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**Public Association “Ravenstvo”  
Issyk-Kul province union of the disabled**



**OBSERVANCE OF THE RIGHTS OF PATIENTS WITH  
DISABILITIES IN ISSYK-KUL PROVINCE**

A research report conducted with the support of the Soros Foundation Kyrgyzstan and Law and Health Initiative of the Open Society Institute Public Health Program

*Once I fell from my wheelchair after a spinal trauma and broke my leg...The doctors told me cynically: “You don’t walk anyway, so why do you need plaster cast? You just lay there and it will heal itself.”*

*“Saimyk,” a 43 year old from Issyk-Kul province with a group I disability*

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### **LIST OF ABBREVIATIONS**

WHO – World Health Organization  
IRP – Individual rehabilitation program  
KSB – Kyrgyz society of the blind  
KSD – Kyrgyz society of the deaf  
KR – The Kyrgyz Republic  
TPT – Therapeutic physical training  
MH KR – Ministry of Health of the Kyrgyz Republic  
MSCE – Medical-social commission of experts  
CMSEE&RD – Center of medical-social expert examination and rehabilitation of the disabled  
MLSP – Ministry of Labor and Social Protection of the Kyrgyz Republic  
PMSCE – Province medical-social commission of experts  
PA “Ravenstvo” – Public Association “Ravenstvo”

**TABLE OF CONTENTS**

List of Abbreviations.....	3
Introduction.....	4
Summary of Findings.....	7
Summary of Conclusions.....	13
Summary of Recommendations.....	14
Methodology.....	14
Legal Analysis.....	15
The right of access.....	16
Accessibility of medical services.....	16
Non-discrimination.....	16
The right to informed consent.....	16
The right to free choice.....	17
The right to privacy and confidentiality.....	18
The right to respect for patients' time.....	18
The right to the observance of quality standards.....	19
The right to safety.....	19
The right to avoid unnecessary suffering and pain.....	19
The right to file a complaint.....	20
Legal protection for the disabled.....	21
Legal obligations to provide rehabilitation.....	23
Violations of Patients' Rights.....	24
Infringement of the reproductive rights of disabled women.....	24
Infringement of the rights of patients upon provision of medical-sanitary care.....	26
Discrimination and negative attitudes toward disabled patients.....	27
Infringement of the rights of patients upon provision of emergency care and infringement of patients' dignity.....	29
Infringement of the rights of patients for due diagnostic.....	30
Failure to provide individual rehabilitation programs for the disabled.....	31
Conclusions.....	32
Recommendations.....	33
Acknowledgements.....	35

## INTRODUCTION

### BACKGROUND

The Kyrgyz Republic is a newly independent state in Central Asia. It borders Kazakhstan, Tajikistan, Uzbekistan, China. Administratively, the country is divided into seven provinces and 41 districts; there are 20 cities in the republic. Bishkek city is the capital of the country.

According to data provided by the National Statistics Committee, the population of the Kyrgyz Republic is 5.2 million people.<sup>1</sup>

According to the data of the World Health Organization (WHO), people with disabilities comprise 10% of the world population. Information provided by the Ministry of Labor and Social Protection of the Kyrgyz Republic indicates a growing trend in the number of disabled people who are officially registered as disabled through an examination process. For instance, in 2005, it was recorded that the number of disabled people in the country had grown by 7.9% since 2003. The number of disabled people was 36,325. As of January 1, 2008, there were 110,700 citizens with disabilities in the Kyrgyz Republic, 44.6% of whom were women. The number of people with disabilities amounted to 2% of the total population of the country, 3% of the adult population. The statistic indicating that 3% of the adult population is disabled is explained by the fact that many people do not know how to draw up documents to register as disabled, or do not want to be labeled as "disabled" and therefore do not seek categorization and official examination. In fact, the real numbers of disabled people in the Kyrgyz Republic can be assumed to be a good deal higher. The fact that people disabled from childhood comprise the majority of the disabled, according to the specialized psychiatric medical-social commission of experts (MSCE), is a matter of concern. Developmental disability is the main disease that causes disability from childhood. Of those disabled since childhood, the percentage of disabled people with developmental or intellectual disabilities is 80%.<sup>2</sup>

A number of problems that disproportionately affect people with disabilities have become more acute since Kyrgyzstan declared independence from the Soviet Union; these include growing rates of poverty and unemployment, the deterioration of social support and services, the closure of specialized schools and kindergartens, and a worsening of the quality of health care services.

With regard to receiving necessary treatment, the majority of respondents interviewed for this research reported that after the disintegration of the USSR everything is supposed to be paid for, it is impossible to go to centers for treatment, it is impossible to have a course of rehabilitation therapy in a good sanitarium. The number of sanitarium-and-spa treatment permits that the disabled are authorized for are not sufficient. Thus, the disabled from group I are authorized to get a sanitarium-and-spa treatment permit once every 5 years, while the disabled of group II can access this once every 3 years with a 50% discount.

In 1991, the law on social protection of the disabled in the Kyrgyz Republic was adopted,<sup>3</sup> stipulating the fundamental rights of the disabled. In addition to this law, the

<sup>1</sup> As of May 1, 2005.

<sup>2</sup> National Program of State Support for the Disabled, June 29, 1999.

<sup>3</sup> Adopted by Jogorku Kenesh (Parliament) on April 17, 1991. The law was subsequently amended.

national program of state support for the disabled, approved by the President of the Kyrgyz Republic in 1999, is one of the most important documents defining state policy toward the disabled. This program emphasizes social equality and the equal rights of people with disabilities, addresses problems related to social rehabilitation, creates conditions necessary for integration of disabled people into society and for regulation of existing social support for the disabled, taking into account market conditions and international standards.<sup>4</sup>

Based on experience gained during the course of the UN Decade of Disabled Persons (1983 – 1992), a set of standard rules were developed to provide equal opportunities for the disabled. International human rights standards, including that the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural rights, and the International Covenant on Civil and Political Rights, as well as the Convention on the Rights of the Child, Convention on the Elimination of all forms of Discrimination against Women, and the World Programme of Action concerning Disabled Persons create the moral and political basis for rules regarding the rights of the disabled.

In addition, a series of laws were adopted by the Kyrgyz Republic to protect the rights of the disabled. These include: the national program of state support for the disabled<sup>5</sup>; the Labor Code of the Kyrgyz Republic;<sup>6</sup> the Family Code of the Kyrgyz Republic;<sup>7</sup> and the law of the Kyrgyz Republic "On social protection of the disabled in the Kyrgyz Republic."<sup>8</sup> Other laws relevant to people with disabilities include: construction norms and rules of the Kyrgyz Republic;<sup>9</sup> the state program of integration and rehabilitation of the disabled for 2004-2007 and action plan for the implementation of the state program of integration and rehabilitation of the disabled for 2004-2007;<sup>10</sup> a complex of state support measures for the disabled for 2006-2010;<sup>11</sup> and the law of the Kyrgyz Republic "On the rights and guarantees of persons with disabilities."<sup>12</sup> These legal instruments provide measures for medical, social, pedagogical and labor rehabilitation of the disabled, facilitating their integration into a full life.

Despite the above-mentioned domestic laws, the disabled routinely experience discrimination. The majority of the disabled have difficulty surviving, due to their low income. The average monthly pension for disabled people in groups I and II<sup>13</sup> is between 600-1000 som, while the cost of living is estimated at 800 som per month.

In the state program on guaranteed provision of medical care to citizens of the Kyrgyz Republic for 2006<sup>14</sup> the government improved the accessibility of health care services for the most vulnerable categories of the population and addressed issues related to the

<sup>4</sup> National program of state support for the disabled (approved by Decree of the President of the Kyrgyz Republic on June 29, 1999, #157).

<sup>5</sup> Approved by Decree of the President of the Kyrgyz Republic on June 29, 1999 #157.

<sup>6</sup> This set of laws contains "Features of labor regulation for the working disabled" in chapter 25, section VIII. Adopted on August 4, 2004.

<sup>7</sup> See iterations of this law adopted in July 26, 2004 #96, February 25, 2005 #38, and June 20, 2005 #80.

<sup>8</sup> Adopted on April 17, 1991 #421-XII. This law was succeeded by the Law of the Kyrgyz Republic "On the rights and guarantees of persons with disabilities" adopted on April 3, 2008 #38.

<sup>9</sup> This went into effect in 2001. The law was adopted and put into effect by order of the State Committee under the government of the Kyrgyz Republic on Architecture and Construction on April 16, 2001, #62. These regulations take into account needs of people with impaired mobility.

<sup>10</sup> Approved by order of the government of the Kyrgyz Republic on August 9, 2004, #583.

<sup>11</sup> Approved by order of the government of the Kyrgyz Republic on May 31 2006, #395.

<sup>12</sup> Adopted on April 3, 2008.

<sup>13</sup> Groups of physical disability indicate a person's degree of disability with rankings from I up to III. Group I indicates the most severe form of disability. People included in this category might be bedridden or in need of round-the-clock assistance. Group II disability indicates that a person can take care of him or herself, but is disabled and cannot work. There are, however, many cases when people with group I and II disabilities are able to work when special conditions are created or they are able to compensate for their limitations. The group III category of disability is applied to people with the least loss of function and who are considered to be able-bodied.

<sup>14</sup> Adopted on January 30, 2006. This law was amended by the order of the government of the Kyrgyz Republic on August 24, 2007, #363. An order of the Ministry of Health regarding co-payments was made based on this document and adopted on December 6, 2007, #431B.

exemption of these categories of people from responsibility for co-payment for health services. The types of health care services provided for free on an out-patient basis were widened considerably for the disabled in groups I and II. The only limitation placed on these services is that they are conditioned on the relevance of the treatment and whether it is approved by the Ministry of Health as a clinical protocol and has been introduced into clinical practice. People with disabilities are entitled to have two planned procedures involving hospitalization each year and to receive free health care services. People with disabilities are also provided certain privileges regarding the provision of medicine.

Issyk-Kul province has the largest number of people with disabilities in the Kyrgyz Republic; 44.2 disabled for 10 thousand of the population. <sup>15</sup> .			
Information on the number of persons who passed examination by the MSCE <sup>16</sup> :			
<b>Karakol</b>		<b>Issyk-Kul province</b>	
2006 (for the first time)	First half of 2007	2006 (for the first time)	First half of 2007
56	25	151	848
Information on the number of persons who passed re-examination in 2006:			
Karakol		Issyk-Kul province	
391		21035	

The town of Karakol is the administrative center of Issyk-Kul province. It has 5,000 disabled residents for every 70,000 in the general population. There are problems related to rehabilitation and adaptation of the disabled but often resolution of these problems is just declared. Despite measures taken in Kyrgyzstan to improve the living conditions, health care services, quality of education, labor and vocational training for people with disabilities, the broader social, economic, psychological, pedagogical and medical problems remain unresolved.

This survey investigated issues affecting people with disabilities, including obstacles the disabled face when seeking and receiving medical rehabilitation services, and discrimination against people with disabilities on the part of health care personnel, including ambulance and MSCE personnel. These issues define the quality of health care that people with disabilities receive and the capacity of the disabled in Kyrgyzstan in future.

Violations that are taking place include discrimination against,<sup>17</sup> rudeness toward, and mistreatment of the disabled on the part of health care personnel. Health care workers are failing to provide the disabled with the necessary supportive treatment. There are also cases of forced sterilization and infringement of the reproductive rights of disabled women. There is also a lack of accessible infrastructure adjusted to the needs of the disabled.

These failings and violations lead to deep depression among people with disabilities,

<sup>15</sup> According to the Center of Medical-Social Expert Examination and Rehabilitation of the Disabled.

<sup>16</sup> According to the Issyk-Kul province medical-social commission of experts. As part of the examination by the commission, one's state of health and supporting documents related to one's ability to work are checked. Through this process, a person is categorized as belonging to group I, II or III of the disabled. One's status is then periodically reviewed (every year for a period of 7 years). The commission is comprised of doctors with a variety of specialties.

<sup>17</sup> The Law of the Kyrgyz Republic "On the rights and guarantees for the people with disabilities" as of April 3 2008.

mistrust of doctors, and, as a consequence, avoidance of medical treatment. This in turn leads to various health complications, even early death and aggravation of existing health problems. People with disabilities have a sense of being useless to society and see medical treatment as pointless. People's self-confidence disappears and they develop inferiority complexes. This results in disabled people's isolation from society, which can be a contributing factor in alcoholism and suicide.

## THE NOTION OF REHABILITATION OF THE DISABLED

Rehabilitation for people with disabilities is a system of medical, psychological, pedagogical, social and economic measures aimed at eliminating, or as far as possible compensating for, people's functional limitations caused by health problems. The objective of rehabilitation is to restore a person's social status and to help him or her achieve financial independence, as well as adaptation to society.<sup>18</sup>

The individual rehabilitation program (IRP) is a detailed and thorough map or plan that is developed based on the decision of the medical-social commission of experts (MSCE) upon the official recognition of a person as disabled. The IRP includes measures aimed at the rehabilitation of personal capabilities to every day, social, and professional activity in accordance with a person's needs, interests, and claims, as well as consideration for his or her expected health condition. The IRP encompasses all elements of rehabilitation, including the type and form of recommended measures, the scope and duration of such measures, those who are responsible for implementation of the measures, and the expected results.<sup>19</sup>

The problem of violation of the rights of people with disabilities has been raised, but it has been poorly studied and there is little reliable data available – there are few reliable and well-founded examples or facts available. Taking this into account, this research project was initiated to study the existing state of affairs.

## SUMMARY OF FINDINGS

The performance of the individual rehabilitation program, or features of its performance, was reviewed during this study, along with relations between people with disabilities and medical personnel, procedures for receiving IRP in the regions, and problems related to rehabilitation of the disabled in Bishkek and other regions.

Currently, people with disabilities receive rehabilitation services that are insufficient and fail to meet the program's requirements. Although the Law of the Kyrgyz Republic on social protection of the disabled<sup>20</sup> and the national program of state support for the disabled<sup>21</sup> stipulate that every disabled person is authorized for IRP, this provision is not being fully implemented and remains declarative only.

<sup>18</sup> The Law of the Kyrgyz Republic "On the social protection in the Kyrgyz Republic", adopted in 1991, the Law of the Kyrgyz Republic "On the rights and guarantees for the people with disabilities" as of April 3 2008.

<sup>19</sup> the Law "On social protection in the Kyrgyz Republic," adopted in 1991; and the Law "On rights and guarantees for persons with disabilities," adopted on April 3, 2008.

<sup>20</sup> Adopted on April 17, 1991 #421-XII. This law expired after the adoption of the Law of the Kyrgyz Republic "On rights and guarantees for persons with disabilities," adopted on April 3, 2008 #38.

<sup>21</sup> National program of state support for the disabled, decree of the President of the Kyrgyz Republic, June 29, 1999 #157.

Failure to implement the IRP has several causes, including a lack of funding for the rehabilitation program, a lack of qualified rehabilitation therapists, location of rehabilitation centers without consideration for the physical capabilities of the patients and their places of residence (and specifically the location of centers on upper floors of buildings without elevators, and absence of rehabilitation centers in areas outside the capital), disabled people's lack of awareness about their rights regarding rehabilitation, and health care workers' indifference toward the rehabilitation process.

This study answered the most commonly asked questions about the process of developing individual rehabilitation programs, the structure of the IRP map,<sup>22</sup> and about what might be included in this map. This matter is important, since the scope of future rehabilitation services for a person with disabilities depends on a thoroughly filled out IRP map. Without registering for and receiving an IRP card, a disabled person cannot receive any rehabilitation services, rehabilitation equipment, or free sanitarium treatment from the state. Also without drawing up an IRP plan, a disabled person cannot be registered as unemployed and, therefore, cannot take advantage of services such as vocational training or collect unemployment benefits. The modern structure of IRP includes rehabilitation actions, services, and equipment necessary to eliminate the causes and symptoms that contribute to disability.

### **ACCESS AND RECEPTION OF QUALITY HEALTH CARE SERVICES**

Our survey conducted among 24 staff members of government agencies showed that 80% of them prefer to think that the state takes care of the disabled, who receive various benefits. There is a program of integration and rehabilitation of the disabled for 2004-2007 that was developed in 1999. In addition, domestic legislation provides for a doctor specializing in rehabilitation to be on staff and take responsibility for directing patients referred to him or her to rehabilitation services and providing patients with relevant recommendations.

Specialists from the province medical-social commission of experts confirm that a part-time doctor dealing with rehabilitation is on the staff of the PMSCE, however, they note that this position is filled by a specialist without special training and, therefore, without the relevant qualifications. This is a result of legislation that provides for a rehabilitation therapist to be put on staff. In reality, these specialists do not have the relevant qualifications in the field of rehabilitation of the disabled and, moreover, the current system of medical education in Kyrgyzstan does not train specialists on work therapy and physical therapy, although these approaches are successfully implemented elsewhere in the world. It is also necessary to note that one part-time rehabilitation therapist is absolutely not enough to provide full implementation of the rehabilitation program. Because they have insufficient time to fulfill all of their duties, rehabilitation therapists prescribe the recommendations on work activity only for people categorized as having group III disabilities. According to the Issyk-Kul PMSCE chairman, the center for rehabilitation and expert examination does not

<sup>22</sup> Registration of one's individual rehabilitation program (IRP) should occur automatically at one's first or second examination of disability conducted at an institution providing medical-social expertise. If one's designated group of disability is registered as permanent, then one must apply in writing to the MSCE for formulation of one's IRP. The process of registering one's IRP involves a comprehensive examination of one's health, social status, and potential for rehabilitation. On the basis of the expert diagnosis reached and the prognosis for the benefits to be gained through use of rehabilitation equipment and services, the IRP outlines the person's ability to restore lost functions or compensate for lost abilities to perform household, public, and professional activities. To fill out the part of IRP related to medical rehabilitation, a person is sent for medical examination at a local polyclinic or, if necessary, treatment in a hospital. A person with a disability or his or her lawful representative (such as a parent or guardian) has the right to participate in the development of his or her IRP. A completed IRP card should be signed by the head of the institution providing medical-social expertise and the person with a disability (or his or her representative), stamped by the institution, and given to the disabled person.

issue an IRP map for disabled people from groups I and II. This practice is in contradiction to the law and the state program on IRP.

Public servants also note that the formation of individual rehabilitation programs for the disabled are made when the disabled personally apply for IRP, whereas the majority of people with disabilities are not aware of the requirement to apply for IRP. People with disabilities do not have full information on IRP due to their lack of access to this information (often physical access to places where they would get such information is blocked, due to the lack of elevators and ramps).

In addition, there are contributing factors that were inherited from Soviet times, when the absence of public associations for the disabled resulted in a lack of institutional protection for the rights of the disabled and failure to represent the interests of the disabled at the state level and in society. For instance, organizations such as the Kyrgyz Society of the Blind (KSB) and Kyrgyz Society for the Deaf (KSD), which have existed for more than 70 years, provided for their members to enjoy better living conditions (such as the availability of special benefits for these categories of disabled people and their family members) and to be better able to protect their interests in terms of social activity than did people with physical disabilities related to motor activity or those disabled since childhood. The law tasks the staff of the MSCE with responsibility to inform people with disabilities about IRP during their primary examination. However, as mentioned above, the lack of qualifications among the rehabilitation therapists means they do not fully provide the disabled with all types of rehabilitation.

The staff of the MSCE in Issyk-Kul province have made reference to an alleged letter they say was received by the Center of Medical-Social Rehabilitation of the Disabled that contains a directive to make IRP available only to disabled people categorized as belonging to group III. Depending on the degree of functional limitation that the MSCE finds a person to have, a disabled person is able to undertake work under certain conditions, including an easing of the requirements regarding qualifications or provision of a decreased scope of work. People belonging to group II of the disabled who voluntarily insist on working are excluded. This fact indicates that the legislation is being violated by the MSCE. The letter contradicts domestic legislation and this fact should be reported as a case of violation. According to the legislation, "the individual rehabilitation program for the disabled is a complex of optimal rehabilitation measures, including certain types, forms, complexes, durations and procedures for the implementation of medical, professional and other rehabilitation measures and types of social aid aimed at the restoration of or compensation for disordered or lost functions and abilities of the disabled to perform certain types of activity."<sup>23</sup>

In accordance with the law, the individual rehabilitation program for the disabled should be implemented by the relevant public authority, local public administration, and local self-governance bodies, as well as by enterprises, organizations, and institutions, regardless of their ownership structure and type of economic activity.<sup>24</sup>

The lack of knowledge of the relevant legislative instruments demonstrated by MSCE staff responsible for carrying out the law speaks to their incompetence in the legal sphere.

<sup>23</sup> Article 18 of the Law of the Kyrgyz Republic "On social protection of the disabled."

<sup>24</sup> Article 19 of the Law of the Kyrgyz Republic "On social protection of the disabled."

The action plan on the implementation of the state program for the integration and rehabilitation of the disabled for 2004-2007<sup>25</sup> provides for the adoption of measures by state ministries, state committees, administrative agencies, local public administration and local self-governance bodies to implement the program. Information regarding the implementation of such measures should be provided to the Ministry of Labor and Social Protection of the Kyrgyz Republic on a quarterly basis. Implementation of the program is then discussed annually at a session of the Council on the Disabled under the President of the Kyrgyz Republic.

### **FAILURE TO PROVIDE ACCESS TO REHABILITATION AND OTHER VIOLATIONS OF DISABLED PATIENTS' RIGHTS**

Analysis of the available data has shown that many provisions of the action plan and state program for integration and rehabilitation of the disabled have not been implemented at either the national or local level.

According to government representatives interviewed for this report, the main problems hindering government effectiveness in addressing the problems of the disabled are insufficient funding provided for the relevant programs, a lack of medicine, inaccessibility of buildings and health care facilities, passivity on the part of the disabled, and a lack of information about IRP among the disabled.

There is an acute problem of inaccessibility of health care facilities, government premises, residential buildings, industrial buildings, and social and cultural venues to people with disabilities. The special requirements of the disabled are not considered, while the government agencies and structures responsible for providing for the disabled shut their eyes to the problem.

The most acute problems are: limited access for disabled people in wheelchairs; difficulties accessing the Bishkek city center from other regions; and the lack of opportunity for disabled people to choose from among the rehabilitation centers for the disabled. The rehabilitation center for the disabled with restricted mobility is open only in Bishkek and is designed to accommodate only 50 people. Unfortunately, people with disabilities are not able to receive complex treatment and rehabilitation there, since only medical rehabilitation is provided; this, in turn, is not fully implemented due to a shortage of medicine and technical rehabilitation resources. Disabled people who use wheelchairs cannot receive treatment at the Bishkek center due to the lack of infrastructure enabling their access, as well as the inaccessibility of the premises where the disabled might stay. There are no rehabilitation centers at all in the regions outside Bishkek.

The spaces allotted for rehabilitation are not accessible to the disabled. For instance, the rehabilitation room located at the family medical center in Karakol city is located on the third floor of a building without an elevator. One can only guess how disabled people in wheelchairs or on crutches can get to the room to receive their prescribed daily treatment.

The lack of necessary special equipment for examination of disabled patients by specialists—gynecologists, proctologists, obstetricians, dentists and others—is a

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<sup>25</sup> Approved by order of the government of the Kyrgyz Republic on August 9, 2004 #583.

problem that makes it practically impossible for these patients to access the services of such specialists.

Research found that the quality of relations between patients with disabilities and medical staff is also a huge problem. Indifferent, condescending treatment by medical personnel was reported by the majority of the respondents to our survey; specialists view disabled patients as social outcasts, show them disdain, try not to notice them, may be rude during communications with such patients, demonstrate an aversion to their patients, exhibit a shortness of temper, and mistreat their patients who are disabled. That said, all of the respondents with disabilities reported that medical personnel's attitude could be changed; it always just depends on whether the disabled patient is rich or poor.

At one round table held in 2007, the words of the head of a rehabilitation room demonstrated the real state of affairs: "What do you want from us? There are many of you, and few of us."<sup>26</sup>

Officials' responses to the issues point to external circumstances and do not acknowledge their personal responsibility; they demonstrate indifference to the problems and the position of disabled people.

The existence of relevant legislation does not mean that good rehabilitation is available. The problem comes down to the quality of implementation of the legislation, including the availability of secondary legislation providing for the mechanisms of IRP implementation and taking into account the necessary allocation of funds both from the state and local budgets.

According to the director of the Center of Medical-Social Expert Examination and Rehabilitation of the Disabled, Kimbat Abazbekova, "None of the health care facilities is accessible to the disabled in wheelchairs. Conditions in the hospitals do not meet the requirements of full scale rehabilitation for people with disabilities."<sup>27</sup>

Speaking about regional services for the disabled, the respondents, including people with disabilities, reported that the fact that such facilities are located in the capital defines the provision of care and accessibility of health care institutions. They said that the disabled in Bishkek have better opportunities to receive rehabilitation, and have more information about their rights compared with disabled people living in other regions. In the provinces, for instance in Issyk-Kul province and in particular in the town of Karakol, it is possible to receive at least some rehabilitation services (massage, physical therapy training, sanitarium-and-spa treatment). This is out of the question in more rural areas.

Certain interaction is reported between the ministries and agencies working on the issues of the disabled, however, a shortage of financial resources impedes their effective response and ability to address the existing problems.

The state program for the integration and rehabilitation of the disabled for 2004-2007 was adopted by the government, including the Ministry of Transport and Communications. The ministry directly participated in the process of development and approval of this document.

<sup>26</sup> Karakol, August 28, 2007.

<sup>27</sup> "Ravenstvo" interview with Kimbat Talgarbekovna Abazbekova, Bishkek, June 26, 2007.

It is reported in the letter of the Ministry of Transport and Communications dated June 11, 2007—a letter researchers familiarized themselves with—that: “...regarding paragraph 67 of the state program for the integration and rehabilitation of the disabled for 2004-2007, approved by the Order of the Government of the Kyrgyz Republic #583, as of 09.08.2004, concerning the matter of providing the disabled with specialized route taxi vehicles equipped with special facilities for free access, the Ministry is neither able to perform renewal of its pool of vehicles, nor purchase vehicles adjusted for the transportation of the disabled in wheelchairs, due to financial problems under the current market conditions.”

The matter of corruption in society also affects the disabled, so researchers asked questions within the frame of this survey about bribes. When the disabled try to access state benefits, they face red tape that creates the conditions that facilitate extortion or imply the need for remuneration. The process of examination of the disabled is a bureaucratic process; disabled people undergoing examination are required to obtain a large number of references, a circumstance that forces the disabled to give bribes in order to be examined quickly.

When asked about bribe taking during the process of assignment of disability categories, health care personnel gave various answers: from flat denials to the answer, “I cannot 100% guarantee there are no cases of bribery.” Doctors from the commission of experts said they think that bribery may be practiced in the institutions that revise the diagnosis upward, assigning people to a group for people with aggravated disability. Each MSCE office has written rules describing the prohibitions on giving and receiving bribes and indicating where to complain in the case of extortion. Despite such official guarantees, visitors offer remuneration voluntarily in order to avoid obstacles and problems.

During the course of our research, people with disabilities recalled the humiliating treatment that they received during examination. In an effort to improve relations with the medical professionals who conduct the examination, some people with disabilities resort to bringing bribes or “gifts.”

“I am disabled with a group I disability (the disabled in this group are recorded with the MSCE as ‘incapable’ and they do not have the right to work). I have a young son, that is why I had to transfer to the second group of disability to be able to work, but then, due to aggravation of my health condition I decided to return to the group of disability that was assigned to me initially. I spent the whole day there waiting in line to be re-examined, although I showed up early. Eventually, the MSCE chairman, having called me in, humiliated me with his questions and attitude, which caused me to go into a deep depression that took me a very long time to recover from.”<sup>28</sup>

*Guljan (a pseudonym), an interviewee with a group I disability, Issyk-Kul province*

Extortion is not taking place openly, but the answers disabled people gave to interview questions demonstrate that they suffer indignity and humiliation and that this forces the disabled to bring gifts in order to just receive assignment in the proper category of disability.

<sup>28</sup> “Ravenstvo” interview with Guljan (a pseudonym), an interviewee with a group I disability, Issyk-Kul province, June 20, 2007.

"I am disabled since childhood. I had a group II disability before 1989. After an operation I couldn't go to be re-examined for a long time, so they assigned me to group III of disability. Then my condition became aggravated and I went for re-examination, where I received categorization as having a group II disability. During this process, I was humiliated to such an extent that I suffered from an upset stomach because of nervous exhaustion."<sup>29</sup>

*Sairagul (a pseudonym), an interviewee with a group II disability, Issyk-Kul province*

Contradictory answers were received for the question "What, in your opinion, hinders the implementation of IRP and what should be done to make IRP an effective program?" Senior officials state with confidence that IRP works very well in the republic. There was less optimism regarding this matter from employees in regions outside of Bishkek. They state that there is currently no rehabilitation program.

The lack of necessary state support, regional rehabilitation centers, qualified personnel, and funding for rehabilitation worsen the living conditions of the disabled.

During a round table discussion, the chairman of the Issyk-Kul province MSCE, Genadiy Asakovich Kalychbaev, in answer to the question "What needs to be done to make IRP work and what are your recommendations?" said, "Let it be a headache for those who receive money for that."<sup>30</sup> The law entrusts this task to the province MSCE.

Research for this report also found that the requirement that people with group III disabilities pay a co-payment for rehabilitation treatment is burdensome, since the disabled do not have sufficient financial means. People with group III disabilities are considered a working group, so they receive a very small pension, although they are unemployed in the majority of cases. As a result, many people who needed treatment had to go without it.

Based on analysis and processing of the survey data, the interviewers have come to the conclusion that, in practice, receiving drug therapy in the local hospitals is understood by many as IRP, while the actual IRP program remains unfulfilled. Many people responsible for the program do not have a clue that IRP exists.

## SUMMARY OF CONCLUSIONS

The law on social protection of the disabled in the Kyrgyz Republic and the national program of state support for the disabled stipulate that every person with a disability is authorized to receive IRP, but IRP is not being implemented fully and so this remains a declarative right only.

This situation is caused by a lack of funding for the rehabilitation program, a lack of qualified rehabilitation therapists, the inconvenient location of rehabilitation centers or absence of required equipment in some health care institutions, a lack of easy access to rehabilitation rooms (no elevators, mechanical devices, or ramps), the absence of rehabilitation centers in regions outside Bishkek, the indifferent attitude of health care personnel regarding the rehabilitation of disabled people, and disabled people's lack of awareness about their rights in matters of rehabilitation.

<sup>29</sup> "Ravenstvo" interview with Sairagul (a pseudonym), an interviewee with a group II disability, Issyk-Kul province, June 23, 2007.

<sup>30</sup> The participants of the round table along with the correspondent of "Vesti Issyk-Kulya" (Issyk-Kul news) witnessed this.

The development and implementation of individual rehabilitation programs were and are one of the most important issues for people with disabilities. IRP should give a person with a disability a sense of self-confidence, provide independence, establish a purpose in life, and help him or her to be better integrated into society and to overcome certain aspects of his or her disability.

Timely rehabilitation, adaptation, and the assistance of professional psychologists can considerably improve the position of the disabled. A person quickly becomes withdrawn upon becoming disabled and being left without the necessary help. Formation of psychological complexes, self-isolation from the outside world, depression, aggravation of one's health condition, alcoholism, early death, and suicide are reported in these kinds of situations. Eventually, the disability impacts a person's personality, psychological peculiarities, life, and spiritual development.

Our study has shown that senior officials confirm that no health care institution has made adjustments to accommodate the disabled in wheelchairs. Under current conditions, hospitals cannot provide full-fledged rehabilitation for people with disabilities. The approved guarantees are not being implemented, or are being violated.

### **PROVISION OF QUALITY HEALTH CARE SERVICES**

With regard to receiving relevant treatment, the majority of the respondents to our survey reported that after the disintegration of the USSR all services require payment; it is impossible to go to centers for treatment, it is impossible to undergo a course of rehabilitation therapy in good sanitariums. Disabled people are not authorized to receive a sufficient number of sanitarium-and-spa treatment permits. Thus, the disabled belonging to group I are authorized to receive a sanitarium-and-spa treatment permit once every 5 years, while the disabled in group II receive such a permit once every 3 years, with a 50% discount.

Many participants in our survey reported an indifferent, condescending attitude on the part of health care personnel. Some respondents emphasized that they are looked at as if they are social outcasts; they are disdained and ignored.

Interviews were conducted with the disabled of various social groups, with disabilities from birth and acquired disabilities. As noted above, 62.5% of the respondents had acquired disability, while 37.5% had a disability from birth. Fifty percent of the respondents said they think that they were diagnosed correctly, 25% were sure that they had been diagnosed incorrectly, which had caused serious complications, and 25% replied that they did not know and had difficulty answering the question. For the question regarding the form in which medical staff informed them about their disability, participants gave the following answers: "Tactfully," said 12.5 % of respondents; "Roughly," said 6.2 %; "Straight," said 24%; "Indirectly," said 48.1%; "Tactlessly," said 6.2%; and "They wrote it down and I read it myself," said 3 %.

### **ACCESS TO INFORMATION**

Ninety four percent of the respondents answered that they did not know about and had not heard about the existence of the individual rehabilitation program for

the disabled. Six percent answered that they had a rough idea of what it was, but did not know exactly. This fact indicates that the government is not taking the necessary measures to inform potential recipients about the service. As a result, IRP actually exists only on paper, even though, according to the order of the government of the Kyrgyz Republic #583, each province department of the Ministry of Labor and Social Protection of the Kyrgyz Republic should have rehabilitation centers that provide consultation and methodological coordination. These centers undertake implementation of the recommendations on the individual rehabilitation program for the disabled.

## **SUMMARY OF RECOMMENDATIONS**

What is needed is effective state policy toward the disabled that would emphasize the system of social benefits and enable integration of the disabled into society, with the objective of maintaining social connections and fostering perception of a disabled person as an individual, citizen, and member of society.

It is necessary to develop rehabilitation for the disabled as a system of measures aimed not only at addressing the impact of the above factors on the disabled, but also at creating opportunities for the disabled to achieve social integration and adaptation to social life.

## **METHODOLOGY**

Researchers prepared questionnaires to conduct surveys with people with disabilities, health care personnel, including doctors, Ministry of Health officials, Ministry of Labor and Social Protection officials, representatives of the MSCE, and parents of disabled children. Official statistics were used as part of the research for this report. The members of "Ravenstvo" conducted the survey and other research for this report.

Seventy individual interviews were conducted during the period from July to August 2007 in Bishkek and Karakol: 50 persons with disabilities were interviewed in the town of Karakol, 5 staff members of the department of social protection (DSP) were interviewed in Karakol, 14 health care workers were interviewed in Karakol, 3 representatives of the PMSCE were interviewed in Karakol, and 2 staff members of CMSEE&RD were interviewed in Bishkek.

A round table was conducted with the purpose of developing recommendations for improving access to IRP, with the participation of government representatives and municipal representatives directly involved with the implementation of IRP.

The survey conducted dealt with the matters of health protection, namely with the issue of the attitude of medical personnel toward disabled patients, the provision of timely and quality health care services, the reproductive rights of disabled women, rehabilitation, and disabled people's access to social infrastructure. We conducted analysis of the existing domestic legislation in this context, as well as other normative and legal acts calling for the protection and provision of the rights of people with disabilities.

### *Characteristics of the respondents*

There were a total of 70 people surveyed for this report. Forty-two of them were men (57% of the total) and 28 were women (43% of the total).

Government representatives interviewed for the report included: 4 people from the Ministry of

Labor and Social Development (5% of the total), 16 people from the Ministry of Health (21% of the total), 2 people from the province medical-social commission of experts (3% of the total), and 2 people from the center for medical-social expertise and rehabilitation of the disabled (CMSEE&RD) (3% of the total).

All of the respondents were guaranteed anonymity, excepting responsible officials.

During the course of research, "Ravenstvo" applied the following research methodologies: semi-structured discussions, individual interviews, interviews with key informants, group interviews, and targeted group discussions (focus-groups).

## **LEGAL ANALYSIS**

The rights of patients in the Kyrgyz Republic are protected by constitutional guarantees providing equal rights for all citizens and specific legislation on health care, including the law "On protection of the health of citizens of the Kyrgyz Republic." Violation of domestic legislation protecting patients' rights is punishable under the law. In addition, the government has agreed to provide to Kyrgyz citizens the rights enshrined in core UN human rights documents, such as the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

The most comprehensive articulation of patients' rights is provided in the European Charter of Patients' Rights. While the Charter is not legally binding on the government of the Kyrgyz Republic, as domestic legislation and UN obligations are, it does represent the regional standard for patients' rights to which countries should aspire and it therefore provides a useful framework for analyzing the performance of state healthcare systems in meeting the needs and rights of the citizenry.

The Committee on Economic, Social and Cultural Rights' General Comment to article 12 of the ICESCR elaborates on the right to the highest attainable standard of health.<sup>31</sup> The General Comment establishes the international standard for important patients' rights issues such as consent to treatment, confidentiality of health information, and non-discrimination.

### **THE RIGHT OF ACCESS**

*Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services.*<sup>32</sup>

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<sup>31</sup> Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights. General Comment No. 14 (2000). The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights).

<sup>32</sup> Article 2 of the European Charter of Patients' Rights.

### Accessibility of medical services

International agreements urge states to create conditions that would assure to all medical service and medical attention in the event of sickness.<sup>33</sup>

The Constitution of the Kyrgyz Republic recognizes the need for regulation of the healthcare system through legislation. It guarantees the free delivery of first-aid, as well as free medical care in certain cases of disease. The Constitution also recognizes the right of socially vulnerable groups to obtain medical care. The delivery of care is guaranteed both at private and public medical institutions.<sup>34</sup> The right to emergency care is further elaborated in domestic legislation that guarantees immediate medical intervention will be provided in life-threatening situations.<sup>35</sup>

### Non-discrimination

International agreements to which the Kyrgyz Republic is a party prohibit discrimination in the provision of the rights and freedoms therein.<sup>36</sup> The ICESCR specifically guarantees access to healthcare facilities and services without discrimination.<sup>37</sup>

Domestic legislation also guarantees the equality of all people before the law. It states that no one can be exposed to any kind of discrimination or infringement of his or her rights based on origin, gender, race, ethnicity, language, confession, political and religious beliefs, or by any circumstances of a personal or public nature.<sup>38</sup>

Domestic legislation explicitly guarantees that medical care will be provided to all without discrimination.<sup>39</sup> The doctors' oath includes a promise to deliver medical care to patients, respecting their human dignity, regardless of ethnicity, social position, political views or religion.<sup>40</sup>

## THE RIGHT TO INFORMED CONSENT

*Every individual has the right of access to all information that might enable him or her to actively participate in the decisions regarding his or her health; this information is a prerequisite for any procedure and treatment, including the participation in scientific research.*<sup>41</sup>

Obligations adopted by the Kyrgyz Republic in the framework of international agreements guarantee each person's freedom from non-consensual medical treatment.<sup>42</sup> These international instruments also assert rights integral to the exercise of informed consent, including the rights to security of person<sup>43</sup> and to seek and obtain information.<sup>44</sup>

<sup>33</sup> Article 12, paragraph 2 (d) of the International Covenant on Economic, Social and Cultural Rights.

<sup>34</sup> Article 34, sections 1 and 2 of the Constitution of the Kyrgyz Republic.

<sup>35</sup> Articles 22 and 23 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>36</sup> Article 2, paragraph 1 of the International Covenant on Civil and Political Rights; article 2, paragraph 2 of the International Covenant on Economic, Social and Cultural Rights; and others.

<sup>37</sup> Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights. General Comment No. 14 (2000). The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights).

<sup>38</sup> Article 13, section 3 of the Constitution of the Kyrgyz Republic.

<sup>39</sup> Article 61 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>40</sup> Article 92 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>41</sup> Article 4 of the European Charter of Patients' Rights.

<sup>42</sup> Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights. General Comment No. 14 (2000). The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights).

<sup>43</sup> Article 9, paragraph 1 of the International Covenant on Civil and Political Rights.

<sup>44</sup> See the International Covenant on Civil and Political Rights, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, and the International Convention on the Protection of the Rights of all Migrant Workers and Members of their Families.

The right to obtain information is recognized by the Constitution.<sup>45</sup> Domestic legislation gives patients the right to information about their health, including the right to receive information in a comprehensible form and to receive information about the results of examinations, the occurrence of a disease, its diagnosis and forecasting, methods of treatment and related risks, options for medical intervention, their consequences, and the results of treatment that has been conducted.<sup>46</sup> It is prohibited to conduct medical, biological and psychological experiments on people without their properly expressed and certified voluntary consent.<sup>47</sup>

### **THE RIGHT TO FREE CHOICE**

*Each individual has the right to freely choose from among different treatment procedures and providers on the basis of adequate information.*<sup>48</sup>

The exercise of conscious and responsible choice can take place only when a patient has been provided the relevant information by medical professionals. International human rights instruments affirm a person's right to obtain information<sup>49</sup> and to recognition as a person before the law.<sup>50</sup>

In accordance with the laws of the Kyrgyz Republic, a patient has the right to obtain comprehensible information about methods of treatment, the risk related to a particular treatment, options for medical intervention and their consequences, and data on medical personnel participating in the patient's examination and treatment.<sup>51</sup> Patients also have the right to select their attending physician, to reject the participation of students in diagnosis and treatment,<sup>52</sup> and to choose a family physician and general practitioner.<sup>53</sup>

### **THE RIGHT TO PRIVACY AND CONFIDENTIALITY**

*Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general.*<sup>54</sup>

International human rights law holds that nobody can be exposed to arbitrary or illegal intervention in his or her private or family life. Every person has the right to legal protection from such intervention or encroachment<sup>55</sup> and a specific right to have his or her personal health data treated with confidentiality.<sup>56</sup>

The Constitution of the Kyrgyz Republic recognizes the right to protection of one's private life<sup>57</sup> and does not allow for collection, storage, use or dissemination of confi-

<sup>45</sup> Article 14, section 3, paragraph 13 of the Constitution of the Kyrgyz Republic.

<sup>46</sup> Article 73 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>47</sup> Article 19, section 2 of the Constitution of the Kyrgyz Republic.

<sup>48</sup> Article 5 of the European Charter of Patients' Rights.

<sup>49</sup> See the International Covenant on Civil and Political Rights, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, and the International Convention on the Protection of the Rights of all Migrant Workers and Members of their Families.

<sup>50</sup> Article 16 International Covenant on Civil and Political Rights.

<sup>51</sup> Article 73 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>52</sup> Article 72 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>53</sup> Articles 61 and 66 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>54</sup> Article 6 of the European Charter of Patients' Rights.

<sup>55</sup> Article 17, paragraphs 1 and 2 of the International Covenant on Civil and Political Rights.

<sup>56</sup> Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights. General Comment No. 14 (2000). The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights).

<sup>57</sup> Article 14, section 3 of the Constitution of the Kyrgyz Republic.

dential information about a person without his or her consent, except in cases established by law.<sup>58</sup>

Guarantees of confidentiality are part of the notion of medical secrecy, which covers information regarding referral to medical care, one's health status, diagnosis of a disease, and other data obtained upon examination or treatment of a patient.<sup>59</sup> People who obtain data comprising medical secrets during training or execution of professional, official or other duties are not permitted to disclose such information.<sup>60</sup>

### **THE RIGHT TO RESPECT FOR PATIENTS' TIME**

*Each individual has the right to receive necessary treatment within a swift and pre-determined period of time. This right applies at each phase of the treatment.*<sup>61</sup>

The ICESCR requires the creation of conditions that would ensure delivery of medical care to everyone in case of sickness.<sup>62</sup> The Committee on Economic, Social and Cultural Rights has interpreted this provision to include a guarantee of equal and timely access to medical treatment. The core UN documents do not set out standards for the timeliness of specific treatments.

The Constitution of the Kyrgyz Republic establishes that procedures for obtaining medical care shall be specified by the law.<sup>63</sup> The legislation entrusts healthcare facilities with the responsibility to provide timely medical care in accordance with their material and financial resources.<sup>64</sup> The right to respect for a patient's time is defined by programs approved by the authorized state body of the Kyrgyz Republic on public health.<sup>65</sup>

### **THE RIGHT TO THE OBSERVANCE OF QUALITY STANDARDS**

*Each individual has the right of access to high quality health services on the basis of the specification and observance of precise standards.*<sup>66</sup>

International agreements to which the Kyrgyz Republic is a party assign the state the responsibility for ensuring protection of the rights of each person to the highest achievable level of physical and psychological health.<sup>67</sup>

In the Kyrgyz Republic, the law recognizes the right of the patient to access to quality medical and sanitary care at medical facilities, including private medical practices.<sup>68</sup> The law also establishes penalties for the failure of persons that deliver health services to provide quality care.<sup>69</sup> In order to improve the quality of medical care, the authorized body in the health sector maintains accreditation of people in the medical field,<sup>70</sup> controls the quality of medical care and disease-prevention services, coordinates the quality of education, ensures quality control, safety, and the effectiveness of medications.<sup>71</sup>

<sup>58</sup> Article 14, section 4 of the Constitution of the Kyrgyz Republic.

<sup>59</sup> Article 91 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>60</sup> Article 91 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>61</sup> Article 7 of the European Charter of Patients' Rights.

<sup>62</sup> Article 12, paragraph 2 (d) of the International Covenant on Economic, Social and Cultural Rights.

<sup>63</sup> Article 34, section 2, paragraph 2 of the Constitution of the Kyrgyz Republic.

<sup>64</sup> Article 95 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>65</sup> Article 10 of the Law "On protection of the health of citizens of the Kyrgyz Republic." Under most circumstances the relevant authorized state body would be the Ministry of Health or the national Obligatory Insurance Fund.

<sup>66</sup> Article 8 of the European Charter of Patients' Rights.

<sup>67</sup> Article 12, paragraph 1 of the International Covenant on Economic, Social and Cultural Rights.

<sup>68</sup> Article 72 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>69</sup> Article 4 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>70</sup> Article 6 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>71</sup> Article 10 of the Law "On protection of the health of citizens of the Kyrgyz Republic." Here too, the authorized state body would most likely be understood to be the Ministry of Health or the national Obligatory Insurance Fund.

### **THE RIGHT TO SAFETY**

*Each individual has the right to be free from harm caused by the poor functioning of health services, medical malpractice and errors, and the right of access to health services and treatments that meet high safety standards.*<sup>72</sup>

The safety of medical care is provided for through legislatively fixed procedures for healthcare delivery.<sup>73</sup> People responsible for delivering healthcare are held accountable for failure to provide such care safely.<sup>74</sup> The authorized state body responsible for healthcare regulates the observance of safety procedures.<sup>75</sup>

### **THE RIGHT TO AVOID UNNECESSARY SUFFERING AND PAIN**

*Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness.*<sup>76</sup>

Each person has the right to security of his or her person.<sup>77</sup> International human rights standards include recognition of the inherent dignity of all people.<sup>78</sup> Legal instruments specifically assert that no one shall be exposed to torture or cruel, inhuman and degrading treatment or punishment.<sup>79</sup> The infliction of severe pain or physical or moral suffering by an official or any other person acting in an official capacity based on discrimination of any type is to be considered torture.<sup>80</sup>

The Constitution of the Kyrgyz Republic provides for protection from torture and inhuman or degrading punishment.<sup>81</sup> A doctor's oath includes a pledge to relieve a patient's suffering to the best of his or her knowledge and skill.<sup>82</sup> Domestic legislation further stipulates that patients have the right to be treated with a humane attitude by medical staff and attendants.<sup>83</sup>

### **THE RIGHT TO FILE A COMPLAINT**

Each individual has the right to complain whenever he or she has suffered a harm and the right to receive a response or other feedback.<sup>84</sup>

UN agreements on human rights guarantee each person the right to effective remedy for rights violations.<sup>85</sup> In its General Comment to article 12 of the ICESCR, the Committee on Economic, Social and Cultural Rights explicitly asserts that the covenant provides that, "Any person or group 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. All victims of such violations should be entitled to adequate reparation, which may take the form of restitution, compensation, satisfaction or guarantees of non-repetition. National ombudsman, human rights commissions, consumer forums, patients' rights associations or similar institutions should address violations of

<sup>72</sup> Article 9 of the European Charter of Patients' Rights.

<sup>73</sup> Article 34, section 2, paragraph 2 of the Constitution of the Kyrgyz Republic.

<sup>74</sup> Article 4 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>75</sup> Article 10 of the Law "On protection of the health of citizens of the Kyrgyz Republic." The Ministry of Health and other bodies to whom the state delegates authority are responsible for regulation of safety procedures.

<sup>76</sup> Article 11 of the European Charter of Patients' Rights.

<sup>77</sup> Article 9, paragraph 1 of the International Covenant on Civil and Political Rights.

<sup>78</sup> The Universal Declaration of Human Rights.

<sup>79</sup> Article 7 of the International Covenant on Civil and Political Rights.

<sup>80</sup> Article 1 Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.

<sup>81</sup> Article 19, paragraph 1 of the Constitution of the Kyrgyz Republic.

<sup>82</sup> Article 92 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>83</sup> Article 92 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>84</sup> Article 13 of the European Charter of Patients' Rights.

<sup>85</sup> Article 2, paragraph 3 (a, b, c) of the International Covenant on Civil and Political Rights.

the right to health.”<sup>86</sup> The right to file a complaint is also explicitly provided for in cases of torture and cruel treatment or punishment.<sup>87</sup>

In the Kyrgyz Republic, in case of violation of a patient’s rights, the patient can file a complaint directly with an official of the healthcare facility, as well as to corresponding state medical institutions or to the court. The legislation establishes a thirty-day period for the examination of complaints.<sup>88</sup> When a case involves a legally defined crime or violation of law, the applicant should appeal to the authorized agencies, such as a department of the Ministry of Internal Affairs (the police), the Prosecutor’s office, and the courts.<sup>89</sup>

## LEGAL PROTECTION FOR THE DISABLED

The fundamental rights of the disabled are detailed in the UN Convention on the Rights of Persons with Disabilities – an important international document that sets out the standards for state policy toward people with disabilities. Unfortunately, Kyrgyzstan has not ratified this convention yet. The rights of the disabled were also provided earlier in such documents as the Declaration on the Rights of Disabled Persons,<sup>90</sup> which was supported by Kyrgyzstan, the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Declaration on the Rights of Mentally Retarded Persons, and the Declaration on Social Progress and Development, which declare the requirement to protect the rights of the disabled and provide for the well-being and rehabilitation of the ability to work for people with physical and mental disabilities.

The Convention on the Rights of Persons with Disabilities recognizes the right of the disabled to the highest achievable level of health without discrimination based on disability. Member states are obliged to take all necessary measures to provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons. Care should be provided on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care and the state should not permit discriminatory refusal to provide health care or health care services due to a person’s disability.<sup>91</sup> Although the Kyrgyz Republic has not yet signed on to the Convention, the provisions in this international instrument are widely seen as the standard to which all states should aspire.

The Constitution of the Kyrgyz Republic, the law “On social protection of the disabled,” the law “On the rights and guarantees of persons with disabilities” and the law “On protection of the health of citizens of the Kyrgyz Republic” are important legislative acts that define public policy toward the disabled. These documents are aimed at providing equal opportunities to implement the rights and freedoms, to eliminate limi-

<sup>86</sup> Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights. General Comment No. 14 (2000). The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights).

<sup>87</sup> Article 13 of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.

<sup>88</sup> Article 8 of the Law of the Kyrgyz Republic “On procedures to examine complaints of citizens.”

<sup>89</sup> The authorized body is defined by its investigative jurisdiction, in accordance with article 163 of the Criminal Code of the Kyrgyz Republic or Chapter 41 of the Code of Administrative Responsibility of the Kyrgyz Republic.

<sup>90</sup> Adopted on December 9, 1975 by Resolution of 13-th session of the UN General Assembly 3447 (XXX).

<sup>91</sup> Article 25 of UN Convention on the Rights of Persons with Disabilities.

tations in vital activity, to create favorable conditions allowing for the disabled to lead full value life and actively participate in economic and political life of the society and to perform civil duties in accordance with generally recognized principles of international law and international agreements, which the Kyrgyz Republic is part of.

Kyrgyzstan declares that while providing social protection for the disabled, the state creates the necessary conditions for individual development, realization of creative abilities and work opportunities, taking into account the needs of the disabled in various national programs, the provision of social assistance as set out by the legislation to eliminate obstacles to the implementation of the rights to health care, work, education and vocational training, housing, and other social and economic rights of the disabled.<sup>92</sup> The disabled are provided additional guarantees to implement their rights and legitimate interests; special care is provided to disabled children.

People with disabilities, including disabled children and people disabled since childhood, are guaranteed the right to medical care, rehabilitation, the provision of medicine, prosthetic devices, prosthetic orthopedic items, the means of affordable transportation, and professional training and retraining.<sup>93</sup> In addition, according to the law, disabled people deemed incapable are entitled to free medical care at state health care institutions within the framework of the program of state benefits, to care at home, and, in cases when a disabled person cannot meet his or her vital needs, to maintenance in an institution of social protection.

The procedures for providing medical care to the disabled, as well as the list of state benefits, should be determined by the legislation of the Kyrgyz Republic.

Each patient referred to a health care institution is entitled to the following rights: respectful and humane treatment by primary and secondary health care personnel; examination; preventive treatment; treatment; medical rehabilitation; and maintenance in conditions that meet sanitary-hygienic requirements; as well as affordable medical care at health care institutions and from health care providers in private practice.<sup>94</sup>

Kyrgyz legislation in the field of reproductive health guarantees that any woman should have the right to independently decide whether she is going to give birth, have an abortion, or undergo sterilization, without compulsion or other interference by the state. Medical sterilization, as medical interference with the purpose of depriving one of one's reproductive ability, or as a contraceptive method, should be undertaken in health care institutions only upon the written application of an adult patient.<sup>95</sup>

The law sets out that health care institutions should provide affordable, timely, qualified health care of a necessary volume set out for a certain level of health care, in accordance with the material and financial resources allocated; that they should provide emergency health care; and that they should be prepared to work in extreme conditions (in case of epidemic, emergency situations, during a state of martial law, natural disasters, or in difficult to access and dangerous conditions).<sup>96</sup>

In addition, disabled patients are entitled to choose their attending physician in out-patient and in-patient health care institutions; to receive preferential health care,

<sup>92</sup> Article 3 of the Law of the Kyrgyz Republic "On social protection of the disabled." This law was adopted on April 17, 1991.

<sup>93</sup> Article 70 of the Law of the Kyrgyz Republic "On protection of the health of citizens of the Kyrgyz Republic."

<sup>94</sup> Article 72 of the Law of the Kyrgyz Republic "On protection of the health of citizens of the Kyrgyz Republic."

<sup>95</sup> Article 36 of the Law of the Kyrgyz Republic "On protection of the health of citizens of the Kyrgyz Republic."

<sup>96</sup> Article 95 of the Law of the Kyrgyz Republic "On protection of the health of citizens of the Kyrgyz Republic."

medicine, orthopedic, and other services at health care institutions in accordance with the procedures established by the government of the Kyrgyz Republic; to consultation and consultation with other specialists; to access to a lawyer or other legal representative to protect his or her rights; to provision of a religious cleric, and, when in the hospital, to be provided conditions to perform religious ceremonies, including a separate room, unless this violates the internal rules of the hospital; to refuse the participation of medical students in the process of diagnosis and treatment; and to other rights provided for by the legislation of the Kyrgyz Republic.

If the rights of a patient are violated, he or she can appeal directly to the director or other official at the health care institution where care has been provided, and to the relevant professional public health care organizations, or to the court.

The code of professional ethics of health care workers in the Kyrgyz Republic, regulating relations between health care personnel and patients, obliges health care workers to respect the honor and dignity of the patient, to demonstrate a kind and patient attitude toward him or her and his or her relatives.<sup>97</sup>

Rude and inhumane treatment of the patient, humiliation of his or her dignity, as well as any demonstration of superiority or hostility on the part of health care personnel, or demonstration of favor or dislike to any patient, are not acceptable. Medical personnel should provide health care in such a way that provides for the minimum possible constraint on the freedom and dignity of the patient.<sup>98</sup>

Health care and pharmaceutical personnel should be held responsible for violations of medical ethics, damage caused to the health of a citizen, and the disclosure of medical secrets, as provided for by legislation.<sup>99</sup> Domestic legislation provides for disciplinary, civil, administrative and criminal responsibility for such acts.

The matter of creating condition for free access and use by the disabled requires special attention. Existent transportation means, means of communication and information as well as other social infrastructure objects should be adjusted to be used by the disabled. According to the law, when the indicated objects cannot be adjusted to make them accessible for the disabled, the relevant enterprises, institutions and organizations should develop and implement necessary measures providing conformity with minimum requirements of the disabled<sup>100</sup>.

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<sup>97</sup> Article 6, section II.

<sup>98</sup> Article 7 of the Law of the Kyrgyz Republic "On protection of the health of citizens of the Kyrgyz Republic."

<sup>99</sup> Article 102 of the Law of the Kyrgyz Republic "On protection of the health of citizens of the Kyrgyz Republic."

<sup>100</sup> Article 10 of the Law of the Kyrgyz Republic "On social protection of the disabled."

## LEGAL OBLIGATIONS TO PROVIDE REHABILITATION

Rehabilitation consists not only of prevention, treatment, and employment, but rather, principally, it involves a new approach toward the patient, including socialization and restoration of the personal and social status of the disabled.

Rehabilitation should be multidimensional in its nature, i.e. it should take into account the various aspects of life, depending on the individuality of each person, as well as including the obligatory medical, social, professional, and employment aspects.

Medical rehabilitation is aimed at the restoration of lost functions. To accomplish this, it is necessary to provide the disabled with all types of health care in out-patient polyclinics, at home, and at in-patient facilities, in order to maximize the use of treatment to restore one's abilities.

The goal of social rehabilitation is to form stable psychological aims for a person's full participation in society, as well as to provide training on how to lead an independent life and care for oneself.

The final stage of the rehabilitation process involves returning the disabled person to professional work. Special expert examination allows for the establishment of a person's capacities, based on which the individual rehabilitation program is developed.

Currently, there are no multidimensional rehabilitation centers in the Kyrgyz Republic that would provide medical, social and professional rehabilitation to the disabled. Considering this, in order for the state to come into compliance with the standards for rehabilitation, the main task is to create rehabilitation centers in all regions of the republic at the state and non-governmental levels.

Under the law, the individual rehabilitation program for the disabled is a complex of optimal rehabilitation measures, including certain procedures for the implementation of medical, professional and other rehabilitation measures and types of social aid aimed at the restoration of or compensation for disordered or lost functions and abilities of the disabled person.<sup>101</sup>

The individual rehabilitation program includes both rehabilitation measures provided to the disabled for free in accordance with the state program of rehabilitation for the disabled, and also rehabilitation measures provided to the disabled in exchange for payment by the disabled person or an organization.

The individual rehabilitation program for the disabled should be implemented by the relevant public authority, local public administration, and local self-governance bodies, as well as by enterprises, organizations, and institutions, regardless of their form of ownership and economic activity.<sup>102</sup>

According to article 20 of the law on social protection of the disabled, the institutions that should implement the rehabilitation of the disabled include national and local public administration bodies that, taking into account the needs of the disabled for rehabilitation, should create a rehabilitation network, including research and industrial centers, divisions of rehabilitation treatment in out-patient and in-patient health care facilities, special training institutions, specialized sanatorium-and-spa institutions, and

<sup>101</sup> Article 18 of the Law of the Kyrgyz Republic "On social protection of the disabled."

<sup>102</sup> Article 19 of the Law of the Kyrgyz Republic "On social protection of the disabled."

specialized enterprises and institutions to provide social and everyday services to the disabled.

The state should organize and facilitate development of the system of medical, professional and social rehabilitation of the disabled, consisting of a complex of measures aimed at the restoration of and compensation for disordered or lost functions, the ability to care for oneself, and various types of professional activity, as well as allowing for the disabled to lead a life in which they are able to exercise their rights and abilities.<sup>103</sup>

## **VIOLATIONS OF PATIENTS' RIGHTS**

### **INFRINGEMENT OF THE REPRODUCTIVE RIGHTS OF DISABLED WOMEN**

During the course of the survey, disabled women reported numerous cases of discrimination and violations by health care specialists. Disabled women reported that gynecologists had negative attitudes toward pregnant disabled women. Most often, disabled women receive recommendations not to give birth or are told that they need to be sterilized. Medical sterilization as medical interference with the purpose to deprive a woman of the ability to reproduce, or as a method of contraception, should be carried out in health care institutions only upon the written application of an adult patient.<sup>104</sup> Therefore, infringements of patients' rights have taken place.

The problem of discrimination is compounded by a lack of recognition on the part of the relevant government structures that disadvantaged women have the same needs in the sphere of health care and family planning as other women; this causes disabled women to be deprived of comprehensive treatment. This problem is even more aggravated for rural women.

The special needs of disabled women, such as the lack of special technical equipment, special facilities, and special entrances to clinics and consultations are being ignored. In addition, the disrespectful attitude of health care personnel causes disabled women to avoid examination and treatment. In accordance with the legislation, any woman should be entitled to independently decide if she wants to give birth, or terminate a pregnancy, without compulsion or interference by other persons.<sup>105</sup>

The Kyrgyz system of health care does not provide adequate protection of the reproductive rights of disabled women. In some cases, doctors insist that these women should not give birth, without trying to explain the reason. These and other actions by doctors hinder the realization of disabled women's reproductive rights. Thus, the majority (70%) of female respondents surveyed for this research reported negative attitudes toward disabled female patients on the part of gynecologists. Such attitudes of specialists explains the fact that almost one third (30%) of female respondents do not go to the gynecologist.

Disabled women made up 37.5 % of the total number of respondents interviewed for this report. In response to the question "How often do you go to the gynecologist?"

<sup>103</sup> Article 17 of the Law of the Kyrgyz Republic "On social protection of the disabled."

<sup>104</sup> Article 36 of the Law of the Kyrgyz Republic "On protection of the health of citizens of the Kyrgyz Republic."

<sup>105</sup> In accordance with the Law of the Kyrgyz Republic "On the reproductive rights of citizens and guarantees of their implementation," August 10, 2007 #147, a woman is also entitled to make free choices regarding reproduction, to choose motherhood, and to protection of her reproductive health.

50% of women surveyed answered that they “Did not go for a long time (4, 8, or 15 years),” while 33.4 % of disabled women said they never went to the gynecologist, and 16.6 % had not seen a gynecologist until the delivery of a child.

Disabled women are not educated in matters of reproductive and sexual health; programs on reproductive health do not consider the needs and requirements of disabled women. The government needs to conduct educational campaigns with this category of the population. All of the disabled women surveyed said that there were no special conditions created for the reception of disabled women at the gynecologist or in maternity hospitals.

All surveyed female participants gave a negative answer when asked whether they had been invited to participate in any programs dedicated to family planning.

When asked whether they received special advice or additional observations from their doctor related to their disability, 15 % of respondents said yes. All 15% of these female respondents received advice and additional observations from a doctor only during pregnancy or delivery, which indicated inadequate educational work on the part of the state.

Some disabled women who were surveyed reported on the negative attitude of gynecologists toward pregnant disabled patients. Most often, doctors recommended the women not give birth or said they needed to be sterilized. These patients were convinced by their doctors that disabled women cannot be mothers and that their children will also be disabled.

One patient was sterilized without her consent, according to doctors, for medical reasons. Another woman, Ainura, has been diagnosed with cerebral spastic infantile paralysis with preserved mental ability; she walks with the help of a cane. After visiting a gynecologist who told her she should not have children, she became depressed and had an abortion. Not many patients are literate in the matter of indications for sterilization and abortion and so trust the advice of health care specialists.

“I was very glad that I got pregnant. But when I went to the gynecologist, the doctor started dissuading me from giving birth, moreover, she started saying that my kids might also become disabled. The doctor’s words upset me and I even started thinking “maybe I should have an abortion.”<sup>106</sup>

*Ainura (a pseudonym), a 32 year old with a group I disability, Issyk-Kul province*

Almost 40% of women surveyed reported the difficult economic status of their family as one of the reasons for having an abortion, while 30% stated that they had an abortion because the doctor strongly insisted on it. Some doctors tell disabled women that they should not have children and offer them sterilization operations.

According to the law, “The voluntary consent of a citizen should be a necessary precondition of medical interference,”<sup>107</sup> but in reality this does not always happen. In one case reported by a respondent, a woman was not only not informed about certain decisions by the health care staff, but as a result of their arbitrary actions she was deprived of the ability to have children.

<sup>106</sup> “Ravenstvo” interview with Ainura (a pseudonym), a 32 year old with a group I disability, Issyk-Kul province, June 30, 2007.

<sup>107</sup> From the Law of the Kyrgyz Republic “On protection of the health of citizens of the Kyrgyz Republic.”

"Five years ago during an operation to remove my appendix I was sterilized, but before the operation there was no discussion about this, nobody asked me. As the doctor explained me later on, sterilization was done based on medical indications. My diagnosis is CSIP [cerebral spastic infantile paralysis]. Nobody explained to me what caused this decision."<sup>108</sup>

*Tatyana (a pseudonym), a 24 year old with a group II disability, Issyk-Kul province*

"As a consequence of a spinal injury I started using crutches. A year later I was expecting a child and the doctors tried to dissuade me from giving birth, saying that I could have a disabled child, although I knew that my disability was acquired and I knew of cases when disabled women had children. They did a Cesarean section and a healthy child was born, but unfortunately, he died from pneumonia when he was three months old. When I wanted to [try again to] have a child, it turned out that my tubes had been tied [by the doctor] and I will never be able to have kids..."<sup>109</sup>

*Alla (a pseudonym), a 33year old with a group I disability, Issyk-Kul province*

### **INFRINGEMENT OF THE RIGHTS OF PATIENTS UPON PROVISION OF MEDICAL-SANITARY CARE**

Upon referral for health care and upon reception of health care, a patient should be entitled to respectful and humane treatment by health care workers and secondary personnel; as well as to examination, preventive treatment, treatment, medical rehabilitation, and conditions that meet hygienic requirements; and to receive affordable medical care in health care institutions, as well as from medical professionals in private practice.<sup>110</sup>

Unfortunately, the statements of our survey respondents confirm that there are numerous cases of discrimination and violations by health care specialists towards disabled patients. However, none of them wrote a complaint or appealed to authorities, because, they said, they think that it is useless and that no one will listen to them, and because they fear that when they go to the same doctor the next time the doctor's attitude might be even worse.

"My legs and arms are paralyzed as a consequence of cervical spine fracture; the functions of my pelvic organs are disordered. Now I have a cystostomy. This is a pipe that removes urine from the urinary bladder, and that is why blockage of the pipes often happens, causing infection of the urinary tract and kidneys, high blood pressure, and temperature. Sometimes I go to the hospital to replace the pipes. Once the doctor who replaced the pipes started rudely shouting at me saying that I stink, and my wheelchair stinks, and that I block the passage. She inserted an untreated pipe and, as a result, I have big problems with my kidneys now."<sup>111</sup>

*Respondent "U," an interviewee with a group I disability, Issyk-Kul province*

<sup>108</sup> "Ravenstvo" interview with Tatiana (a pseudonym), a 24 year old with a group II disability, Issyk-Kul province, June 24, 2007.

<sup>109</sup> "Ravenstvo" interview with Alla (a pseudonym), a 33 year old with a group I disability, Issyk-Kul province, June 20, 2007.

<sup>110</sup> Article 72 of the Law of the Kyrgyz Republic "On protection of the health of citizens of the Kyrgyz Republic."

<sup>111</sup> "Ravenstvo" interview with "U," Issyk-Kul province, June 30, 2007.

Seventy five percent of survey participants reported indifferent, condescending treatment of them by health care personnel. As noted above, according to the survey participants, specialists look at disabled patients as social outcasts, show them disdain, try not to notice them, may be rude during communications, demonstrate an aversion to their patients, exhibit a shortness of temper, and mistreat their patients who are disabled. Again, all of the respondents reported that the attitude of health care personnel could be changed; it always depends on whether the disabled patient is rich or poor.

Lack of appropriate facilities for disabled people and indifference to them on the part of medical personnel amount to infringements of the right to quality medical care.

"I had to stay at the hospital due to the condition of my health, but every day my father took me home so I could use the restroom. In the hospital the doors into the bathrooms are very narrow, so the wheelchair cannot go through, and it is very dirty there. Sometimes when I wanted to go to the bathroom, I called and called, but hardly got an answer. If they give you a bedpan, the urine might stay all day long, until you ask them to pour it out. That is why I do not receive treatment at the hospital these past years."<sup>112</sup>

*Alexander (a pseudonym), a 47 year old with a group I disability, Issyk-Kul province*

If the rights of a patient are infringed, he or she can appeal directly to the head or other official of a health care institution, and to the relevant professional medical public organizations, or to the courts. Unfortunately, none of the respondents exercised this right.

"This is a waste of time and nerves, it is unlikely that justice will be on the side of the disabled and violators will be punished. We cannot even count on getting an apology from health care personnel."<sup>113</sup>

*Respondent "N," Karakol city*

## **DISCRIMINATION AND NEGATIVE ATTITUDES TOWARD DISABLED PATIENTS**

Many participants in the survey reported indifferent, condescending attitudes by health care personnel. Some respondents emphasized that they are looked at as if they are social outcasts; and that they are disdained and ignored.

The overwhelming majority of respondents say that there is a different attitude towards them as compared with other patients; it depends on the person. In most cases, the attitude of health care personnel is negative: the disabled person's wheelchair is considered annoying, the disabled are humiliated, rudeness is demonstrated. The disabled say that they are looked at with open irritation and disgust, and even if someone is not talking to them in a rude way, people indicate that they find the disabled to be annoying. The disabled feel like they are second class citizens. A bribe changes the situation. This is evidence that the quality of service provided depends on the material status of the patient – whether the patient is rich or poor.

<sup>112</sup> "Ravenstvo" interview with Alexander (a pseudonym), Issyk-Kul province, June 25, 2007.

<sup>113</sup> "Ravenstvo" interview with "N," (name withheld at the request of the interviewee), Issyk-Kul province, June 26, 2007.

Although many disabled people suffer social persecution daily, society does not notice this problem, mainly due to the lack of integration of the disabled into social life. Isolation of the disabled is a mechanism that hides the problem and thus keeps the current state of affairs unchanged.

Due to a generally inaccessible environment and infrastructure, stereotypes held by society, the disabled experience a lowered self-esteem and often isolate themselves. This in turn leads to the emerging of inferiority complexes, spiritual suffering, self-blame and despair. To remain passive and stay at home is the most common way to cope with the pain. People with disabilities begin to think that their difficulties are related to their own deficiencies, which makes them even more passive. Direct interaction with other people in society is a difficult experience for people with disabilities, because the society as a whole does not recognize the presence of the disabled and the existence of their vital needs. Thus, on the one hand, the problem weighs on the individual. People who are not disabled remain indifferent to the problem of disability due to the isolation of the disabled. Isolation in turn makes discrimination a norm.

Discrimination against the disabled manifests in different ways in the health care field, including through failure to provide adequate facilities to accommodate people with disabilities. All survey participants expressed the opinion that hospitals do not meet the requirements for the disabled to stay and to be treated. There are narrow, inconvenient beds with broken springs; there are no elevators. So, the disabled are taken to upper floors in their wheelchairs. Narrow doors make it impossible to pass through to the bathrooms, the toilet is not adjusted, and that is why the disabled are taken home to use the toilet.

Regarding referral to specialists, the majority of the respondents reported that there was a problem visiting dentists, gynecologists, proctologists, and surgeons. Buildings and offices are not adjusted to receive patients with special needs. These institutions do not provide services such as house calls.

Undesirable consequences were observed due to the late provision of consultation or treatment by the above-mentioned specialists.

One respondent said that in the province hospital, where he went due to a high temperature, he was not received for a long time. He was received only after making a telephone call to the help line. Then, the doctor who received him said: "Where are you going with that wheelchair? It stinks, you will break all the corners, and you will block the passage and disturb people."<sup>114</sup>

Another survey participant said that he had a toothache for a week, edema emerged and inflammation started. The tooth had to be extracted in the car.<sup>115</sup> Another patient couldn't get to the dentist, so his teeth rotted and now he has almost no teeth.<sup>116</sup> Others noted that because they could not get timely treatment by various specialists, they developed piles and bedsores.

One patient referred to a private dental clinic; they treated him at home, but it was very expensive. Repeated referral to such services definitely is not affordable for the disabled, he said.

<sup>114</sup> This incident took place at the Province Hospital in Karakol. "Ravenstvo" interview, name of interviewee withheld at his request, Issyk-Kul province, June 24, 2007.

<sup>115</sup> "Ravenstvo" interview with "C," name withheld at the request of the interviewee, Karakol city, Issyk-Kul province, June 24, 2007.

<sup>116</sup> "Ravenstvo" interview with Rafik (a pseudonym), Karakol city, Issyk-Kul province, June 27, 2007.

Another unpleasant case was described regarding the reception a patient received at a urologist. Because of kidney problems, the patient experiences blockage of the urinary track, causing infection of the system and high blood pressure. The doctor who changed the pipes shouted rudely that the patient had a foul smell and that his wheelchair stank. As the patient reported, an untreated pipe was inserted into him; as a result, the patient has serious problems with his kidneys. The patient states that the unpleasant smell of urine appeared only because of the fact that the pipe got blocked.<sup>117</sup>

A female patient told researchers about a doctor who neglected her duties. Once her doctor was absent. Another doctor, to whom she referred, gave her medication without even looking at the patient. The patient lost consciousness once she took the medication. After that, according to her, complications emerged and she began to experience epileptic seizures. It is likely that the epileptic seizures were observed in the patient earlier; however, the indifferent attitude of the doctor caused an acute negative condition in the patient.<sup>118</sup>

### **INFRINGEMENT OF THE RIGHTS OF PATIENTS UPON PROVISION OF EMERGENCY CARE AND INFRINGEMENT OF PATIENTS' DIGNITY**

In the survey we conducted, a block of questions dealt with calls to emergency medical services: How urgently did this service respond to the call, or did it not respond at all? What kind of care was provided? And if there was no care, what were the consequences?

Due to discrimination by emergency medical staff and the systematic under funding of the emergency services by the government, people with disabilities are not a priority. The response to their calls is slow, or they do not receive any care at all, which can cause negative consequences for their health. It was found during the course of the survey that the staff of emergency medical services sometimes refuse to come to the aid of people with disabilities or treated them rudely, if they did come in response to their calls.

“Once I fell from my wheelchair after a spinal trauma and broke my leg, so I called the emergency medical services. The ambulance came and took me to the hospital, where I had to lay in the corridor for an hour. Nobody paid attention to me, until one old lady saw me and started crying: ‘What are you doing? Are you human or not? He is loosing consciousness!’ Only then did the doctors show up. No treatment was prescribed. The doctors told me cynically: ‘You don’t walk anyway, so why do you need plaster cast? You just lay there and it will heal itself.’ Due to the cruelty and indifference of the doctors and because the law is ignored and is not observed I have decided that I will never, even if I die, refer to doctors again.”<sup>119</sup>

*Saimyk (a pseudonym), a 43 year old with a group I disability, Issyk-Kul province*

The described case confirms that not all medical personnel stick to the code of professional ethics of health care personnel of the Kyrgyz Republic, section II of which ad-

<sup>117</sup> “Ravenstvo” interview with Ulan (a pseudonym), Issyk-Kul province, June 23, 2007.

<sup>118</sup> “Ravenstvo” interview with Lyubov (a pseudonym), Issyk-Kul province, June 24, 2007.

<sup>119</sup> “Ravenstvo” interview with Saimyk (a pseudonym), a 43 year old with a group I disability, Karakol city, Issyk-Kul province, June 23, 2007.

dresses respect for the honor and dignity of the patient: "Health care personnel should respect the honor and dignity of the patient, demonstrate a kind and patient attitude toward the patient and his or her relatives."<sup>120</sup>

"I was forced to refer to the emergency services twice. The first time they took me to the hospital, since I was unconscious. The second time when I felt bad and called the emergency services, they responded that I exaggerate and pretend to be ill and that I should not disturb them. They advised me to take haw tincture. They were very hostile and rude."<sup>121</sup>

*"R," a 43 year old with a group I disability, Issyk-Kul province*

Health care staff should provide health care under the conditions of minimum possible constraints on the freedom and dignity of the patient.<sup>122</sup>

"I live in a rural area, literally three kilometers from the city. Feeling bad, I called the emergency medical services, but they refused to come because "the road was bad, and [we have] no fuel". So I had to get there myself by taxi, (I have tetraparesis) [a muscle weakness affecting all four limbs]. I lost consciousness on the way and suffered severely."<sup>123</sup>

*Bakyt (a pseudonym), a 34 year old with a group I disability, Issyk-Kul province*

Many of survey participants reported that they try not to call on the emergency medical services; they are forced to refer to them only in the most urgent instances.

### **INFRINGEMENT OF THE RIGHTS OF PATIENTS FOR DUE DIAGNOSTIC**

According to the survey results, 62.5% of the respondents had an acquired disability, while 37.5% had a disability from birth.

Fifty percent of the respondents said they think that they were diagnosed correctly, 25% of the survey participants were sure that they had been diagnosed incorrectly, which had caused serious complications.

Incorrect diagnosis can lead to improper or delayed treatment.

"In the province hospital where I went, the doctors did not recognize a fracture of my cervical spine at once. When I suffocated they treated my lungs. Only three months later, in Bishkek in the department of neurosurgery, did they diagnose "fracture of the cervical spine." They operated on me very late, and as a result, my legs do not work, my arms work poorly, a stoma has been inserted in my bladder. The doctors said it was temporary, and then six years later they told me it was for good now and that treatment was useless."<sup>124</sup>

*Ulan (a pseudonym), a 32 year old with a group I disability, Issyk-Kul province*

The young man in the case described above couldn't get used to this thought for a long time, and then he fell into a deep depression and started drinking. He cannot create a family and thinks that his life is destroyed. Consultations with a psychologist were not provided. Once, upon the request of "Ravenstvo," through the Ministry of

<sup>120</sup> Article 6.

<sup>121</sup> "Ravenstvo" interview with "R," name withheld at the request of the interviewee, Karakol city, Issyk-Kul province.

<sup>122</sup> Article 7.

<sup>123</sup> "Ravenstvo" interview with Bakyt (a pseudonym), a 34 year old with a group I disability, Aksy district, Issyk-Kul province.

<sup>124</sup> "Ravenstvo" interview with Ulan (a pseudonym), a 32 year old with a group I disability, Karakol city, Issyk-Kul province.

Health, he was placed in the department of urology of the Republican clinic where very expensive medications were prescribed. The doctors mocked him, saying: "Since you got here through the ministry, you probably have money to buy these drugs." The attitude was indifferent and rude. He could not purchase the drugs and was discharged from the hospital four days later without receiving the required treatment. This was another shock for him, after which he did not want to deal with doctors, believing it was useless anyway, that one only can run into rudeness, humiliation and indifference.

### **FAILURE TO PROVIDE INDIVIDUAL REHABILITATION PROGRAMS FOR THE DISABLED**

Ninety four percent of people with disabilities do not know about and never heard of IRP for the disabled. While formation and adjustment of IRP should be implemented by MSCE institutions, the question of the necessity and feasibility of conducting rehabilitation measures should be considered mandatory in all instances when a disability group is assigned during a first or subsequent examination of a disabled person.

According to the law, IRP should be established within a month after determination of a person's disability group. MSCE agencies are entrusted with the task of arranging the necessary explanatory work with the disabled regarding the rehabilitation objectives, tasks, expected results, and rights of the disabled during the implementation of IRP. The staff members of Issyk-Kul province MSCE referred to an alleged official letter from the Center of medical-social expert examination and rehabilitation of the disabled from 2002 that researchers for this project were not given the chance to see with their own eyes, in which there is an order to provide IRP only to the disabled with group III disabilities, since this is working group. It may be assumed that these statements by the MSCE staff members are groundless.

Thus, as noted above, at the round table "The individual rehabilitation program for the disabled and its implementation" conducted with the purpose to develop recommendations for the future full implementation of IRP in Karakol, the head of the province MSCE, Genadiy Kalychbaev, expressed the following opinion: "*What do you want from us, let it be a headache of those who receive money for that.*"<sup>125</sup> When statistical data was given indicating that Issyk-Kul province has the largest number of disabled people in the Republic, he also stated: "*This is good we are in the first place, this means that we are working well and have good detection!*"

Centers that provide consultations and methodological coordination that should function in each province department of the Ministry of Labor and Social Protection of the Kyrgyz Republic, dealing with the implementation of the recommendation on the individual rehabilitation program for the disabled, are absent, while the order approved by the government of the Kyrgyz Republic #583 states they will be available.

In the state program of the integration and rehabilitation of the disabled for 2004-2007 developed with the purpose of creating a real opportunity to implement measures on the individual rehabilitation program for the disabled, as well as conditions to implement social benefits provided by the national program of state support for the

<sup>125</sup> Round table event, Karakol city, August 28, 2007.

disabled and in the approved action plan on its implementation, concrete measures, time frames and responsible ministries, state committees, administrative agencies, local public administrations, and local self-governance bodies are indicated. We have to state, based on the results of the survey, that the measures on the implementation of the state program of the integration and rehabilitation of the disabled are being implemented at a slow pace in the sphere of medical rehabilitation, while there is no progress in the sphere of social and professional rehabilitation.

## CONCLUSIONS

It may be concluded based on the information obtained as a result of the survey that there is a lack of provision for the interests of the disabled that would consider their specific needs and facilitate their integration into society. Conclusions that have been made may be specified depending on the areas.

Despite the availability of programs for the disabled, those are not individual programs and do not consider the individual needs of the disabled. The peculiarities of different groups of the disabled (those with limited mobility, the wheelchair disabled, etc.), their places of residence, and the location of rehabilitation centers are not taken into account upon the implementation of programs. Approved benefits and programs are not always provided the necessary funding, or there are problems related to the absence of necessary organizational measures.

Health care institutions considered in our survey have not made adjustments to accommodate and receive disabled patients. None of the health care institutions undertook adjustments to accommodate disabled people in wheelchairs; the conditions in these hospitals do not meet the requirements needed for full rehabilitation of the disabled.

The limited physical capabilities of the disabled are not taken into account when health care facilities are designed and put into operation; required infrastructure is lacking. Buildings do not have convenient access, there are no elevators, no lifting equipment, the toilets are not adjusted for the disabled, and the doors are too narrow. The needs of the disabled are not included in renovation programs that are undertaken.

Neither public establishments, nor health care institutions tasked with providing for the needs of different groups of the population are adjusted to provide service to disabled patients. The offices of various specialists (dentists, gynecologists, urologists, proctologists, obstetricians, and others) are not equipped to receive disabled patients.

The problems of the disabled are ignored by society due to the isolation of this group, the lack of special programs of socialization and development, and due to the medical approach to disability. Isolation of the disabled is the result of inadequate infrastructure, the absence of comprehensive support programs for the disabled (including medical, social, and legal support) aimed at the correction of the current state of affairs.

Public transportation is absolutely beyond the reach of the disabled. In particular, the special needs of disabled people who use wheelchairs are not considered. Because of the fact that state owned public transportation has disappeared, the disabled have found themselves deprived of the means of transportation. The state does not encourage the development of private transportation that takes into account the entitlements and needs of the disabled, as provided for by legislation.

The establishment of rehabilitation and adaptation centers was not brought into line with the system of training and re-training of health care personnel.

The disabled face denials of, or delays in, emergency medical care. People with disabilities also report rudeness on the part of emergency personnel when services are rendered.

There is a poor degree of awareness among disabled people regarding the existence of IRP for the disabled; 94% of respondents to our survey did not know about it and had never heard of it. This information shows that the MSCE service is not duly performing work related to the explanation and formation of IRP.

## RECOMMENDATIONS

1. The Ministry of Health and other relevant government agencies should exercise control over the observance of specific requirements of the disabled at the stages of design and construction of public establishments, including health care institutions, the offices of government authorities, utilities, and industrial buildings.
2. The Ministry of Health should further ensure that medical professionals fulfill their duties in the treatment of people with disabilities. Authorities should hold accountable health care workers who violate patients' rights.
3. The Ministry of Health and other relevant agencies should educate the population about where to lodge a complaint in case of violation of patients' rights and should ensure that all complaints are investigated and taken seriously.
4. The government of the Kyrgyz Republic should develop the relevant industrial and social infrastructure to integrate the disabled into society.
5. The laws should encourage the disabled to work, for instance, by means of a government order or flexible taxation policy. This is also relevant for the transportation system.
6. The government should ensure suitability of the premises where disadvantaged people live, to ensure these meet their needs. Given the small size of the allowance currently provided to the disabled, this task might be addressed only with outside support provided by society.
7. The government should sponsor a special program supported by the allocated funding to correct drawbacks in infrastructure and residential construction, taking into account the requirements of the disabled. The implementation of this program should be linked to the introduction of an individualized approach, which would consider the individual features and requirements of each disabled person.
8. It is necessary to organize the layout of objects in a way that would enable independent access by the disabled and give them an opportunity to live in a building without someone else's assistance. With this in mind, it is necessary to develop a mechanism of implementation and control over architectural and construction norms that should be approved legally.
9. A reconstruction plan should be developed for each public establishment that would enable the reception of disadvantaged people. This plan may be included into the above-mentioned individualized program on equal opportunities and may envisage stage-by-stage implementation.
10. The Ministry of Health and other responsible agencies should ensure that health care institutions and social objects that play an important role in providing for the needs of the disabled are included in corrective programs in the first turn to consider the needs of the disabled.

11. The transportation system and its vehicles should be adjusted to meet the needs of the disabled. The matter of creating conditions for free access and enabling use by the disabled requires special attention. Current means of transportation, means of communication and information, as well as other social infrastructure objects should be adjusted to be used by the disabled. When the indicated objects cannot be adjusted to make them accessible to the disabled, the relevant enterprises, institutions and organizations should develop and implement necessary measures in order to at least meet the minimum requirements of the disabled.
12. Sidewalks, crossroads and other street infrastructure should be accessible for people with physical disabilities. Technical improvements are needed to enable movement by the disabled with limited mobility and the disabled in wheelchairs, as well as access to buildings.
13. The implementation of programs aimed at the support of the disabled should be supplemented with a government sponsored information component. Such an information campaign should cover the general public, the disabled, and responsible staff tasked with providing relevant entitlements to the disabled. Information provided to the public should serve to shape public opinion so that people come to understand the problems of disability and perceive the disabled as equal members of society. The disabled who receive services and benefits should be aware of the existing relevant benefits and programs. The responsible staff of health care institutions, government authorities, utilities, transportation companies and others should feel their involvement in and responsibility for the implementation of the relevant benefits provided to disadvantaged people.
14. The government should ensure that this staff is trained to understand the problems of disability.
15. It is necessary to establish legal aid centers to protect the rights and interests of the disabled, including providing "hot line" services to enhance responsibility for the implementation of the entitlements provided to the disabled.
16. It is necessary to equip rehabilitation centers for the disabled, taking into account the set up tasks, as well as to study the matter of physical therapy training rooms. It is necessary to consider matters related to the availability of rehabilitation therapists as part of the staff of family medical centers.
17. It is necessary to harmonize the legislative and normative basis for IRP in relation to medical rehabilitation. It is necessary to develop a job description for rehabilitation therapists. It is necessary to arrange training and upgrading of qualifications for rehabilitation therapists. It is desirable to envisage examination of the disabled by doctors from national clinics, when doctors pay visits to the patient as a measure that could compensate for the inaccessibility of some specialists for the disabled.
18. It is necessary to introduce inclusive education for disabled children.

### **ACKNOWLEDGEMENTS**

We thank everybody who helped us to conduct this monitoring – our respondents, international organizations, and volunteers.

We would like to express our appreciation to the Law and Health Initiative of the Open Society Institute Public Health Program, the Soros Foundation Kyrgyzstan, and personally to the former director Mr. Medet Tyulegenov and project coordinator Ms. Aisuluu Bolotbaeva, to the Polish Helsinki Foundation for Human Rights (Warsaw), and to Acacia Shields – consultant to the Open Society Institute and the Soros Foundation Kyrgyzstan.

We express special gratitude to disabled respondents to our survey for their participation in the research.

We thank the staff members and volunteers of the Public Association “Ravenstvo,” Issyk-Kul province union of the disabled, for their participation in the survey – Rinata Djabalieva, Nurgul Ishebekova, Gulnara Khalikova, and Dinara Myrzaeva.

We also thank Ms. Ainura Kabylova, staff member of the Public Association “Leader” center for citizens’ initiatives, for providing us legal advice.





