

# A Human Rights Perspective on Infectious Disease Laws in Japan

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## Abstract

This article examines infectious disease laws in Japan from a human rights perspective using international standards.

**Background** In public health, frameworks and assessments integrating human rights concerns are beginning to be developed. One challenging area is infectious disease control where human rights offer and approach for addressing the rights and health of infected and vulnerable populations.

**Methods** We examined the jurisdictional transformation of human rights concerns in infectious disease laws through chronological and conceptual analysis. In particular, we looked at relevant laws with special attention to the recently amended Infectious Disease Prevention Law by focusing on HIV/AIDS and tuberculosis.

**Results** Attention to human rights in infectious disease laws in Japan has improved. This may partially be the result of (1) attention to international norms and standards, and (2) civil society efforts to advocate for the rights of infected and vulnerable populations.

**Conclusion** Three prime areas remain challenging: (1) inclusion of infected and vulnerable populations in decision-making concerning relevant law and practice, (2) attention to the health and rights of health professionals, and (3) accurate criteria for restricting the rights of infected and affected populations. Consideration of international standards and approaches in these areas could facilitate a well-balanced health and human rights perspective to infectious disease control.

**Key words** Human rights, HIV/AIDS, Tuberculosis, Infectious Disease Prevention Law, Japan

## Introduction

### Human rights

Human rights are legally guaranteed internationally and in the national laws of governments, protecting fundamental freedoms and the human dignity of individuals and groups.<sup>1,2</sup> Governments are obliged to respect, protect, and fulfill human rights.<sup>3,4</sup>

International human rights law was developed principally after World War II. A large number of human rights related treaties, declarations, and legal instruments with implications for health

have been promulgated globally. The United Nations (UN) adopted and proclaimed the Universal Declaration of Human Rights in 1948.<sup>1</sup> Two major international human rights treaties were created in 1966; the International Covenant on Economic, Social and Cultural Rights (ICESCR),<sup>5</sup> and the International Covenant on Civil and Political Rights (ICCPR).<sup>6</sup> Japan ratified these two treaties in 1979 as well as the six other major human rights treaties by October 2007. A number of international bodies exist to support governmental compliance with their human rights obligations and most recently, in June 2006, the UN established the Human Rights Council to

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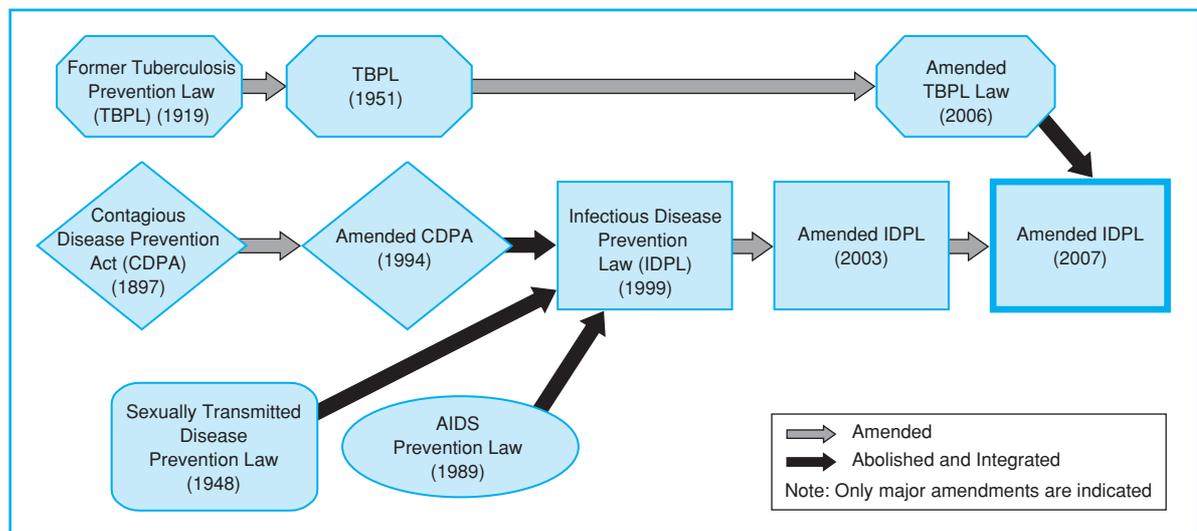


Fig. 1 Jurisdictional transformation: Major infectious disease related laws in Japan

promote and encourage respect for human rights and fundamental freedoms.<sup>7</sup>

### Human rights in global health

In the context of health, human rights have been progressively promoted at the global level.<sup>8–10</sup> The World Health Organization (WHO) affirmed “the right to the highest attainable standard of health” in its 1946 Constitution.<sup>11</sup> The concept was developed over half a century with “health for all” (1978),<sup>12</sup> “health promotion” (1986),<sup>13</sup> “health promotion in the 21st century” (1998).<sup>14</sup> The right to health also exists in many health specific documents and declarations.

Governments have a responsibility to deliver essential health and social services, and to enable people and their families to achieve better health by respecting human rights, which are a prerequisite to health and wellbeing.<sup>10</sup> Framework and assessment methodologies to include human rights concerns in health are increasingly being developed by the international community.<sup>8,15,16</sup> Governmental obligations include the obligation to respect, protect, and fulfill human rights. A “rights-based approach” is a process that uses human rights as an integral dimension of the design, implementation, monitoring, and evaluation of health-related policies and programs.<sup>17</sup> In particular, attention is given to the principles of non-discrimination, participation, transparency, and accountability. Increasingly, governments

have understood that the promotion and protection of human rights in the context of public health is not only a legal obligation but can also make their policies and programs more effective.

Since the 1980s, the global pandemic of HIV/AIDS has raised awareness of the rights of infected and vulnerable populations in global health.<sup>3</sup> Infectious disease control is a challenging area for considering the rights of infected and vulnerable populations.

### Human rights and public health in Japan

In 2001, an epoch-making event occurred regarding human rights concerns in Japan’s public health policy. The Japanese court ordered the government to award compensation to former leprosy patients. The Leprosy Prevention Law (Law No.214: 1953–1996), which was based on patient isolation in the 13 national leprosaria, was found to be a violation of the human rights of leprosy patients.<sup>18</sup> Later, compensation was also awarded to those claiming maltreatment<sup>19</sup> while isolated in the overseas leprosaria built by the Japanese government during the colonial period.<sup>20</sup>

Along with this case, concerns for the human rights of people living with HIV/AIDS (PLWHA), the potential threat of the use of infectious disease pathogens for world terrorism, and the outbreak of emerging infectious diseases, e.g., severe acute respiratory syndrome (SARS) and the H5N1 strain of flu, have all raised awareness of the role

of human rights in public health considerations.<sup>21</sup>

### Jurisdictional transformation in Japan: Infectious disease related laws

Perhaps as a consequence, the structure of infectious disease related laws has been drastically transformed in the last decade (Fig. 1). The aims are to strengthen surveillance and prevention on the one hand, and on the other to promote a human rights perspective in infectious disease control.<sup>21</sup> Japan has been observing the continuous increase of PLWHA from the mid-1980s, and the plateau prevalence of TB. These two infectious diseases are targets of the UN Millennium Development Goals<sup>22</sup> and of direct concern to Japan.

### Epidemics of HIV/AIDS and TB

**HIV/AIDS:** The human immunodeficiency virus (HIV) causes acquired immune deficiency syndrome (AIDS), which was first recognized in 1981 in the United States.<sup>23</sup> In the world, 39.5 million people were estimated to be living with HIV/AIDS in 2006.<sup>24</sup>

In Japan, 1,358 PLWHA were newly reported in 2006, with a 13% increase from the previous year, a consecutive 3-year growth.<sup>25</sup> The cumulative number of PLWHA in Japan was estimated to be 12,394 by the end of 2006.<sup>26</sup> Although the estimated HIV infection rate among its population is under 0.1%, Japan is experiencing an increase in PLWHA since the first reported AIDS patient in 1985.<sup>25</sup> Specialists note that HIV/AIDS in Japan is shifting from a concentrated to a generalized epidemic and advise that more resources need to be invested in prevention.<sup>27</sup> In terms of related laws, the AIDS Prevention Law (Law No. 2: 1989) was integrated into the Infectious Disease Prevention Law (Law No. 114: IDPL) in 1999 (Fig. 1).

**TB:** TB is an infectious disease that spreads through the air. People who are sick with TB in their lungs are infectious.<sup>28</sup> The WHO declared TB a Global Emergency in March 1993. In 2005, it was estimated that globally 8.8 million people were newly infected with TB and 1.6 million people died by it.<sup>29</sup>

In Japan, TB was the top cause of death in the 1930s and 1940s and remained a high-prevalence disease until the 1950s.<sup>30</sup> The prevalence was lowered to 33.7/100,000 in 1996.<sup>31</sup> However, in 1997–1998, Japan experienced the first rise in TB

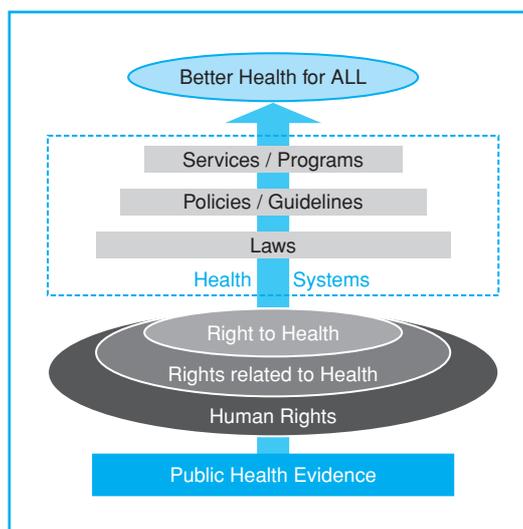


Fig. 2 Integration of human rights to improve health

patients (34.8/100,000) after having decreased for four decades. Thus the Japanese government declared a national TB emergency in 1999.<sup>32</sup> Currently, Japan remains as a middle TB-prevalent country. The TB prevalence (17.2/100,000) in 2006<sup>33</sup> was approximately two- to three-fold of that of other developed nations. With respect to relevant laws, the TB Prevention Law (Law No. 96: 1951) was amended in 2006 and integrated into the IDPL in April 2007 (Fig. 1).

### Study objectives

Given the rising HIV and TB prevalence in Japan, jurisdictional transformation is taking place alongside elevation of human rights concerns. We therefore examined the concepts and implementation of a human rights perspective in the scope of infectious disease control in Japan by focusing on HIV/AIDS and TB related laws in relation to international standards.

### Methods

#### Conceptual framework: Human rights integration to improve health

We designed a conceptual framework, which illustrates the integration of human rights to improve health (Fig. 2). Human rights are understood here to include “rights related to health” and the “right to health.” “Rights related to health” include: the rights to food, housing, work, edu-

cation, human dignity, life, non-discrimination, equality, prohibition of torture, privacy, access to information, and the freedoms of association, assembly, and movement. These and other rights and freedoms address integral components necessary for achievement of the right to health.<sup>34</sup> The “right to health” directly involves the underlying determinants of health and the delivery of health care services. Within health systems, laws determine policies such as those relating to infectious disease control, which set specific guidelines that encompass service and programs delivered to accomplish “better health for all.”

## Analysis

### 1. Chronological analysis: 1897 to 2007

A two-tiered methodology was used for the examination. First, we performed a chronological analysis to investigate the development of concepts and application of human rights to Japan’s infectious disease control in relation to international standards. We examined the changing status of the epidemics, human rights related laws of Japan and the world, as well as related health policies, and programs from the approximately 100 years since the first related law, the Contagious Disease Prevention Act (Law No. 36), was enacted in 1897.

### 2. Conceptual analysis

Second, we conducted a conceptual analysis to examine the development process and relation of the themes. This method<sup>17</sup> allows the analysis of complex situations of broadly conceived inquiry. We investigated how governmental obligations regarding human rights protection are embedded in HIV/AIDS and TB related laws in Japan. Analysis was conducted of: academic papers, laws, policies and guidelines, government and non-governmental organizations’ programs, public reports and minutes, and media reports. For the governmental materials at the national level, we also examined the minutes issued by the Ministry of Health, Labour and Welfare, the Ministry of Justice, the Ministry of Education and Science, the Management and Coordination Agency, and the General Administrative Agency of the Cabinet in Japan. At the local level, we studied the disclosed information of prefectures and municipalities as well as the health care centers posted in prefectures, municipalities, and ordinance-designated cities.

## Results

The jurisdictional transformation incorporating human rights protections in HIV/AIDS and TB related laws in Japan is shown (Table 1 and 2). Specific articles within the relevant law are displayed with regards to their positive and negative aspects from a human rights perspective. In this section, notable issues are summarized from a rights perspective according to each disease.

### Governmental Obligations regarding Human Rights: HIV/AIDS related laws

#### Jurisdictional transformation

The AIDS Prevention Law (1989) was the first law promulgated to control HIV/AIDS in Japan. In 1999, it was abolished and integrated into the IDPL along with the Sexually Transmitted Disease Prevention Law (Law No.167: 1948) and the Contagious Diseases Prevention Act (1897). Most of the articles related to HIV/AIDS control were inherited to the Amended IDPL in 2007 (Fig. 1).

#### Positive aspects

##### *Human rights protection*

The 1989 AIDS Prevention Law obliged the state to consider human rights protection for patients (Art. 2-3) as did the 1999 IDPL (Art. 2, 3-1). The Amended IDPL (2007) goes a step further in obligating national and local government authorities to respect the human rights of patients (Art. 2, 3-1).

**Abolishment of mandatory name reporting:** The 1989 Law stated that physicians shall send an alert notice to the governor with the names and addresses of infected people who are non-compliant and suspected of infecting others (Art. 7-1), and of people who have had contact with infected person(s) and are suspected of doing the same (Art. 7-2). On the positive side even at that time, physicians were advised to protect the privacy of those whom they report by making a confidential notice to the governor.<sup>35</sup>

HIV/AIDS was designated as a Category-4 disease in the 1999 IDPL, and a Category-5 disease in the 2007 IDPL. As diseases in these categories are the target of surveillance only, the alert notice system was abolished in 1999. The surveillance report written by a physician to the governor contains; the patient’s age, sex, nationality, and cause of infection (Art. 5 in 1989; 12 in 1999). In

**Table 1 Governmental obligations regarding human rights protection: HIV/AIDS related laws**

AIDS Prevention Law (1989)	Infectious Disease Prevention Law* (1999)
Objectives: To enhance and advance public health by preventing an HIV/AIDS epidemic	To prevent the emergence of infectious diseases (IDs) and epidemics by establishing necessary measures for ID patients and prevention
Disease Classification: None	Category-4 (out of 4)
<Immediately relevant articles (Article number)>	
• Promotion of accurate knowledge regarding AIDS through educational activities (2-1)	• Enhancement of accurate knowledge on ID through educational activities and public relations (3)
• Collection of AIDS-related information and promotion of research (2-2)	• Collection, analysis, and provision of ID-related information (3)
• Consideration for human rights protection for patients (2-3)	• Recognizing the patient's situation and consider his/her human rights (2, 3)
• National and local government cooperation for implementation of the HIV preventive measures (2-4)	• Ibid. (3) • International collaboration (3)
• Citizens' duty not to violate the human rights of patients (3)	• Citizens' duty to obtain accurate knowledge on IDs, be alert to prevention, and not to violate the human rights of patients (4)
• Physicians' cooperation with prevention efforts (4)	• Health professionals' collaboration with prevention (5-1)
—	• Promotion of research, advancement of testing ability, and education of human resources (3)
—	• Provide good quality of care for the ID patients (3)
—	• National government's support for local governments in technology and finance (3)
• Report of the age, sex, and address of patients by a physician to the governor within 7 days (5)	• Ibid. (12)
• <b>Ban on "HIV infecting activities" by infected people (6-1)</b>	—
• <b>Compliance of infected persons with the physicians' order (6-2)</b>	—
• <b>Alert notice to the governor with the names and addresses of non-compliant patients or people whom a physician suspects of infecting people with HIV (7-1, 2)</b>	—
• Governor's advice to test reported vulnerable individuals during a certain period (8-1)	—
• <b>Governor's order of health examination to those who are non-compliant with the above advice (8-2)</b>	—
• <b>Governor's instruction on prevention of HIV infection to the reported people/guardians (9)</b>	—
• <b>Questioning reported patients/guardians regarding necessary information (10-1)</b>	• <b>Questioning and investigation of patients and concerned parties regarding necessary information (15-1)</b>
• Right to demand reinvestigation by the Minister (13)	• Ibid. (65)
• Imprisonment or fining of physicians, government employees, and professionals for disclosing patient information (14, 15)	• Ibid. (67–69)
• <b>Fining of non-compliant patients for failing to obey governor's order of health examination (16-1)</b>	• <b>Fining of patients in case of non-cooperation (69)</b>
• <b>Fining of patients in case of false report when questioned (16-2)</b>	• Ibid. (69)
—	• Ministers' and governors' obligation to provide preventive information (16-1)
—	• Minister's and governors' obligation to protect privacy (16-2)
—	• <b>Fining of physicians in failing to report regarding the health status of patients (69-1)</b>

\* When the Law was amended in 2007, most of HIV/AIDS related articles were carried forward.  
 Bold letters = Possible infringements on the human rights of infected/vulnerable people.

**Table 2 Governmental obligations regarding human rights protection: TB related laws**

TB Prevention Law* (1951)	Amended TB Prevention Law (2006)	Amended Infectious Disease Prevention Law** (2007)
Objectives: Promotion of public welfare by preventing TB from harming individuals and society through TB prevention and dissemination of proper care	Ibid.	To prevent the emergence of infectious diseases (IDs) and their epidemics by establishing necessary measures for ID patients and prevention
Disease Classification: None	None	Category-2 (out of 5)
<Immediately relevant articles (Article number)>		
• Consideration of human rights protection for patients (2-1, 3-2)	• Ibid. (2-1)	• Promotion of comprehensive measures for ID prevention and care for patients with respect for their human rights (2)
• Provision of adequate care (2)	• Ibid. (2-1)	• Ibid. (3)
—	—	• Collection of ID- and pathogen-related information and promotion of research (3-3)
—	—	• Cooperation by patients and asymptomatic pathogen carriers relating to questioning and investigation (15-3)
—	• Enhancement of accurate knowledge on TB through education and public relations (2-1)	• Citizens' duty to obtain accurate knowledge on infectious disease (4)
—	• Collection, analysis, and provision of TB-related information (2-1)	• Ibid. (3)
—	• Promotion of research, advancement of testing ability, and education of human resources (2-1)	• Ibid. (3)
• Comprehensive measure by national and local governments for prevention and provision of adequate care (2)	• Collaboration of national and local governments for preventive measures (2-2)	• Ibid. (3)
—	• Promotion of research, advancement of testing ability, and education of human resources (2-3)	• Ibid. (3)
—	• International collaboration (2-3)	• Ibid. (3)
—	• National government's support for local governments in technology and finance (2-3)	• Ibid. (3)
—	• Physicians' cooperation for preventive measures, recognition of patients' situations, consideration for their human rights and provision of adequate care (3-2)	• Physicians' collaboration for preventive measures and recognition of the patient's situation, provision of proper care, and achieving patients' understanding by providing adequate explanations (5)
• <b>Governor's advice on testing of suspected people (5-1)</b>	• Ibid. (5-1)	• Ibid. (17-1)
• <b>Governor's authority to test non-compliant people according to the above advice (5-2)</b>	• Ibid. (5-2)	• <b>Governor can compel health officials to test the suspected people in case of non-compliance with above advice (17-2)</b>
—	• Governors' written report for above 5-2 measure (5-3)	• <b>Ibid. (17-3)</b>
• Disclosure of the test result per request from the immunized person (19-2)	• Ibid. (19-2)	• Disclosure of the test result per request from the recipient of health examination (53)
• Target persons' immunization (17-1, 2, 3)	• Ibid. (17-1)	—
• Governmental disbursement of benefit in case of occurrence of disability or death by immunization (21-2)	• Ibid. (21-2)	—
• <b>Physicians' report of patients</b> to the nearest health center within 2 days (22)	• Ibid. (22)	• <b>Physician's immediate report of the name, age, sex, occupation, and address of patients and asymptomatic pathogen carriers (12, 53-7)</b>

• Home visits for preventive and care instructions to registered patients (25)	• Home visits for DOTS*** for registered patients (25)	• Home visits for DOTS for registered patients (53-14)
• <b>Physician's order of sterilization, isolation, or necessary measures to the patients/guardians (26)</b>	• Physician's order of DOTS, sterilization, or necessary measures to the patients/guardians (26)	• Physician's order of DOTS, sterilization, or necessary measures to the patients/guardians (53-15)
• <b>Governor's ban on employment of patients (28-1)</b>	• Ibid. (28-1)	• Governor's restriction on work of patients and asymptomatic pathogen carriers for a designated period (18-2)
—	—	• Patient's/guardian's request for the confirmation of the end of restriction on work (18-3)
• Screening committee on the 28-1 decision (28-2)	• Ibid. (28-2)	• Screening committee on the 18-2 decision (18-5)
• Governor's consultation with the Labor Department chief at the local government level if a working ban is applied to health professionals (28-3)	• Ibid. (28-3)	—
• <b>Governor's order of hospitalization (29)</b>	• <b>Ibid. (29)</b>	• Governor's advice for hospitalization (19, 26-2)
—	—	• Screening committee on governor's advice of hospitalization, extension of hospitalization, or co-payment (24)
—	—	• Review of the extension of hospitalization every 30 days (20-2, 26-2)
• <b>Governor's order of sterilization and necessary measures regarding the patients' residence, and isolation of the patient (30)</b>	• Governor's order of sterilization and necessary measures regarding the patients' residence (30)	• Governor's order of sterilization and necessary measures regarding the contaminated area (27)
—	—	• Right to file a complaint by the inpatient/guardian to the governor regarding the treatment (24)
—	—	• Right to demand reinvestigation by the inpatient/guardian to the Minister regarding extended hospitalization (25-1)
• <b>Questioning of patients/concerned parties regarding necessary information (32-1)</b>	• <b>Ibid. (32-1)</b>	• <b>Ibid. (35-1)</b>
• The authority of questioning should not be interpreted as identical to the authority for criminal investigation (32-3)	• Ibid. (32-3)	• <b>Ibid. (35-3)</b>
• The composition of the screening committee is more than 5 persons from government and knowledgeable about TB (49)	• The composition of the screening committee is 3 persons knowledgeable about TB and from the non-medical profession (49)	• The composition of the screening committee is more than 3 persons knowledgeable about ID medicine or law, and from the non-medical or non-legal professions (24-1)
• Imprisonment or fining of physicians, government employees, screening committee members, and professionals for disclosing patient information (62)	• Ibid. (62)	• Ibid.
• <b>Fining of patients in case of false report when questioned (63)</b>	• Ibid. (63)	• Ibid. (77)
• <b>Fining of patients in case of interfering with or rejecting the measures given by the government (63)</b>	• Ibid. (63)	—
—	• Citizens' duty to obtain accurate knowledge on TB, be alert to prevention, and not to violate the human rights of TB patients (3)	• Ibid. (4)

\* The original law was enacted in 1919.

\*\* The TB Prevention Law was abolished and integrated into the Amended Infectious Disease Prevention Law. The disease classifications of HIV/AIDS and TB differ in the 2007 IDPL as do the measures.

\*\*\* Directly observed treatment, short-course.

Bold letters = Possible restrictions on the human rights of infected/vulnerable people.

cases where patients' information is disclosed, physicians, government employees, and related professionals may be sentenced to imprisonment or receive a fine (Art. 14 to 15 in 1989; 67 to 69 in 1999, 73 to 74 in 2007).

**Abolishment of testing order:** In the 1989 Law, the governor was to advise people who had been reported to be tested (Art. 8-1) and in the case of non-compliance, the governor could order the test be done (Art. 8-2). These articles were deleted in the 1999 IDPL.

**Compliance:** The 1989 Law stated two compliance rules for infected people: a ban on activities that risk infecting others (Art. 6-1), and mandatory compliance with the physicians' recommendations (Art. 6-2). The ban was abolished and patients' cooperation with the questions and investigations is requested in the 1999 and 2007 IDPL (Art. 15-2).

**Right to appeal:** People infected by or vulnerable to HIV/AIDS have had the right to appeal since the first law enacted in 1989 (Art. 13 in 1989; 65 in 1999).

**Respect for the rights of infected persons:** The 1989 Law obliges citizens not to violate the rights of infected and vulnerable populations (Art. 3). The 1999 Law was more articulate in stating citizens have a duty not to violate the rights of infectious disease patients (Art. 4).

**Quality of care:** Previous laws were silent on the point of quality of care, and the 1999 Law added the establishment of adequate care with good quality for infectious disease patients (Art. 3). This provision was carried forward to the 2007 IDPL (Art. 3).

#### Possible areas of concern

**Questioning and fines:** Since the 1989 Law, the governor has been empowered to question reported infected and vulnerable individuals or their guardians as deemed necessary (Art. 10-1). In the case of false answers, the person shall be fined (Art. 16-2). The 1999 IDPL and the 2007 Amended IDPL carry these articles (Art. 69 in 1999; 77 in 2007).

#### Government Obligations regarding Human Rights: TB related laws

##### Jurisdictional transformation

TB control initially started with the former Tuberculosis Prevention Law (TBPL; Law No. 26) in 1919. In 1951, it was fully revised (TBPL;

Law No. 96) with the aim of promoting public welfare by preventing TB through prevention and the dissemination of proper care (Art. 1). After the amendment in 2006, the TBPL was abolished and integrated into the IDPL in April 2007 (Fig. 1). Hence, the objectives of the law changed accordingly (Table 2).

#### Positive aspects

##### Human rights protection

The 1951 Law and its 2006 revision obliged the state to consider the protection of human rights of patients (Art. 2-1, 3-2). The term respect appears clearly in the 2007 IDPL (Art. 2).

**Abolishment of mandatory isolation:** A physician and a governor had the authority to order isolation of patients (Art. 26, 30) under the 1951 TBPL. This provision was omitted in the Amended TBPL in 2006. A governor can advise hospitalization (Art. 19, 26-2) according to the 2007 IDPL. Instruction for directly observed therapy, short-course (DOTS) was also included from the 2006 Law (Art. 25 in 2006; 53-14 in 2007).

**Abolishment of ban on employment:** A governor could ban the employment of patients (Art. 28-1) in the previous laws. This adverse disposition was changed to a limitation, while the target was expanded to asymptomatic pathogen carriers in the 2007 IDPL (Art. 18-1).

**Right to appeal:** Prior to 2007, the right of appeal and of fair trial for vulnerable populations was not explicitly mandated. This occurred only when TB control was integrated into the IDPL (Art. 65).

**Shortened hospital stay:** Each of the earlier laws suggested a 6-month period of hospitalization (Art. 34). The 2007 IDPL states that hospitalization should be reconsidered every 30 days when advised hospitalization occurs (Art. 20-2, 26-2).

**Respect for the rights of infected persons:** The 2006 TBPL obliged citizens not to violate patients' human rights (Art. 3) as does the 2007 IDPL (Art. 4).

**Independent review:** The 2007 IDPL mandated law specialists, medical and non-medical professionals to be members of a screening committee (Art. 24-1), which reviews the governor's advice and any extension of hospitalization.

#### Possible areas of concern

**Mandatory name reporting:** As TB is an infectious disease, in human rights terms, some restrictions on rights may be permissible. Previously,

physicians were obliged to report the names and addresses of patients to the nearest health center (Art. 22). In the 2007 IDPL, TB is classified as a Category-2 disease, equivalent to SARS (Art. 53-7). Occupation or place of work of the patient has been added to the information (age, sex, and name) required for the surveillance report.

**Questioning and fines:** Questioning of infected populations has been lawfully allowed since the 1951 TBPL (Art. 32-1) through to the current 2007 IDPL (Art. 35-1). In the 2007 Law, assumed asymptomatic pathogen carriers may also be questioned. In case of false answers, fining of those questioned remains permissible (Art. 63 in 1951 and 2006; 77 in 2007).

**Note:** It is too early to fully judge the impact of the changes noted above with respect to the 2007 Amended IDPL, but these are areas that will require attention as they are implemented going forward.

## Discussion

### A Human Rights Perspective on HIV/AIDS and TB Related Laws

#### Achievements

Both HIV/AIDS and TB related laws have progressively moved towards protecting human rights in how they are drafted over the past decades, especially through the recent establishment and amendment of the IDPL. The preamble to the IDPL (1999), a comprehensive law for infectious disease control, recognizes the prejudice and discrimination against leprosy patients and PLWHA that occurred in the past and promotes learning from these lessons. The term respect was inserted into the wording of the law when amended in 2007. This is a significant advancement in infectious disease law. The Guideline for AIDS Prevention (2006) also added respect for the human rights of infected and vulnerable populations.<sup>36</sup> Similarly, the Guideline for TB Prevention sets up a comprehensive measure to respect the human rights of patients in September 2007.<sup>37</sup> We note two issues that might have influenced such development in Japan.

#### 1. Attention to international norms and standards

The inclusion of human rights language occurred in the 1990s during a period where Japan was participating in international conferences on a

range of health and development related issues, which included the promotion and protection of human rights as fundamental to the achievement of public health goals—most notably the 1993 International Conference on Population and Development and the 2001 UN General Assembly Special Session on AIDS. Additionally, Japan participated in the UN Decade for Human Rights Education (1995–2004)<sup>38</sup> that among other movements, resulted in the establishment of the Human Rights Education and Edification Policy (2004), which aims to reduce social prejudice and discrimination against certain groups including infectious disease patients.<sup>39</sup> Likewise, on the medical side, the Japan Medical Association released Guideline for Professional Ethics of Physicians (2004) that suggest prioritizing the rights and privacy of patients.<sup>40</sup>

#### 2. Growing civil society efforts to advocate for the rights of infected and vulnerable populations

A human rights perspective suggests that the views of affected communities, including non-governmental organizations (NGOs), be taken into account in the development of all aspects of health policy and programming. Over the past decade, NGOs have increasingly come into existence advocating for the rights of PLWHA within Japan.<sup>41,42</sup> This, and other efforts from a growing civil society, may have helped to raise awareness among citizens, health professionals, and policy makers resulting in positive changes in law and practice.<sup>36</sup>

#### Challenges and suggestions

While infectious disease law has greatly advanced in the past years, three areas require attention in future efforts.

##### 1. Participation of infected populations

Participation of infected, vulnerable and affected communities in public health decisions that concern them has been recognized as key from a human rights perspective but also in order to successfully achieve public health goals. Yet, it appears that inclusion of affected communities in legal and policy efforts in the HIV and TB arena has been minimal.

The UN proposes availability, accessibility, acceptability and quality as indicators related to the provision of health services under the “right to

health.”<sup>34</sup> Attention to these issues as understood by affected communities may help in monitoring the impact of the new law and in determining its effectiveness, e.g. by participation of infected populations. Some issues for further attention in each category are noted below.

**Availability of health care:** HIV antibody tests are provided free of charge at 246 health centers,<sup>43</sup> and X-ray tests for TB are provided by schools for free and by medical facilities with a minimum of 95% coverage by the government (Art. 37-2 in 2007 IDPL). Further consideration to expand availability, e.g. the offer of voluntary HIV testing during weekends, might be promoted by incorporating the needs of vulnerable populations.

**Affordability (a sub-concept of accessibility):** The IDPL obliges the governments to shoulder a large part of the medical fees for diseases, including HIV/AIDS and TB. The Ministry of Health, Labour and Welfare annually allocates 8.3 billion yen (69 million US dollars) for HIV/AIDS measures.<sup>44</sup> National Health Insurance or Employees’ Health Insurance covers 30% of HIV/AIDS-related medical treatment, e.g., anti-retroviral therapy (ART) that costs about 150,000 to 200,000 yen (1,250 to 1,700 US dollars) per person per month.<sup>45</sup> Similarly, the Ministry allocates 7.1 billion yen (59 million US dollars) for TB measures including DOTS.<sup>44</sup> Attention to whether the resources allocated are sufficient to ensure that the most vulnerable populations have access to the services they need could be useful.

**Acceptability:** A recent survey showed that nearly 30% of dental clinics and psychiatric departments in Japan are uncomfortable accepting patients with HIV/AIDS.<sup>46</sup> TB patients also have long been the target of discrimination in Japan<sup>47,48</sup> as in other nations.<sup>49</sup> While these are only a few examples, it appears that discrimination in the context of HIV and TB remains rampant. As the Japanese public health administration was originally established under the police system in 1893.<sup>47,50</sup> The 2007 IDPL and related laws may still not adequately protect the rights of infected individuals.

**Quality of health care:** ART (AIDS treatment) and DOTS (TB treatment), both of which are the highest standard of care, are provided in Japan. Attention to the extent to which the quality is the same throughout the country, to all populations in need, and in all facilities could help to ensure

that the law and resources given to implement it are having their desired effect.

## 2. Protection for health professionals

Measures to support the rights and health of health professionals were little observed in the laws studied. Guidelines and preventive regimens are provided by the Ministry of Health, Labour and Welfare with an annual budget of 27 million yen (225,000 US dollars).<sup>44</sup> However, TB prevalence among nurses was 1.9 times higher, and among laboratory technicians was 1.2 times higher in hospitals with TB units than among the general public in 1992–1996.<sup>51</sup> Concrete efforts to determine why this is the case and to ensure the health and rights of health professionals may be necessary.

Additionally, approaches to ensuring the rights and health of health professionals suggests additional attention to the information and education provided to patients, as well as to their responsibilities once they are diagnosed with an infectious disease. This is an area that may require further study with due attention to the rights and health of all concerned. For example, the Center for Disease Control and Prevention in the United States gives a practical suggestion regarding patients’ responsibility, i.e. to cover mouth/nose when coughing to prevent infection.<sup>52</sup> How this is actually communicated, understood and acted upon by infected persons requires further study.

## 3. Accurate criteria for restrictions on human rights

The legal ability to restrict the freedom of movement of infected and affected people exists in the laws studied. At a national level, it is likely to be grounded in the Constitution of Japan (1947) that guarantees the liberty of individuals unless it interferes with the public welfare (Art. 13). Under human rights law, the ICESCR (1976) also gives governments the right to take the steps they consider necessary for the prevention, treatment, and control of epidemic, endemic occupational and other diseases (Art. 12-2 (c)).<sup>5</sup>

The international community considers that such limitation must be a last resort even if for the protection of public health. The United Nations Economic and Social Council suggests such limitation to be valid only when all five criteria are met: the restriction must be; (1) in accordance

with the law, (2) a legitimate objective of general interest, (3) strictly necessary in a democratic society to achieve the objective, (4) not intrusive or unnecessarily restrictive, and (5) not imposed arbitrarily. This is indicated in the so-called Siracusa Principles.<sup>53</sup>

The 2007 IDPL states that the restrictions on the rights of infected and vulnerable people should rarely occur (Art. 22-2). The Ministry of Health, Labour and Welfare has newly published specific criteria for human rights restriction of TB patients in hospitalization and discharge in 2007.<sup>54</sup> Further attention to the internationally agreed-upon criteria might be a way at the national level to validate any restrictions in laws and practice on human rights considered necessary to prevent the spread of infectious disease.

### Limitations of the study

This study analyzed only published materials. Unpublished materials on programs or services were outside the scope of this study. It has been only a few months between the enactment of the 2007 IDPL in April 2007 and the time this article was written. Further, the focus of this article is on the written law and not on its implementation. More achievements and challenges may be revealed as it permeates practice.

### Conclusion

Attention to human rights in supporting infectious disease control efforts in Japan is progressing. Yet three prime areas remain challenging. First, participation of infected and vulnerable populations in this area was found to be low. Second, attention to the interactions between the health and rights of health professionals and of their patients requires further exploration. Third, accurate criteria for the restriction of rights of infected and affected populations are

not yet apparent in the laws or in how they are to be implemented.

Consideration of international standards in these areas, such as the rights-based approach promulgated by the UN and the Siracusa Principles, might facilitate development of a well-balanced health and human rights perspective in infectious disease control. In 2006, Japan was elected to be one of 47 members of the United Nation's Human Rights Council.<sup>55</sup> As a leader in international cooperation, Japan is poised to demonstrate further accomplishments in the application of human rights concepts to its actions in public health, both in the country and abroad. This path could be an example to other nations.

**Note:** Official names of the studied laws are as in follows.

- AIDS Prevention Law: Law concerning the Prevention of Acquired Immunodeficiency Syndrome (Law No. 2; 1989)
- Infectious Disease Prevention Law: The Law concerning the Prevention of Infectious Diseases and Patients with Infectious Diseases (Law No. 114; 1999)

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