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Ulla Pape: An Uneasy Partnership: NGOs and the Russian State in their Fight against HIV/AIDS

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Abstract

This paper deals with the fight against HIV/AIDS in the Russian Federation, which has developed into a serious social and political problem. The paper focuses on the role of NGOs in the response to the epidemic and investigates their collaboration with state institutions and their influence on domestic policy making. The political interplay between NGOs and the Russian state is particularly interesting because of the paradoxical predicament of a state that aims, on the one hand, to monitor and control civil society activity and, on the other, a state that needs NGO expertise to effectively address the HIV/AIDS epidemic.

From a theoretical perspective, the paper applies the global governance approach by L. Gordenker and T.G. Weiss, which enables us to analyse the particular power capabilities of NGOs. On the basis of a case study of two AIDS-service NGOs in the region Tomsk, the paper shows how NGOs responded to the emerging epidemic and to what extent they have been able to influence policy making. The paper argues that NGOs are indeed key players in the fight against HIV/AIDS in Russia and have often played a pioneering role by conducting the first prevention programmes and allocating funds from international donor organisations. The main functions of AIDS-service NGOs can be seen in advocacy, service provision and empowerment, which allow them to effectively influence policy making in the field of HIV/AIDS and achieve social change.

1. Introduction

Neglected for a long time, the HIV/AIDS epidemic in the Russian Federation has developed into a serious social and political problem. According to the United Nations Programme on HIV/AIDS (UNAIDS), Russia is currently facing the biggest HIV/AIDS epidemic in all of Europe with an estimated number of 940,000 people infected with HIV.¹ An important factor in the unfolding of the epidemic in Russia has been the high number of injecting drug users (IDUs) among young people. Other specifically vulnerable groups include prison inmates, commercial sex workers (CSWs) and homosexual men. In the past, the Russian government has been very slow in responding to the AIDS epidemic. For a long time, it has relied on testing rather than on broad prevention campaigns. Today, there are signs of a growing recognition that the epidemic's ongoing growth demands a stepped-up response. Russia's government has understood that HIV/AIDS forms a threat to social security and demographic development and, thus, is striving to develop new response strategies that also include collaboration with civil society.

Non-governmental organisations (NGOs), as the most prominent civil society actors, have been essential in the response to HIV/AIDS in the Russia.² In many regions NGOs started the first prevention programmes throughout the 1990s when public response in this area was practically non-existent. One example for NGO activity today is the GLOBUS project, which is financed by the Global Fund and implemented by a consortium of five international and Russian NGOs. The development of civil society in post-Soviet Russia, however, has been far from unproblematic. Civic engagement and the formation of a participatory political culture can still be regarded as weak. Moreover, many Russian and foreign NGOs face difficulties from state authorities. The 2006 law on NGOs tightened the regulation concerning registration, programming and financing of NGOs, and is commonly understood as a sign that the government is seeking to extend its control over the non-governmental sector.³ This overall political context creates a practical dilemma for NGOs in Russia as they need cooperation with state authorities on the local and national level if their programmes want to be successful.

1 UNAIDS: Eastern Europe and Central Asia: AIDS Epidemic Update 2007, March 2008, http://data.unaids.org/pub/Report/2008/jc1529_epibriefs_eeurope_casia_en.pdf, accessed 25 May 2008.

2 Brown, Hannah: 'Russia's Blossoming Civil Society Holds the Key to HIV', in: *The Lancet*, August 5 2006, Vol. 368, pp. 437–440.

3 International Centre for Not-for Profit Law (ICNL): Analysis of Russian NGO Law, 28-02-2006, <http://www.icnl.org/knowledge/news/2006/02-28.htm>.

This paper aims to analyse the role of NGOs in the fight against HIV/AIDS in the Russian Federation. Based on the global governance approach by L. Gordenker and T.G. Weiss, the particular power capabilities of NGOs in the response to HIV/AIDS in Russia will be investigated.⁴ The paper will thereby focus on the influence of NGOs on policy making in the field of HIV/AIDS and their collaboration with state institutions. The political interplay between NGOs and state institutions has been singled out as a field of particular interest as it shows both sides of a difficult – often paradoxical – relationship: on the one hand, civic initiative is still weakly developed and state institutions are often reluctant to cooperate with NGOs; on the other hand, however, state institutions do need NGO expertise and joint work with civil society in order to address effectively the HIV/AIDS epidemic in Russia. In short, the paper will address the following research question: how did NGOs respond to the emerging HIV/AIDS epidemic in the Russian Federation, and to what extent have they been able to influence HIV/AIDS policy making over the past decade? As a case example, the activity of two AIDS-service NGOs in the region Tomsk will be discussed.

2. Background: Russia's HIV/AIDS Crisis

The HIV/AIDS epidemic arrived in the region of Eastern Europe much later than in other parts of the world. Due to its political isolation, the first case of HIV infection in the then Soviet Union was only diagnosed in 1987. In 1995, the number of HIV infections in Russia was still as low as 1,000.⁵ Twelve years later, the situation had changed dramatically. By the end of 2007, the number of registered HIV infections had risen to more than 400,000,⁶ whereas the estimated number of unreported cases is believed to be much higher.

The rapid spread of HIV since the middle of the 1990s is predominantly driven by transmission via needle sharing among IDUs. To date, drug users remain the most vulnerable risk group. Furthermore, sexual transmission of HIV is on the rise, resulting in a growing number of women infected with HIV in Russia. The HIV/AIDS epidemic mainly affects young people. According to UNAIDS, 80% of those infected with HIV are between 14 and 30 years old.⁷ Although efforts to combat HIV/AIDS have been intensified in recent years, the epidemic continues to grow, albeit not as fast as in the years 2000 and 2001. Today, HIV/AIDS affects more people in Russia than in any other country of Eastern Europe.

How could this alarming situation emerge? The underlying factors that enabled the spread of HIV/AIDS in Russia are complex. Next to a sharp increase in drug use, sexual behaviour has significantly changed after the end of the Soviet Union. There are no systematic sexual education programmes at schools which could provide reliable information on HIV/AIDS and prevent risky behaviour. Moreover, widespread stigma and discrimination against those groups of society which are most at risk, for instance drug users, sex workers and homosexual men, contributed to the spread of HIV and made prevention efforts more difficult. Finally, the emergence of the HIV/AIDS crisis is closely linked to the transition process in Post-Soviet Russia, which seriously affected the health care system. In a period of decline and serious under-funding, Russian health care institutions have been unable to respond effectively to the emerging HIV/AIDS epidemic.

3. The Response to HIV/AIDS in Russia

The public response to HIV/AIDS in Russia has many shortcomings. First of all, the epidemiological surveillance of HIV infection is insufficient for tracking and understanding the epidemic in Russia. The statistics of

4 Weiss, Thomas G. and Leon Gordenker (ed.): *NGOs, the UN and Global Governance*, London: Lynne Rienner Publishers, 1996.

5 Russian Federal AIDS Centre: Number of HIV-infected by 31 December 1995, <http://www.hivrussia.org/stat/1995.shtml>, accessed on 22 May 2008.

6 Russian Federal AIDS Centre: Number of HIV-infected by 31 December 2007, <http://www.hivrussia.org/stat/2007.shtml>, accessed on 22 May 2008.

7 UNAIDS: *Global Summary of the AIDS Epidemic*, December 2006, http://www.unaids.ru/en/HIV_data, accessed on 27 May 2008.

the Federal AIDS Centre is based on officially registered cases of HIV infection. Systematic sentinel surveillance of high-risk groups, such as persons with tuberculosis or sexually transmitted infections, does not take place in many regions.⁸ As a result, many experts believe that the official data does not reflect the actual epidemiological development of HIV/AIDS in Russia. Without credible official statistics, Russian health care officials and politicians are disinclined to view HIV/AIDS as a public health priority. Moreover, the incredibility of Russian HIV/AIDS statistics makes it difficult to design concrete prevention programmes, particularly as it comes to difficult to reach high-risk groups.

The main state institution in the field of HIV/AIDS is the Federal AIDS Centre, which was already established during Soviet times, shortly after the first case of HIV infection had been diagnosed in 1987.⁹ The Federal AIDS Centre is in charge of the epidemiological surveillance of HIV infection in the Russian Federation, as well as prevention, clinical diagnosis and medical care.¹⁰ Directed by V.V. Pokrovsky, it consists of a network of federal, regional and municipal AIDS centres and is part of the Federal Service for Surveillance on Consumer Rights Protection and Human Wellbeing. The legal basis for the response to the epidemic is the 1995 Federal AIDS law, which guarantees free medical treatment for patients with HIV infection.¹¹

During the 1990s, the Russian AIDS centres, as the health care system in general, suffered from structural under-funding. Due to lack of financial resources, the centres were unable to fulfil their tasks, particularly in the field of prevention. In most cases their work was restricted to diagnosis and registration of HIV infections in their specific region. Russian politicians to a large extent neglected the potential impact of the HIV/AIDS epidemic. This situation changed only after HIV/AIDS started to spread rapidly among young people after 1998.¹² The Russian government then realised that the epidemic required a political strategy. In 2003, president Putin first officially mentioned the problem of HIV/AIDS in Russia. After this political step, a number of new institutions were created with the aim of organising and coordinating HIV/AIDS policy. At the political level, a Governmental Commission on HIV/AIDS was established in 2006. Chaired by Duma representative Michail Grishankov, it aims to coordinate federal and regional authorities in the implementation of key directions of the national HIV/AIDS policy. In addition, public funding of HIV/AIDS programmes was substantially increased over the past years.¹³

Although the Russian government has dedicated itself to the fight against HIV/AIDS,¹⁴ its response to the epidemic still lacks a clear strategy. The importance of HIV/AIDS prevention has been recognised politically, but there is no consensus about *how* this could best be achieved. Acknowledged prevention strategies, as for instance harm reduction programmes, are not conducted on a scale that would allow them to have a real impact on the epidemic. Substitution therapy, which has been successfully applied in other countries of the region, is not approved in Russia. Moreover, attempts to introduce sexual education programmes in schools that could provide a basis for HIV/AIDS prevention for teenagers failed due to the opposition of the Russian Orthodox Church.¹⁵ Those examples show that there is still a lot to be done before an effective response to the HIV/AIDS epidemic in Russia will be developed.

8 Wallander, Celeste A.: Russian Politics and HIV/AIDS, in: Twigg, J. (ed.): HIV/AIDS in Russia and Eurasia, New York: Palgrave Macmillan, 2006, pp. 33–55.

9 Russian Federal AIDS Centre, <http://www.hivrussia.org>, accessed on 24 May 2008.

10 Russian Federal AIDS Centre: Main Tasks of the Federal AIDS Centre, <http://www.hivrussia.org>, accessed on 11 March 2008.

11 Federal AIDS Law 1995, in: Kodeks Russian Law Database, accessed on 10 November 2006.

12 Russian Federal AIDS Centre: Statistics, <http://www.hivrussia.org/stat/index.shtml>, accessed on 2 June 2008.

13 Federal Service for Surveillance on Consumer Rights Protection and Human Well-being: National Report of the Russian Federation, 30 March 2008, in: http://data.unaids.org/pub/Report/2008/russia_2008_country_progress_report_ru.pdf.

14 Speech of Tatyana Golikova, Russian Minister of Health and Social Development, at the closing ceremony of the Second Eastern Europe and Central Asia Conference (EECAAC), 5 May 2008.

15 Kon, Igor: Better AIDS than sex education, in Sandfort, Theo (ed.): The Sexual counter-revolution in Russia, London: Routledge, 2000, pp.119–134.

4. Civil Society and HIV/AIDS

In the international context, the fight against HIV/AIDS has received much attention. Changing realities in a globalising world and the threat of increasing global insecurity has led many country governments to support, at least partially, new governance arrangements in the area of international health, and in particular HIV/AIDS. For this emerging structure of global health politics the notion of 'global health governance' has been coined.¹⁶ As a new field of international public policy, global health governance encompasses the formation of new organisations and programmes dealing with the response to the epidemic (UNAIDS),¹⁷ international declarations (UNGASS),¹⁸ funding mechanisms (Global Fund),¹⁹ as well as guiding principles, strategies and implementation mechanisms.²⁰

Within the emerging field of global health governance, civil society plays an important role. On the one hand, civil society actors, for instance NGOs, take an active part in the formulation and implementation of policies;²¹ on the other hand, the involvement of civil society itself constitutes a principle in the regime of global health governance. According to the UNGASS Declaration of Commitment on HIV/AIDS, the 'full involvement and participation of civil society actors in the design, planning, implementation and evaluation of programs is crucial to the development of effective responses to the HIV/AIDS epidemic'.²² As a main institution of global HIV/AIDS policy, UNAIDS acknowledges the essential role of civil society. It is believed that the active participation of NGOs makes prevention strategies more effective since NGOs can fulfil a bridge function to the most vulnerable and hard-to-reach populations, and thereby guarantee that HIV/AIDS prevention becomes rooted in local communities.

5. The Role of NGOs in the Response to HIV/AIDS in Russia

NGOs have been active in the response to HIV/AIDS from the beginning of the epidemic. Today, approximately 300 Russian NGOs are active on the local, regional and national levels.²³ The biggest and probably most well-known AIDS-service NGOs in Russia are the members of the NGO-consortium of the GLOBUS project, including the *Open Health Institute (OHI)*, the *AIDS Foundation East-West (AFEW)*, *Focus-Media*, *Population Services International (PSI)* and *AIDS Infoshare*. Those Moscow-based NGOs have a network of partner organisations in the Russian regions, with which they are conducting HIV/AIDS prevention programmes. AIDS-service NGOs in the regions vary from small initiatives to big grass-roots organisations with their own access to international donor organisations, for example the St. Petersburg NGO *Humanitarian Action*. Moreover, there are several networks of regional organisations which unite NGO activities on a federal level. One example is the *Russian Harm Reduction Network*, a partnership of NGOs promoting harm reduction strategies in Russia; another is the *Association of People living with HIV/AIDS*, which unites self-help groups and advocacy organisations of HIV-positive people in Russia. The *Forum of AIDS-service*

16 Hein, Wolfgang, Bartsch, Sonja and Lars Kohlmorgen (ed.): *Global Health Governance and the Fight Against HIV/AIDS*, Basingstoke: Palgrave Macmillan, 2007.

17 UNAIDS: *Uniting the World Against AIDS*, <http://www.unaids.org/en>, accessed on 16 May 2008.

18 Declaration of Commitment on HIV/AIDS, United Nations General Assembly Special Session on HIV/AIDS, 25 – 27 June 2001, http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf.

19 The Global Fund to Fight AIDS, Tuberculosis and Malaria, <http://www.theglobalfund.org>.

20 UNAIDS: *Towards Universal Access*, <http://www.unaids.org/en/PolicyAndPractice/TowardsUniversalAccess/default.asp>, accessed 12 May 2008.

21 Bartsch, Sonja and Lars Kohlmorgen: *The Role of Civil Society Organizations in Global Health Governance*, in: Hein, Wolfgang, Bartsch, Sonja and Lars Kohlmorgen (ed.): *Global Health Governance and the Fight Against HIV/AIDS*, Basingstoke: Palgrave Macmillan, 2007, pp. 92–118.

22 Declaration of Commitment on HIV/AIDS, United Nations General Assembly Special Session on HIV/AIDS, 25 – 27 June 2001, http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf.

23 Twigg, J. and Skolnik, R.: *Evaluation of the World Bank's Assistance in Responding to the AIDS Epidemic: Russia Case Study*, Washington, D.C.: The World Bank, 2005.

NGOs in Russia, finally, is an informal platform which aims to enhance the exchange and cooperation between Russian NGOs in the field of HIV/AIDS.

In order to analyse the role of AIDS-service NGOs and their influence on HIV/AIDS policy, we will turn to the global governance approach and take a closer look at their capability of achieving social change in the field of HIV/AIDS. According to Gordenker and Weiss, NGOs are concerned with gaining access and seeking influence in a globalising world.²⁴ In contrast to traditional views on international relations, NGOs in this perception are regarded as having power capabilities and hence are able to play their roles, notwithstanding the differences between dominant states and small private actors.²⁵ NGOs can be understood as organisations which are private in their form and public in their purpose.²⁶ The heart of the matter, according to Gordenker and Weiss, is their advocacy of special interests of public importance, both in domestic politics and in intergovernmental arenas.²⁷

Gordenker and Weiss propose studying NGO activity on the basis of the organisations' functions, including goals, relationships with other organisations and operating methods.²⁸ Regarding AIDS-service NGOs in Russia, we can observe three main functions: (1) advocacy, (2) service provision and (3) empowerment. Advocacy can be understood as the representation of interests from civil society, which otherwise are not been taken into account sufficiently.²⁹ From this perspective, NGOs act as agents for the marginalised and weak groups of society. Advocacy includes political lobbying in order to influence decision-making processes directly, as well as the mobilisation of public opinion in order to prepare policy transformation and information campaigns with the aim of changing attitudes within society. The advocacy function is of particular importance in the field of HIV/AIDS policy in Russia as the epidemic mostly affects marginalised and disadvantaged groups that often do not have access to regular social and health care services. NGOs put the issue of HIV/AIDS on the political agenda by emphasising that the epidemic is not a negligible phenomenon but affects the whole society, and particularly young people, who represent Russia's future. NGOs have, thus, played an important role in the policy shift towards the political recognition of HIV/AIDS in Russia. They have called attention to the epidemic and have campaigned for a comprehensive response strategy. The growing awareness within Russian society and among politicians demonstrates that AIDS-service NGOs achieved sustained success in their advocacy work.

The second function of NGOs includes the provision of services in the field of HIV/AIDS prevention, treatment and care. In fact, NGOs are today the most important service providers in this area. Since the early 1990s, NGOs have been conducting prevention programs as well as medical and social services. In many cases, NGOs are filling the gap left open by insufficient governmental health care services. An advantage of NGOs is that they enjoy trust within society and have access to difficult-to-reach high-risk groups, which are traditionally reluctant to approach state institutions. In comparison to public services, NGOs have a better understanding of the problems within society and are able to respond faster and more adequately. Moreover, NGOs are flexible and able to adopt new problem-solving strategies, which make their programmes more effective. In the area of HIV/AIDS prevention, NGOs have introduced new approaches and methods to Russia, including outreach, counselling and needle exchange, which consequently have also been adopted within the health care system. NGOs have, thus, been innovators in social policy. Furthermore, they have been successful in raising substantial funds for the fight against the HIV/AIDS epidemic

24 Weiss, Thomas G. and Leon Gordenker (ed.): *NGOs, the UN and Global Governance*, London: Lynne Rienner Publishers, 1996.

25 Ibid.

26 Gordenker, Leon / Weiss, Thomas G.: *Pluralising Global Governance: Analytical Approaches and Dimensions*, in: *Third World Quarterly*, 1995 (Vol. 16), No. 3, pp. 357–387.

27 Ibid.

28 Ibid.

29 Bartsch, Sonja and Lars Kohlmorgen: *The Role of Civil Society Organizations in Global Health Governance*, in: Hein, Wolfgang, Bartsch, Sonja and Lars Kohlmorgen (ed.): *Global Health Governance and the Fight Against HIV/AIDS*, Basingstoke: Palgrave Macmillan, 2007, pp. 92–118, p. 98.

in Russia by working together with international donor organisations. NGO programmes, financed by international donors, form the main part of the response to HIV/AIDS. In addition, high-scale funding of NGO programmes by the Global Fund led to an increase in governmental funding. In 2006, the Russian government decided to raise its funds on HIV/AIDS and, at the same time, to refund the resources the Global Fund had spent in Russia. In this way, NGOs indirectly achieved an increase in government funding on HIV/AIDS.

Apart from advocacy and service provision, the third function of AIDS-service NGOs in Russia is empowerment, which can be understood as the process of gaining equal rights by those who are affected by the epidemic. In many cases, AIDS-service NGOs emerged from self-help initiatives. They often consist of HIV-positive people who aim to improve their living situation and advocate their rights.³⁰ The opportunity to exchange experiences with others and to get involved with an NGO helps them to take their lives into their own hands.³¹ In many regions, self-help groups and associations for people living with HIV/AIDS were created to exchange experiences and provide mutual support. Their activity is closely related to advocacy, as the focus is on the protection of human rights. Many organisations, for instance the NGO *Positive Dialogue* in St. Petersburg, have their own legal consultations for people living with HIV/AIDS.³² Self-help organisations of people living with HIV/AIDS played a crucial role in ensuring access to medical treatment, including antiretroviral therapy. It is partly due to those NGOs that access to antiretroviral treatment has been expanded to all regions of Russia.

Assessing the role of AIDS-service NGOs and their functions of advocacy, service-provision and empowerment, we can conclude that they indeed possess specific power capabilities in the response to HIV/AIDS. Their strengths include the capability to raise funds, to develop services that respond to the needs of the population, transfer know-how regarding new approaches and methods in social work, develop and apply expertise, and enable people to assert their rights.

6. The Example of Tomsk

In order to better understand the role of NGOs in HIV/AIDS prevention in Russia, we will take a closer look at two AIDS-service NGOs in the West Siberian region Tomsk. With a HIV prevalence of 97.2 per 100,000 members of the population, Tomsk is considered to be a region with middle HIV prevalence in the Russian Federation.³³ The region distinguishes itself by the active involvement of civil society in the field of HIV/AIDS. The two main AIDS-service NGOs are *Siberian AIDS Aid* and *Tomsk Anti SPID*.

The Regional Charitable Fund *Siberian AIDS Aid* was founded as a grass-roots organisation in December 1995. It owes its existence to the pioneering spirit and assertiveness of its two founders, who started the NGO as a private project. Today, *Siberian AIDS Aid* has developed into a professional AIDS-service organisation with seven staff members and about 50 volunteers. The NGO aims 'to realise the right of every person to receive reliable and up-to-date information concerning sexually transmitted diseases, including HIV/AIDS, drug addiction and human rights in the field of public health.'³⁴ In the 1990s, *Siberian AIDS Aid* was the first organization that started HIV/AIDS prevention programmes in Tomsk region. With no state programmes on HIV/AIDS existing at that time, the NGO thus responded to a basic information need among the population. Today, *Siberian AIDS Aid* predominantly focuses on young people by organising information and awareness-raising campaigns in schools, universities and youth clubs. Working with

30 Bartsch, Sonja and Lars Kohlmorgen: The Role of Civil Society Organizations in Global Health Governance, in: Hein, Wolfgang, Bartsch, Sonja and Lars Kohlmorgen (ed.): Global Health Governance and the Fight Against HIV/AIDS, Basingstoke: Palgrave Macmillan, 2007, pp. 92–118.

31 Ibid., p. 100.

32 Positive Dialogue, <http://www.aidsinfo.spb.ru>, accessed on 28 May 2008.

33 Kmietowicz, Zosia: Tomsk – A Glimpse of one Russian Region's Experience with HIV/AIDS, in: British Medical Journal, 20 May 2006; 332 (7551): 1176.

34 Siberian AIDS Aid, <http://www.aids.tomsk.ru>, accessed on 12 May 2008.

volunteers is very effective in Tomsk as the student city has a very young and active population. In addition to its general volunteer programme for young people, *Siberian AIDS Aid* runs a special programme for MSM (men having sex with men). On the regional and local level, the NGO cooperates with other NGOs as well as with state institutions such as the Municipal Department of Education and the Department of Youth Policy, Physical Culture and Sport of Tomsk Region. On the federal level, *Siberian AIDS Aid* is in close contact with the NGO consortium of the GLOBUS project, which funds part of its programmes.

In contrast to the grass-roots NGO *Siberian AIDS Aid*, the second AIDS-service organisation of the region, *Tomsk Anti SPID*, was established in the year 2000 with active involvement from the Regional AIDS Centre and can thus be regarded as a government-organised non-governmental organisation. According to its profile, the organisation has the goal of 'preventing HIV/AIDS and drug use in Tomsk region by information provision and services.'³⁵ *Tomsk Anti SPID* focuses on secondary HIV/AIDS prevention and programmes for high-risk groups, such as IDUs and CSWs. A team of medical doctors, psychologists and social workers offers services such as testing for HIV and other sexually transmitted infections, pre- and after-test counselling and psychological support. The NGO is working with a network of trusted medical specialists in Tomsk, who are ready to treat its clients. Moreover, *Tomsk Anti SPID* is in contact with the drug rehabilitation centre and the tuberculosis clinic in the city, where clients can decide to enrol for treatment. The organisation also carries out outreach work, which includes the provision of condoms and health information to drug users and sex workers on the street or at meeting places. One of the biggest achievements of *Tomsk Anti SPID* is the harm reduction programme, which provides sterile equipment for IDUs as well as condoms and information on health issues. The programme in Tomsk is one of the first in Russia and can be regarded as a pioneer project. A notable strength of the NGO is the contact with and access to difficult-to-reach high-risk groups such as IDUs and CSWs, who are often disinclined to approach a state institution like the AIDS Centre or a regular clinic. *Tomsk Anti SPID* sees its role as a mediator between its clients and the health care system. The organisational link with the Regional AIDS Centre helps *Tomsk Anti SPID* in the realisation of its programmes by facilitating close cooperation with medical institutions and case management. Due to this institutional backing, the NGO is able to take up difficult issues such as harm reduction, develop social services and influence social policy in the region from the bottom up.

Both examples show that AIDS-service NGOs establish close links with state institutions on a regional level such as the AIDS centres and the regional and municipal administration. This cooperation enables them to further develop their services and to assert their influence on the planning of HIV/AIDS response strategies in the region. NGOs are valued because of their expertise, their innovative working style and their access to both high-risk groups and youth in general. The main challenge for the future remains the acquisition of state funding for AIDS-service NGOs and the political recognition of those programmes that are not easily incorporated into the public response strategy, for instance harm reduction and HIV/AIDS prevention programmes for homosexual men.

7. Conclusions: Power and Limits of NGOs

NGOs are indeed key players in the fight against HIV/AIDS in Russia. They were the first to understand the urgency of the HIV/AIDS epidemic and to take up action. In many regions in Russia, NGOs played a pioneering role in starting HIV/AIDS prevention and care programs. AIDS-service NGOs were also the first to address the most vulnerable and marginalised groups, which were often excluded from government health services and exposed to discrimination and stigma. NGOs understood that HIV prevention and care programmes for those groups that run a high risk of HIV infection are not only a moral imperative, but also an essential precondition to stem the epidemic in general.

The examples of the organisations *Siberian AIDS Aid* and *Tomsk Anti SPID* demonstrate that NGOs are currently making an important contribution to HIV/AIDS prevention in Russia. The NGO *Tomsk Anti SPID* is

35 Tomsk Anti Spid, <http://aids.xemi.info>, accessed on 14 May 2008.

successful in prevention programs, addressing injecting drug users and commercial sex workers. *Siberian AIDS Aid*, on the other hand, focuses on prevention and harm reduction programs for a broader public and has been able to reach many young people in the region. In comparison to government services, NGOs have the advantage that they can address the needs of society more directly. They raise money for the fight against HIV/AIDS that can directly be used for projects on the ground. Moreover, they are able to involve volunteers in their projects, thereby increasing the coverage and impact of their activities.

However, NGOs should not be misunderstood as a mere substitute for government action. On the contrary, the objective should be to include HIV/AIDS prevention and care into the Russian health care system and to make services available to all citizens. Therefore, the state and the NGO sector need to cooperate in mutual trust for a successful and comprehensive HIV/AIDS policy in Russia.