



Anya Sarang

RUSSIA

Against the grain: the story of the Andrey Rylkov Foundation

Introduction

In the 1990s, Russia went through a period of unprecedented political and economic change. With the fall of communist economic and political systems, unemployment, poverty and crime began to increase. At the same time, new drug markets opened up, contributing to an increased availability and demand for drugs in the country. Health problems related to the use of drugs quickly emerged as pressing social and public health challenges.

A growing number of non-governmental organisations (NGOs) began to respond to this crisis, providing clean needles and other support to people who use drugs. However, by the early 2000s Putin's leadership had begun to devolve into dictatorship, and political repression and state distrust of NGOs were on the rise. Shortly after Putin's re-election as president in 2012, the situation worsened dramatically. A number of NGOs became a target of new anti-NGO laws, including the Foreign Agents Act, which imposed steep penalties on organisations involved in activities the state deemed to be 'political'.

While NGOs in the harm reduction sector are yet to be directly affected by the Foreign Agents Act, it has created a climate of fear both for them and for social activists across the country.

From 2010, the state began to use the populist language of 'morality' and 'traditional values' in public health policy to discourage drug use, promoting a range of ideologies that were out of step with the realities of economically and socially challenged populations. At the same time it stepped up its stigmatising language against people who did not fit its vision of 'proper behaviour'.

In the two decades since the fall of the Soviet Union, the health system failed to keep pace with the transforming circumstances of poor and marginalised Russians. Despite expanding health budgets, many activists became increasingly critical of the waste of government money, the ineffective management of health infrastructure, and the massive corruption of state officials. The situation had created a paradox: more money was allocated to health but the health of ordinary people deteriorated. This was compounded by ever decreasing opportunity for NGOs to influence their environment.

In today's Russia it is very difficult for NGOs that stand up for scientific evidence, human rights and effective policies to advance their agendas openly. Because of increasing levels of political and social repression, few organisations have managed to challenge the state on social issues. In the area of drug policy and treatment and AIDS, the Andrey Rylkov Foundation has been one of the few prepared to take up the challenge. In order to understand its efforts, it is important to first explain the terrain on which it operates.

Injecting drug use and related health problems in Russia

Nearly 5 million people use illegal drugs in Russia,¹ 1.7 million of whom are opiate users.² Of the officially registered HIV cases in 2013,³ almost 60% are also people who use drugs. In some cities, HIV prevalence among people who inject drugs is as high as 74%.⁴ The trends in HIV prevalence and incidence show an epidemic that is on the rise,^{5,6} with 800,000 people officially registered as HIV positive⁷ and many others who simply do not know their status. In many cases, HIV treatment access is limited for people who use drugs.⁸ Russia also has other HIV-related health problems, such as hepatitis C virus (HCV) and tuberculosis (TB).

TB has now reached epidemic proportions in the country, including in its drug resistant forms. Russia's high TB burden is matched by one of the lowest treatment success rates for new cases in the world.

The country has the dubious distinction of the second-worst rate of TB-related mortality, and ranks third globally in total cases of multi-drug resistant TB after China and India.⁹

People who inject drugs are especially vulnerable to TB because they have high HIV prevalence rates. They are also incarcerated at higher rates than the general population and seldom have access to prevention and treatment services. TB remains the primary cause of death among people with HIV, and 78% of men with the dual infection of TB and HIV also inject drugs.¹⁰

An average of 74% of people who inject drugs also carry HCV. In some cities, up to 90% of people who inject drugs have HCV,¹¹ and the total number of people who

1. (4 February 2010), Interview with head of the Federal Drug Control, *Rossiyskaya Gazeta*, Federal issue 5101(22).

2. UNODC (2011), *World drug report 2011*, Vienna: United Nations Office on Drugs and Crime.

3. Russian Federal AIDS Center (2014), *Data on HIV in the Russian Federation in 2013*.

4. Mathers, B. et al. (2008), 'Global epidemiology of injecting drug use and HIV among people who inject drugs: a systematic review', *Lancet* 372(9651): 1733–45.

5. Esvero (2011), *HIV and hepatitis prevalence and risk behavior among injecting drug users in Moscow, Ekaterinburg, Omsk and Orel in 2011*. Available at: www.esvero.ru/files/referat_rus_web.pdf [in Russian]

6. Niccolai, L.M. et al. (2011), 'Estimates of HIV incidence among drug users in St. Petersburg, Russia: continued growth of a rapidly expanding epidemic', *European Journal of Public Health* 21(5): 613–9.

7. Russian Federal AIDS Center (2014), *Data on HIV in the Russian Federation in 2013*.

8. Sarang, A., Rhodes, T., Sheon, N. (2013), 'Systemic barriers accessing HIV treatment among people who inject drugs in Russia: a qualitative study', *Health Policy and Planning* 28(7): 681–91.

9. WHO (2013), *Global tuberculosis report 2013*. Available at: http://apps.who.int/iris/bitstream/10665/91355/1/9789241564656_eng.pdf

10. Andrey Rylkov Foundation (2011), *Provision of effective TB treatment to drug dependent patients living with HIV*, Moscow.

11. UNODC, NGO Stellit (2010), *Research conducted amongst street drug users in St. Petersburg*.

inject drugs with HCV is estimated to be over one million.¹² While co-infection with HIV represents a clear indication of treatment need, less than 10% of all people with HIV receive treatment for HCV, while people who inject drugs simply are not provided with access to HCV treatment at all.¹³

Despite this grave public health situation, the state provides no services to stem drug dependency and its related health and social problems.¹⁴

People who use drugs are depicted by state officials as “deviant” and as criminals, and therefore undeserving of equal access to healthcare.

The Russian government refuses to adopt even the most mainstream and well-studied approaches to drug treatment, including opioid substitution treatment with methadone and buprenorphine. These are illegal in Russia due to the government’s ideological opposition to modern forms of drug treatment.^{15,16} Instead, antipsychotic drugs that were used against Soviet dissidents are part of the standard regimen for treating drug dependency in state facilities.¹⁷ This approach to drug treatment is both heavily outdated and does not conform to international standards.¹⁸

A uniquely Russian approach

Back in the mid-1990s when the first needle and syringe programmes appeared with the support of international organisations, many Russian activists as well as donors believed that once there was sufficient ‘proof of concept’ the state would step in, take over and expand the distribution of clean and safe needles. Instead, today’s programmes continue to be implemented in an atmosphere of political hostility.

As post-Soviet Russia’s drug and HIV crisis deepened during the early 2000s, resources started to become available from international agencies, and new NGOs sprang up to attend to the growing need. These organisations played a crucial role in delivering prevention services to people who use drugs, as well as sex workers, men who have sex with men and young people. Many of them also advocated for better access to state-funded services and HIV prevention. Several networks were formed, including the Russian Harm Reduction Network that became a strong force in mobilising resources to support harm reduction initiatives in the country.

Around the time when these broader social upheavals and crackdowns were occurring, government opposition to harm reduction began to harden. Before 2010, activists had worked in the hope that the small but highly effective pilot harm reduction interventions they were running would be picked up by the government. With this in mind, a lot of money and effort were spent on conventional advocacy approaches. Many round tables with government representatives were held. Innumerable study tours and site visits were undertaken. Millions of pages of newsletters, bulletins, research studies and best-practice manuals were produced. None of these activities made any difference.

12. Hope, V.D., Eramova, I., Capurro, D., Donoghoe, M.C. (2014), ‘Prevalence and estimation of hepatitis B and C infections in the WHO European Region: a review of data focusing on the countries outside the European Union and the European Free Trade Association’, *Epidemiology and Infection* 142(2): 270–86.

13. Andrey Rylkov Foundation (2013), *Hepatitis C in Russia: an epidemic of negligence*. Available at: <http://rylkov-fond.org/blog/health-care/hepatitis/hepatitis-report/> [in Russian].

14. Human Rights Watch (2007). *Rehabilitation required: Russia’s human rights obligation to provide evidence-based drug dependence treatment*.

15. Moscow Komsomolets (16 November 2010). Available at: www.mk.ru/social/interview/2010/11/15/544237-klinika-v-posledniy-put.html [in Russian]

16. Andrey Rylkov Foundation (2011), *Ensuring the effective TB treatment of drug dependent HIV positive patients*, Moscow.

17. Faraone, S. (1982), ‘Psychiatry and political repression in the Soviet Union’, *The American Psychologist* 37(10): 1105–12.

18. Order of the Ministry of Health of the Russian Federation N 140 of 28 April 1998. On approval of drug treatment standards (model protocols).

The government simply refused to respond to the scientific evidence in support of needle and syringe programmes and methadone substitution therapy.

Few organisations were able to actively resist the state's stubborn stance. After 2010, civil society groups quickly understood that the only way to survive without incessant harassment was to avoid active advocacy work and exclude phrases like 'harm reduction' and 'opioid substitution treatment' from their literature. Even the Russian Harm Reduction Network decided to change its name to ESVERO in response to the new environment.

Many activists believed that the only way forward was to cooperate with the government. This was, of course, the common sense thing to do in a repressive environment. The examples of what would happen to those who opposed the state were only too evident in the daily headlines.

The Andrey Rylkov Foundation fights back

However, one organisation decided to go against the grain. The Andrey Rylkov Foundation for Health and Social Justice (ARF) started as an initiative aimed at protecting the health and human rights of people who use drugs. It was officially registered as an NGO in 2009, the same year that the Russian minister of health declared to the State Security Council (in the presence of the president and the prime minister) that the distribution of sterile needles and syringes "stimulates social tolerance of drug addicts, and violates the Criminal Code of the Russian Federation".¹⁹

This marked a decisive shift in policy against harm reduction. Until then, the ministry of health had simply ignored or withheld financial support from harm reduction programmes. Now an era began of active ideological opposition to people who use drugs by officials who should have been responsible for protecting and promoting their rights, and for their care, treatment and support.

For ARF volunteers, this policy reversal meant that the time for passive advocacy and negotiations with the government was ended. They were no longer under any illusion that building an evidence base would make any difference.

So the NGO began to strategise about how it would need to look, think and act if it were to tackle AIDS and injecting drug use head on in the new Russia.

ARF emerged from this as a small but flexible administrative platform that saw its role as fundraising for and supporting community initiatives and activists. The NGO had only two people working for it full time, as well as a part-time accountant, and no physical infrastructure. Without an office, it was able to cut down on administrative fees.

This approach allowed ARF to build dynamic, horizontal projects that were conceptualised, led and managed by community activists. It created a more decentralised approach that would allow for flexibility as needed. These strategies were designed to minimise risks stemming from any crackdowns by the increasingly heavy-handed authorities.

19. Rhodes, T., Sarang, A., Vickerman, P., Hickman, M. (2010), 'Policy resistance to harm reduction for drug users and potential effect of change', *British Medical Journal* 341:c3439.



Then ARF decided that ten years has been time enough waiting for the city authorities to approve harm reduction services in Moscow, provide clean syringes and condoms, and information and counselling to people who use drugs on the streets. Unlike other local authorities in Russia who could be flexible, Moscow had always been aggressively and openly opposed to needle and syringe programmes, to the point where many donors and NGOs actually believed that harm reduction was illegal in Moscow, whereas in fact there was no such law.

As a result, no NGO had ever had the audacity to start providing needles to people who use drugs. Instead, they had resigned themselves to quiet advocacy, trying to convince city health officials of the benefit of such programmes, despite their cynical opposition.

However, ARF believed that in order to serve the community it needed to engage in real action. So a small group of volunteers started to work on the streets of Moscow, giving their time for free and receiving small donations of syringes, condoms and brochures from other organisations.

When ARF applied for funds from the Global Fund to Fight AIDS, Tuberculosis and Malaria, Russia's principal recipient refused to allocate them on the basis that there was insufficient cooperation with the city authorities. Instead, it supported another NGO that had better liaison with the city health officials but refused to hand out needles and syringes to people who use drugs. So for six months, ARF's initiative continued to run without funding until the United Nations Office on Drugs and Crime started to support ARF's Moscow needle and syringe programme, acknowledging that it was based on sound evidence and met international public health standards.

In 2011 ARF was vindicated when it received the prestigious Crystal of Hope Award for its courageous action in fighting HIV. The cash prize funded the initiative for a further two years, and today its work continues to grow. Former participants in the programme, other people who use drugs, and activists continue to volunteer, and the organisation still operates without an office or other facilities. However, it has established an excellent communication infrastructure that allows it to coordinate and manage cases with the many different providers of vital services for people who use drugs in and around the Moscow area.

ARF's activities have not gone unnoticed by the state. In 2012 the NGO's website was shut down for providing "drug propaganda", and the head of the Federal Drug Control Service has publicly accused them of smuggling of methadone into Russia. ARF answered these absurd charges by turning to the law. It chose to fight for the right to distribute and provide information rather than be intimidated by the repression or ignore it.

ARF sued the Federal Drug Control Service that had ordered it to close down the website. Unsurprisingly, it lost the case in the Russian justice system. The NGO then decided to take the case to the European Court of Human Rights. It also reported the closure of the website on grounds that it believes are untrue and unfair to the United Nations Special Rapporteurs on the right to health, Cultural Rights, Freedom of Opinion and Expression and Human Rights Defenders. These actions have meant that ARF has received significant attention from a number of organisations, including Human Rights Watch and Article 19, which have spoken out against state harassment.

Beyond needle and syringe programmes: fighting the law with the law

Besides direct service provision, ARF engages in other key strategies to advance its mission. It monitors cases where the human rights of people who use drugs have been violated; it creates bold campaigns aimed at the general public; and it conducts strategic litigation. The NGO's strategies are always imaginative, which is why they have been successful.

As with all efforts that are devised and managed by the people who are most affected, ARF's activists refuse to play by the normal rules. The NGO's work relies heavily on the voluntary support of activists from the drug-using community, and ARF's spokespeople talk openly about their drug dependency, HIV status and battles with TB. While ARF's work is intended primarily to provide practical help to people who use drugs, it also builds their capacity to engage in self-advocacy and service provision.

All of this is reflected in the excellent media coverage ARF receives both locally and from the international press. ARF volunteers are articulate and compelling experts who have themselves lived through the challenges they are working with. As a result, they have been in demand from, among others, the BBC, Voice of America, *Financial Times*, *Independent*, *Associated Press*, *The Lancet*, *Scientific American* and *New York Times*.

In 2013 ARF added a legal and human rights dimension to its work by starting a street lawyers project. This uses paralegals (outreach workers and case managers) to provide legal education and basic legal aid to people who use drugs who are victimised by police and other law enforcement officials, who are discriminated against in medical facilities, and who are forced to encounter barriers while trying to fulfil their right to health and dignity. When these cases fail in the Russian courts, ARF pushes them further. The project has taken more than a dozen cases to national and international courts, claiming violations of the rights of people who use drugs to health,²⁰ protection from torture and inhumane treatment,²¹ information²² and the benefits of scientific progress.²³

Activism is necessarily political in the new Russia

ARF is an important example of how the fight for better and more comprehensive treatment for key populations can also be a fight for the rights and dignity of all people living in a society.

Its approach, moving beyond 'paper advocacy', has been powerful and successful precisely because it is brave and straightforward.

Above all, ARF has managed to tackle its work with courage and strategic insight because it has also organised itself differently to other NGOs. What it does and

20. Andrey Rylkov Foundation (2010), *Report to the International Committee on Economic, Social and Cultural Rights on implementation by the Russian Federation of article 12 of the International Covenant on Economic, Social and Cultural Rights as it relates to access of people who inject drugs to drug treatment and HIV prevention, care and treatment programs*. Available at: [http://en.rylkov-fond.org/blog/arf-advocacy/arf-international-advocacy/report-to-the-international-committee-on-economic-social-and-cultural-r/](http://en.rylkov-fond.org/blog/arf-advocacy/arf-international-advocacy/report-to-the-international-committee-on-economic-social-and-cultural-rights-on-implementation-by-the-russian-federation-of-article-12-of-the-international-covenant-on-economic-social-and-cultural-r/)

21. Andrey Rylkov Foundation (2011), "ATMOSPHERIC PRESSURE": *Russian drug policy as a driver for violations of the UN Convention against Torture. Shadow Report to the UN Committee against Torture in relation to the review of the Fifth Periodic Report of the Russian Federation*. Available at: <http://en.rylkov-fond.org/blog/arf-advocacy/arf-international-advocacy/atmospheric-pressure/>

22. Andrey Rylkov Foundation (2012), *Information note regarding retaliation of the Government of the Russian Federation against the Andrey Rylkov Foundation for Health and Social Justice (ARF) for promoting the recommendations made by the UN Committee on Economic, Social and Cultural Rights (CESCR) to the Russian Federation in its Concluding Observations*. Available at: <http://en.rylkov-fond.org/blog/drug-policy-and-russia/drug-policy-in-russia/information-note-regarding-retaliation-of-the-government-of-the-russian-federation-against-the-andrey-rylkov-foundation-for-health-and-social-justice/>

23. Andrey Rylkov Foundation (2012), *Appeal lodged with UNESCO on Russia's violation of the right to enjoy the benefits of scientific progress*. Available at: <http://en.rylkov-fond.org/blog/ost/rost/arf-appeal-unesco-scientific-progress/>



how it does it has been devised in direct response to the political repression it encounters. AFR is less administratively vulnerable to its hostile environment because it is lean. It has adopted flexible situational planning rather than long-term strategic planning. It also has a highly mobile, almost instantaneous and horizontal decision-making process. This means that volunteers on the ground make decisions about their work, and the NGO doesn't rely on approvals by boards and committees that have little interface with its everyday work.

But perhaps most impressively, embedded in ARF's very DNA is a rejection of the notion that good advocacy requires government approval and collaboration.

In other contexts, working with the state is an absolute requirement. Yet in today's Russia, the instinct to continue to please the state has led many NGOs to paralysis.

ARF's refusal to seek government approval has meant that it doesn't get bogged down in their fake promises. It isn't lured by the possibility of cooperation from a state that has demonstrated that it is disinterested in partnering with people who use drugs. It is able to be uncompromising because it isn't subject to the kinds of ideological blackmail that can occur when NGOs strike deals with certain parts of the state even as they are opposed to other parts.

Much of the litigation that the group has pursued in recent years is at the level of regional and human rights courts. The danger is that the Kremlin can ignore it if it so chooses. Despite this, ARF's legal strategies have been successful in establishing a strong voice for the rights of people who use drugs and for effective HIV responses in a context where the state has abrogated its responsibilities.

A new set of development goals and targets will be worked out in September 2014, and ARF's work will continue. Regardless of the post-Millennium Development Goal environment, it is likely that Russia will continue to avoid its international treaty obligations and deny its citizens access to essential public health services. In this worsening political climate, with growing state pressure on NGOs and diminishing amounts of foreign assistance, there is much to learn from the way that ARF has fought back.

The NGO stands as a proud example of how direct, confrontational activism is often the only way for the most vulnerable communities to access their rights. In this kind of charged political environment, ARF's work offers lessons for how to exist outside the framework of technical public health responses. In Russia, activism is by necessity political.



People who use drugs defend their rights

In October 2011, Irina Teplinskaya conducted an interview in which she took the rare step of revealing her identity as a woman who uses drugs. The interview was published in a large Russian newspaper called Moskovskiy Komsomolets. Her story was then picked up and broadcast widely on radio and television. Teplinskaya filed a complaint to the United Nations Special Rapporteur on the right to health, and in 2012 she also filed a case in the Russian courts on her inability to access opiate substitution therapy (OST). The case is now under review with the European Court of Human Rights.

Ivan Anoshkin, Alexey Kurmanaevskiy and Dmitry Polushkin became involved with ARF through the Working Group on OST Advocacy. Their complaints about the absence of OST in Russia are currently under review by the European Court of Human Rights.

Maxim Malyshev, an ARF outreach coordinator and blogger, started an advocacy and litigation process in 2011 in order to protect his right to receive free diagnostics for HCV, and won the case against the Tver Oblast administration. The case protected the rights of all people to receive free diagnostics as part of treatment.

Other brave activists currently fighting in the courts include Oksana Shpagina, who has been fighting for access to OST for pregnant women. Tatyana Kochetkova and Natalya Vershinina from Togliatti, Larisa Solovieva from Kaliningrad, and Ludmila Vins and Ivan Zhavoronkov from Ekaterinburg are now committed case managers, whose skills continue to grow and whose work supports treatment access for people who use drugs.



BIOGRAPHY

Anya Sarang

Anya's work over the past 11 years has focused on developing and supporting the emerging harm reduction movement in Russia. She has lobbied for access to health; protection of human rights; as well as dignity for people who use drugs and humane drug policies. She is President of the Andrey Rylkov Foundation for Health and Social Justice in Moscow.

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