HIV/AIDS and Human Rights in Russia: Compliance and the Rule of Law

William F. Flanagan

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Abstract
This article examines Russia's legal response to its ongoing HIV/AIDS epidemic. Russia's international human rights obligations are reviewed and the article then critically assesses the extent to which Russia's current HIV/AIDS law and practice are consistent with those obligations. The paper demonstrates that most aspects of Russia's HIV/AIDS laws are consistent with Russia's international obligations. However, the paper also documents key parts of HIV/AIDS practice in Russia that are seriously inconsistent with both Russian HIV/AIDS law and Russia's international human rights obligations. This inconsistency between HIV-related de jure norms and de facto practice raises the question of compliance with the rule of law in Russia. Long a political and social culture hostile to the rule of law, Russia has encountered many barriers as it attempts to develop a legal culture governed by the rule of law, its HIV/AIDS practice being only one example. To address this challenge, the article proposes a theory of compliance relating to HIV-related domestic law in Russia that can facilitate the development of a legal culture governed by the rule of law in Russia: the improvement of human rights literacy of people living with HIV and those at risk, and an increased capacity of health care professionals to understand and apply legal and human rights obligations in the delivery of care.

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HIV/AIDS AND HUMAN RIGHTS IN RUSSIA: COMPLIANCE AND THE RULE OF LAW®

BY WILLIAM F. FLANAGAN

This article examines Russia's legal response to its ongoing HIV/AIDS epidemic. Russia's international human rights obligations are reviewed and the article then critically assesses the extent to which Russia's current HIV/AIDS law and practice are consistent with those obligations. The paper demonstrates that most aspects of Russia's HIV/AIDS laws are consistent with Russia's international obligations. However the paper also documents key parts of HIV/AIDS practice in Russia that are seriously inconsistent with both Russian HIV/AIDS law and Russia's international human rights obligations.

This inconsistency between HIV-related de jure norms and de facto practice raises the question of compliance with the rule of law in Russia. Long a political and social culture hostile to the rule of law, Russia has encountered many barriers as it attempts to develop a legal culture governed by the rule of law, its HIV/AIDS practice being only one example. To address this challenge, the article proposes a theory of compliance relating to HIV-related domestic law in Russia that can facilitate the development of a legal culture governed by the rule of law in Russia: the improvement of human rights literacy of people living with HIV and those at risk, and an increased capacity of health care professionals to understand and apply legal and human rights obligations in the delivery of care.

Cet article examine la réaction juridique de la Russie face à son épidémie du VIH-SIDA. L'auteur examine les obligations de la Russie en matière de droit international de la personne et évalue jusqu'à quelle mesure la législation russe est compatible avec ces obligations internationales. L'article révèle que la plupart des aspects de la législation russe face au VIH-SIDA satisfaisent à ces obligations internationales. Toutefois, l'article fait ressortir certains éléments de la pratique du droit dans le domaine VIH-SIDA qui s'écarte de façon perceptible à la fois des normes énoncées au sein de la législation russe et des obligations internationales en matière des droits de la personne.

Ces incohérences entre les normes juridiques et la pratique de fait soulèvent la question de l'application de la règle du droit en Russie. La Russie, qui a longtemps eu une culture hostile au droit, a rencontré de nombreux obstacles en essayant de développer une culture juridique gouvernée par la règle du droit, sa pratique HIV/AIDS étant l'un d'entre eux. Pour résoudre cette question, l'article propose une théorie de la conformité au droit russe en matière du VIH-SIDA: l'amélioration de la connaissance des droits de la personne et l'augmentation de la compétence des professionnels de santé à comprendre et à appliquer les obligations édictées par le droit, y compris les droits de la personne.
Russia is facing a serious HIV/AIDS epidemic. A disease that was largely absent in Russia prior to the collapse of the Soviet Union, HIV/AIDS is now growing at an alarming speed. According to the recent estimates of the Joint United Nations Programme on HIV/AIDS (UNAIDS), at the end of 1999 there were approximately 130,000 people living with HIV/AIDS in the Russian Federation. In 2000, Russia registered over 56,000 new cases of HIV. This sharp increase in new cases indicates that Russia is in the midst of a rapidly growing epidemic. According to one of Russia's leading AIDS

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1 This paper was funded in part by a grant by the Canadian International Development Agency (CIDA). The author is currently serving as the Executive Director of the Canada AIDS Russia Project (CARP), a charitable organization that recently completed a two-year HIV/AIDS training programme in Russia with a $850,000 grant from CIDA. The programme, based in St. Petersburg, involved providing training sessions four times a year to over sixty HIV/AIDS specialists and community workers from over eight different regions of Russia. Training activities included topics such as HIV/AIDS prevention, clinical management, psychosocial care, epidemiology, testing and laboratory issues, non-governmental organization and management, and legal and human rights issues. CIDA has recently announced additional funding for CARP in the amount of $2.1 million for a three-year HIV/AIDS training programme in Russia that will begin in September, 2001.


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experts, if the current infection rate continues, one million Russians may be infected with HIV/AIDS in the next two to three years. According to UNAIDS, the Russian epidemic is concentrated heavily in injection drug users. In 1999, a new outbreak of HIV among injecting drug users in the Moscow region resulted in three times as many new cases in 1999 than in all previous years combined. Recent estimates of the number of injecting drug users in the country range between 1 and 2.5 million. Although efforts are being made to increase the availability of needle and syringe programmes in Russia, particularly through the work of foreign donors such as the Open Society Institute, progress is slow and there remains little political and financial support for such harm reduction programmes. The potential exists for many more infections to occur among injecting drug users, in addition to the risk of further spread of HIV into other parts of the population.

This article examines Russia’s international human rights obligations and the extent to which Russia’s current HIV/AIDS law and practice are consistent with those obligations. Part II of this article demonstrates that, with a few notable exceptions, most aspects of Russia’s HIV/AIDS laws are consistent with Russia’s international obligations. Moreover, Russian constitutional law and its HIV/AIDS law specifically provide that in the event of conflict, international human rights obligations will take precedence. Most theories of compliance in the area of international law attempt to answer a question that has long puzzled international law scholars: why do the majority of nations comply with international law most of the time, and what can be done to ensure an even


5 Supra note 2 at 18.

6 Ibid. at 18–19.

7 Ibid. at 19.

8 For an excellent review of injection drug use, HIV, and harm reduction strategies in Russia, see: Open Society Institute, “Drugs, AIDS, and Harm Reduction: How to Slow the HIV Epidemic in Eastern Europe and the Former Soviet Union” (2001), online: Open Society Institute Homepage <http://www.soros.org/harm-reduction/frame_pub.htm> (date accessed: 23 July 2001). The report details many of the existing harm reduction programmes in Russia (at 53–61), noting that the existing programmes are small in comparison to the exploding rates of injecting drug use and HIV infection (at 29). Significant political, legal, and fiscal barriers remain, and in the “absence of consistent and diverse funding, substantial government support, and wider public acceptance, harm reduction efforts will fail to contain an HIV infection rate growing faster than anywhere else in the world” (at 29).
greater level of compliance?9 Because Russia's HIV-related laws largely conform to international obligations, compliance with HIV-related international law is not the most pressing question in present day Russia. Instead, the more urgent concern is the extent to which these laws are widely disregarded and rarely enforced in Russia.

This issue is examined in Part III of this article which documents key parts of HIV/AIDS practice in Russia that are seriously inconsistent with both Russian HIV/AIDS law and Russia's international human rights obligations. This inconsistency between HIV-related de jure norms and de facto practice in Russia raises a serious question of compliance with the rule of law generally in Russia. Long a political and social culture hostile to the rule of law, Russia has encountered many barriers as it attempts to develop a legal culture governed by the rule of law. Its HIV/AIDS practice is only one example of the challenges facing Russia as it attempts to develop the rule of law. The lack of a rule of law has also been a significant factor in Russia's ongoing and dramatic economic decline.

This article concludes with suggestions about what might be done to promote the rule of law in Russia, with a particular focus on the potentially influential role that can be played by Russian HIV/AIDS experts in cooperation with the small but growing HIV/AIDS community-based movement in Russia. The article proposes a theory of compliance relating to HIV-related domestic law in Russia that can facilitate the development of a legal culture governed by the rule of law in Russia: the improvement of human rights literacy of people living with HIV and those at risk, and an increased capacity of health care professionals to understand and apply legal and human rights obligations in the delivery of care.

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II. HIV/AIDS AND INTERNATIONAL HUMAN RIGHTS

International human rights law provides a general framework for understanding a state's obligations with regard to HIV/AIDS. Russia has signed a number of international treaties that relate in a general manner to HIV/AIDS legal and social issues. These include the Universal Declaration of Human Rights (1948), the International Covenant on Civil and Political Rights (1976), the International Covenant on Economic, Social and Cultural Rights (1976), and the Convention for the Protection of Human Rights and Fundamental Freedoms (1950). These agreements provide for the recognition of a variety of human rights that relate to HIV/AIDS. For

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Russia ratified the European Convention, infra note 15, on 5 May 1993 and it entered into force on the same day. See infra note 14, Chart of signatures and ratifications, online: Council of Europe <http://conventions.coe.int/treaty/EN/searchsig.asp?NT=005&CM=8&DF=24/07/01> (date accessed: 24 July 2001).

For a discussion of the implications of the inclusion of Central and Eastern European countries into the European Convention, see D. Seymour, "The Extension of the European Convention on Human Rights to Central and Eastern Europe: Prospects and Risks" (1993) 8 Conn. J. Int'l L. 243. The author argues that with the inclusion of these states, the human rights enforcement system under the convention should focus on larger human rights issues and the most serious and widely recognized abuses of human rights rather than attempt to develop a "common European standard in the enjoyment of certain civic and political rights" (at 260).


example, the *Universal Declaration* provides for the “right to life, liberty and security of person,” the “right to marry and to found a family,” the right “to freedom of opinion and expression,” the “right to a standard of living adequate for the health and well-being” of all people, and the “right to work.”

The *ICESCR* provides for a variety of economic rights that may relate to HIV/AIDS, such as the right to work in “just and favourable conditions,” the right to the “enjoyment of the highest attainable standard of physical and mental health,” and the right of everyone to “an adequate standard of living.” The Committee on Economic, Social and Cultural Rights, trusted with monitoring compliance with the *ICESCR*, periodically prepares “General Comments” on the rights and provisions contained in the *ICESCR* as a means of promoting the implementation of it. The Committee’s *General Comment No. 14* focuses on the right to health contained in Article 12 of the *ICESCR* and includes a number of specific references to HIV-related obligations arising out of Article 12. For example, the *Comment* states that the right to health requires “the establishment of prevention and education programmes for behaviour-related health

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16 Brownlie, supra note 11 at 570–71. According to Brownlie, the *Universal Declaration* is “not a legal instrument” (at 571) and there is no specific machinery for the enforcement of these obligations. However, Brownlie notes that it [the *Universal Declaration*] has had “indirect” (at 571) legal effect, as it is frequently invoked by various international tribunals and the political organs of the United Nations.

17 Supra note 12, art. 3.

18 Ibid., art. 16.

19 Ibid., art. 19.

20 Ibid., art. 25.

21 Ibid., art. 23.

22 Supra note 14, art. 7.

23 Ibid., art. 12.

24 Ibid., art. 11.


concerns such as sexually transmitted diseases, in particular HIV/AIDS.” It notes that a state that “restricts the movement of, or incarcerates, persons with transmissible diseases such as HIV/AIDS … has the burden of justifying” that such measures are consistent with Article 4 of the ICESCR, which permits limits on ICESCR rights only in restricted circumstances. A state’s obligations under Article 12 include the provision of “information campaigns, in particular with respect to HIV/AIDS.” Recognizing that non-governmental organizations have important responsibilities in the field of health promotion, the Comment notes that “State parties should therefore provide an environment which facilitates the discharge of these responsibilities” by non-governmental organizations. Recognizing the right of individuals and groups to participate in decision-making processes, it states that promoting health must also “involve effective community action in setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health.” It remarks that violations of the right to health can occur not only from a failure to enact necessary laws, but also from a “failure to enforce relevant laws” already in existence. This may have particular application to Russia where, as discussed later, there is a widespread failure to enforce existing HIV-related laws. The Comment adds that any victim of “a violation of the right to health should have access to effective judicial or other appropriate remedies at both national and international levels.”

The ICCPR provides for the right to “liberty and security of [the] person,” the right to be free from “arbitrary or unlawful interference” with privacy, family, home or correspondence, the right to freedom of expression, including the freedom to “seek, receive and impart information

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27 Ibid., para. 16.
28 Ibid., para. 28. Article 4 of the ICESCR provides that a state may subject covenant rights “only to such limitations as are determined by law only in so far as this may be compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society.” Paragraph 29 of the Comment notes that any such limitations must be proportional; that is, the least restrictive alternative must be adopted. The Comment adds that limitations relating to public health “should be of limited duration and subject to review.”
29 Ibid., para. 36.
30 Ibid., para. 54.
31 Ibid., para. 49.
32 Ibid., para. 59.
33 Supra note 13, art. 9.
34 Ibid., art. 17.
and ideas of all kinds..." and the right to "take part in the conduct of public affairs, directly or through freely chosen representatives." It also states that all persons are "equal before the law" and entitled to be free from discrimination on the basis of "race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."

These two covenants have the legal force of treaties for the parties to them. States generally comply with their treaty obligations for the same reasons that states generally comply with customary international law; all states have some interest in the maintenance of a stable system of international rules. These covenants also have a variety of additional mechanisms designed to increase the likelihood that the parties to the treaties will comply with their treaty obligations. For example, the ICESCR includes an obligation to submit reports to the Economic and Social Council of the United Nations on measures adopted. The ICCPR includes a similar obligation to submit such reports to the United Nations Human Rights Committee. The ICCPR also includes a complaint procedure whereby parties to the Covenant may complain of non-compliance by other states. Such complaints are only admissible if both the states have recognized the competence of the Human Rights Committee to receive the complaints. The Optional Protocol to the International Covenant on Civil and Political Liberties also provides for applications by individuals who are...

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35 Ibid., art. 19.
36 Ibid., art. 25.
37 Ibid., art. 26.
38 Brownlie, supra note 10 at 572.
39 See references supra note 9.
40 Supra note 14, art. 16. See also Brownlie, supra note 10 at 572.
41 Supra note 13, art. 40. See also Brownlie, supra note 10 at 573.
42 Supra note 13, art. 41(1).
complaining of non-compliance with the Covenant.\textsuperscript{45} The state charged with the violation is required to submit a written explanation to the Human Rights Committee clarifying the matter and the remedy, if any, taken by the state. Russia is a signatory to this \textit{Optional Protocol} as of September 1991.\textsuperscript{45}

The \textit{European Convention} contains similar human rights provisions, including the right to "liberty and security of person,"\textsuperscript{47} the right to "respect for his private and family life,"\textsuperscript{48} and the "right to freedom of expression."\textsuperscript{49} Any party may refer to the European Court of Human Rights for an alleged breach of the \textit{European Convention} by another party.\textsuperscript{50} The Court may also receive applications from any person, non-governmental organization, or group of individuals claiming a contravention of the \textit{European Convention}.\textsuperscript{51} Decisions by the court are binding on respondent states.\textsuperscript{52} The court has dealt with a number of HIV/AIDS related cases.\textsuperscript{53}

\textsuperscript{45} Ibid., art. 4(1). See also Brownlie, supra note 10 at 573.


\textsuperscript{47} Ibid. note 15, art. 5(1).

\textsuperscript{48} Ibid., art. 8(1).

\textsuperscript{49} Ibid., art. 10(1).

\textsuperscript{50} Ibid., art. 33.

\textsuperscript{51} Ibid., art. 34.

\textsuperscript{52} All final judgments of the court are binding on the respondent states concerned, ibid., art. 46(1). Responsibility for supervising the execution of judgments lies with the Committee of Ministers of the Council of Europe. They verify whether a respondent state has taken adequate remedial measures to comply with the specific or general obligations arising out of the court's judgments, ibid., art. 46(2).

\textsuperscript{53} For example, in \textit{Karara v. Finland}, [1993], 26 E.H.R.R. (Ser. A), C229, Application No. 40900/98, decision of admissibility 29/05/1998, online: HUDOC (Database of the Case-Law of the European Convention on Human Rights) <http://hudoc.echr.coe.int/hudoc/> (date accessed: 25 September 2001), the applicant, a person with HIV infection but not advanced AIDS, contended that his deportation to Uganda would result in an irrevocable deterioration of his state of health and subject him to inhuman and degrading treatment in violation of Article 3 of the \textit{European Convention}, supra note 16. The court found that the applicant's illness has not yet reached such an advanced stage that his deportation would amount to treatment proscribed by Article 3.

In \textit{R. M. v. the United Kingdom}, [1994], Application No. 22761/93, decision of admissibility 14/04/1994, online: HUDOC (Database of the Case-Law of the European Convention on Human Rights) <http://hudoc.echr.coe.int/hudoc/> (date accessed: 25 September 2001), the applicant complained, among other things, that he has been discriminated against in respect of sentencing policy and treatment in prison as a result of being a person with AIDS, in violation of Article 5 (right to liberty) of the convention. On the facts, the Court found no such violation.

There have also been a number of cases dealing with complaints from Russia, relating to matters such as election procedures, admission to law school, labour matters, and the right to a fair trial. There are no Russian cases to date dealing specifically with HIV/AIDS issues.

The rights outlined in these various agreements apply to many of the challenges that arise in the HIV/AIDS epidemic. In 1998, the Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS produced an “international consultation” paper on HIV/AIDS and human rights: HIV/AIDS and Human Rights: International Guidelines. These guidelines were drawn up by a group of thirty-five experts in the field of HIV and human rights. These experts outline the various United Nations international human rights obligations that relate to HIV, and consider the types of HIV-related policies and practices that are most consistent with these international obligations. The guidelines emphasize the importance of avoiding HIV prevention and care programmes that contain coercive or punitive measures, as such programmes are likely to reduce the participation of people living with HIV and increase the risk of alienation of those at risk. Instead, HIV

deportation to Zaire that would amount to treatment contrary to Article 3 of the convention as it would reduce his life expectancy because he would not receive the medical treatment he needed. Because the French government had made an undertaking not to deport the applicant, the court found no violation.


59 Ibid., paras. 72–77. Unlike other infectious diseases, HIV is not contagious by casual contact or susceptible to cure, thus the guidelines argue that coercive measures are unnecessary and counterproductive, ibid., para. 83.
The International Guidelines, much like the Comment considered earlier, do not enjoy the legal status of a treaty and are not binding in any formal way on state parties to the United Nations human rights agreements. Like the Comment, the goal of these guidelines is instead to promote a better understanding and implementation of human rights obligations. For example, the United Nations Secretary-General notes that the development of the International Guidelines is to “provide an international framework for discussion of human rights considerations at the national, regional and international levels in order to arrive at a more comprehensive understanding of the complex relationship between the public health rationale and the human rights rationale of HIV/AIDS.”

The purpose of the guidelines is to “assist States in translating international human rights norms into practical observance in the context of HIV/AIDS.” As a result, the International Guidelines can only be regarded as, at most, persuasive when interpreting the content and scope of the United Nations human rights agreements as they relate to HIV/AIDS. For example, should an HIV/AIDS-related complaint arise before the Human Rights Committee, this committee would likely take these guidelines into consideration when determining if there had been some violation of the ICCPR. But the guidelines themselves do not specifically create obligations or rights in international law, nor are they binding on any decision of the Human Rights Committee. It is also relevant to note that the June 2001 United Nations Special Session on HIV/AIDS specifically rejected reference to the International Guidelines in its final declaration. This special session involved the participation of all members of the United Nations General

60 See discussion supra note 25.
61 Ibid., para. 2.
62 Ibid., para. 10.
64 See K. DeYoung, “U.N. Delegates Agree on AIDS Declaration Wording Resolved; Vote May Come Today” The Washington Post (27 June 2001) A20, where the author notes the ongoing disagreement about inclusion of any reference to the International Guidelines during the final stages of negotiation. As it turned out, the Commitment, infra note 65, omitted any specific reference to these guidelines.
Assembly, including Russia, and resulted in the United Nations Declaration of Commitment on HIV/AIDS. The omission of any reference to the International Guidelines in this final declaration casts further doubt on the question of whether these guidelines can be regarded as creating international obligations. Nonetheless, it can be expected that these guidelines, endorsed by the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS, will have some impact on the interpretation of the United Nations human rights agreements as they relate to HIV/AIDS.

Although the Commitment omitted any specific reference to the International Guidelines, the Commitment nonetheless makes reference to the importance of protecting human rights in the context of HIV/AIDS. For example, article 58 commits states to enact legislation by 2003 to "eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups ... while respecting their privacy and confidentiality." Specific mention is made of human rights in the context of education, employment, health care, support, and treatment, among other areas. Articles 59 and 61 also contain specific mention of gender and human rights with states committing, by 2005, to implement national strategies to promote "women's full enjoyment of all human rights."

There is further mention of the full and equal enjoyment of human rights by children in article 66, "through the promotion of an active and visible policy of de-stigmatization of children orphaned and made vulnerable by HIV/AIDS."

Finally, the Commitment includes reference to developing a national legal framework, by 2003, that protects "in the workplace the rights and dignity of persons living with and affected by HIV/AIDS ... taking into account of established international guidelines on HIV/AIDS in the workplace."

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66 Ibid., art. 58.

67 Ibid., art. 59.

68 Ibid., art. 66.

69 Ibid., art. 69. These international workplace guidelines would most prominently include the guidelines produced by the International Labour Organization (ILO): International Labour Organization, "An ILO Code of Practice on HIV/AIDS and the World of Work" (Geneva, 2001), online: International Labour Organization Homepage <http://www.ilo.org/public/english/protection/tra/aid/aids>
In short, there are a large number of international legal instruments and guidelines relevant to HIV/AIDS in Russia, ranging from the *Universal Declaration* in 1948, all the way to the recent *Commitment* in June, 2001. Of these various international human rights, perhaps the most important HIV-related human right is the right to equal treatment before the law, free of discrimination on the basis of physical disability. Much of the discrimination against people living with HIV/AIDS is directly a result of their physical disability: HIV infection. A broad prohibition of discrimination on the basis of physical disability offers the greatest protection of the rights of those living with, and affected by, HIV/AIDS. However, the United Nations human rights agreements do not specifically mention physical disability as a prohibited ground of discrimination.

Nonetheless, the *International Guidelines* argue that the general equality provisions found in the *ICCPR* can be interpreted to include a prohibition of discrimination on the basis of physical disability. Article 26 of the *ICCPR* provides that all persons are equal before the law and entitled to be free from discrimination on the basis of "race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."\(^7\) Physical disability, such as HIV infection, is not one of the enumerated grounds. However, resolutions passed by the United Nations Commission on Human Rights in 1995 and 1996 indicate that, in the Commission's view, the reference to "other status" in Article 26 "is to be interpreted to include health status, including HIV/AIDS."\(^7\) The result is
that, according to the Commission, under the ICCPR, people with HIV/AIDS are entitled to the equal protection before the law, and freedom from discrimination, on the basis of their physical disability. The International Guidelines further argue that this obligation also requires that states enact laws and policies to eliminate discrimination against people with HIV/AIDS.73 The Human Rights Committee formed under the ICCPR might find this interpretation persuasive should it consider an HIV/AIDS-related complaint.74

The right to freedom from discrimination on the basis of physical disability is of great importance to people with HIV/AIDS because it provides the broadest protection against discriminatory treatment based specifically on HIV/AIDS status. Such a right could be used to demonstrate, for example, that the denial of health care services to people with HIV/AIDS might constitute unwarranted discrimination on the basis of a physical disability. The denial of employment in areas where there is little or no risk of HIV transmission might also constitute unwarranted discrimination, as may the mandatory testing of international travelers.75

However, there are also a number of other human rights that might apply to various HIV/AIDS-related situations. For example, the Universal Declaration provides for “the right to marry and to found a family.”76 The

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73 International Guidelines, ibid., para. 87.
74 The Commission on Human Rights is distinct from the Human Rights Committee. The Commission is a political organ of the United Nations, established under the United Nations Charter. The Commission is a forum where governments, international organizations, NGO’s, and individual experts discuss a wide range of human rights violations. The Commission meets annually and drafts resolutions for adoption by the Commission. Individuals may also submit complaints to the Commission, but the complaint must indicate a consistent pattern of gross violations of human rights. With the consent of the state where the violations are alleged to have occurred, the Commission may also conduct an official investigation. In contrast, the Human Rights Committee is a treaty body created under the ICCPR, supra note 13, and its Optional Protocol, supra note 44. The Committee is responsible for overseeing states’ compliance with the European Convention. The Committee can also accept complaints of individual human rights violations if a state has ratified both the European Convention and the Optional Protocol. Russia has ratified both. See UNAIDS, The UNAIDS Guide to the United Nations Human Rights Machinery: For AIDS Service Organizations, People Living with HIV/AIDS and Others Working in the Area of HIV/AIDS and Human Rights (Best Practice - Key Material) (1997), online: UNAIDS Homepage <http://www.unAIDS.org/publications/documents/human/law/unaguide97kme.pdf> (date accessed: 25 September 2001).
75 Employment discrimination would also likely violate article 23 of the Universal Declaration, supra note 12, which provides for the “right to work.” See International Guidelines, supra note 58, para. 127. See also the discussion of the Code, supra note 69 and accompanying text.
76 Supra note 12, art. 16.
International Guidelines argue that this provision makes it clear that mandatory pre-marital testing would violate the rights of people with HIV/AIDS. Likewise, forced abortions or sterilization of women with HIV/AIDS would violate the right to found a family. The ICCPR provides that no one "shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence ...." The International Guidelines argue that this right to privacy includes an obligation to seek informed consent to HIV tests and an obligation to maintain the privacy of all HIV-related information. The authors also argue that mandatory HIV testing or registration, except in cases of blood/organ/tissue donation, are inconsistent with this right to privacy.

The ICCPR includes the "right to liberty." The International Guidelines interpret this provision as including a right to liberty of movement within a state, including the right to choose one's residence, as well as a right to enter and leave the country. There is no public health rationale to limit the movement of persons on the grounds of HIV status, thus, the HIV screening of international travelers is inconsistent with the right to liberty. The Comment, considered above, also provides further support for this position by stating that limits on the freedom of movement of people with HIV are permitted only in very restricted circumstances. The International Guidelines also state that the right to liberty includes the right to be free from compulsory HIV testing, such as compulsory testing in the military or prisons, or the compulsory testing of sex workers, injecting drug users, or men who have sex with men. There is no public health justification for such compulsory testing and it is thus an unwarranted interference with the right to liberty.

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77 Supra note 53, para. 96.
78 Ibid.
79 Supra note 13, art. 17.
80 Supra note 58, para. 97.
81 Ibid., para. 93.
82 Supra note 13, art. 9.
83 Supra note 58, para. 104.
84 Ibid., para. 105. The International Guidelines concede that some restrictions on permanent residency might be justified due to the costs associated with health care for persons with HIV/AIDS, ibid., para. 105.
85 See supra note 27 and accompanying text.
86 Supra note 58, para. 113.
The *ICCPR* states that everyone has "the right to freedom of expression" including the freedom "to seek, receive and impart information and ideas of all kinds."\(^8\) The *International Guidelines* state that this right to receive information includes detailed uncensored information about the HIV-related risks associated with injecting drug use and sexual activity, and the measures available to reduce these risks.\(^8\) On this point, the *International Guidelines* find further support in the *Comment*, which states that the right to health requires the establishment of HIV-related prevention and education programmes.\(^8\) The *ICCPR* also provides that everyone has the right "[t]o take part in the conduct of public affairs."\(^9\) According to the *International Guidelines*, this means that governments should not deprive HIV/AIDS service organizations and advocacy groups from the right to organize and the right to have their organizations registered. Instead, states should encourage the interaction and dialogue with, and among, HIV/AIDS non-governmental organizations.\(^9\) Again, this point finds further support in the *Comment*, which states that the right to health includes promoting the involvement of non-governmental organizations making decisions and implementing health promotion programmes.\(^9\)

There are also specific international human rights obligations to women under the *Convention on the Elimination of all Forms of Discrimination Against Women* (1981).\(^9\) The convention provides that the

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\(^8\) *Supra* note 13, art. 19.

\(^8\) *Supra* note 58, para. 116.

\(^8\) See *supra* note 26 and accompanying text.

\(^9\) *Supra* note 13, art. 25. Likewise, article 20 of the *Universal Declaration*, *supra* note 12, provides that everyone has the "right to freedom of peaceful assembly and association."

\(^9\) *Supra* note 58, para. 117.

\(^9\) See discussion *supra* notes 29–30 and accompanying text.

parties to the agreement "condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women."\(^9\)

Noting that women are disproportionately vulnerable to HIV/AIDS due to systemic discrimination on the basis of gender, the *International Guidelines* argue that women's needs must be specifically addressed. This includes the right of women to have control over all matters relating to their sexual and reproductive health, and measures to empower women to leave relationships that threaten them with HIV infection, including appropriate divorce, child custody, and property rights.\(^9\)

Finally, international human rights include some economic rights relevant to people with HIV/AIDS, including "the right to a standard of living adequate for the health and well-being" of all persons.\(^5\)

According to the *International Guidelines*, an adequate standard of living for all people is essential to reduce the vulnerability to the risk and consequences of HIV infection. If state services are limited, people with HIV should therefore be entitled to preferential treatment due to their dire circumstances.\(^7\)

Likewise, the right "to the enjoyment of the highest attainable standard of physical and mental health"\(^9\) means that states should provide appropriate HIV/AIDS-related information, education, and support, including voluntary and confidential testing, with pre- and post-test counselling.\(^6\)

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\(^9\) Recommendation includes HIV specific measures, including, at paragraph 18, the need to "ensure sexual health information, education and services for all women and girls" and the need to address unequal power relations based on gender that make it impossible for women and adolescent girls to refuse sex or insist on safer sex practices. This *Protocol* came into force in December 2000. Russia is not yet a signatory to this *Protocol* (see: [http://www.unhchr.ch/html/menu3/b/cedaw.htm](http://www.unhchr.ch/html/menu3/b/cedaw.htm)).

\(^9\) *Discrimination Convention*, ibid., art. 2.

\(^5\) *Supra* note 58, para. 89. Article 59 of the *Commitment, supra* 65, also provides that states commit to implement national strategies to promote "women's full enjoyment of all human rights" by 2005. See discussion *supra* note 67.

\(^9\) *Universal Declaration*, *supra* note 12, art. 25.

\(^7\) *Supra* note 58, para. 125.

\(^9\) *ICESCR, supra* note 14, art. 12, provides that everyone has the right "to the enjoyment of the highest attainable standard of physical and mental health" including measures necessary for the "prevention, treatment and control of epidemic ... diseases."

\(^9\) *Supra* note 58, para. 122. See also *supra* note 26 and accompanying text.
A. International Law and Russian Constitutional Law

The international human rights treaties to which Russia is a signatory contain enforcement mechanisms of varying strength. The European Convention has developed the most effective mechanism. It grants individuals the right to bring human rights violations before the European Court of Human Rights, and provides that the court's decisions are binding on member states. The United Nations human rights treaties contain less effective enforcement mechanisms, composed largely of a requirement to report on measures taken to comply with the treaty obligations, and less expansive rights for individuals to bring complaints. Decisions taken under these treaties by the Human Rights Committee or the Economic and Social Council are not formally binding on member states. However, Russian law specifically provides that Russia's international treaties are a component part of Russia's legal system, with the result that Russian domestic courts must in theory enforce Russia's international human rights obligations. This has the potential to extend the enforceability of international human rights obligations in Russia, well beyond the enforcement mechanisms contained in the treaties themselves. Article 15.4 of the 1993 Russian Constitution provides:

The generally recognized principles and norms of international law and the international treaties of the Russian Federation shall be a component part of its legal system. If an international treaty of the Russian Federation establishes other rules than those stipulated by the law, the rules of the international treaty shall apply.100

The incorporation of international law into Russia's legal system represented a dramatic departure from previous Soviet practice. In the Soviet Union, international law could not be directly invoked before and

100 For a critical discussion of the Russian efforts to incorporate international law into Russian domestic law, see G. Ginsburgs, From Soviet to Russian International Law: Studies in Continuity and Change (Boston: Martinus Nijhoff, 1998). The author provides a pessimistic appraisal of Russia's efforts to incorporate international law, noting the general lack of adherence to law in Russia, as well as insufficient training of judges and other legal officials in international law. The result is that international law is infrequently invoked before Russian courts, notwithstanding its incorporation into Russian domestic law.

enforced by domestic courts.\textsuperscript{102} Under the Soviet system, international obligations would be applicable domestically only if they were transformed by the legislature into a specific statute or administrative regulation. As a result, the Soviet Union was able to sign the various United Nations human rights treaties yet still avoid any implementation of these rights in domestic law. This position on international law reflected the longstanding isolationist tendency of the Soviet Union. However, this attitude began to change under \textit{perestroika}, fueled by a growing desire to build a modern society based on the rule of law and operated in a manner consistent with international human rights norms.\textsuperscript{103}

Some reformers proposed a gradual change of Soviet laws to bring them into compliance with international standards. Others proposed a more radical constitutional reform that would open the domestic legal system to the direct application of international principles and norms: a general constitutional principle proclaiming international law as part of the law of the land. The reform began with the 1989 \textit{Law on Constitutional Supervision}\textsuperscript{104} that gave to the Committee of Constitutional Supervision the power to review domestic laws with a particular focus on human rights.\textsuperscript{105} For the first time in Soviet history, there was a mechanism for the direct incorporation of various international rules into the domestic legal system. During its short existence, this Committee found a number of Soviet laws to be inconsistent with Soviet international obligations. For example, some criminal law practices were found to be inconsistent with the presumption of innocence found in Article 14 of the \textit{ICCPR}.\textsuperscript{106} The infamous Soviet regulations requiring residence permits were found to be inconsistent with mobility rights found in the \textit{Universal Declaration} and the \textit{ICCPR}.\textsuperscript{107}

This lead to further reform in November 1991 when the Congress of the People's Deputies adopted the \textit{Declaration of the Rights and Freedoms of Person and Citizen}.\textsuperscript{108} This declaration incorporated international human rights norms into Russian domestic law and provided

\begin{footnotesize}
\textsuperscript{102} See, for example, Danilenko, \textit{ibid.} at 458. The 1977 Soviet constitution did not allow the direct operation of international law.
\textsuperscript{103} Danilenko, \textit{ibid.} at 459.
\textsuperscript{104} \textit{Ibid.} at 459.
\textsuperscript{105} \textit{Ibid.} at 460.
\textsuperscript{106} \textit{Ibid.}
\textsuperscript{107} \textit{Ibid.}
\textsuperscript{108} \textit{Ibid.} at 461.
\end{footnotesize}
that these international norms had priority over Russian law and directly created rights and obligations under Russian law. In 1991, the Russian parliament also created the Russian Constitutional Court and permitted individuals to bring complaints of human rights violations before this court. The constitutional court found various Russian laws to be inconsistent with international obligations. For example, labour laws that were used to annul contracts with persons who reached a pension age were found to be inconsistent with the age discrimination provisions of the *Universal Declaration* and other international treaties. Such cases demonstrated that even before the 1993 Constitution, the Constitutional Court was paving the way for the application of international norms in Russian domestic law.

This process finally lead to the constitutional reforms of 1993, with the direct incorporation of international law into the Russian legal system in Article 15.4 of the 1993 Russian Constitution. The provision is significant in a number of ways. First, the article incorporates both treaties and customary international law, and more specifically, provides that treaties shall apply over inconsistent domestic laws. Second, with its broad reference to "generally recognized principles and norms of international law," the article incorporates international law as it may develop in the future, including decisions of competent international bodies such as the United Nations Human Rights Committee. The general incorporation of international law means that individuals may invoke all kinds of norms of international law as part of the legal system of the land before any national administrative agency or tribunal in Russia. Moreover, national tribunals must give precedence to treaty norms, including all human rights-related treaties, over domestic law. As a result, the application of international law is not limited only to cases before the constitutional court. All levels of Russian courts have the jurisdiction to rule on questions of international law. To date, Russian courts have had little experience with the direct application of international law and perhaps little knowledge of these international norms. It remains to be seen the extent to which this dramatic constitutional reform will be reflected in the lower courts in Russia. However, article 15(4) of the *Constitution* may open the eyes of lawyers and judges to the possibilities and relevance of international law, which may lead to greater reliance on that body of law when pleading cases. As many

109 Supra note 101 at 461.
110 ibid. at 462–63.
111 ibid. at 465.
of these rights relate to HIV/AIDS-related claims, the incorporation of international human rights law into Russia domestic law may have a significant impact on future HIV/AIDS-related cases in Russian courts.

B. Russian Federal Law on HIV/AIDS

Under both international law and Russian constitutional law, Russian laws, including those relating to HIV/AIDS, must comply with Russia's international human rights obligations. It is within this context that Russian law and practice relating to HIV/AIDS must be examined. In August 1995, the Russian Federation enacted the Russian Federal Law On the Prevention of the Further Spread of Human Immunodeficiency Virus on the Territory of the Russian Federation. This is the most important piece of Russian HIV/AIDS-related legislation, touching on a broad range of issues including laws governing HIV testing, confidentiality, anti-discrimination measures, and the right to medical treatment.

The following section of this article will focus on the specific provisions of this legislation to determine the extent to which Russia's HIV/AIDS-related laws are consistent with Russia's international obligations. As this section indicates, much of the Russian law demonstrates a substantial commitment to comply with Russia's international obligations. However, as illustrated below in Part III, much of Russia's HIV/AIDS-related practice violates both Russian law and Russia's international obligations.

Consistent with the provisions of the Constitution that incorporate international law, article 2(3) of the Federal Law provides that if international treaties establish rules other than this federal law, the rules of the international treaty take precedence over domestic law. This article restates the obligations already established in article 15.4 of the 1993 Russian Constitution, making it clear that international treaties, including all human rights treaties, take precedence over any contrary provisions in the Federal Law on HIV/AIDS. The legislation then outlines the "guarantees of the state," the "rights and freedoms of HIV-infected individuals," and the laws governing HIV testing and confidentiality. Much of this law is

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113 Federal Law, ibid.: "In the event that international treaties of the Russian Federation establish rules other than this Federal Law, the rules of corresponding international treaties apply."
consistent with Russia's international human rights obligations. For example, the legislation provides for "regular information for the populace" on ways to prevent HIV infection. The state "guarantees" the availability of anonymous testing with pre- and post-test counselling. The legislation provides that HIV testing shall be voluntary except where HIV testing is required by law. Such testing is mandatory for donors of bodily tissues, workers in fields specified by regulation, and those in confinement.

According to the International Guidelines, the mandatory testing provisions of the Federal Law, with the exception of the mandatory testing of donors of bodily tissues, are inconsistent with international human rights law. The Federal Law specifically contemplates the mandatory testing of prisoners and such testing of prisoners is widely done throughout Russia.

\[114\]\textit{Ibid.}, art. 4.1. This provision is consistent with the International Guidelines, supra note 58, para. 116, which argue that the right to freedom of expression requires the right to receive detailed information about HIV prevention: see discussion supra note 81 and accompanying text. It is also consistent with the Comment, supra note 26. See also CESCR, Concluding Observations of the Committee on Economic, Social and Cultural Rights: Russian Federation, 20/05/97, E/C.12/1/Add.13, online: United Nations HCHR Homepage <http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/bca0697cecf2471802564b203d06a6?OpenDocument> (date accessed: 25 September 2001). The Committee on Economic, Social and Cultural Rights has specifically recommended to Russia "an information campaign which explains the nature of the disease [HIV], the modes of transmission, including sexual modes of transmission, and prevention techniques be undertaken in the mass media" (at para. 40): It also recommended that Russia "adopt laws and take all necessary measures to prevent discrimination against persons who are HIV-positive," \textit{ibid.}

\[115\] Federal Law, supra note 112, art. 4.1. The International Guidelines, supra note 58, paras. 97–99, do not argue that international human rights obligations require the availability of anonymous testing; however, they do argue that the right to privacy requires that all testing take place with informed consent and in a manner that respects confidentiality.

\[116\] Federal Law, \textit{ibid.}, art. 7.7. The International Guidelines, \textit{ibid.}, paras. 121–22, argue that pre- and post-test counselling is required by international human rights law that provides for the right to the highest attainable standard of physical and mental health. See also article 12 of the ICESCR, supra note 14, art. 12. See also the discussion supra at 81.

\[117\] Federal Law, \textit{ibid.}, art. 7(3). The International Guidelines, \textit{ibid.}, para. 113, argue that the right to liberty includes the right to be free from compulsory testing. See supra note 68.

\[118\] Federal Law, \textit{ibid.}, art. 9.

\[119\] The International Guidelines, supra note 58, para. 98, argue that mandatory testing is unjustified except in the case of donors of bodily tissues.

\[120\] Federal Law, supra note 112, art. 9(3).

\[121\] \textit{Ibid.}, art. 9(5).

\[122\] \textit{Ibid.} "Rules for the mandatory examination of individuals located in places of confinement, is established by the Government of the Russian Federation and is reviewed by it not less than once every five years."
According to the *International Guidelines*, there is no public health justification for the mandatory testing of prisoners and such testing is therefore inconsistent with the right to liberty and security of the person found in article 9 of the *ICCPR*. Article 9.3 of the *Federal Law* also permits the Russian government to specify a list of workers who shall be required to undergo HIV testing. In September 1995, the government issued regulations requiring the mandatory testing of all health care workers who perform medical examinations, diagnosis, and treatment of people with HIV/AIDS. To date, these are the only regulations issued under Article 9.3, however, the practice of mandatory testing of workers in Russia extends considerably beyond this small class of health care workers, notwithstanding the absence of any regulations permitting this widespread mandatory testing. In requiring the testing of health care workers who care for people with HIV/AIDS, the government appears to be concerned that these health care workers might be infected in the course of their employment. Of course, universal precautions are the only effective measure to protect health care workers from occupationally acquired HIV

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123 *Supra* note 58, paras. 111–13.
124 *Supra* note 112, art. 9(3).
125 *Supra* note 112, art. 9(3).
126 This concern is also reflected in article 21 of the *Federal Law*, *supra* note 112, that provides for “mandatory state insurance” for health care workers who care for people with HIV/AIDS. Curiously, article 22, *ibid.*, also provides for additional pay, reduced working day, and additional vacations to compensate these health care workers for their “particularly dangerous labour conditions.”
Mandatory testing will do nothing to provide these workers with any greater level of protection. The rationale behind Russia’s selective mandatory testing is unclear. According to the International Guidelines, in the absence of any rational public health objective, such testing is inconsistent with Russia’s international human right obligations.

The Federal Law also deals with the controversial issue of the mandatory testing of foreigners, providing that such foreigners are required to present a “certificate of absence of HIV-infection” if they wish to remain in Russia for more than three months. When the legislation was under consideration, it was proposed that all foreigners who visit Russia should be required to present such a certificate. After heated debate, this proposal was rejected with the result that only longer-term visitors to Russia are required to present such a certificate. According to the International Guidelines, the HIV screening of international travelers is inconsistent with the right to liberty of movement. At the same time, the International Guidelines acknowledge that longer-term residency may raise concerns

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127 International Guidelines, supra note 58, para. 128. See also discussion supra note 69. Article 5.2(i) of the Code, supra note 69, endorses the use of universal precautions in workplaces where workers come into contact with human blood and body fluids.

128 For a general discussion of this issue, see W. F. Flanagan, “AIDS-Related Risks in the Health Care Setting: HIV Testing of Health Care Workers and Patients” (1993) 18 Queen’s L.J. 71. Elsewhere in the world, the concern has focused more on whether health care workers should be tested as a measure to reduce the risk of HIV transmission from an infected health care worker to a patient. In Russia, the concern appears to be the reverse, that is, focused more on protecting the uninfected health care worker rather than patients in the health care setting. As noted, testing health care workers does nothing to reduce the risk of infection to them, so if that is the Russian rationale for such testing, it is weak. In Canada, for example, a general consensus has emerged that the mandatory testing of health care workers is, in most cases, an unnecessary and ineffective way to reduce transmission in the health care setting. In exceptional circumstances where there is a significant risk of transmission, for example where the health care worker is performing highly invasive procedures such as surgery, and the health care worker demonstrates inadequate infection control procedures, some mandatory measures may be required. See M. Gardam, W. Flanagan & I. Salit, “The HIV-Positive Dentist: Balancing the Rights of the Health Care Worker and the Patient” (2001) 164(12) Canadian Medical Association Journal 1715.

129 Supra note 58, paras. 127–28. The mandatory testing of workers, without any public health rationale, is inconsistent with article 23 of the Universal Declaration, supra note 12, which provides all with the “right to work.” Such testing is also inconsistent with the right to liberty found in article 9 of the ICCPR, supra note 13, paras. 110–13. See also discussion supra note 69.

130 Supra note 112, art. 10. Article 11(2) also provides for the deportation of any foreign citizen with HIV infection, “unless otherwise established by international agreements” to which Russia is party. Article 11(2) is not limited only to foreigners residing in Russia for more than three months. In theory, any visitor to Russia with HIV could face deportation, even short-term visitors, unless such deportation violated Russia’s international obligations.

131 International Guidelines, supra note 58, para. 105. See discussion supra note 78.
about health care costs and suggest that some kind of testing requirement may not be inconsistent with international human rights law.\textsuperscript{132} It is thus likely that the Russian laws governing the testing of foreigners are not inconsistent with Russia's international obligations.

Finally, the \textit{Federal Law} provides for the creation of "conditions for the realization of the rights of HIV-infected individuals provided for by this federal law, and also for prevention of the spread of HIV infection."\textsuperscript{133} Article 14 provides a right of medical care for people with HIV/AIDS "on a common basis with all types of medical care in accordance with clinical indications."\textsuperscript{134} Article 17 includes a broad prohibition of discrimination:

\begin{quote}
Dismissal from work, refusal to provide employment admission to educational institutions and institutions providing medical care, and the infringement of other rights and legitimate interests of HIV-infected individuals on the basis that they have HIV-infection, as well as infringement of right to accommodation and other rights and legitimate interests of members of families of HIV-infection individuals, are not allowed if not otherwise stipulated in this Federal Law."
\end{quote}

The legislation contains a vaguely worded enforcement provision, providing that the violation of the law will entail "disciplinary, administrative, criminal and civil legal liability in established procedure."\textsuperscript{135} On the whole, however, the equality provisions contained in the legislation are broadly consistent with article 26 of the \textit{ICCPR}, which provides for the right to be equal before the law and, according to the \textit{International Guidelines}, requires states to enact anti-discrimination legislation.\textsuperscript{137}

\section*{III. COMPLIANCE WITH FEDERAL LAW}

Key provisions of the \textit{Federal Law} are consistent with international norms, including the requirement for voluntary testing with pre- and post-test counselling, and a broad prohibition on discrimination against people with HIV/AIDS. The most apparent inconsistencies relate to the mandatory testing provisions for prisoners and health care workers who care for

\begin{itemize}
\item \textsuperscript{132} \textit{Ibid.} at 106.
\item \textsuperscript{133} \textit{Supra} note 112, art. 16.
\item \textsuperscript{134} \textit{Ibid.}, art. 14.
\item \textsuperscript{135} \textit{Ibid.}, art. 17.
\item \textsuperscript{136} \textit{Ibid.}, art. 24.
\item \textsuperscript{137} \textit{Supra} note 58, para. 85. The \textit{Comment, supra} note 26, also calls for the enactment and enforcement of anti-discrimination legislation. See \textit{supra} notes 30–31.
\end{itemize}
people with HIV/AIDS. In theory, a Russian judge might find such testing provisions to be unlawful because they are inconsistent with Russia's international human rights obligations. However, in modern day Russia, the more pressing question is the extent to which Russian practice is consistent with Russian law. There is considerable evidence that Russian government and medical authorities commonly ignore this law. According to two reports published by the Names Foundation, and another report published by AIDS Infoshare, there are a wide range of human rights violations of Russian law in at least three major areas: HIV testing, confidentiality, and the provision of health care. According to these reports, testing without informed consent, the mandatory testing of a wide range of groups, breaches of confidentiality, discrimination in employment, and discrimination in the provision of health care services, are all commonplace in Russia. Such practices are inconsistent with both Russia's domestic HIV/AIDS law and Russia's international human rights obligations.

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138 Widespread failure to comply with Russian law is not confined to the health law field. For example, although Russia has enacted sweeping reforms in its new criminal code, adopted in 1996, one author has observed that a study of this new law, although important, reveals "next to nothing about its functioning in practice." He adds that in Russia, the "correspondence between normative promises on one hand and operational reality on the other is extremely loose and at many crucial points plainly non-existent." S. Pomorski, "Reflections on the First Criminal Code of Post-Communist Russia" (1998) 46 Am. J. Comp. L. 375 at 376.

139 Names Foundation, "Report: AIDS Related Violations of Human Rights and the Russian Legislation" Report (May 1998) [hereinafter Report #1]; and Names Foundation, "Report #2: Violation of Human Rights of Russian Federation Citizens in the Context of the AIDS Epidemic" Report (Fall 1998) [hereinafter Report #2], online: Names Foundation Homepage <www.aids.ru> (date accessed: 25 September 2001). The Names Foundation, founded in 1993, is a national non-profit non-governmental organization located in Moscow that provides HIV/AIDS education services, provides social support to people affected by HIV/AIDS, and advocates for effective and non-discriminatory HIV/AIDS policies. The Names Project has documented numerous cases of human rights violations in its two reports, both published on its web page. Report #1 notes that the information in the report "is based on testimonies by people living with HIV/AIDS, their families and friends, medical professionals, state officials, [and] workers at non-governmental organizations" (at 1). Report #1 adds that only some of the most "recent and obvious" cases are described in the report and the actual number of cases is significantly higher.


141 Report #1 and Report #2, supra note 139, also document abuses in the area of Russian criminal law and in the treatment of prisoners.
A. HIV Testing

The *Federal Law* requires that HIV testing be undertaken only "voluntarily at the request of the individual ... with his or her consent." Nonetheless, the *Names Foundation* documents numerous examples of cases of mandatory testing and testing without the consent or knowledge of the patient. Under Russian law, mandatory testing is only permitted in specific professions designated by the Russian government, namely health care workers who treat people with HIV/AIDS. However, according to the *Names Foundation*, in Russia, workers in many other professions are regularly subjected to mandatory HIV testing even though they are not included in this government decree. Such workers include salespersons in stores and workers in restaurants who may be required to carry a "sanitary booklet." The Moscow Sanitary Surveillance Department requires such booklets containing health-related information including HIV test results. Certain drivers of public transportation must get tested every six months and police are tested as a condition of employment. Moreover, other entire populations are systematically tested, although this is not required or permitted under the law. These populations include medical checkups for children participating in summer camps and when enrolling in colleges and universities. Senior citizens entering institutions for the elderly are regularly tested, as are pregnant women, and women seeking abortions. All hospital admissions are routinely tested without their knowledge or consent.

142 Supra note 112, arts. 7(3), 8(1).
143 *Federal Law*, ibid., art. 9. See discussion supra note 102.
144 Report #1, supra note 139 at 3.
145 Report #1, supra note 139 at 6, documents a 1997 case dealing with a restaurant chef who was HIV-positive and lived with a roommate who was also HIV-positive. In November 1997, the roommate died of AIDS. The restaurant director, who knew that the two shared an apartment, harassed the chef with questions and innuendoes, finally demanding that he provide an HIV certificate. Aware that his diagnosis would be disclosed and used as a reason for dismissal, the restaurant chef chose to leave the job.
146 Ibid.
147 See discussion supra note 105.
148 Report #1, supra note 139 at 5, provides one example, from March 1993, where a patient was tested for HIV while he was hospitalized, without his consent or knowledge, and the results turned out to be positive. By the time the test results came back, the patient had already left the hospital. The hospital informed the Moscow AIDS Center that this individual had HIV. In order to get this patient to come and register at the AIDS Center, a request was sent to his local health care clinic mentioning his HIV diagnosis and his home address. His diagnosis was thereby disclosed to all staff at the local
According to the *Names Foundation*, most people are unaware of their right to refuse to consent to an HIV test. Even if aware of their right to refuse to consent, most recognize that if they refuse consent, they may be denied access to services. The effect of the threat of the denial of services makes such testing, in effect, mandatory and not voluntary.

In October 1999, I conducted an anonymous written survey of the project participants in the CARP training programme in St. Petersburg, Russia. The forty-three survey participants were mostly health care workers in the HIV/AIDS field, including medical doctors, epidemiologists, psychologists, and social workers. They came from St. Petersburg and seven other regions of Russia, not including Moscow. Although the sample size was small, the survey results can be regarded as a reasonable snap shot of some of the more common attitudes and practices among HIV/AIDS health care workers in Russia. The survey revealed a number of interesting findings. Fifty-six per cent of those surveyed indicated that they were aware of cases where patients had been tested for HIV without their knowledge or consent.

The participants were also asked: “If a person is tested without their knowledge or consent, and the results are negative, little or no harm has been done.” Fifty-three per cent indicated that in such a circumstance, little or no harm has been done.

The results suggest that most HIV/AIDS health care workers are aware of cases where testing has been done without the knowledge or consent of the patient. In conversation, most of our participants also freely

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150 See *supra* note 1 and accompanying text for a description of the Canada AIDS Russia Project (CARP). Forty-three of the sixty trainees in our Project participated in the anonymous survey, that is, 72 per cent of the participants. The trainees come from St. Petersburg and seven other regions of Russia (excluding Moscow). Of those participating in the survey, 29 per cent were medical doctors, 23 per cent were epidemiologists, 14 per cent were psychologists, 9 per cent were social workers, 7 per cent were members of the communities affected by HIV/AIDS, including those involved in a non-governmental HIV/AIDS organization, and 18 per cent identified as “other.” Sixty-three per cent worked in a city of over one million residents. The rest (37 per cent) worked in a city between 100,000 and one million residents. Thirty-three per cent were between the ages of thirty-six and forty-five; 30 per cent between the ages of forty-six and fifty-five; 20 per cent between the ages of twenty-six and thirty-five; 9 per cent over the age of fifty-six; and 5 per cent under the age of twenty-five. Just over 50 per cent of the survey participants were either doctors or epidemiologists. Including the social workers and psychologists, 76 per cent of the survey participants were professionals working in the HIV/AIDS field.

151 Twenty-eight per cent were not sure and 14 per cent were unaware of any testing without informed consent.

152 Twelve per cent “strongly” agreed that little or no harm had been done, and 42 per cent agreed; 28 per cent disagreed, and 14 per cent “strongly” disagreed.
admitted that the testing of hospital admissions, for example, was routinely done without the knowledge or consent of the patient. The results support a finding that testing without informed consent is widely practiced in Russia, notwithstanding the fact that such testing is directly in conflict with the Russian *Federal Law.* The survey results also suggest that the majority of health care workers view the practice of testing without consent as relatively harmless, particularly if the results are negative. Finally, 75 per cent indicated that they disagreed with the statement that there is broad compliance with the *Federal Law.* This result suggests that most are aware of the widespread lack of compliance with this law.

This casual attitude towards unlawful testing without consent fails to appreciate that such testing is inconsistent with the autonomy and privacy rights of the patient and a patient's right to determine the nature of his or her health care. This practice also breeds distrust of the medical system if people know that they might be tested without their knowledge or consent. Establishing such trust is a vital part of fighting the HIV/AIDS epidemic. If people at risk know that they cannot trust their health care providers, they will avoid any circumstance where they might be tested without their consent. The very people who should be encouraged to seek testing, counselling, and treatment, are the same people that the system will be actively discouraging from seeking this treatment.

**B. Confidentiality**

The *Names Foundation* has documented a large number of cases where doctors and nurses have failed to respect a patient's right of confidentiality. One 1997 case deals with wrongful disclosure in the health care setting. According to the *Names Foundation* reports, the mandatory
testing of migrant workers from states of the former Soviet Union is commonplace and the results are routinely reported to their employers without the knowledge or consent of the workers.\textsuperscript{156} There is also a 1998 case dealing with wrongful disclosure by a school manager of a teenage pupil's HIV-positive status.\textsuperscript{157} The pupil's physician had informed the principal who had in turn informed the school manager. The manager then announced the pupil's HIV status to the entire class.

Such breaches of confidentiality are inconsistent with Russian law\textsuperscript{158} and Russia's international obligations.\textsuperscript{159} They are also inconsistent with a physician's obligation to respect the confidentiality of medical information. Wrongful disclosure is not only damaging to patients and their family, but it also breeds distrust of medical practitioners and brings the practice of medicine into disrepute. This is of particular concern with regards to HIV/AIDS where it is crucial that people at risk have reason to believe that they can trust the medical system to provide them with proper care and respect their confidentiality. If this trust cannot be established, then people at risk will be reluctant to seek out testing, treatment, and counselling. This fear will increase the likelihood that they will transmit the infection to others, because they will remain unaware of their HIV status and uninformed about how to prevent its transmission.

C. Health Care

At least two key issues arise in Russia with regard to the provision of health care to people with HIV/AIDS: (1) inadequate access to health care, and (2) the lack of pre- and post-testing counselling. According to the \textit{Federal Law}, all HIV positive persons are entitled to the "[f]ree provision..."
of all forms of qualified and specialized medical care." This provision assumes that there will be adequate funding for these services but such adequate funding is rarely available. Access to adequate HIV/AIDS care is particularly difficult in the regions, so many Russians with HIV move to Moscow or St. Petersburg to seek treatment. According to the Names Foundation, these Russians are frequently prevented from doing so due to the strict system of residence registration. Non-residents are also not entitled to free medical care because free health care is accessible only to residents. People with HIV/AIDS are also expected to seek treatment at the local AIDS centre, which might not have the specialized care needed in a particular case. However, people with HIV are frequently denied treatment at other health centres because the staff at these centres refuses to examine or treat people with HIV.

In the course of my work with non-governmental HIV/AIDS organizations in the context of the Canada AIDS Russia Project, one of the NGO participants informed me of his ongoing HIV/AIDS human rights related court cases in Russia, deals with allegations of breach

160 Supra note 112, art. 4(1).
161 Report #1, supra note 139 at 6-7.
162 These residency laws have been deemed an unconstitutional limit on freedom of movement and choice of residence. See S.P. Boylan, "The Status of Judicial Reform in Russia" (1993) 13 Am. U. Int'l L. Rev. 1327 at 1336-37, where he notes that these residency permits are prohibited by the 1993 Russian Constitution. Nonetheless, the Mayor of Moscow has stubbornly attempted to preserve this pass system to prevent people from moving to Moscow, notwithstanding repeated rulings by the constitutional court of Russia declaring the pass system to be unconstitutional.
163 Report #1, supra note 139 at 7.
164 Ibid. at 7-8. Report #1 documents one case, in March 1993, where an HIV-positive patient was referred by the Moscow AIDS Center to a Moscow City Hospital for the treatment of a neurological condition. The Moscow AIDS Center did not have neurologists qualified to treat this condition. The Head Doctor of the hospital refused to treat this patient saying that, although he was not afraid of getting AIDS, there is nothing he could do for the patient because his hospital treats "a totally different type of disease."
165 Ibid. at 7. This refusal to provide care is contrary to article 124.1 of the Criminal Code of the Russian Federation, Sobraniye Zakonodatelstva Rossiskoi Federatsii (1996), No.25, item 2954; trans. W. Butler, The Criminal Code of the Russian Federation, (Simmonds & Hill Publishing Ltd., London, 1997) which provides that "[f]ailure to offer medical assistance to a patient by an individual who is obliged to offer such assistance in accordance with a law or a special regulation, if such negligence caused medium harm to the patient's health ..." is a criminal offense.
166 For a description of this project, see supra note 1.
of confidentiality and the wrongful denial of medical services. The complainant underwent an "anonymous" HIV test in 1988 and the results were positive. The complainant alleged that because the local medical authorities could not locate him to inform him of the result, they undertook a search that included informing his employer of the results of this test. The complainant also alleged that the AIDS Centre had violated his right to health care under Article 14 of the Federal Law. He complained that the AIDS Centre should compensate him for the cost of certain trips to St. Petersburg to seek treatment that was unavailable at the Centre. He also alleged that the Centre had denied him access to dental treatment for which he was eligible. On the question of access to care, the Court found in favour of the complainant, ordering the AIDS Centre to reimburse the complainant the costs of his trips to St. Petersburg for treatment and reimburse him for the costs of certain dental treatment. The AIDS Centre had argued that because the complainant had gone to St. Petersburg for treatment without any referral from the AIDS Centre, his travel costs should not be covered. The Court found that notwithstanding the lack of a referral, the plaintiff had a right to choose his place of treatment and the reasons given by the AIDS Centre for refusing to pay these travel costs were "unreasonable." Regarding the allegations of breach of confidentiality, the Court found that there was insufficient evidence to find a breach of confidentiality, noting that the alleged breach took place in 1988 and the

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167 Shestakov v. Sochi City Centre on Prevention and Fight of AIDS and Infectious Diseases, Central City Court of Sochi, Krasnodar Territory (March 20, 2000) [hereinafter Sochi]. This is an unofficial court record; it is available on file with the author.

168 Ibid. The complainant also alleges that when he challenged the medical authorities for having disclosed his status to his employer, the medical authorities then issued a statement to his employer stating (falsely) that the complainant was HIV negative.

169 Article 14 of the Federal Law, supra note 112, provides that persons with HIV/AIDS are "provided on a common basis with all types of medical care in accordance with clinical indications."

170 The plaintiff was awarded damages of approximately 5000 rubles, or $180 US, about the equivalent of a typical monthly wage in Russia.


172 The complainant had alleged that the breach of confidentiality had caused him "psychological harm," entitling him to compensation under articles 151 and 1099 of the Grazhdanskii Kodeks Rossiskoi Federatsii/Russian Civil Legislation (Part I and II) and Other Surviving Civil Legislation of the Russian Federation, eds., compil., trans. from Russian, W. Butler (London: Simmonds & Hill, 1999). Article 151 provides that monetary damages shall be paid for psychological harm, including physical and
plaintiff had delayed bringing any action against the physician in question until twelve years later.

The case is significant because it is the first case in Russia where a court has actually found that a local AIDS centre has failed to provide the level of care required by the *Federal Law*. It challenges the widespread and casual disregard within which many health care institutions in Russia hold the *Federal Law*. Unfortunately, however, the case can only have a limited impact. Russian law, like most continental European systems, has not adopted the principle of *stare decisis*, thus cases have little or no precedential value.\(^{173}\)

In addition to inadequate health care, the *Names Foundation* has also documented examples of a failure to provide adequate pre- and post-test counselling. According to the *Names Foundation*, none of the 10 state-run anonymous testing sites in Moscow provides adequate pre- and post-test counselling.\(^{174}\) If the screening test result is positive, the patient is told that the test is unclear, and referred to the Moscow AIDS Center to confirm the result. No other information or counselling is offered. Moreover, many people fail to attend the AIDS Centre to receive further treatment and care. The failure to provide proper pre- and post-test counselling is inconsistent with the *Federal Law* which requires that pre- and post-test counselling be provided whenever one undergoes a medical examination for HIV.\(^{175}\)

IV. RUSSIA AND THE RULE OF LAW

In Russia, there is a widespread failure to comply with the provisions of the *Federal Law*. This raises broader questions about the role of law and the courts in Russian society, and the issue of the extent to which the "rule of law" exists in Russia. The "rule of law" is a term used to describe a legal system in which the law is transparent and effectively binds all, including the state and its most powerful citizens, and is generally respected by most members of society. Such a society is governed by the "rule of law." A number of writers have commented on the lack of the rule

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173 Boylan, *supra* note 162 at 1341–42. There is also no system for reporting cases in Russia. I was able to gain access to the handwritten decision of the court only because the complainant gave it to me.


175 *Supra* note 112, art. 7(1).
of law and a mature legal culture in Russia. They note that this lack of the rule of law can be traced to a number of factors, including a history of corruption, the "paradox of over-legislation," the traditional role of law in Soviet society, the historic lack of an independent and well-informed judiciary, and difficulties in enforcing judicial decisions.

The rise of organized crime in Russia has undermined the development of a rule of law culture in Russia. For example, the voucher privatization programme in Russia, whereby many state industries were sold to private shareholders, was done in such a manner that organized crime groups were able to illegally acquire control of a significant percentage of enterprises undergoing privatization. Two-thirds of Russians polled have stated that their opinion of privatization was that it was "legalized theft." The result is that criminal organizations exercise broad control over economic activity in Russia, resulting in widespread corruption and leading to a broadly held contempt for judicial and state institutions that appear unable to exercise any control over these organizations.

Although the state is weak, Russian legislators have nonetheless vigorously pursued the enactment of new legislation, particularly in the economic sphere, resulting in many laws that have been imprecisely drafted and are inconsistent with other laws or regulations. One writer has described this phenomenon as a "paradox of over-legislation." The Federal Law reflects this legislative enthusiasm in Russia. Progressive laws largely consistent with international best-standards are enacted, but such laws, frequently referred to in Russia as "paper rights," have little influence on ongoing unlawful practices. The inclusion of international obligations in the Russian constitution also reflects this optimistic zeal for sweeping legislative reform that in reality has little social impact. Such laws fail to address the large gap that exists between the de jure and de facto practice of law in Russia, reinforcing a tradition where the formal content of the law


177 Halverson, ibid. at 95.


179 Ibid.

180 Ibid. at 95. This is particularly the case in economic regulation, where "it is difficult to conduct business in Russia without being in technical violation of the myriad, constantly changing laws and regulations issued by the Russian bureaucracy," ibid.
is less significant than the selective and uneven manner in which the law is enforced in practice.

The history of the Soviet system also contributes to the lack of a rule of law in Russia. Under the Soviet system, the law was primarily a means to reinforce the power of the state and the Communist Party.\(^{164}\) The law was subordinate to these institutions, which were free to disregard the law if it interfered with conflicting political objectives. It was not only the Party and the state that casually disregarded the law when convenient to do so. Although the Soviet system outlawed essentially all private economic activity, the failings of the system lead to widespread bartering and other informal transactions, in effect creating a sphere of private economic activity that functioned outside the law. Such conduct was commonly accepted in the Soviet Union, creating an entire range of illegal activity that was popularly regarded as legitimate. The historic failure of Soviet law to command broad compliance and respect, both from the population and the state, lingers and contributes to the barriers in establishing the rule of law in modern Russia.

The courts were also weakly developed institutions during the Soviet era. The power that Communist Party officials wielded over the judiciary was commonly referred to as "telephone justice."\(^{162}\) Judges would clear their decisions with the Communist Party prior to rendering any decision, leading to a long history where they were susceptible to coercion and even bribery. The prestige and power of the courts suffered. Although efforts have been made to enhance the independence of the judiciary,\(^{163}\) funding is limited and Russian judges remain poorly paid. Most judges in Russia are now appointed for life,\(^{164}\) but the majority of those currently serving as judges were appointed prior to the adoption of this policy. As a result, the majority of judges are still serving out a variety of terms with hopes of a reappointment for life, making them more susceptible to political influence.\(^{165}\) Moreover, there may still remain other ways for local

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\(^{161}\) Ibid. at 98.

\(^{162}\) Ibid. at 100. See also Boylan, supra note 162 at 1327.

\(^{163}\) See T.E. Plank, "The Essential Elements of Judicial Independence and the Experience of Pre-Soviet Russia" (1996) 5 Wm. & Mary Bill Rts. J. 1, for a discussion of the elements essential to judicial independence, including fixed tenure, fixed and adequate compensation, minimum qualifications, and limited civil immunity.

\(^{164}\) Boylan, supra note 162 at 1332.

\(^{165}\) Boylan, ibid. at 1332, published in 1998, estimated that as of publication, only 20 percent of Russian judges were appointed for life.
political officials to influence judges, since these officials may control aspects of the judge's livelihood, such as access to public housing. Questions also remain about the competence of Russian judges. One author has argued that some of the brokerage firms appearing before economic court judges are more knowledgeable about the law than the judges. There is also a lack of familiarity among judges of many of the newer legal developments, particularly with the incorporation of the international legal norms into Russian law, via the 1993 Russian Constitution, and in specific cases, such as the Federal Law. Because Russian judges have no tradition of interpreting and applying international law in domestic cases, they remain unfamiliar with these norms. Finally, there are ongoing difficulties in enforcing judicial decisions, a matter that impairs judicial prestige and respect. The most prominent example of disregard for judicial decisions is the ongoing attempts by the Mayor of Moscow to preserve the residency permits system notwithstanding the fact that the Constitutional Court of Russia has repeatedly declared the pass system to be unconstitutional.

These factors lead to a weak judiciary and weak legal culture in Russia. Russians remain suspicious of their judiciary's capacity to understand and enforce the law. Substantive reform requires a reorientation of the court system from the bottom up, as well as a change in social attitudes towards law and legal institutions. Some change is underway with the development of an independent and stronger judiciary. There are also other encouraging examples. Recent cases before Russian courts have successfully challenged various Russian practices and laws. The HIV/AIDS-related case discussed earlier is another important example where a Russian court successfully enforced the provisions of the Federal Law. Although the progress is slow, there is reason to believe that the

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186 Halverson, supra note 176 at 102.
187 Ibid.
188 See discussion supra note 89.
189 Boylan, supra note 162 at 1332.
190 Boylan, ibid. at 1339–40, cites a number of examples. Russians typically charge different prices for foreigners and Russians for hotels, trains, and plane tickets. In one case, this practice was successfully challenged as inconsistent with Russian law that provides that prices for goods will be the same regardless of nationality. Russian judges have also successfully challenged the constitutionality of various procedures in Russian criminal law, including the practice of allowing prosecutors to appeal acquittals and the failure of the Russian government to extend throughout Russia the right to jury trial.
191 Sochi, supra note 167. See also discussion supra note 161.
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Russian judiciary is gradually growing in independence, stature, and influence.

V. CONCLUSION: TOWARD COMPLIANCE WITH THE RULE OF LAW

This article has examined Russia's international human rights obligations and the extent to which Russia's current HIV/AIDS law and practice are consistent with those obligations. With some exceptions, notably the mandatory testing of prisoners and health care workers who care for people with HIV/AIDS, most aspects of Russia's HIV/AIDS laws are consistent with Russia's international obligations. Indeed, both Russian constitutional law and its Federal Law specifically provide that international human rights obligations will take precedence in the event of conflict. However, this article has also documented key elements of HIV/AIDS practice in Russia that are inconsistent with both the Russian HIV/AIDS law and Russia's international human rights obligations, demonstrating that there is a casual and widespread disregard of HIV/AIDS-related laws in Russia. As noted in the Comment, this failure to enforce domestic law is itself inconsistent with Russia's obligations under the ICESCR.192

These findings raise the question of what domestic reform efforts can be undertaken to promote practices consistent with the rule of law in Russia, especially as it regards HIV/AIDS-related matters. In particular, what might be the role of medical professionals and community groups in the enforcement of the Federal Law in a manner consistent with Russia's international human rights obligations? The rule of law largely starts and ends with the recognition of the supremacy of law by all citizens. The developing HIV/AIDS non-governmental organizations in Russia have a crucial role to play. As these groups grow in number and strength, in part through the assistance of international development donors,193 they can become more active about improving the human rights literacy of their members, including their rights to: confidentiality, consent to medical treatment, and freedom from discrimination. Interested citizens must develop the capacity to do more to turn these "paper rights" into legally enforceable and widely recognized rights, as demonstrated by the successful

192 See discussion supra note 31-32.

193 One of the key objectives of CARP has been the development of nine community-based non-governmental HIV/AIDS organizations, two in St. Petersburg, and seven other groups in seven different regions of Russia. There are also a number of other donors involved in NGO development in Russia, notably the Soros Foundations Network. For a discussion of CARP, see supra note 1.
legal effort to challenge the practices in the Sochi AIDS Centre. Workshops, publishing of pamphlets, and general education, are all means to accomplish this objective. Documenting human rights abuses, as has been done by the Names Foundation and AIDS Infoshare in Moscow, is also crucial to the promotion of the rule of law. A single story of disregard for the Federal Law, if unrecorded and unrecognized, simply supports an argument that the rule of law has no application in Russia. However, if these stories are collected together, documented, and made readily available to the public, the lack of rule of law becomes increasingly visible. The rule of law will gain in strength over time. It is easy to despair in circumstances where the rule of law is so broadly disregarded, but the law, even in Russia, can provide important moral and political support for the protection of the rights of people with HIV/AIDS. As the rule of law grows, so will the protection of the interests and rights of Russians living with HIV/AIDS.

Medical professionals also have an important role to play. They need to take a leading role in informing themselves of their legal obligations, and developing policies and practices that are consistent with Russian law and international standards. For example, medical professionals must be trained to understand the importance of informed consent to HIV testing as required by the Federal Law. Health care professionals must challenge the casual and widespread disregard of this law. The continuation of this practice by medical professionals contributes to contempt for the rule of law in Russia and brings the medical profession into disrepute. It is corrosive of Russia's larger goal to develop a society governed by the rule of law.

These measures can help to build a legal culture based on rule of law in Russia. Perhaps even more importantly, they can assist Russia in its fight against HIV/AIDS. Respecting the rights of persons with HIV is a crucial component of any effective HIV/AIDS strategy. Effective public health measures to prevent the spread of this disease require the respect, confidence, and trust of affected populations. This can only be maintained in an atmosphere where the rights and dignity of people with HIV are protected by law, and where the law commands the respect of its citizens.

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194 As noted by in the AIDS Infoshare Report, supra note 140, the law must be "brought down from the shelves and put into the hands of the people ... [i]t must be presented in a way that it becomes a tool ... ." People need to be "armed with the knowledge of their rights before entering into a relationship with medical professionals."