

3. Interview with Oksana Rusnak

conducted by Katarzyna Kinga Kowalczyk

Katarzyna Kinga Kowalczyk: Can you introduce yourself?

Oksana Rusnak: My name is Oksana Rusnak. I am from Uzbekistan and live in the city of Tashkent. I turned 48 on September 11th, 2024. I am a woman living with HIV and a woman who uses drugs. Nowadays, I use drugs less than I did in my youth, mainly because of work and because I lead a very active lifestyle. With my open and active stance on both drug use and HIV, I am also an activist in this field.

Katarzyna Kinga Kowalczyk: Can you tell me about your work?

Oksana Rusnak: Currently, I work as a peer consultant for HIV and tuberculosis at Ishonch va Hayot. Since I've personally experienced tuberculosis, I also receive support. We consult people on how to accept their HIV status and continue living. For example, we help [HIV-positive] women who have given birth. We have a service that guides them through pregnancy until their child reaches one and a half years of age. Once a month, after the last PCR test, we deliver formula milk to them. Right now, I'm the driver in our organization, delivering the formula to women on specific days. It's difficult for these women to travel with a newborn, and many can't afford a taxi or even the bus fare. Some can afford delivery services like Yandex Taxi, but not all of them. I deliver the formula to women who can't visit the center, whether they are sick, have no one to leave their child with, or face other challenges, such as a broken leg. So, I handle deliveries for women in such situations.

Additionally, I live openly with my HIV status and try to show those around me that we are not dangerous or contagious. We provide psychosocial support, and we have a psychotherapist in the project to consult women, especially those dealing with psychological issues. We also offer legal help, as many people don't know their rights.

Our organization, which is a NGO, focuses a lot on supporting women, especially those living with HIV, but there are no specific state services for women who use drugs. Even in shelters, women who use drugs are often not accepted, even with our recommendation.

The NGO "Ishonch va Hayot" in Uzbekistan is a prominent organization focused on supporting people living with HIV (PLHIV) and key vulnerable populations. The organization's activities are centered on reducing stigma and discrimination, providing psychosocial support, and advocating for the rights of PLHIV.

Key activities include:

- Comprehensive Care and Support: Providing emotional, legal, and social support to PLHIV; helping to improve their quality of life.
- Advocacy and Public Education: Raising public awareness to reduce the stigma against PLHIV; Fighting for policy changes that promote the rights of these individuals.
- Legal and Social Services: Legal consultations to help PLHIV understand and protect their rights.
- Community Mobilization: Uniting PLHIV and other vulnerable groups through self-help groups and advocacy initiatives to strengthen community support.

Ishonch va Hayot also works in partnership with organizations like UN-AIDS and the Global Fund to expand access to HIV treatment and care, aiming to improve the quality of life for those affected by the epidemic in Uzbekistan.

Work also includes specialized projects for women and addressing barriers faced by people who both use drugs and live with HIV www.plwh.uz

We also have trust rooms available to the public where people can get tested or consult with a narcologist. We try to refer people to both free and paid services so that they can get help.

Trust rooms (кабинет доверия) are facilities or services where people, especially from key populations like people who use drugs or those living with HIV, can receive support without judgment. These rooms often offer harm reduction services, such as providing clean needles, psychological

consultations, and access to HIV testing. Trust rooms are crucial in reducing the spread of infectious diseases like HIV and hepatitis and providing a space where individuals can receive medical and social support (Zakhidova 2024).

Most people here don't openly disclose their HIV status. They tend to only trust certain people [with this information]. Our organization is the only one in Uzbekistan that specifically works with people living with HIV. We're the only one so, naturally, everyone eventually turns to us. We rely a lot on word-of-mouth.

That's why, even now, in different settings, I openly say that I am a former drug user and that yes, I am HIV-positive. However, in order to avoid reinforcing the stereotype that HIV-positive people are drug users, I've started to hide it from casual acquaintances. I realize that by hiding it, I can change their perception. However, when I meet someone I think is ready to understand, I openly say, "Look, I'm living, I was a drug user, and I'm HIV-positive. I'm alive because I started treatment on time. What's stopping you from starting treatment?" I was an HIV denier myself for many years, now when I meet people like that, I try to give them more attention. I know what it's like to be in denial about HIV.

We have successes. For example, there was a person in the community who was HIV-positive but refused to take antiretroviral therapy (ART). No one could convince him, so he was sent to me. I usually handle cases like that. [I convinced him to start.]

I am also an outreach worker. Currently, we are running a testing project. Outreach workers go to locations where women engage in commercial sex work. We provide them with materials and information on where they can seek help if they face issues like drug addiction, abuse, and so on. This is all part of our outreach work. We conduct testing among sex workers, but we also provide screening for tuberculosis and sexually transmitted infections (STIs). While we do more STI testing during outreach work in the trust rooms, screenings for tuberculosis and HIV are more common in the testing centers.

We also have our own website and Telegram groups where we try to spread awareness and let people know these services exist. The services are there, but unfortunately, none are specifically designed for women.

Nowadays, even narcologists will reach out to us if they find out someone is HIV-positive. [This shows] our work isn't just a drop in the ocean. I've been reflecting, and there have definitely been [positive] changes. We now have

strong contacts with both the tuberculosis and narcology services, even if it's only at the doctor level, not at a global scale yet. But it's a start and it's already working. They now see the value in our work. If before they questioned us, saying, "What are you doing here? We've been studying this for centuries," now they're starting to say that much less.

Katarzyna Kinga Kowalczyk: What is life like for women in Uzbekistan?

Oksana Rusnak: I wouldn't say it's particularly difficult for us to live here. Every country presents its challenges. On one hand, women are somewhat revered, for example, as mothers or in other roles that grant them a certain status. However, on the other hand, it feels like there's actually no real respect for women. It's all just words because, in practice, true respect is lacking.

I'm of an age where I remember what it was like before, and I see how things have changed since the collapse of the Soviet Union. Yes, things have become harder; I can say that women here face something close to violence. It's one of the many problems women deal with. For example, if your husband beats you, older women might say, "It's nothing, don't take this outside the home, it's normal." Society - especially mothers-in-law and mothers - are largely okay with this. About 90% of people have this mindset. We don't live in a European society where, if you're beaten at home, you can go and complain. Even when women do report it, they are often told, "It's family, you fought today, you'll make up tomorrow."

We've encountered situations where wives later come back and withdraw their complaints. Why do they withdraw them? Because when their husbands find out that they reported them, they get beaten again. The husband's mother might also interfere, saying, "Why are you airing our dirty laundry?" So, yes, there are difficulties in this regard, especially within traditional families. While I believe this also happens in other countries, our mentality doesn't allow for problems to be taken outside the home.

According to the Uzbek Ministry of Internal Affairs, approximately 14,800 protection orders were issued in 2020 to protect individuals, usually victims of domestic violence, from their abusers. The majority of violence against women occurs within families, with husbands identified as the perpetrators in 82% of the 13,230 domestic violence cases reported the same year (Eurasian Women's Network on AIDS 2023).

We do have some services available, and shelters have opened where a woman can go and stay for a while. However, if you are a woman who uses substances, you won't have access to these shelters.

Katarzyna Kinga Kowalczyk: Are there HIV or drug treatment services for women only?

Oksana Rusnak: We don't have separate state services for women living with HIV or women using psychoactive substances. In general, only NGOs provide support to women living with HIV who also using drugs. These NGOs specifically focus on key populations. While there are some government services, such as the narcological dispensary and the Mahalla Committee, which help resolve family conflicts, their approach is often conservative. For example, they often tell women to endure their situation for the sake of their families, children, and societal expectations, imposing many restrictions on women while men face fewer consequences. Our NGO has held lectures with these organizations because they are the first ones to spread information about someone's diagnosis which leads to stigma and discrimination. The neighbors don't understand what HIV is, for example. People who use drugs are not even considered human beings. They aren't considered being people.

A mahalla (district, quarter, ward, or neighborhood) in Uzbekistan is a traditional neighborhood or community organization. It plays an important role in daily life, where people living in the same area can come together to support each other. Mahallas are responsible for organizing social events, providing help to families in need, and solving local problems. They also help with things like distributing welfare, managing local disputes, and maintaining community values.

Katarzyna Kinga Kowalczyk: What is the attitude toward using mental health support among people living with HIV?

Oksana Rusnak: When someone is told they need to see a psychotherapist, they often respond with, "I'm not mentally ill." People don't understand that mental health is also part of overall health. A psychotherapist is just like any other doctor, like a general practitioner or a pediatrician for children. When they prescribe something, people often refuse, saying they won't take the medication because they don't understand its importance. We even had a lawyer once, someone with multiple degrees, and when we hired him, he

said, "What mental health? Why are you girls bothering with this?" It's then you realize that even well-educated people don't grasp the significance of mental health.

It's difficult, but it's so necessary. I've personally gone to a psychotherapist because I realized I couldn't handle my emotions anymore. I was burning out at work, and sometimes there's no feedback or recognition for all the work you do. You keep working and working without getting anything in return.

My principle is to "do good and let it be." But after a while, it's not just physical exhaustion—you can't even open your eyes in the morning or face going to work. You start hating people. For example, when someone living with HIV comes in and says they're disabled, you feel like hitting them because they don't seem like they're disabled at all.

I realized I couldn't keep working with people in this state. I had to see a psychotherapist and eventually left my role as a peer consultant. I didn't leave because of that, but I had lost empathy. When I looked at someone, I didn't feel sorry for them anymore. And you can't work in this field without empathy.

Burnout and mental health challenges are highly prevalent among activists and healthcare workers in the HIV and drug use fields. Several studies highlight the unique stressors faced by these professionals, including frequent exposure to trauma, resource limitations, and the emotional toll of working with marginalized populations. In Eastern Europe and Central Asia, according to studies conducted in the region, burnout is often exacerbated by underfunded programs, a lack of mental health support, and limited organizational resources (Central and Eastern European Harm Reduction Network 2006; Sarata n.d.).

Katarzyna Kinga Kowalczyk: What should be changed to help to support women?

Oksana Rusnak: If I had a magic wand and could do whatever I wanted, I think it would go beyond just helping women with HIV. The main issue here is stigma, which is deeply ingrained in our society. Stigma and discrimination go hand in hand, like twins. If we could eliminate that, things would already be better.

However, beyond HIV, I think women in general need more support. I would create shelters, real places where women could go. There should

be separate shelters for drug users, where a woman can go and reach her lowest point or find a safe space, surrounded by people who understand her struggles. A place where - like returning to your parent's house - you can always return when needed.

And this should be the case for all women, not just those living with HIV or using drugs, especially here in Uzbekistan. It's like trying to turn a huge ship around, but with a magic wand, I'd want equality, where everyone has the same rights and isn't restricted by their status. For example, women with HIV or who use drugs, especially in rural areas, endure so much humiliation. Even from their own in-laws. I remember staying with a woman who had just given birth. She had stitches from a difficult delivery, and her mother-in-law came in and told her to get up and clean. When the woman explained she was in pain, her mother-in-law replied, "So what? I worked in the fields right after giving birth." There's no compassion, even from woman to woman.

Katarzyna Kinga Kowalczyk: On a more personal note, what are your dreams?

Oksana Rusnak: I've been living with my status for a long time, and I've accepted it as a consequence of my past lifestyle. What hurts me the most is children born with HIV. I hope that by the time they grow up, there will be a vaccine. I want children to have access to the newest vaccines and thorough screenings.

I've seen children brought in almost lifeless, and it takes years for them to recover, learn to speak or walk again. It's heartbreak. I've seen many deaths, and although I consider myself a tough person, I wish there were no diseases at all.

I hope I live long enough to receive that magic cure. Even if drugs exist in the world, everyone should at least have the chance to avoid suffering.

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