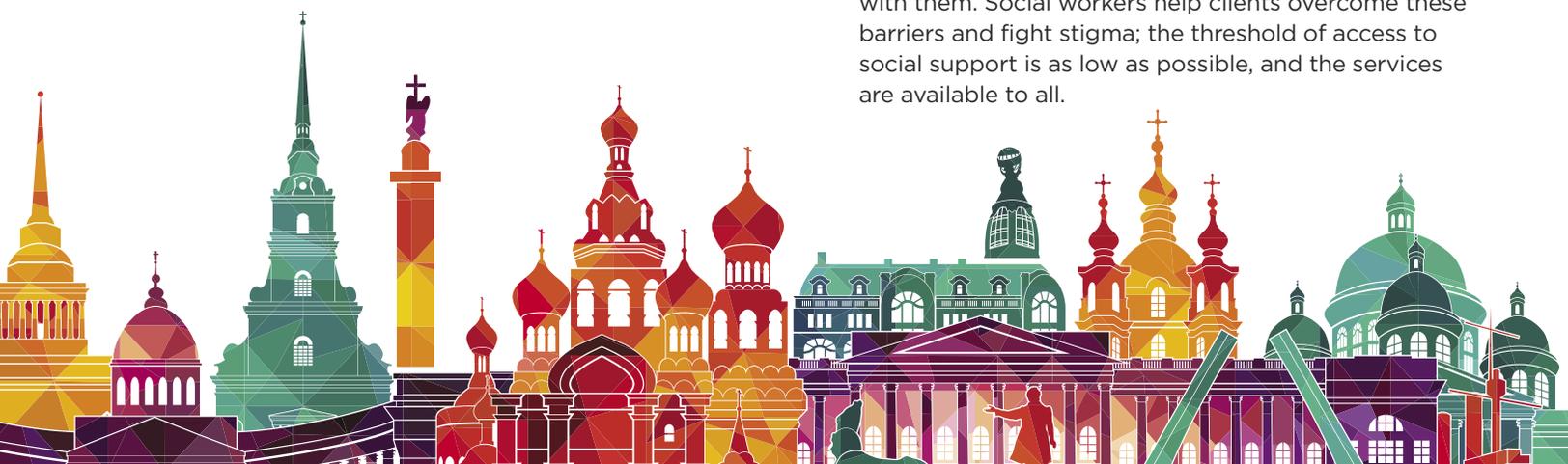
This approach is consistent with the definition of **social support** provided in Art. 22 of the Federal Law of December 28, 2013 No. 442-FZ "On the Basics of Social Services for Citizens in the Russian Federation." According to Art. 22, social support means the facilitation of the provision of health care, psychological, pedagogical, legal, and social assistance that is separate from direct social services themselves. In other words, social support serves as a bridge between the client and social services. According to the Law, social support is performed by organizations that provide such facilitation in collaboration between them and different state bodies and services. Social support activities are listed in the individual program for a client.

Taking this provision of the federal law as its official starting point, the project adopted an approach to social and legal support that included the principle of collaboration with public and municipal services and the principles of interaction with client based on the individual program/plan. By keeping the social support activities within the national legal framework, the project ensures better sustainability of the project's work.

These guidelines indicate the need to establish HIV prevention programs specifically tailored for key populations, which programs help keep patients in the social services system to develop and maintain their adherence to ART.

The services' appeal to clients is ensured by two components: (1) access to harm reduction packages for free (sometimes referred to as the motivation packages) and (2) assistance in solving legal problems and overcoming discrimination.

- **Motivation packages** consist of sterile needles and syringes, sanitising tissues, and other items that reduce the risk of spreading HIV infection (and other sexually transmitted or bloodborne infections), depending on the specific needs of the key population, that motivate and support people to change their behaviours to lessen the chances of HIV infection and other harms, and to seek preventive services from specialized public and non-governmental organizations.¹⁹
- **Assistance in solving legal problems and overcoming discrimination** stimulates long-term engagement with the client, which in turn provides for the client's better adherence to ART and retention in medical and social services. "Overcoming discrimination" in the context of social assistance for PWUD includes efforts to fight the underlying stigma in which discriminatory actions are rooted. Stigma is at the core of most of the legal and social barriers that prevent people who use drugs from accessing guaranteed services or remaining engaged with them. Social workers help clients overcome these barriers and fight stigma; the threshold of access to social support is as low as possible, and the services are available to all.



As recommended by WHO, UNODC, and UNAIDS, a comprehensive package of HIV-related interventions for people who use drugs includes the following components:

- Needle and syringe programs
- Access to drug dependence treatment services
- HIV counselling and testing
- Access to ART
- Prevention and treatment of STIs
- Access to condoms
- Targeted information distribution and education of partners
- Prevention, vaccination, and treatment of viral hepatitis
- TB prevention, diagnosis, and treatment

In other countries, a similar approach is indicated, for example, in the Health and Human Rights Resource Guide developed by the François-Xavier Bagnoud (FXB) Center for Health and Human Rights at the Harvard School of Public Health.²⁰ The European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) also supports interventions of the WHO comprehensive package.²¹



The work of syringe exchange site

Management of project activities and interaction with partners

Interaction with a wide range of partners from the municipal, public, academic, and civil society sectors, in Russia and internationally, is the basis for successful work providing social and legal support. This approach is effective and enables agencies to provide the clients with a wider range of services.

For example, the social security system in St. Petersburg is organized as follows: Each district of the city (the district is the administrative-territorial subdivision of the city, i.e. the regional government, not the municipal authority) has social security office (SSO). The objectives of the SSOs include, among other things, “social protection of the population, health care and sanitary and epidemiological wellbeing of the population.” In order to facilitate the operation of the SSOs, the districts and city authorities have to “to ensure the provision of social support, public support, emergency support and support in difficult life situations to various categories of citizens in accordance with the law.” The SSOs provide social services to people in difficult life situations based on Federal Law FZ-442 “On the Basics of Social Services.” There are social workers in the SSOs. However, people who use drugs are not always recognized as people “in a difficult life situation,” nor does everyone have the opportunity to reach a social worker. Therefore, Art. 22 of the federal law provides for social support, which is not a direct social service itself, but instead serves as a bridge, helping people access health care, psychological, pedagogical, legal, and social assistance.



Access to social services as stipulated by law does not always guarantee that a person can receive this service in full.

For example: the country provides citizens with free ART, but some of the drugs require refrigeration. A social worker working with key populations may face a situation when the client does not have a refrigerator. In theory, the client can receive treatment, but in fact, they have nowhere to store the medicines, which deteriorate, and the client stops treatment. There are no medical indications for changing the course of treatment in this situation, but there is a barrier to high-quality and uninterrupted treatment. Such issues can be easily resolved on an individual basis through mediation with the medical doctor or a medical institution that is authorized by make a decision to change the ART medication.

The fundamental differences between social support implemented by NGOs, and the support implemented by public services such as SSOs, are the level of involvement and the duration of support. NGOs should take a comprehensive approach to social support, using both their own resources (and partner organizations) and the resources of public authorities.

The key document, which guarantees legality, voluntariness, and mutual understanding between the social worker and the client, is **the social support contract**. The purpose of the contract is to formalize the relationship between a client and an NGO, so there is a clear framework for the work that the NGO is doing together with the client or on behalf of the client, and always in the interest of client and with the client’s informed consent. Signing a contract is a demonstration of commitment by both parties to the basic principles underlying the relationship between them, such as a respect for human rights, pro bono services, acting in good faith and in the best interests of a client, and confidentiality of personal data. The contract helps clients and service providers understand the nature of their relationship, so there are no false expectations on either side.

A clear framework for the relationship is also helpful in other ways. For instance, if an outreach worker at an NGO must testify before the court, it is easier for a judge to recognize the outreach worker's relationship with the client when there is a contract. In some countries, NGO staff can be admitted as so-called public defenders in criminal cases at the request of the accused. A judge is much more likely to admit a layperson as a public defender in a criminal case when there is a contract outlining the reasons for, and parameters of, the relationship between the accused and the person who is requesting to be her or his public defender.

There is no single form or structure for this type of contract. Therefore, an NGO or outreach worker can vary the number and the nature of the rights and responsibilities of each party, depending on the particular circumstances. See a sample contract in **Annex 2**.

One of the areas of social support implemented by NGOs within the cascade of services is assistance in interaction with the state in conditions when the client cannot receive state-guaranteed services.



Meeting with the project partners

When building relationships with government authorities, it is important to do so in a non-confrontational manner, so that assistance is provided not through complaints and courts, but within the framework of existing legal norms and with a mutual understanding of each other's responsibilities.

The step-by-step algorithm for providing social and legal support in the context of HIV infection is described in detail in the UNDP legal empowerment handbook "Know Your Rights, Use Your Laws."²² In this project, the following steps of social and legal support were applied:

Step 1: Documentation, with the signing of a social support agreement, an assessment of the client's needs, and preparation of an agreed social support plan.

Step 2: Mediation to resolve legal issues as soon as possible through partnership and cooperation, restoring the trust of the client and the official/doctor.

Step 3: Dealing with authorities, including appeals and complaints in the interests of the client.

Step 4: Working with law enforcement, judicial authorities, as well as the criminal executive inspection in the interests of clients who are in conflict with the law.

The most important component of social and legal support within the project was the development of strategic partnerships in the interests of the client. The partners included representatives of government authorities, health care systems, lawyers, legal clinics, human rights defenders, scientists, and journalists.

Mediation can be an effective tool for achieving goals, as well as for turning a one-time appeal to an official into a long-term cooperative relationship. Formalized interactions between NGOs and public/municipal services frequently leads to faster and better resolution of most issues.



Meeting with a wide range of civil, municipal, state, and academic partners

The steps mentioned above were built into the HIV cascade according to the following principles:

1. Access to testing, registration at the AIDS Centre, receiving ART, and reaching an undetectable viral load were considered as objectives when establishing a contact, documenting the case, and subsequently supporting a client.
2. Each individual plan of social support and legal support for a client included targets and indicators to measure their achievement along the HIV cascade.
3. Solving legal issues has always been a part of motivating and supporting a client to access and adhere to treatment.
4. High-quality social and legal support helps maintain contact with the client and support the client's ability to adhere to treatment and achieve viral suppression.



Two categories of cases of social and legal work in supporting clients along the cascade should be highlighted: complicated and common cases



Complicated cases:

Very often there is need to solve problems that are the result of a combination of factors. These include psychiatric problems (for example, impaired perception due to brain damage because of opportunistic complications), the use of new little-studied psychoactive substances, a person being investigated or wanted on suspicion of committing a crime, lack of citizenship, etc.

Complicated case study: Igor: Person who uses drugs, has HIV and TB co-infection, and is stateless as a result of court decision

- Received a referral to the Botkin Infectious Disease Hospital
- Admitted to hospital
- ART was brought by a community legal worker (because he cannot receive therapy in a hospital as he lacks citizenship and registration in St. Petersburg)
- Got advice at Visa and Registration for Foreigners Office (VRFO)
- Documents for identification have been submitted to the VRFO
- After discharge, he was registered with the TB clinic where he lives and continues to receive TB drugs
- Buys ART on his own at the pharmacy



Common cases:

The commonly occurring situations have been sufficiently studied and well-developed algorithms of work exist for these cases. For example, it is commonly the case that people lack the necessary documentation (passports, insurance number of individual personal account [INIPA], registration at the place of residence).

Type of assistance:

- Issuing temporary registration
- Assistance in obtaining a certificate of a homeless person in “Nochlezhka.”²³

Common case study: Masha is a person who uses drugs, lives with HIV, is homeless with a minor child, and has lost all documents. Her newborn child was taken from a dysfunctional apartment.

- Registered in “Nochlezhka” as a homeless person
- All documents have been restored (passport, INIPA, health care insurance)
- Admitted to the City Narcological Hospital, where she underwent a course of detoxification and rehabilitation
- Registered with the guardianship authority
- All vaccinations have been administered, and a vaccination certificate received
- Registered in the AIDS Centre
- Started taking ART
- Received permission to visit her child
- An agreement was reached with a specialized NGO on the placement of the child with another mother
- **Masha is committed to ART, employed, and continues to visit her child.**

Type of assistance:

- Assistance in registering homeless persons in St. Petersburg state public institutions “Centre for registration”
- Assistance in obtaining social housing
- Assistance in access to treatment for HIV, TB, and other socially significant diseases

Common case study: Alexander is a person who uses drugs, has both HIV and TB, is not registered in the AIDS Centre, has limited mobility and is homeless

- Admitted to the TB clinic
- The necessary documents have been restored (passport, INIPA)
- Registered in the Center for Registration of Homeless Persons in St. Petersburg
- A pension has been arranged
- Registered on a waitlist of people in need of housing
- An individual program for the provision of social services was developed (jointly with the Social Support Services of the Frunzensky District)
- An application has been submitted for a free residence for 11 months
- Was sent to a TB rehabilitation centre to continue treatment
- ART drugs were delivered to a TB sanatorium in the Leningrad Region to continue HIV treatment alongside TB treatment

Type of assistance:

- Solving the problem of adherence to ART
- Assistance in obtaining benefits, disability pensions
- Help in solving problems with the law

Common case study: Maxim is a person living with HIV who injects drugs. He was convicted more than 20 times for drug-related offences under Articles 228, 158, and 161 of the Criminal Code of the Russian Federation. The Correctional Service Officer brought a case to the court to cancel the conditional sentence, as Maxim did not check in with authorities and did not undergo drug dependence treatment.

- Completed “detox” at the City Narcological Hospital
- Used the drug “Vivitrol,” works with psychologists
- Registered in the AIDS Centre
- Started taking ART
- Is undergoing rehabilitation at the Department of Medical Rehabilitation
- A character reference was presented in court, considering the work that has been completed

The judge postponed the hearing in order to allow further assessment of Maxim’s progress and, if Maxim remains sober, the judge will reject the Correction Service’s petition to replace the conditional sentence with a prison term. He continues to take ARVT drugs; his viral load is undetectable.

Type of assistance:

- Drug/alcohol addiction (The City Narcological Hospital accepts patients with a referral from the “Humanitarian Action” Foundation)
- HIV/drug addiction and pregnancy
- Representation of clients’ interests in court

Common case study: Kira is a person who uses drugs and lives with HIV. She lost all documentation and has been convicted 27 times for the criminal theft under Art. 158 of the Criminal Code of the Russian Federation and has served three sentences in places of detention.

- The necessary documents were restored (passport, IPPSS, Individual Taxpayer Number)
- Completed detox at the City Narcological Hospital
- Used the drug “Vivitrol,” works with psychologists
- Registered at the AC
- Started taking ART
- Is undergoing rehabilitation at the Department of Medical Rehabilitation
- A character reference was presented in court, considering the work that has been completed

She received a conditional (i.e. non-custodial) sentence of 11 months with a probation period of 2.5 years, is committed to ART, and her viral load is undetectable.



Monitoring of the impact of social and legal support on health outcomes, using the indicators along the HIV cascade

During this social and legal support project, a unique monitoring system was created that enabled recording the impact of support on the cascade indicators, considering the following assumptions and limitations:

1. The project accepted clients for social and legal support when there were reasonable grounds to assume that without such services, the client either would not start moving along the HIV cascade or that the movement would be complicated by the client's drug use.
2. Viral load indicators were monitored based on self-reporting of clients who received social and legal support.
3. In the project reporting, clients were tracked by codes to protect personal data.
4. Social and legal support was a team effort with the possibility of dividing areas of work between social workers at their request (for example, some social workers worked on criminal cases, and others worked on cases of restoration of parental rights).
5. Social and legal support was treated as a service to improve health outcomes along the cascade, but not as part of advocacy activities to remove systemic barriers. At the same time, the project had the task of tracking and documenting systemic barriers to help resolve them in cooperation with public authorities. (See Annex 5 for systemic problems identified and attempts to solve them).

As part of the project, a simple and informative reporting form was developed, which also served to track the impact of case management on the following project indicators:

Quantitative indicators:

- The number of clients who got access to initial HIV testing.
- The number of HIV+ tests in relation to the number tested.
- The ratio of clients registered with specialized medical institutions to the number of clients with diagnosed HIV.
- The ratio of clients who received ART to the number of clients who registered with a specialized medical institution.
- The number of patients who achieved undetectable viral load for twelve months or more in relation to those who received treatment.

Qualitative indicators:

- The nature of the legal, social, and other barriers that prevent patients from accessing services on the cascade.
- Logged changes in legal, social, and other conditions that prevent patients from receiving services along the HIV cascade.
- Satisfaction of social workers with the support of professional lawyers (measured in part quantitatively by Likert scale).
- Satisfaction of professional lawyers with the actions of social workers on social and legal support (measured in part quantitatively by Likert scale).
- Customer satisfaction with the project services (measured in part quantitatively by Likert scale).

When planning a project, it is necessary to establish dynamic indicators, considering that the project will be picking up speed for some time, and that some changes will occur as a result of external factors (changes in the law, the emergence or reduction of certain services, decrease in funding, staff changes).

It is impossible to definitively separate all quantitative and qualitative indicators. A complex case can take up as much of a social worker’s time as they would usually spend on three clients. For example, disability registration may require several hundred hours of waiting in lines.

Below are the examples of information recorded during the social support activities along the cascade to inform monitoring and evaluation of the project’s impact in achieving the goals and targets:

Logged information	Explanation	
Client’s first and last name	Client ID; allows tracking dynamics. It is recorded in the social support agreement. In reporting tables, it is logged by code.	
Date of registration in support service	In most cases, this is the date of the first interview if the interview and the conclusion of the social support contract do not happen at the same time.	
Client’s code	This must be indicated in all consolidated reporting tables to protect the client’s personal information. The full name is recorded only in the social support contract and in the documents necessary for work with the authorities.	
Logged information	Type of indicator (quantitative, qualitative)	Explanation
HIV status +/-	Quantitative	+/-
Case description, completed work	Qualitative	Based on data obtained during interviews and additional information obtained during social support. Brief information of no more than 300 words is required for interaction with partners, including doctors, experts, and lawyers.
CD4 cells count (CD4) at the moment of registration with support service	Qualitative	Establishes a baseline from which the dynamics can be traced
Viral load (VL) at the moment of registration with support service	Qualitative	
ART (yes/no)	Quantitative	Allows to set the exact number of clients on ART (at the beginning/at the end)
Date of last contact	Qualitative	Assessment of the level of contact with the client and the stability of the relationship
CD4 at the moment of the report	Quantitative	Allows to see the difference between the number of those who do not know their indicators, and those who do, and to track the client’s progress (e.g. “were few, became many”)
VL at the moment of the report	Quantitative	Allows to see the difference between the number of those who do not know their indicators, and those who do, and to track the client’s progress (e.g. “VL was determinable, became undetectable”)
Complications and comments		Anything that doesn’t fit into other columns
Where to look for a client?		Identifier (phone number, address, known “hangout”)

This table combines simple wordings that are clear and easy to evaluate. In addition, quantitative indicators (CD4, VL) enable to evaluate the clients moving along the cascade and maintaining an undetectable viral load.

For example, the log for a particular client, updated as appropriate, might indicate the following information: the client did not know his VL and immune status indicators at the time of initial intake; in the process of receiving social support, he registered with the AIDS Centre, was tested for HIV, STIs, HCV, TB, and received the result. There are many such clients. Logging this kind of data enables support workers to obtain numbers useful for tracking the impact of the project and progress toward achieving the project's targets: for example, there were 30 clients who did not know their viral load and immune status indicators at intake; three months later, 15 of them had received this information, and eight months later, 10 of them had achieved an undetectable viral load.



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