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The Most Vulnerable Suffer

ACCESS TO SOCIAL AND MEDICAL ASSISTANCE FOR PEOPLE LIVING WITH HIV AND DISABILITIES

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Summary

The *Access to social and medical services for persons with disabilities living with HIV* study was carried out in May and June 2022 with the objective of identifying barriers and complexities for people living with HIV and disabilities in Russia during the coronavirus pandemic and at the outset of the war in Ukraine.

The study included analyses of regulatory statutes and of semi-structured interviews with 10 people living with HIV in the cities of Kaliningrad and Yekaterinburg (seven men and three women), as well as with three social workers. All study participants provided informed consent. All study participants had previous experience with the use of injection drugs. Average age was 48 years (39-52); average time after diagnosis with HIV was 14 years; average time with an officially registered disability was seven years. Participants generally were people with musculoskeletal disorders of diverse etiologies and disorders of the central nervous system; all participants have experienced difficulty with mobility and finding employment as a result. Study participants cited pension payouts below the poverty level, inability to work, and absence of relatives able to provide material support as primary causes of financial difficulties they encountered.

The study identified significant barriers to people getting their disabilities diagnosed and officially registered, independent of COVID or war. These barriers grew as a result of restrictions put in place in March 2020 to combat the spread of COVID-19, followed by the social and economic crisis caused by the war in Ukraine. Besides adding legal and policy barriers, the war also had a negative impact on mental health, stigma, and quality of life.

The study ends with the conclusion about the essential role of social services organizations in providing support for people with disabilities. These organizations must be brought into the process of supporting people with disabilities, including vulnerable subgroups such as people living with HIV and tuberculosis. The efforts of these organizations should focus on social, medical, and legal support specific to disabilities, HIV, tuberculosis, and factors such as stigma and discrimination faced by people with disabilities as well other groups who are particularly affected by HIV and tuberculosis (people who use drugs, formerly incarcerated people, LGBTQ people, migrants, and women). Health professionals, social workers, and staff of municipal services shall receive training on the implementation of the Convention on the Rights of Persons with Disabilities. Laws and policies of Russia shall be reviewed and brought in line with the Convention, taking into account recommendations of the Committee on the Rights of Persons with Disabilities to the Russian Federation in 2018.

Introduction

One of the advantages of sociological research based on qualitative methods is the ability to generate new theories and questions that were not previously evident. In this project, one such profound issue is: why do individuals living with HIV who have used injection drugs and encounter constant stigma and discrimination due to this history strive to register for official disability status, despite the many barriers and modest payouts and benefits to which they would be entitled with this status?

Participants in this project, for whom the average age is 48 years, have spent the majority of their lives unsettled: they have used drugs, they have been treated for drug dependency, they have been debtors owing back rent, utilities payments, or fines; they have spent time in prisons or penal colonies; they have encountered constant violations of their rights, discrimination, and violence; and, finally, they have been left with many chronic illnesses and on the verge of poverty.

The primary objective of this project is to describe the barriers and difficulties that these individuals encountered during the new crises in their interactions with government institutions charged with providing medical, social, and material assistance to all who require it.

These new crises — the COVID-19 pandemic and the war in Ukraine — have exacerbated existing difficulties and brought new ones. Accordingly, the question of why people living with HIV, disabilities, and many illnesses expend their resources to preserve their status as people with disabilities in the Russian Federation, despite the exceedingly meager pensions, the complexity of interactions with government entities, and other barriers, remains open. One unexpected and counterintuitive result of this project is the question of **why people living with HIV and disabilities in Russia — to whom the government has not provided essential support in the form of effective programs to reduce harm, opioid substitution therapy, science-based rehabilitation programs for drug dependency that include job placement assistance, as well as legislative measures to reduce sentences for crimes associated with the purchase and use of drugs — nevertheless strive to integrate into society.** This desire is based on decades spent living outside socially approved roles and constructs, without acceptance from loved ones, outside a "normal" life. For such people, receiving disability, pensions, and benefits is necessary for survival, but is also a ticket to another life, one they have never experienced before. We will open and close this report with a quote from one of the participants, who died before this project was complete and did not have time to realize her dream of visiting Kamchatka:

"I simply want to live, because **during that life, before prison and drugs, I wasn't living.** I only began living once I got out of that. **I just would like to live that quality of life that we didn't experience."** (Female, 45, Kaliningrad)

Description of inclusion criteria and relevance of research

International scientific literature describes research directed at the study of vulnerable population groups after the implementation of measures to prevent the spread of SARS-CoV-2. During the first two and a half years of the pandemic, the majority of people living with chronic illnesses, and those with acute conditions, encountered additional difficulties, growing uncertainty, and increased risks to their health and welfare every day.[1]

In the Russian Federation, the primary difficulties encountered by people living with HIV during the COVID-19 restrictions included more difficult access to antiretroviral therapies (ART), lack of equipment required for testing of immune status and viral load, complications with getting appointments to see infectious-disease and other specialists, and an inability to get regular doctor's appointments.[2] Another shock for people living with HIV was the Russian invasion of Ukraine and the many sanctions against the country enacted by other governments, which have negatively affected quality of life and access to medications, as well as internal Russian trends, such as reallocation of budgetary resources for military needs, sharp reductions in the availability of medical specialists, inflation, and more.

The negative effects of the lockdowns and the war are even more palpable for pensioners and people with disabilities. People living with HIV and disabilities are in the most complicated situation, especially considering external factors that, even before the pandemic and the war, significantly lowered quality of life and hindered access to effective medical assistance for people with disabilities living with HIV. Such factors include the closure of many non-profit organizations (NPOs) working with vulnerable population groups, restrictions placed on the activities of foreign social services organizations and programs within Russia, universal aging, and the high level of stigma and discrimination against people living with HIV and people who inject drugs.

Legislation regulating disabilities and HIV

Before beginning an examination of the legal status of people with disabilities in the Russian Federation, we should first define "disability."

One of the primary regulatory and legal enactments establishing the rights of people with disabilities is the UN Convention on the Rights of Persons with Disabilities (CRPD). This international agreement was ratified by the Russian Federation and is therefore part of the nation's laws.[3]

According to Article 1 of the CRPD, "persons with disabilities" shall include those with long-term physical, psychiatric, intellectual, or sensory impairments, which, upon encountering various barriers, may hinder their full and effective participation in society on an equal basis with others.

As is clear from this definition, disability consists of a couple of criteria:

1. The presence of long-term impairments.
2. An inability, due to such impairments, to overcome barriers that may hinder their full and effective participation in society **on an equal basis** with others.

At the core of this concept is not the medical aspect, but rather the societal. Accordingly, society and governments must not only provide medical assistance but also foster conditions that allow all people with disabilities to participate in society on an equal basis with others; that is, they must create conditions that support the full enjoyment of human rights and freedoms unencumbered by discrimination of any type.

The accepted medical model in Russia emphasizes diagnosis of patients, their illnesses, and all types of impairments — physical, intellectual, sensory, and psychiatric. In social models, disability is viewed as a cumulative effect of stigma and discriminatory policies that restrict the participation of such people in society on an equal basis with others.

Today in Russia, despite the adoption of the UN Convention, social policy toward people with disabilities is based on the medical model. *Federal Law On Social Protections for Persons with Disabilities in the Russian Federation No 181-FZ of 24 November 1995* defines people with disabilities as "anyone experiencing a deterioration of their health associated with bodily dysfunction caused by illness, trauma, or defects that restrict daily living and generate a need for social protections." This definition medicalizes disability status without any accounting for societal or environmental barriers. As a result of this approach, medical services remain the priority, while social work with people with disabilities remains outside the social policy agenda.

According to Article 1 of the *Federal Law on Social Protections for Persons with Disabilities in the Russian Federation*, "disabled persons" are defined as anyone experiencing a deterioration of their health associated with bodily dysfunction caused by illness, trauma, or defects that restrict daily living and create a need for social protections.

The law further defines "restrictions on daily living" as a complete or partial loss of the ability or capacity to live independently, move independently, orient oneself, socialize, control one's own behavior, learn, and engage in work activities.

It is not difficult to see that the wording used in the federal law makes no mention of the need to participate fully in society on **an equal basis** with people who have no health impairments.

Both the convention and Russian law state the need for cooperation between civil society and government to ensure the full enjoyment of rights by people with disabilities.

The Convention defines "discrimination on the basis of disability" as any distinction, exclusion, or restriction on the basis of disability with the purpose or effect of impeding or denying the recognition, enjoyment, or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other realm. It encompasses all forms of discrimination, including denial of reasonable accommodation.

The Russian Federation, like other state-parties to the Convention, has committed to providing for and supporting the full enjoyment of all human rights and fundamental freedoms by all persons with disabilities, unencumbered by discrimination on the basis of their disability.

To fulfill this commitment, Russia is required to, for example:

- Enact all necessary legal, administrative, and other measures to guarantee the rights recognized in the Convention;
- Enact all necessary measures, including legal measures, to change or repeal existing laws, decrees, customs, and precedents that discriminate against people with disabilities;
- Provide for, in all policies and programs, the protection and support of the human rights of people with disabilities; and
- Refrain from any actions or methods that violate the Convention and ensure that government agencies and institutions act in accordance with the Convention, etc.[4]

Another important commitment of the Russian Federation is to engage in close consultation with civil society entities (NPOs) representing the interests of people with disabilities during the process of developing and applying laws and policies.

It is worth noting that Russian legislation also literally requires the government (specifically the executive branch) to cooperate with NPOs.

Thus, executive branch institutions at all levels, regardless of organizational or legal configuration or form of incorporation, shall engage authorized representatives of civic associations of people with disabilities in the preparation and adoption of resolutions that affect the interests of persons with disabilities. Resolutions adopted in violation of this guideline may be declared invalid by court decision.[5]

This is how both international and national laws underscore the critical role played by civil society and civic organizations in the implementation of government policy toward people with disabilities.

Russian law defines disabilities as belonging to Groups I, II, or III, depending on the degree of impairment. As a rule, disability status is granted for a defined period: two years for Group I, and one year for Groups II and III. There are exceptions to this rule that permit the establishment of disability status for an unlimited period.

Determination of disability group requires analysis of two criteria:

1. Degree of bodily dysfunction.
2. Degree of restriction on one or more categories of daily activity.[6]

As stated above, disability status is generally determined for a defined term of from one to two years. One month before the end of the term, people with disability status must undergo recertification in order to renew their status for another term.

In some cases, disability status is certified for a longer or even for an indefinite term. For example, the category of "child with disabilities" may be certified for an extended term (including until the child's 18th birthday) for illnesses and incurable impairments noted in the law. Among others, this list will include HIV that has reached the secondary illnesses stages (Stages 4B, 4C) and in the terminal fifth stage.[7]

Procedures for certification of disability status

To certify disability status, a citizen must undergo a disability determination by Medico-Social Evaluation (MSE).[8]

1. Obtaining an MSE referral.

In order to receive an MSE referral, it is necessary first to visit a medical facility for observation, after which the medical facility will schedule a medical panel to determine whether to refer the patient for an MSE. After the medical panel's decision, the patient must provide written consent to undergo the MSE.

If the medical panel refuses the referral, the patient is given a copy of the medical panel's report, which may be appealed. Appeals are submitted to the local offices of Roszdravnadzor (Russian Federal Healthcare Oversight Service) (if the medical facility is at the municipal or regional level) or directly to Roszdravnadzor itself (if the medical facility is part of the federal system).

2. Disability determinations

Disability determinations may take place at local, regional, or federal MSE offices depending on the objectives noted in the referral.

The MSE referral is registered upon receipt by the MSE office, and the patient (or their representative) is informed either by telephone (including text message) or by registered letter. In addition, a notification is posted to the user dashboard in the patient integrated portal.

Upon review of submitted documents, the MSE office decides whether the determination will be conducted with the patient present (including by a visit to the patient's location or via communications technologies) or without the patient. This decision is made with consideration given to the patient's preference.[9]

Disability determinations with the patient present are conducted in the following locations:

- At MSE offices (regional, federal), with the patient travelling to the office;
- At the patient's location if the patient cannot travel to the office due to health conditions confirmed in the medical panel's report;
- At a social services facility where the patient is receiving social services on an inpatient basis (for example, elder care facilities, orphanages, etc.);
- At a detention facility where the patient is serving a sentence;
- At a medical facility providing medical services to the patient on an inpatient basis.

In addition, the MSE office may return the referral to the medical panel if it is determined that the patient has not undergone the complete series of required medical examinations.

Procedures for disability determinations

Records are kept during disability determinations, which include data on the patient, his or her family, living conditions, health conditions, etc.[10]

The patient has the right to request participation in the disability determination by any specialist on an advisory basis.

A report is created based on the results of the disability determination.

Copies of the records, report, and individual rehabilitation or habilitation plans are issued to the MSE office conducting the determination and to the patient upon written request (same day).

Appealing MSE Office determinations

Disability determinations may be appealed within a month of receipt of a copy of the determination. Appeals may be submitted to the office conducting the determination.

A repeat determination shall be conducted at the regional office within 30 working days of submission of the patient's appeal.

If the appeal concerns a decision issued by the regional office, then the repeat determination shall be conducted by the same office, but with a different panel of experts.

Similarly, a decision by a regional office may be appealed further. In such cases, the repeat determination shall be conducted by the pertinent federal office.

In addition, all aforementioned decisions may be appealed in a court of law.

Disability and HIV

Living with HIV alone does not grant a person the right to benefits. However, inasmuch as HIV infection is a socially significant illness, one to which the law pays special attention, people living with HIV are entitled to special protections of their rights.

Specifically, all citizens living with HIV shall have the right to free antiretroviral therapy.[11]

Russian laws prohibit all forms of discrimination against citizens living with HIV.

For an adult citizen, living with HIV alone cannot be considered grounds for certification of disability status; however, as stated above, in cases in which a citizen's HIV status has caused a loss of the ability to work or physical restrictions, disability status may be granted.

A person's HIV status and stage shall be evaluated during disability determinations, as specified by law.[12]

As stated above, one of the criteria for certification of disability status is the presence of bodily dysfunctions, which shall be evaluated on a numeric scale in percentages.

For example, with Stage 3 (subclinical) and Stage 4A HIV, impairments in the circulatory and immune systems may be discovered, which may lead to a clinical grade of 10%-30%. HIV in Stages 4A to 4B may lead to a clinical grade of 40%-100%, depending on the degree of impairment.

Stage 5 HIV (end stage) results in a clinical grade of 90%-100%.

Disability and tuberculosis

Tuberculosis may be considered grounds for certification of disability status and receipt of benefits available to people with disabilities.

In addition, the law provides subsidized housing for people living with tuberculosis and experiencing bacterial discharge.[13]

If a person living with tuberculosis is already living in subsidized housing, they may apply to improve their housing conditions, as tuberculosis is grounds for receipt of additional living space in subsidized housing.[14]

The law provides priority housing for citizens falling into such categories.

In addition, people undergoing follow-up observation due to tuberculosis shall have the right to the following social services:

- Citizens who lose the ability to work due to tuberculosis shall retain their position of employment.
- Citizens who miss work due to tuberculosis shall receive compensation from government social insurance.
- Citizens undergoing follow-up observation shall receive free medication for the treatment of their tuberculosis.[15]

Social support for people with disabilities

The law states that people with disabilities shall have the right to a range of privileges and guarantees, including pensions, monthly cash payments, social services, and guarantees in housing, labor, and education.

Disability pensions

People with Group I, II, or III disabilities who have qualifying pensionable service[16] shall have the right to receive disability pension payments.[17]

People with disabilities who lack qualifying pensionable service but are permanent residents of Russia shall receive social insurance disability payments.[18]

Where a person has the right to both a retirement pension and a disability pension, such right shall be limited to only one of the two pensions.[19]

Monthly cash payments

People with disabilities shall have the right to monthly cash payments, the amount of which shall depend upon the certified disability group.[20]

People receiving monthly cash payments shall have the right to receive a range of social services; however, where such services are received, the amount of monthly payments shall be reduced by the amount of the cost of such services.

The law provides for the following types of social services:

- Required medications in indicated dosages, medical devices as prescribed, and specialized nutritional products for children with disabilities;
- Where indicated, temporary residence in treatment centres for maintenance treatment of primary illnesses;
- Free travel on regional rail and municipal transportation to and from treatment visits[21]; and
- Housing.

People with disabilities shall have the right to subsidized public housing. Such housing shall be presented under subsidized public housing agreements.[22]

People with disabilities living with several types of illnesses shall have the right to subsidized housing of greater area than standard, not to exceed said standard by greater than 100%.[23]

The list of such illnesses includes tuberculosis with bacterial discharge and HIV infection in children.

Disability and COVID-19

Simplification of procedures for extension of disability status

During the spread of the novel coronavirus (COVID-19) in Russia, temporary measures were enacted for certification of disability status.[24]

Such measures were necessary to prevent violations of the rights of people with disabilities caused by quarantine measures enacted in Russia to prevent the spread of COVID-19.

The quarantine measures imposed restrictions on the freedom of movement of citizens. Medical institutions worked on a limited basis and were not able to conduct scheduled examinations of patients. These factors significantly decreased the opportunities for people with disabilities to gather medical documentation for timely submission to disability determination (MSE) offices.

The temporary measures were in effect from October 2, 2020, until July 1, 2022, and required that disability determinations (MSE) be conducted by correspondence, upon which an automatic extension of existing disability status would be granted for a period of six months. A letter certifying disability status would be sent to the patient via certified mail.

Expansion of the list of social services

In addition, the pandemic also saw an expansion in the list of social services, which subsequently included services for accompanying people living in residential social service facilities to medical facilities to receive required care.[25]

Deferral of enforcement action

During the coronavirus pandemic, borrowers under credit agreements (loans) who were pensioners (including disability pensioners) and who had an enforcement order issued against them prior to May 1, 2021 (for example, a writ of execution) to recover debts in amounts not greater than 1 million rubles were provided repayment deferrals. These deferrals were provided for a period not greater than 24 months, and until a date not later than July 1, 2022.[26]

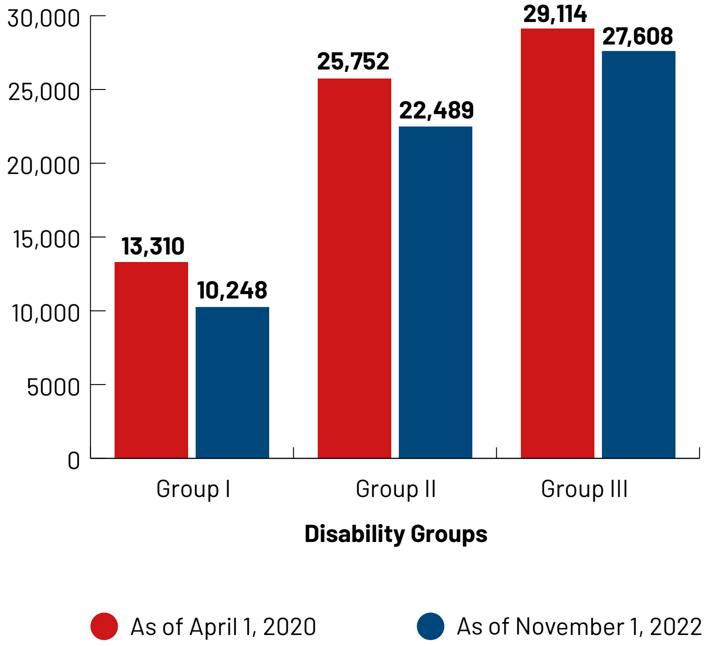
Description of the situation in two regions of Russia where research was conducted

According to the Federal Registry of Disabled Persons, as of October 2022 there were 10.3 million people with disabilities in Russia; Group I had 1.3 million people, while Groups II and III had 4.5 million people each. The overwhelming majority — approximately 8 million people — were age 51 and older.[27] This was a decrease from March 2020, at the start of the COVID-19 pandemic in the Russian Federation, when the total number of people with certified disabled status was greater — 11.2 million people. Of these, there were 1.4 million people in Group I, 5.2 million in Group II, and 4.6 million in Group III.

In the regions chosen for this research, both aforementioned trends continue a downward trajectory in the number of people with certified disabilities and a redistribution of people between Groups II and III (see graphic below).

In the Kaliningrad Region, according to data obtained from the Federal Registry of Disabled Persons, as of April 1, 2020, there were 68,176 people with disability status. By 2022 that number had decreased to 60,345.[28]

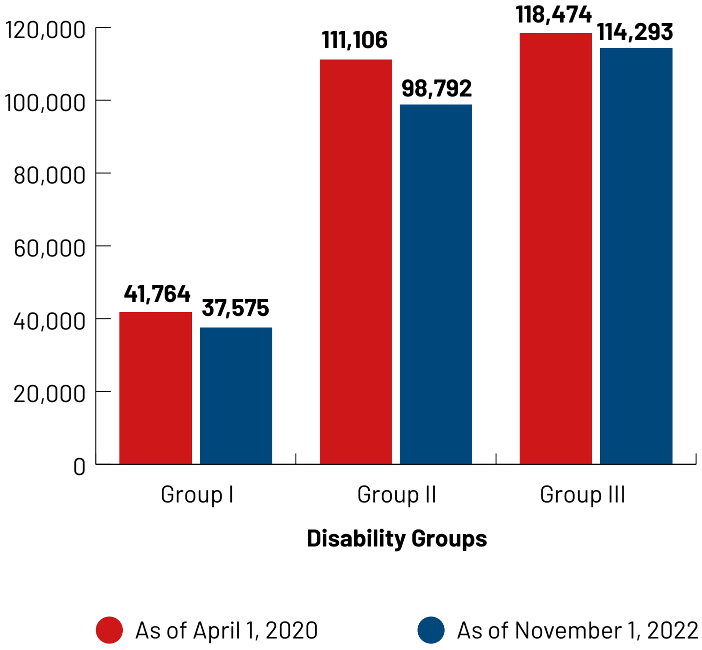
Kaliningrad Region: Total decrease in the number of people in registered disability groups coincides with an increase in the share of people certified with Group III disability (comparison periods are from the beginning of lockdown due to COVID-19 and the escalation of the war in Ukraine)*



** Graphic created using data from the website for the Federal Registry of Persons with Disabilities*

In the Sverdlovsk Region, as of April 1, 2020, there were 271,344 people with disabilities. As of November 1, 2022, that number was 250,660 — a decrease of almost 20,000.

Sverdlovsk Region: Total decrease in the number of people in the registered disabililty group coincides with an increase in the share of people certified with Group III disability (comparison of periods from the beginning of lockdown due to COVID-19 and the escalation of the war in Ukraine)*



** Graphic created using data from the website for the Federal Registry of Persons with Disabilities*

Possible reasons for the decrease in absolute numbers of people with disability status and the shift in percentages between groups may include the use of "stricter criteria during disability determinations" since 2011[29] and/or the institution of "quotas" in government procurement aimed at tightening budgets and sharing resources among affected groups. Thus, in the opinion of the experts working both on this project and with people living with HIV, members of disability determination medical panels began to "lowball" their determinations of group classification when people living with HIV attempted to register or renew disability status, even before the war in Ukraine began:

> *"Not that they're denying disability status, but they're putting people in the third (working) group whose health conditions should probably get them in the first group! They put a wheelchair-bound man in the third group. Or a woman — she's skin and bones, got tuberculosis, lost part of her spine and ribcage, can't lift more than a pound — they put her in Group III after an appeal to Moscow! They initially denied her. And a man, after two strokes, legs amputated, uses a wheelchair just to get around his apartment — working group!* ***They're lowballing. Right now (during the war) we clearly see something going on that never has happened before."*** *(Social Worker 1, Kaliningrad)*

There are no concrete statistics on the number of people living with HIV and disabilities in the Russian Federation, which is largely due to doctor-patient confidentiality and a lack of required coordination between medical facilities and other government agencies. Nevertheless, some data may be available in publications by local AIDS centres, which retain information about their patients with disabilities.

Study methods

The objective of this pilot study is a description of the barriers and difficulties encountered by people living with HIV and disabilities in Russia during the coronavirus pandemic and the war in Ukraine. The study was conducted in two Russian Federation cities — Kaliningrad and Yekaterinburg — which are part of a group of cities with a high prevalence of HIV among the population. In addition, the study team had access to key groups in these cities, a fact that influenced their selection, considering the project's subject matter and the dramatic changes seen in how local NPOs engage in monitoring and advocacy in recent years.

Ten people living with HIV in the cities of Kaliningrad and Yekaterinburg (seven men, three women) and three social workers with experience living with disabilities answered questions between May and July of 2022 in semi-structured interviews, lasting between 60 and 90 minutes. Questions were intended to ascertain the social and demographic traits of study participants, their history and current situations associated with their disabilities, their experience living with HIV, their experience with stigma/discrimination, and a description of opportunities to access social and medical assistance during a) the COVID-related restrictions after March 2020 and b) the socioeconomic crisis caused by the start of the war in Ukraine.

Inclusion criteria for study participation were as follows:

- Age 18 years and older
- Living with HIV as of March 2020 or earlier
- Registered disability status at the time of interview, and disability status maintained from March 2020 to the present
- Familiarity with informed consent and willingness to participate in study procedures

All study participants signed informed consent forms and were compensated for their time. Potentially identifiable patient information was excluded from the data collected during the study analysis; quotes obtained from study participants used in this report were paraphrased and do not contain personally identifiable information.

Social and demographic traits of respondents

All study participants (except one) used injection drugs for an extended period. The average age of respondents was approximately 48 years (39-52); average time after HIV diagnosis was 14 years; average life expectancy with officially registered disabilities was seven years. Project participants had multiple illnesses, both chronic and episodic.

The selection process included people with impairments of the skeletal system of varying etiologies and disorders of the central nervous system, as a result of which almost all participants experienced problems with mobility and employment. Participants cited income levels near or below the poverty level, a lack of earning opportunities, and a narrow circle of close relations able to provide material support as the primary causes of their difficult financial situations.

Analysis of the semi-structured interviews

The results of the analysis are presented in five parts, which describe (1) the barriers and difficulties encountered by respondents during the process of registering and certifying their disability status, (2) the daily complications of living with disabilities, (3) the impact of COVID-19 restrictions, (4) the impact of the socioeconomic crisis caused by the war in Ukraine, and (5) mental health, stigma, and a quality-of-life self-assessment.

Primary difficulties encountered during registration and certification of disability status

- Deterioration of health, progressive worsening of disability during the drawn-out process of clarifying the diagnosis and determining disability group;
- In certain cases, a lack of exact information about the rules governing interactions with doctors and MSEs and a loss of documentation in cases where assistance was rendered by people with whom contact has been discontinued;
- Multiple re-referrals of patients to other medical facilities and other specialists;
- Opacity of processes for registration and certification of disability status for people living with HIV;
- Commercialization of medical analyses and tests for registration and renewal of disability status.

Two different periods were identified as being the most difficult for study participants — during diagnosis and registration of disability group status and during disability group status renewal. Prior to the certification of their disability status, respondents most frequently encountered an exceedingly drawn-out process of categorizing and clarifying their illness. The lack of rapid diagnosis, misunderstanding, and uncertainty about the accuracy of diagnoses by doctors have led to respondents experiencing a deterioration in their condition and greater disability than before their disability determinations:

> *“And that’s the kind of top-notch medical system we have. They denied me, put me on a quota list for joint replacement, probably in 2014.* ***I made the quota, then waited for a year, then the faculty all rejected me. Said my leg was inoperable.*** *(…) Then I came to the centre, and Vanya and everyone helped me. (…) Did that for a year and at last they gave me Group (…)II.”* (FEMALE, 48, YEKATERINBURG)

> *“Called an ambulance 10-12 times, they took me, the nurses all knew me. The swelling and pus began to grow. (…)* ***They dragged their feet*** *until it was too late. Took me to different hospitals, ‘this isn’t for us’ — but they don’t say where to go. Now I can barely walk with a cane.”* (MALE, 47, YEKATERINBURG)

During the registration process, in light of poor health and an inability to overcome systemic barriers, people living with HIV have been forced to seek assistance from relatives, friends, or NPOs. Assistance from other people in some cases has led to ambiguous results. On one hand, such assistance has been effective and respondents have indeed received official disability status. On the other, in cases where respondents were denied status due to poor health, if they later lost later losing contact with the people attempting to help them, they did not know how to interact with official institutions, for which benefits they were registered, how to renew their disability status, or even where to find their documentation.

> *"Honestly, I can't say whether it was after the first or second operation (granted disability), because I was bedridden,* ***my mother took care of all this.*** *All my papers were somewhere at her place. Last October, my mother died.* ***It hasn't hit me yet.*** *Then I was dealing with the funeral. Went to my doctor, he tells me they've canceled my benefits. Looks like these two years that went by, the renewal didn't go through due to COVID, because they were supposed to extend it automatically. They did, but the last month or two have been a pain in the rear. They pay, but the amount became less.* ***I don't know what the payments are,*** *but my pension got smaller."* (MALE, 47, YEKATERINBURG)

> *"After the death of my mother, I spent almost 24 hours with her body. I couldn't open the door because it was blocked by her body, and half of my body is paralyzed. I have no strength in my arms or legs and couldn't get out. (…)* ***A little later, it turned out that my mother had lost my documents: passport, personal insurance number, insurance policy.*** *It's good that at least my disability certificate and some medical documents were found."* (MALE, 46, KALININGRAD)

The lack of systematic assistance for people with severe and chronic illnesses and the crude "road map" for registration/certification of disability status means that many people must handle these complications alone. In addition, people with disabilities find themselves in a situation where obtaining payments and benefits from the government is more often the result of "luck" or "help" from others rather than a guaranteed result of clear, understandable, and transparent procedures common for all.

Re-referral to other treatment facilities and specialists was typical not only at the diagnostics stage, but also during registration and certification as well. On the whole, re-referrals have become the greatest challenge for people living with HIV and disabilities in their interactions with official institutions.

> *"They gave me disability for six months, I was constantly returning to the hospital — couldn't stay out, documents were consistently wrong, they returned them.* ***I spent a long time gathering documents:*** *they said the documents from the infectious diseases specialist were invalid.* ***My doctor said I need someone connected. So I ran around from October 2018 until March.*** *Then every year I have to get down, do an MRI."* (MALE, 50, KALININGRAD)

> *"I also had group status, then they took it away, the basis was that my immune system had recovered and my viral load became undetectable. I tried to prove that my stage hadn't changed, but they took it away anyway. In my opinion, the tendency is, and I'm not accounting for all statistics I encounter:* ***They issue denials frequently, it's exceedingly difficult to get a referral to an attending physician, and this is the story, that everyone re-refers patients to each other.****"* (SOCIAL WORKER, YEKATERINBURG)

> *"I come in,* ***she says 'you don't belong there.'*** *She says, 'you have to go to the medical labor committee,' and nothing else. At home I went online, found the number, called.* ***They said: not sure if it makes sense for you to come, you need doctors' notes, why did she (the doctor) send you here?*** *I say, she didn't even look at my paperwork.* ***I went back to the doctor, she sends me to the 40th to do an MRI, the images are old.*** *Went to the 40th, he looks and tells me I don't need an operation — my spine is crooked and a hump is beginning to form — but this is nothing to worry about. Gives me a referral to a therapist to extend or not extend my disability, I don't know.* ***Went to the therapist, and she again…*** *They don't say anything, they don't say anything at all. She says that the supervisor will return in two weeks and will decide whether they will extend it or not."* (MALE, 47, YEKATERINBURG)

The informal practice of re-referrals, in the opinion of the experts involved in this project, has become more frequent and reflects the need for government institutions to reduce their budgets and redistribute material resources among various populations groups, where some (e.g. people living with HIV who have used injection drugs) are less privileged than others (e.g. combat veterans).

In addition to this expert opinion, it is possible to assume that the **pandemic and the war in Ukraine have led to the "exhaustion" of resources, i.e. medical specialists, who have experience with disabilities** (doctors moving to other regions or countries, dying, retiring). Medical specialists relieving more experienced doctors are not always able to fill out paperwork correctly or help patients to register their disabilities:

> *"I tried myself, but they sent me off, and I'm one of those people who won't argue. I don't even know, honestly, what to write or where to call to complain. (...) And I have either work, or my mother, or something else. I went once, twice. Then (a friend) she took me by the hand, said: let's go, we'll get a referral and do all the tests. And if not for (my friend), probably nothing would have happened.* ***The general practitioner did not know what to do; she had never tried to register anyone for disability status."*** (FEMALE, 45, KALININGRAD)

When general practitioners lack the experience and required skills to work with people with multiple illnesses, HIV, drug use, and constant exposure to stigma and discrimination, re-referrals are common. **This practice of re-referrals and a failure to keep patients informed become yet another informal mechanism to simplify interinstitutional reporting, thereby relieving the doctors of their responsibility for the well-being of patients and, from a long-term perspective, reducing the numbers of "undesirable" patients.**

The practice of re-referral, the opacity of bureaucratic machinery, and the lack of guaranteed systematic assistance for people living with HIV and disabilities have led to an increase in uncertainty and anxiety among "undesirable" patients in conjunction with the renewal of disability status:

> *"It's* ***always scary — will they or won't they — this uncertainty.*** *The question mark won't leave your mind. Constantly, conversations, thinking about it, you think, although you understand very well that your thoughts won't change anything.* ***It's like the iron you forgot to turn off at home: like it or not you'll think about it."*** (MALE, 47, YEKATERINBURG)

> *"Right now, I'm going through renewal, and I don't know. At the tuberculosis hospital they took me off their list and said I need to go to my local surgeon for observation. I had Group II, but I don't consider myself to be a fully healthy individual; I still have pain. My doctor said I'd get used to it; it'll be with me for the rest of my life.* ***Still, no one has told me exactly which specialist will take the lead on my disability.*** *In effect, it should be a surgeon. (...)* ***I fear that I'll go to the surgeon to talk about my disability and hit a wall of misunderstanding. I am afraid that I am an unhealthy person, in fact, and that I'll be naked as a jaybird, and there won't be any help from the government, and I won't be able to take care of myself."*** (MALE, 50, KALININGRAD_2)

The commercialization of medical examinations and obtaining the results of tests and analyses have become more common as people try to cope with the uncertainty and ever more complicated rules for obtaining or renewing disability status. In light of the long waits for free testing and the brief periods of validity of such results for doctors and disability determinations, many people living with HIV are forced to rely on fee-based medical services:

> *"There are few machines in the city, big lines, they go to the pay places — CTs, MRIs, magnetic resonance — the doctor accepts such tests."*
> (SOCIAL WORKER 1, KALININGRAD)

> *"Other analyses were arranged in the parking lot with doctors from the neighboring hospital for 500 rubles, so that they'd take blood."*
> (MALE, 47, YEKATERINBURG)

Everyday difficulties of life with a disability

- Lack of social and rehabilitation resources for preservation and improvement of health after registration of disability;
- Weak provision of effective medications, rehabilitation, and bandage materials;
- Low income and inability to earn extra income because of illness or physical impairment or lack of knowledge, skills, and education to enter the labor market;
- Limited mobility and environmental barriers lead to restricted movement, dependence upon others for movement, inability to use free services;
- Complications with indexing of social pensions since January 2022 and the negligible positive effect of indexing on buying power.

Despite government guarantees to provide people with disabilities with accessible social and rehabilitation services, almost none of the respondents had had the opportunity to use residential treatment services or other means of rehabilitation:

> *"I refused residential — **you have to pay there** anyway."* (MALE, 48, YEKATERINBURG)

> *"**They didn't offer residential; there wasn't anything else.**"* (MALE, 50, KALININGRAD)

> *"There were no free rehab or services. **Paid massages: a lot of people in line for the free ones; they said, 'go find your own.'**"*
> (MALE, 47, YEKATERINBURG)

> *"**Residential is just to take a break, my older sister sent me; medical workers, what can they offer?**"*
> (MALE, 52, YEKATERINBURG)

> *"**They give you a meaningless rehab leaflet, that's it.** They're negligent. They just gave me some meaningless papers."* (MALE, 39, KALININGRAD)

> *"There are residential programs, but it's **a very long wait; I refused this benefit.**"*
> (FEMALE, 50, YEKATERINBURG)

The government's failure to provide rehabilitation is exacerbated by that the removal of the majority of effective and necessary medications from the list of life-saving therapies over the past several years. In addition, the government can provide most rehabilitation equipment (back braces, wheelchairs, walkers, canes) and accessory materials (bandages, saline) for free under the law, but bureaucratic obstacles to registration and long waits force people with disabilities to buy these with their own money. Thus, the financial burden falls on the shoulders of people living with HIV and disabilities who are receiving pensions that are near or below the poverty level:

> *"Sometimes it gets my legs; they're so black. I rub on troxerutin,* ***the dermalex is gone, it's so expensive.****"* (MALE, 48, YEKATERINBURG)

> *"I don't get anything, why would I take anything that doesn't help me? It costs crazy money, these creams (they're not included in the benefits package). I refused it. You know, I've given up on all doctors, because it's useless.* ***The crutch is bought with my money, it's part (of the services), but there's such a line, cheaper to buy it yourself.*** *(...) Around the apartment I use a walker, the walker I got at social services for rent.* ***For rent, I went to my doctor again, he sent me to the neurologist, I got three stamps, they gave me the fourth stamp, and only then could I go to social services. (...) The walker I inherited; my mom's friend's husband died from the coronavirus. (...) Now I have my own walker.****"* (FEMALE, 48, YEKATERINBURG)

> *"Right now, I'm in a residential program, but I have to buy my IVs myself,* ***not enough financing. Even saline I bought myself.*** *In 2020 there were medications, now there's not.* ***I have to buy a lot of medications for my back, and they're not cheap*** *(tramadol). I refused to pay for them. When I ask the neuropathologist, he prescribes medications on general grounds; that is, I have to buy them.* ***Those medications aren't on the list of the most important, life-saving drugs.****"*
> (MALE, 50, KALININGRAD_2)

In some cases, even when services are provided free of charge by the government and on a priority basis, physical inaccessibility of services due to limited mobility of people with disabilities may become barriers:

> *"Dressings you have to buy yourself — creams, chlorhexidine, bandages. They've gotten expensive, cheapest costs 60 rubles.* ***I tried going to the clinic, they said 'it's not on the list, bye! Go to the hospital every day to change the dressing.' That's a problem for me.****"* (FEMALE, 50, YEKATERINBURG)

The government tends to react and adjust its social policy only to "statistically" important phenomena. This is evident by its inaction in response to individual cases, despite the fact that the majority of problematic situations arise precisely in such "individual" cases:

> *"The level of indifference that we have in our government can never be accepted calmly.* ***It cannot be expected that the services offered provide the maximum amount of discomfort and inconvenience.*** *Let's say a patient's leg is rotting; she needs her dressings changed every day. She has disability for her trophic ulcer and they give her painkillers, legally, but the bandages and creams aren't most important, life-saving drugs, and the clinic where they will do all this for free is located very far from her home. So she has a choice, every day: if you want new dressings for free, go to the clinic. But she can't; she's in pain and it's far.* ***We have no client-oriented policies, human, individualized,*** *where an illness may manifest itself differently in each person.* ***And they blame the patients: 'They are giving you free assistance; if you don't want the help don't use it.*** *' In what sense, don't want? She can't even walk with that leg."* (SOCIAL WORKER 2, KALININGRAD)

One of the greatest problems affecting the respondents in this project was **the inability to earn a stable and sufficient income to support their lives and their subsequent dependency on government-funded,** which people with officially certified disability status receive. None of the study participants received a pension that significantly exceeded 20,000 rubles per month (approximately 330 USD). Most respondents received pensions equal to or below the poverty level in the Russian Federation (11,970 rubles/198 USD).

Barriers to entering the labor market were due to:

(1) Physical inaccessibility of many types of work:

> *"I was offered work as a watchman,* ***but I can't sit for a whole day.****"* (MALE, 47, YEKATERINBURG)

> "I try to find work, ***but it's hard to work with my health problems. I tire very quickly.*** The pension isn't enough. I try to get by on side jobs, but it's pointless, such moments come to nothing." (MALE, 48, YEKATERINBURG)

(2) Lack of professional skills or education:

> *"I'm on the market for four months already, and they can't find me work.* ***I wanted to take a computer course, but they can't get a group together.*** *I can't work as a guard or a cook. I want to get a job as a taxi driver."* (FEMALE, 50, YEKATERINBURG)

(3) Certainty about the lack of opportunities in the labour market:

> *"You won't find a job for a normal person,* ***I haven't tried to find one.****"* (FEMALE, 48, YEKATERINBURG)

In some cases, the respondents received pensions below the poverty level due to owing administrative fines or alimony/child support:

> *"****Enforcement takes half of my pension, though it's already less than poverty level.*** *Wrote them several times, they do nothing. I'll have to go to the district attorney."* (MALE, 39, KALININGRAD)

> *"I have a 50% pension. If they indexed it in a normal way and my pension was 20,000 rubles, and they kept around 10,000 rubles, well, I'd at least somehow... But I'm left with 6,000, less than poverty level.* ***I wrote to enforcement, asked that they leave me at least at poverty level, but nope, useless.****"* (MALE, 50, KALININGRAD_2)

Small pensions, limited possibility of "side" earnings, and the need to purchase one's own medications, medical equipment, and services (e.g. massage therapy, taxis, medical tests) combine to create a low quality of life for people living with HIV and disabilities, and leave them in poverty.

Even with indexing of disability pensions, and receipt of food stamps worth 2,000 rubles, the material condition of the respondents has not improved.. **Many respondents could not take advantage of or appreciate any additional assistance from the government because of bureaucratic limitations or prices rising in parallel. Some respondents stated that pensions were not indexed at all:**

> *"****They didn't index the pensions****, they gave the same amounts after the start of the war."* (MALE, 52, YEKATERINBURG)

> *"Because I worked in a camp* ***they didn't give the 2,000 payment or the food stamps****."* (MALE, 50, KALININGRAD)

> *"Right now, to get food stamps, they didn't give them to everyone, only to those whose pension was below the poverty line. The poverty line for Group II is 100 rubles more. Do these 100 rubles make me live well and eat enough? No! No way! This is the trap. Right now they index the pensions by 10% but* ***then index the poverty line by the same amount.*** *And again it's like they indexed all the pensioners and disabled people! While they raise the poverty level to the same sum."* (SOCIAL WORKER 1, KALININGRAD)

The majority of study participants said that they experience **difficulties with movement, coordination, pain, and weakness in response to even minor physical demands:**

> *"**My coordination is wrecked; I walk like a drunkard.** If it's even a little dark outside, my coordination fails, I begin to stagger like a drunk man. It's very hard for me to walk. At work there is a basement with poor lighting — I can barely start to walk."*
> (MALE, 50, KALININGRAD)

> *"**I have to do a lot through the pain,** my attention wanders. My hand is tight, it's constantly swelling. Even when working at the computer, writing some kind of letter, my hand distracts me because it bothers me. I've had moments where I wished they'd just cut it off so it would stop bothering me."*
> (MALE, 39, KALININGRAD)

> *"(I work) on a limited basis, two hours in the garden and I'm out of gas, **can't stand or walk for long**."*
> (MALE, 50, KALININGRAD)

> *"It's become more frequent that I drag myself out of bed, because **I am very weak lately. And my vision has suddenly gotten much worse.** I understand that I'm a little older now, but to catastrophically lose your sight so suddenly?"*
> (FEMALE, 45, KALININGRAD)

Physical limitations caused by illness, in an accommodating environment, might not become barriers to visiting clinics and pharmacies or to getting a job or taking a walk or a trip. Instead, respondents have found themselves in situations where they were unable to take advantage of free transport services to the nearest clinic, or had to wait in line at AIDS centres, or couldn't simply go outside because of a lack of elevators, ramps, or assistive equipment on public transportation, etc.

> *"**Nothing is set up for the disabled on the street; no ramps anywhere, elevators are not common, buses are high off the ground and the seats are tall,** I can't turn. People help me."*
> (FEMALE, 50, YEKATERINBURG)

> *"They don't even have ramps in a lot of places. If a disabled person lives in the building, **their relatives have to pay to get a ramp put in**. ... drag the wheelchair up to the fifth floor, then go top to bottom to secure the ramps to the walls, do it yourself — it's horrible, it's mockery. We're talking about some kind of human compassion, someone we're trying to protect, someone treated like an animal in the Donbass, and we, with our people, treat them like animals, those same disabled people. It's not enough that the **person is beaten down by his health, he's beaten down by not being equipped for this.**"* (SOCIAL WORKER 2, KALININGRAD)

The impact of restrictions enacted in March 2020 as measures to combat the spread of COVID-19

- Restrictions on movement within cities and quarantines in hospitals or detention facilities in effect made access to medical services for people living with HIV and disabilities much more difficult or impossible;
- Reductions in the numbers of medical specialists during the pandemic delayed appointments, diagnostics, and prescriptions;
- Almost all respondents have had a COVID-19 infection. During treatment, they noted that medical specialists prescribed medications that had little effect;
- The lack of coordination between hospitals and clinics repurposed to treat coronavirus patients and local AIDS centres created situations in which people living with HIV were left without ART medications or had their medication regimens interrupted against their wishes;
- An unforeseen negative consequence of so-called "automatic" disability status renewals active during the pandemic was the lack of knowledge among people with disabilities about the rules and deadlines for renewals in the "pre-COVID" period. Many people with disabilities did not receive necessary documents in a timely manner and found themselves unprepared to engage in this process.

Restrictions enacted in March 2020 by the government in order to slow the spread of SARS-CoV-2 made access to quality medical services and ART medications more difficult for people living with HIV and disabilities. Even if the problems with delivering ART medications were resolved between AIDS centres and local NPOs in both Yekaterinburg and Kaliningrad, access to testing, analysis, and appointments was almost impossible for many people living with HIV.

> ***"It was prohibited to enter AIDS centres with a temperature and tuberculosis — I couldn't get my medicines*** *(the social worker got them). There were lines everywhere, no doctors — all the doctors got sent to deal with COVID."* (MALE, 39, KALININGRAD)

> *"During COVID, all homes for the disabled and social services facilities were closed for quarantine (almost to the end of 2022, by the way). They weren't accepting new patients.* ***All six months I spent in closed rooms (due to quarantine, in hospitals it was prohibited to leave the room, even into the corridor, let alone the street). There were no additional visits with doctors I needed;*** *I needed an audiologist to check my hearing and prescribe me a hearing aid and I couldn't get one all this time."* (MALE, 46, KALININGRAD)

Access to medical services for people living with HIV and disabilities was seriously reduced not only during the so-called lockdowns, but also after the lifting of restrictions. During the pandemic, the medical system underwent significant changes due to a decrease in resources and an exodus of specialists. The decrease in the number of medical specialists, and especially specialists in infectious diseases, occurred for various reasons: transfers to other regions and other medical facilities; the SARS-CoV-2 illness and lethal outcomes; retirements, quitting, etc. **"Exhaustion" of human resources in the medical services field led to long waits for doctor's appointments and a need to constantly update analysis and test results:**

> *"Couldn't see a doctor during COVID.* ***Three months on a list, and while you see one doctor, the test results for the second doctor become invalid, and you start over.****"* (FEMALE, 48, YEKATERINBURG)

> *"Most interesting during COVID was I couldn't even see my regular doctor, because it wasn't only infectious diseases specialists activated for COVID.* ***In the clinic they set up a COVID centre and it became impossible even to see your doctor.****"*
> (FEMALE, 45, KALININGRAD)

> *"Many healthcare workers died during the COVID period; many were fired (limitations on age 65+) due to COVID. Many doctors simply quit, some went to Moscow, St. Petersburg, to COVID hospitals where the pay is good, and stayed there. And right now I see that* ***everything has opened up, but the doctors are still gone, and this is obvious because there are huge lines for visits. It wasn't like that before****. Despite the fact that our public health insurance is excellent (a week to accept, schedule, test), right now it's like it's only paper, doesn't work at all.* ***Especially discouraging is oncology, where it was three days for a visit, now it's two to three weeks or a month to get an appointment with a specialty doctor. It's like everything is there, but nothing is actually there****."*
> (SOCIAL WORKER 1, KALININGRAD)

Another unexpected negative impact in the post-COVID period, aside from having fewer working specialists, is the problem of disability status renewals and obtaining benefits due to so-called "automatic" renewals. During the pandemic, people with disabilities were freed from the need to regularly undergo renewal procedures. Automation of renewals, which had a positive effect during the pandemic, led to negative consequences after the lifting of restrictions: few people with disabilities knew that despite automatic extensions of their status, they would need to obtain updated documentation of their disabilities in order to continue to receive benefits or to undergo the renewal process. Many people living with HIV and disabilities found themselves in situations in which they did not receive necessary documentation in a timely manner, because they didn't know they needed updated documents, and were unprepared to undergo the renewal process:

> *"Those who for the first time, only if they were in a facility.* ***It's very difficult if it's the first time you need to get a referral to go in front of the committee.*** *To walk in off the street, to me it seems unrealistic to just come in and do it."*
> (SOCIAL WORKER, YEKATERINBURG)

> *"****People were delighted by disability extensions, but they also fell into this trap.*** *Not many knew that to extend disability status by six months you have to get a new letter from your doctor.* ***They thought that all the records were there, that they didn't have to go anywhere else.*** *Or in other cases if they need an expensive medication – also need a new letter. And people knew nothing about it."*
> (SOCIAL WORKER 1, KALININGRAD)

Project participants encountered other problems when they got sick with SARS-CoV-2 and found unable to independently select their treatment and obtain medications. Thus, in prisons or in special COVID-19 treatment facilities (COVID hospitals) patients were offered ineffective medications.

> *"In jail **they gave us activated charcoal for Omicron, three tablets in the morning, three in the evening. Put us in quarantine for 45 days, with medications it was difficult.**"*
> (MALE, 52, YEKATERINBURG)

> *"And then, the last outbreak, everyone got sick in our barracks. If you went to the infirmary, **they measured your temperature, 'it's 39, so? Take an aspirin.** We have no tests.'"*
> (MALE, 50, KALININGRAD)

> *"Came to St. Petersburg for an operation under quota, caught COVID. The senior nurse gave me a discharge: 'fly home.' I have a subsidized ticket, no return ticket or money. So I went back, spelled it all out for them, they called me up and transferred me to a COVID hospital. There they found my lungs were 8% damaged. **They gave me almost no medicine, only omeprazole, which they'd prescribed to me back at the tuberculosis clinic and gave only one tablet to thin the blood. No other treatment was given.** My discharge papers said COVID of moderate severity, lungs 22% damaged, and a whole bunch of medications given! They inflated the numbers."*
> (MALE, 50, KALININGRAD_2)

In cases where people living with HIV were forced to undergo treatment for COVID-19 in medical facilities the most pressing problem was the **ineffectual coordination between so-called COVID hospitals and infectious diseases specialists in AIDS centres.** Healthcare workers in the "COVID hospitals" and other lesser medical facilities did not know about the need for regular and timely administration of ART medications or the specifics of interactions of ART medications with other medications.

> *"Me and a few other severe cases were taken to one of the city hospitals. They didn't let us bring our medications, **so three days we had no treatment.** (…) They began giving me ART with other pills **at different times, the could give two pills of a single drug, like ritonavir, but not give two others or give only one of the three.**"* (MALE, 46, KALININGRAD)

> *"They understand very little about HIV. He had a temperature there, nothing helped. Had to give them a lecture, tell them that in terms of HIV his health was good, this must be something else. **Just like in other times, they often just blame everything on HIV.** They were sure that it happens with HIV."* (SOCIAL WORKER 1, KALININGRAD)

Impact of the socioeconomic crisis caused by the war in Ukraine

- Fear and anxiety that in the near future disability status renewals will be denied or payments will be reduced due to increases in the number of applications for disability status by those wounded in the war;
- The war has caused inflation and price growth for essential goods and rents; in some cases there have been difficulties in obtaining medications from pharmacies;
- People living with HIV and disabilities have felt the effects of COVID restrictions were different from the effects of the war in Ukraine, and were alarmed by the situation in Ukraine, expecting "worse" in the future.

The war in Ukraine was perceived by project participants in various ways. Some tried to ignore it and not give it great significance ("what will be will be," "hadn't thought about it, they're just laundering money there," "I don't get involved in politics," "it's fine"); others were very worried and anxious about the current and future states of affairs:

> *"In the Kaliningrad region, if some plane is flying by, I immediately think it's war. I already hear echoes of the war, they stopped regularly testing us, and next, what? There won't be any therapy? (...) Prices have gone up a lot, on everything. It affects us both materially and mentally. You feel afraid to look twice, or to say anything. I don't know how it is in greater Russia — maybe it's easier over there, we're cut off from the world — you can really feel it."* (FEMALE, 45, KALININGRAD)

One reason for anxiety common to all respondents was the potential "competition" with those wounded in the war in Ukraine and returning to Russia with disabilities. Project participants were certain that they will be denied renewal of their disability status, their group disability status will be downgraded, or their pensions and benefits will be reduced. In addition, priority will be given to those who became disabled as a result of military action:

> *"**Why don't they want to extend it? Maybe they have some kind of limit. Why do they need you? You can walk. You want grub, you find it yourself. People with war disabilities are on the way.** Who am I?"* (MALE, 46, YEKATERINBURG)

> *"Personally, I'd like them to leave me at least at poverty level. It's so hard for me. **Now these guys (people with war disabilities) are coming and we'll start getting blown off.** In effect, nothing has changed for me, but the risk of paralysis is gone after the operation (...) When all the restrictions began, all this nonsense, Ukraine worries me a lot, in fact."* (MALE, 50, KALININGRAD_2)

> *"**They're downgrading people's groups:** they explain that it's due to the special operation, including because **many, many people are coming back from there who need to be put on disability, and for life. As I understand it, it will work like the Spartans did when they threw the disabled off cliffs. The treasury is not bottomless and the government, faced with choosing between disabled persons and combat veterans, will prefer to support combat veterans** because, from the government's perspective, these are the people who defend it."* (SOCIAL WORKER 2, KALININGRAD)

Some effects of the war are inflation and a rise in prices for food, essential goods, and utilities:

> *"It has an effect, of course.* ***These are people from vulnerable groups who are susceptible to every crisis – economic, political, these are interrelated. Of course it was more difficult for them than for regular people during COVID,*** *and now when prices are rising and life is getting more expensive."*
> (SOCIAL WORKER, YEKATERINBURG)

> *"Grub is pricier. Everything everywhere is the same,* ***it's gotten harder to live.*** *No indexing. Utilities are scary, 7,000 rubles per family. I don't feel anything. It (the war) will drag on. I think other steps need to be taken. At least gotta have a second job."*
> (MALE, 48, YEKATERINBURG)

> *"Prices are insane.* ***It's not enough.*** *Everyone got a pension increase, but mine decreased for some reason. Was 10,600, now it's 10,400."*
> (MALE, 48, YEKATERINBURG)

The worsening quality of life and declining socioeconomic status that have been felt during the COVID-19 pandemic were further affected for people living with HIV and disabilities during the war in Ukraine. Immediately upon the start of the war, medications disappeared from pharmacies and tests and ART medications were delayed in the Kaliningrad AIDS centre.

> *"Everyone forgot COVID right away! The media talk only about the war, nobody gets COVID here anymore. Food prices have gone up.* ***There wasn't enough money before, now there's even less, you have to deny yourself a lot.*** *They raised my pension by 600 rubles, I barely noticed: prices have gone up a crazy amount, and they gave us kopecks.* ***Problems with tramadol this past month,*** *before that there weren't any problems since it's on the list of life-saving medications that should always be available in pharmacies. So, I walk in, and nope, none (...) Now it's become much harder than during COVID."* (FEMALE, 50, YEKATERINBURG)

> *"Shortages have begun in the AIDS centre,* ***no immune status tests and some medications are out,*** *because they used to bring them by rail, and now all these things are under sanction."*
> (SOCIAL WORKER 2, KALININGRAD)

Stigma/discrimination, mental health, and quality of life

- All participants encountered stigma and discrimination due to their illnesses. In addition, they often blamed themselves for their situations, which attests to the serious internal stigma (self-stigma) within this group;
- The respondents didn't self-identify as living with mental illness or other psychological challenges, but all spoke of high anxiety due to instability in their lives, the lack of long-term prospects, and uncertainty about the future;
- People living with HIV and disabilities said that despite the relatively low quality of their lives, they could find satisfaction in the bare minimum and felt no need to improve their lives. This sentiment likely comes as a consequence of the internal stigma felt by many people living with HIV and disabilities – although life is difficult for them, many feel they don't deserve more and should be grateful for what they have, rather than complaining.

Project participants very frequently encountered stigma and discrimination not only because of their HIV status, but also due to past use of drugs and their disabilities.

> *"I went with my wife to her friends' place, and I don't drink at all. I was asked to drive everyone home. I say, what am I, a taxi? Pay me and I'll drive you. They say:* ***You're an invalid, an albatross around your wife's neck.****"* (MALE, 52, YEKATERINBURG)

> *"Of course there are prejudices. Of course I've encountered them.* ***My drunk neighbors dragged me out of my apartment and beat me (...) They changed the locks and sent terrible texts to my mother: 'We have women and children, we don't need any AIDS or tuberculosis patients around here,*** *we're afraid for our children.' This happened."*
> (MALE, 39, KALININGRAD)

Discriminatory actions against the project participants were taken not only by acquaintances, but also by medical personnel and MSEs. Thus, study participants have experienced many instances of discrimination, which, of course, have had a negative effect on their psychological well-being, significantly decreased their quality of life, and frequently led to self-stigma, where the people living with HIV and disabilities blamed themselves for the discrimination and violations of their rights they experienced:

> *"**They took me off therapy** since there was no dynamic cell growth or reduction of viral load. **They decided that I was skipping therapy, but I wasn't.** I just thought that the regimen didn't work for me. So I started arguing with the doctors, and they took me off. **It was a small argument that happened.** Yesterday I went back, we talked normally, **I apologized.** They again prescribed me therapy (the same drugs). I'll take it for a month and then do the tests. Then they'll see whether I've taken it or not. **But this was my outburst, it was on my part, I take the blame for that.**"*
> (MALE, 48, YEKATERINBURG)

> *"They themselves, **drug users, try not to talk about their past use.** Or even if they're still using, no one on the committee will say it. **Because this will be a reason to remove someone from disability group status.** You have to first understand that drug addiction is not recognized as an illness here. As a matter of fact, and medical personnel admit it, addiction specialists say it's a chronic illness. But in other treatment facilities it can play the opposite role: and they will treat you worse. Moreover, if we're talking about determining disability – this will be considered a reason to remove you from a group."* (SOCIAL WORKER, YEKATERINBURG)

Self-stigma due to disability is evident in cases in which the respondents felt "shame" or a refusal to accept themselves as someone living with a disability. In addition, negative feelings most frequently surfaced in communication — while talking with others, which in many ways is the result of a lack of an inclusive environment (including socially):

> *"Getting **priority treatment in hospitals makes me ashamed.** First of all, I never say anything, but sometimes you're in a hurry and you need to. My wife is always with me, and she says, 'he's disabled, you have to let him go first.'"*
> (MALE, 50, KALININGRAD_2)

> *"I simply can feel that **people somehow make exceptions for me, because I'm disabled,** Group I. **I don't feel it myself. In stores, institutions, simply talking to people, who knows** (…) Really anywhere. Wherever there are lines, that's where they'll look at you like that."* (MALE, 48, YEKATERINBURG)

In terms of self-assessment of their mental and emotional states, the majority of respondents did not acknowledge any misfortune, but spoke of high anxiety due to instability in their lives, a lack of long-term prospects, and general uncertainty about the future:

> *“It’s bad, **constant stress.** Only with prayers. Sometimes I buy myself some clonazepam. Sometimes you knock yourself out with methadone or heroin.”* (MALE, 39, KALININGRAD)

> *“It’s not depression, but sadness sometimes gets to you. **Due to this uncertain future, lately I’ve been worried about the disability. If they take it away now, I just don’t know how I’ll live.** With money, they’ll treat me in a facility, even if the waitlist is four years. But if they take it away, well, it’s enough to drive you crazy.”* (MALE, 50, KALININGRAD_2)

> *“Of course I have days when **I go off the rails, have anxieties, but I try to manage it.**”* (MALE, 46, KALININGRAD)

People living with HIV and disabilities said that they have a low standard of living (*“1.5 or 2 on a 5-point scale. Back problems and economic troubles – prices are astronomic,” “I feel like nothing is worth anything when you go about life with a cane”*). Despite the low quality of their lives, the respondents were certain that they could take pleasure in the bare minimum and felt no need to improve their lives, likely as a consequence of internalized stigma making them feel they don’t deserve more than what they have:

> *“**I have clothes, I have a place to live, have food to eat – what else do I need?** I have God and I don’t need anything else.”* (MALE, 39, KALININGRAD)

> *“**There’s food to eat, a roof over my head, clothes and shoes** and thank God. Of course, it’s not much, not enough, but I think that **we don’t live badly.**”* (MALE, 50, KALININGRAD)

The future plans of project participants largely involved the search for work, certification of their disability group, and improving their health. Despite the low everyday mobility of respondents, extremely limited material resources, a lack of inclusive environments, and stigma associated with HIV infection, disability, and drug use in society, most participants dreamed of traveling:

> *“**I’d like to travel to Kamchatka.** One friend went there, we haven’t seen each other in a long time, he returned so inspired, cleansed, like a light was shining from him.”* (MALE, 48, YEKATERINBURG)

> *“**I want to go to Turkey this autumn with my mom. Never been abroad.** Nowhere else will accept us, and it’s cheapest. **I just want to live, work, I want peace, no war, so no one fears anything. I just want to live, because in that other life before prison and drugs I wasn’t living.** I only began living when I got out of it. I’d just like to live the quality life that we haven’t experienced.”* (FEMALE, 45, KALININGRAD)

It is trips and travel that low-mobility groups of people living with HIV and disabilities associate with a “quality” life, a life inaccessible to them previously due to severe physical issues, undiagnosed mental health problems, drug dependency, bouncing between hospitals, rehabilitation centres, and prisons, discrimination by government institutions, problems with close relatives, periods of destitution, and lack of opportunities to work or obtain quality health care.

Sociological conclusions of the project

The analysis of the interviews shows the following barriers in the access of people living with HIV and disabilities to social and medical services:

Problems associated with registering and certifying disability status

- Lack of a clear understanding by people living with HIV of procedures and road maps to obtaining disability status;
- The existence of the informal practice of "re-referrals" from one specialist to another, which enables, in experts' opinions, the government to save money by imposing further barriers to obtaining diagnoses and registering as a person with disabilities;
- A worsening of health, progressive disability during the drawn-out process of refining a diagnosis;
- Exclusion from the process of registering disability status due to poor health has led to a lack of knowledge of rules and procedures for renewals and a loss of required documents when people with disabilities have lost contact with those who assisted them initially;
- Commercialization of medical analyses and tests for registration and renewal of disability status — with free tests and analyses unavailable and brief windows of validity for results, many people living with HIV are forced to rely on fee-based medical services;
- An unforeseen negative consequence of so-called "automatic" renewals active during the pandemic is the lack of knowledge among people with disabilities about the rules and deadlines for renewals of medical panel results. Many people with disabilities did not receive required documents in a timely manner and were unprepared for the renewal process when their turn came.

Everyday complications of life with a disability

- Insufficient social and rehabilitation services for the preservation and improvement of health after registration of disabilities;
- Low availability of effective medications, rehabilitation equipment, and bandages;
- Low income and inability to earn additional income because of illness or physical impairment, or lack of necessary knowledge, skills, or education;
- Limited mobility and environmental barriers have led to restricted movement, dependence upon others for mobility, and an inability to take advantage of free services;
- Complications due to indexing of social pensions as of January 2022 and the negligible positive effect of indexing on buying power.

The impact of restrictions imposed in March 2020 as part of measures to combat the spread of COVID-19

- Restrictions on movement within cities and quarantines in hospitals or detention facilities greatly hindered or eliminated access to medical services for people living with HIV and disabilities;
- Decreases in the number of medical specialists during the pandemic delayed appointments, diagnostics, and prescription of medications;
- Lack of coordination between hospitals and clinics repurposed for treating COVID cases and local AIDS centres has left many people living with HIV without ART medications or interrupted their treatment regimens against their wishes;
- Almost all respondents have had a COVID-19 infection. During treatment, they noted that medical specialists prescribed only ineffective or low-efficacy medications (activated charcoal, Arbidol, fever reducers).

The effect of the socioeconomic crisis caused by the war in Ukraine

Study participants identified three main areas of socioeconomic concern, which are directly caused by the war in Ukraine. First, they expressed fear that their future disability status renewals will be denied or that their disability payments will be reduced due to a sharp increase in the number of new disability status applications by those wounded in the war.

A second real and palpable effect of the war is inflation, growth in prices for essential goods and utilities, and difficulties buying common medications in pharmacies.

Finally, people living with HIV and disabilities felt a difference between the effects of the war and those of the pandemic, were anxious about the situation in Ukraine, and expected "worse" for themselves in the future.

Mental health, stigma, and quality of life

Respondents didn't self-identify as living with mental illness or other psychological challenges, but spoke of high anxiety due to instability in their lives, a lack of long-term prospects, and uncertainty about the future. All respondents also encountered stigma and discrimination due to their illnesses; they frequently blamed themselves for such situations, which attests to serious internal stigma (self-stigma) felt by this group of people living with HIV. People living with HIV and disabilities said that despite the relatively low quality of their lives, they can take satisfaction in the essentials and feel no need to improve their lives.

Discussion

The medical model for disability determinations in the Russian Federation described in the introduction has had an important impact on the lives of people living with HIV and disabilities, their life's fortunes and prospects, and their interactions with bureaucracy and society.

The project's results have shown that the dominance of the medical model is especially noticeable in the practice of assigning disability groups and renewals. The fact is that, in Russian society, people have the right to call themselves disabled only by undergoing a disability determination (during which the medical portion is emphasized and the social component is completely excluded).

Project respondents were focused primarily on resolving personal issues arising during interactions with medical facilities and specialists. Examples included innumerable attempts to understand a diagnosis or gather "correct" documents to support a disability determination, despite constant re-referrals from one specialist or medical facility to another. For many respondents, and even for the project authors, the greatest questions arising during interactions with medical professionals were about the rationale underlying doctors' decisions and what hidden logic lay behind the denials and additional difficulties imposed by various specialists.

From the perspective of these two questions, it is clear that doctors in Russian society are perceived as facilitators and mouthpieces of government policy, especially in the treatment of people living with HIV and disabilities. Such practices are typical for the medical model of disability, where it is medical personnel who hold the administrative power to determine people's value according to their possible contribution to the labour force and the degree of their ability to work.

The unadopted social model of disability, in terms of interactions between officials and persons with disabilities, despite the ratification of the UN Convention and even the national "Accessible environment" project, has led to disability being experienced as a personal problem that must be resolved alone, with relatives, or through NPOs. The focus on the resolution of personal problems and difficulties arising from an unbalanced and, in many ways, discriminatory policy has seriously limited project participants' access to fundamental types of activity, such as: employment, education, socialization, hobbies, travel, and, of course, protection of their rights.

Conclusions and recommendations

The Russian model of determining disability and of providing social and medical support for people with disabilities consists of many significant barriers to accessing social and medical services. People living with HIV, especially people who actively use drugs, are particularly vulnerable to negative impacts of administrative and stigma-related barriers.

Legislation ensuring social protections for people with disabilities shows that providing significant material, social, and housing support to people with disabilities, including those living with HIV and tuberculosis, is possible. However, the likelihood of people with disabilities receiving such support is complicated by the high threshold for disability registration and approval, especially in cases where the disability is not obvious and requires determination by specialists. During the COVID pandemic, additional measures were created for people with disabilities to simplify disability registration and approval, as well as case management in medical institutions. However, no additional services have been created during Russia's current war against Ukraine despite more people becoming disabled due to war injuries, as well as the negative impact of inflation and the increased scarcity of medicines because of war-related sanctions, strong self-stigmatization, and growing anxiety due to social uncertainty.

Russian laws mandate the government to engage civil society organizations to provide support for people with disabilities. However, there is no policy or mechanisms for the government to identify and contract such organizations. It is essential for the government to create mechanisms to involve organizations in supporting such persons, including vulnerable subgroups such as people living with HIV and tuberculosis. Such mechanisms could build upon the best practices of HIV service projects implemented with the support from the Global Fund to fight HIV, TB in Malaria in Russia and other countries of Eastern Europe.

The efforts of these organizations should consider the aspects of social, medical, and legal support specific to disability, HIV, tuberculosis, and factors such as stigma and discrimination toward people with disabilities as well other communities affected by HIV and tuberculosis (people who use drugs, people who were formerly incarcerated, LGBTQ people, migrants, women). Organizations providing services to people living with HIV and the above-mentioned groups are the ideal match to the task of providing services for people with disabilities.

Health professionals, staff at MSE, and municipal workers should receive training about needs and rights of people with disabilities, including those from the affected groups. OHCHR Training Package on the Convention on the Rights of Persons with Disabilities could be of use for this purpose.[30]

Memoranda of understanding should be drafted to ensure cooperation between local health and social services and municipal and non-governmental organizations. These agreements should also establish a list of people to contact if people with disabilities encounter barriers to accessing support services Such memoranda could stipulate mechanisms to deal with systemic barriers, too.

Assessment of correspondence of *Federal Law On Social Protections for Persons with Disabilities in the Russian Federation No 181-FZ of 24 November 1995* to the UN Convention on the Rights of Persons with Disabilities shall be carried out, taking into account recommendations given by Committee on the Rights of Persons with Disabilities to the Russian Federation in 2018.[31]

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[3] UN Convention on the Rights of Persons with Disabilities, adopted December 13, 2006, by the General Assembly (Resolution A/RES/61/106). Ratified May 3, 2012, by the Russian Federation (Statute No. 46-FZ).

[4] The full list is available in Article 1 of the Convention.

[5] Article 33, Federal law No. 181-FZ *Social Protections for Persons with Disabilities in the Russian Federation*, adopted November 24, 1995.

[6] Items 6, 5, Russian Ministry of Labor Order No. 585, *Classifications and Criteria for Citizen Disability Determinations by Federal Government Institutions for Disability Determinations*, issued August 27, 2019.

[7] List of illnesses, defects, irreversible structural changes, and functional impairments of bodily organs and systems, and indications and conditions for establishing disability groups and the category of "child with disabilities" appended to Russian Federation Government Decree No. 95, *Procedures and Requirements for Certification of Disability Status*, issued February 20, 2006.

[8] As of July 1, 2022, new policies regulating the certification of disability status entered into effect by Russian Federation Government Decree No. 588, issued April 5, 2022. The decree contains a general algorithm that aligns with both existing and new regulations.

[9] Governmental and Municipal Services (Functions) Integrated Portal. In this section regulations enter into effect as of February 1, 2023.

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[14] Russian Ministry of Health Order No. 991, *Illnesses for Which Persons with Disabilities Shall Be Granted Additional Living Space*, issued November 30, 2012.

[15] Article 14, Federal law No. 77-FZ *Preventing the Spread of Tuberculosis in the Russian Federation*, adopted June 18, 2001.

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