

# **Public Foundation "Diaron"**

# **Observance of the Rights of Patients in Mental Health Institutions in Jalal-Abad**

This study was conducted with the support of the Soros Foundation Kyrgyzstan and the Law and Health Initiative of the Open Society Institute Public Health Program

> Jalal-Abad 2008

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The doctor has observed me for many years already...I take some pills. When I was a kid I suffered a head trauma. The doctors did not explain what it was and never gave me a diagnosis.

--"Jenishbek," a 32 year old mental health patient

Written by "Diaron" Edited by Acacia Shields and Dmitry Kabak Editorial assistance provided by Nurgul Djamankulova

### List of Abbreviations

GFD – group of family doctors

JPUH - Jalal-Abad Province United Hospital

KR – the Kyrgyz Republic

HCIs - health care institutions

MH KR - Ministry of Health of the Kyrgyz Republic

NMH – National Mental Hospital

FMC – family medical center

# TABLE OF CONTENTS

Introduction	4
Summary of Findings	
Summary of Conclusions	
Summary of Recommendations	6
Methodology	7
Legal Analysis	
International standards on patients' rights	8
The rights of people with mental health problems	8
The right of access	9
Accessibility of medical services	9
Non-discrimination	
The right to informed consent	10
The right to free choice	11
The right to privacy and confidentiality	12
The right to respect for patients' time	12
The right to the observance of quality standards	
The right to safety	
The right to avoid unnecessary suffering and pain	14
The right to file a complaint	
Violations of Patients' Rights	
Violation of the right of access to information and notification of one's rights	
Violations of the right to adequate treatment	
Conclusions	
Recommendations	
To the Government of the Kyrgyz Republic	
To the Ministry of Health	
To donors	
Acknowledgements	21
Annexes	22
Annex A. Questionnaire for the recipients of HCI service	
Annex B. Questionnaire for the directors of HCIs in Jalal-Abad city	24
Annex C. Questionnaire for doctors at HCIs in Jalal-Abad city	
Annex D. Questionnaire for nurses at HCIs in Jalal-Abad city	29

# INTRODUCTION

This report examines the degree to which the provision of health care to people with mental health problems is in conformity with the Kyrgyz Republic's Law on Psychiatric Care and with international standards on patients' rights. The goal of this report is to evaluate current conditions and provide recommendations in order to improve the situation. The report studies the system of health care provided to people suffering from mental health problems in health care institutions (HCIs) in the city of Jalal-Abad, in the southern part of the country. It also analyzes the laws of the Kyrgyz Republic that are relevant to the provision of psychiatric care and protection of the rights of this group of patients.

Psychiatric care in Jalal-Abad province, similar to that found in the country as a whole, is characterized by the isolation of this service from the broader network of treatment services, the dominance of in-patient care, the weakness of out-patient care, a lack of psychiatric care and social rehabilitation programs for people with mental health problems, and a lack of effective means to protect patients' rights.

The public foundation "Diaron" investigated the extent to which the rights of people with mental health problems are observed when they seek and receive treatment and prevention services at health care institutions in Jalal-Abad. The following health care institutions in Jalal-Abad were visited during the course of research for this report: the Province Family Medical Center of Jalal-Abad (FMC #1 and #3); department #10 of the National Mental Hospital of Jalal-Abad (NMH #10); and the Jalal-Abad Province United Hospital (JPUH).

A total of 43 people were interviewed. Of those interviewed, 24 people used the services of a health care institution; this group included 17 people with mental health problems and 7 people who were relatives of patients receiving treatment. We interviewed 19 staff members of HCIs, including 6 top managers, 8 doctors, and 5 nurses. HCI employees' relevant work experience ranged from 2 to 40 years.

The city of Jalal-Abad is served by seven groups of family doctors (GFD) from family medical centers (FMC). Each GFD serves from 17 to 100 patients with mental health problems. There is only one psychiatrist in the city. Services provided by the groups of family doctors include consultation, assignment to other institutions, prescription of medication, out-patient treatment, and medical observation.

The Jalal-Abad Province United Hospital is designed to provide beds for 620 patients. The hospital employs 177 doctors, 540 mid-level medical staff people, and 285 junior staff people. Patients come to the hospital for emergency care and are admitted through the admissions department. Common cases include attempted suicide and somatic ailments. There is no psychiatrist on staff at the hospital. When necessary and appropriate, a psychiatrist from the National Mental Hospital #10 is summoned or patients are referred to a psychiatrist elsewhere.

The psycho-narcological department of NMH #10 in Jalal-Abad is a branch of the National Mental Hospital located in Kyzyl-Jar village. It is designed to accommodate 80 patients. Patients come to the hospital from all over Jalal-Abad province. The department employs five doctors who provide in-patient care and consultation.

The objective of this report is to ensure respect for the rights of people with mental health problems when they seek health care services, and to introduce changes in the work of psychiatric services, with the aim of humanizing and democratizing these services.

# SUMMARY OF FINDINGS

In legal terms, citizens suffering from mental health problems constitute one of the most vulnerable groups in the population. The observance and provision of the right to information in the sphere of mental health is not only an indicator of the degree of civilization of a society as a whole, but also an indicator of the real state of democracy. With this in mind, protection of the rights and freedoms of those citizens who suffer from mental health problems is an important aspect of human rights protection and an important criterion to consider when judging the level of human rights implementation in the country.

During research for this report, it was found that there are violations of patients' rights in all health care institutions. This is due to the lack of an effective informational and legal training mechanism for both health care professionals and their patients. Personnel from HCIs, including top management, have only a superficial knowledge of mental health problems and the principles of psychiatric care. Many of those we interviewed were not familiar with the provisions in the Law on Psychiatric Care. We found that not all of the medical staff have post-graduate training in the area of psychiatric care. The conditions at many facilities are not suitable for the provision of psychiatric care.

Often the rights of the patients are not observed, including the right to provide informed consent for treatment, the right to information, including information about the nature of one's health problem, the proposed methods of treatment, the proposed duration of treatment, and the possible side effects of the treatment being prescribed. In addition, patients are not informed about their rights as patients. The majority of the respondents surveyed in our research were not informed about their rights and did not know how to protect their rights when they were infringed upon. The right to adequate treatment, as guaranteed by the state, is not being implemented adequately; treatment is limited to the prescription of medicine, there are no programs of medical-social rehabilitation or alternative services being provided.

One patient told interviewers: "My relatives receive my drugs. I do not know which drugs I am taking."

Patients demonstrate passivity and inaction with respect to violations of their rights. Patients themselves explain this by saying things such as, "I will not be believed anyway," or, "people will say 'he is sick, isn't he." Thus a vicious circle (of violations and tolerance for violations) is created, facilitating the further violation of the rights of people with mental health problems and increasing the discrimination and stigmatization this group experiences. This in turn affects the health of these patients.

<sup>5</sup> 

<sup>&</sup>lt;sup>1</sup> "Diaron" interview with a mental health patient, name withheld at the patient's request, Jalal-Abad, September 2007.

# SUMMARY OF CONCLUSIONS

The research conducted has demonstrated that in health care institutions in Jalal-Abad city the fundamental rights of patients with mental health problems are being violated during the provision of medical services. Patients' rights that are being violated include the right to information, the right to be informed about one's rights, and the right to adequate treatment. The violations committed against people with mental health problems include violations of legal guarantees provided under the Constitution of the Kyrgyz Republic and the Law on Psychiatric Care. The absence of systematic information and legal training for patients and medical personnel is one of the reasons behind this situation. Despite multiple projects conducted by non-governmental organizations and international experts to monitor the performance of mental health service provision, the problems remain unresolved.

Research for this report indicates that, until serious measures are taken to ensure the implementation of the Law on Psychiatric Care that was adopted in 1999, the situation in the mental health care system will continue to worsen. As a result of the growing number of people in need of psychiatric care, the government has not been able to adequately satisfy even the urgent needs of patients—such as the provision of meals, necessary health care services, and medicine. The downward trend needs to be stopped in order to avoid it becoming a disaster, at the expense of the health, safety and human rights of people suffering from mental health problems in our country.

International human rights agreements to which the Kyrgyz Republic is a party oblige the state to guarantee implementation of the rights therein. The International Covenant on Economic, Social and Cultural Rights (ICESCR)<sup>2</sup> guarantees acknowledgement of the right of each person to the highest achievable level of physical and mental health.<sup>3</sup> To fully implement this right, the state should create conditions that would provide everybody with health care in the case of disease. These guarantees relate to each person, including those with mental health problems. Another UN document, the Declaration on Social Progress and Development<sup>4</sup> states that there is a requirement to protect the rights of people with physical and mental health problems and to provide for their well-being and rehabilitation.

The cases of rights violations that are documented in this report are important guides for the improvement of the current situation, to help increase the accountability of those responsible for oversight, and to ensure respect for the dignity of people with mental health problems when they seek health care services.

# SUMMARY OF RECOMMENDATIONS

It is necessary for the government of the Kyrgyz Republic to allocate adequate funding for the mental health care system, in accordance with the guarantees provided under domestic legislation and international agreements.

Funding should allow for the provision of quality treatment and also the enhancement of public assistance and development of out-patient assistance, as well as the development of community and alternative forms of assistance to those with mental health needs. It is necessary also to ensure that medicine is accessible.

<sup>&</sup>lt;sup>2</sup> The ICESCR came into force in the Kyrgyz Republic on January 7, 1995.

<sup>&</sup>lt;sup>3</sup> Article 12 of the ICESCR.

<sup>&</sup>lt;sup>4</sup> Declared by Resolution 2542 (XXIV) of the UN General Assembly, December 11, 1969.

The Ministry of Health should undertake the necessary measures to enhance the legal education of personnel at health care institutions, and that of patients and their relatives, in order to ensure the proper functioning of health care institutions and realization of patients' rights.

Primary care physicians and general practitioners should be provided with regular and systematic updates in their knowledge of issues related to the provision of care to people with mental health issues.

# METHODOLOGY

To conduct this investigation of the observance of the rights of people with mental health needs during treatment at health care institutions in Jalal-Abad, "Diaron" developed the appropriate research methodology and instruments.

A total of 43 respondents were interviewed; 60% of them were men and 40% were women.

A total of 17 patients were interviewed, ranging in age from 25 to 45 years old. Four of the patients interviewed had higher education, the remainder had secondary and uncompleted secondary education. More than 50% of interview respondents were single or were divorced and lived with their parents under their parents' guardianship. Sixty percent of respondents had been assigned disability and received a social allowance from the state.

In addition to interviewing mental health patients, researchers for this report also interviewed providers of mental health care. We interviewed 19 staff members of health care institutions, including 6 top managers, 8 doctors, and 5 nurses. As noted above, HCI employees' relevant work experience ranged from 2 to 40 years.

During the course of developing a research and monitoring concept, researchers referenced recommendations published by the World Health Organization (WHO), as well as materials provided by the Polish Helsinki Foundation for Human Rights (Warsaw).

Researchers studied issues related to the observance of human rights and the rights of people with mental health problems during treatment at HCIs in Jalal-Abad city. Research surveys were administered among representatives of groups of family doctors (#1 and #3) from the family medical center, hospital administration, treatment departments and the statistics department of the Jalal-Abad Province United Hospital, and department #10 of the Jalal-Abad branch of the National Mental Hospital.

Researchers developed and used semi-structured interviews as the main instruments for their survey. Interviews were conducted on the basis of anonymity. Additional information was obtained from open-ended conversations, observations, and the review of documentation (such as out-patients' cards, visitor registers, medicine supplies, a complaint book, and other sources).

Researchers developed four separate questionnaires for the different groups interviewed in the survey (see the Annex for the text of these): patients and their relatives; directors of HCIs; doctors at HCIs; and nurses at HCIs.

# LEGAL ANALYSIS<sup>5</sup>

This section reviews legal provisions related to the rights of patients with mental health problems that are considered in the current research. This analysis considers provisions of the Constitution of the Kyrgyz Republic and laws "On protection of the health of citizens of the Kyrgyz Republic" and "On psychiatric care and guarantees of the rights of citizens upon its provision." These pieces of legislation are considered along with relevant international agreements and other guiding documents on patients' rights.

### INTERNATIONAL STANDARDS ON PATIENTS' RIGHTS

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 health care 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>6</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 rights articulated in the UN Convention on the Rights of Persons with Disabilities apply to people with mental health problems. The convention declares that all people with disabilities have a right to the same range, quality and standard of free or affordable health care as provided to others and that health professionals must provide people with disabilities the same quality of care, including on the basis of free and informed consent. The convention also emphasizes that the state has a duty to abolish practices that amount to discrimination against people with disabilities, including an obligation to prevent discriminatory denial of health care or health services.

In addition, each patient is entitled to all of the human rights and freedoms guaranteed by the key international agreements on human rights.

The rights of people with mental health problems

The rights of people with mental health problems are addressed in the UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care.<sup>7</sup> This document is used as a guideline for the improvement of legislation to protect the rights of people with mental health problems. According to these prin-

<sup>&</sup>lt;sup>5</sup> This section was prepared with the help of Dmitry Kabak (dkabak@ mail.ru) for the Law and Health Program of the Soros Foundation Kyrgyzstan.

<sup>&</sup>lt;sup>6</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).

Adopted by the UN General Assembly 46/119 on December 17, 1991.

ciples, "All persons have the right to the best available mental health care, which shall be part of the health and social care system." The World Health Organization (WHO) has reported on the interrelation between poverty and mental health, indicating it is complicated and multidimensional. The WHO found that there is a greater prevalence of mental and behavioral problems among poor and disadvantaged people.

In the Kyrgyz Republic, health care is regulated by the Constitution, the laws "On protection of the health of citizens of the Kyrgyz Republic" and "On psychiatric care and guarantees of the rights of citizens upon its provision," and by various secondary legislative acts adopted to implement the stipulated guarantees. The major international agreements to which the Kyrgyz Republic is a party are also a part of domestic legislation. According to expert assessments, the provisions of the law "On psychiatric care and guarantees of the rights of citizens upon its provision" are generally in keeping with the above-mentioned UN principles regarding protection of persons with mental health problems.

#### 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>8</sup>

#### 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>9</sup>

The Constitution of the Kyrgyz Republic recognizes the need for regulation of the health care 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>10</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>11</sup>

The national program on "Mental health of the population of the Kyrgyz Republic for 2001-2010" creates a framework for restructuring the system of psychiatric institutions. The program establishes the Jalal-Abad Province Center of Mental Health (formerly department #10 of the National Mental Hospital). Thus, accessibility of psychiatric care is provided for the local population.

According to the national program on "Mental health of the population of the Kyrgyz Republic for 2001-2010," the main principle of medical policy of the Ministry of Health of the Kyrgyz Republic regarding people with clinically diagnosed mental health problems is to provide them with free psychotropic drugs from the list of life sustaining medications.

According to the law, funding for institutions providing psychiatric care is provided by the state budget, from the mandatory medical insurance fund and from other

<sup>8</sup> Article 2 of the European Charter of Patients' Rights.

Article 12, paragraph 2 (d) of the International Covenant on Economic, Social and Cultural Rights.

Article 34, sections 1 and 2 of the Constitution of the Kyrgyz Republic.
 Articles 22 and 23 of the Law 'On protection of the health of citizens of the Kyrgyz Republic.'

sources, in the amount necessary to assure the guaranteed level and high quality of psychiatric care.12

International standards oblige psychiatric institutions to have adequate resources to provide guaranteed care. Psychiatric institutions should have access to the same resources as other health care institutions, and in particular: (a) Qualified medical and other appropriate professional staff in sufficient numbers and with adequate space to provide each patient with privacy and a programme of appropriate and active therapy; (b) Diagnostic and therapeutic equipment for the patient; (c) Appropriate professional care; and (d) Adequate, regular and comprehensive treatment, including supplies of medication <sup>13</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>14</sup> The ICESCR specifically guarantees access to health care facilities and services without discrimination.<sup>15</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>16</sup>

Domestic legislation explicitly guarantees that medical care will be provided to all without discrimination.<sup>17</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>18</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>19</sup>

Obligations adopted by the Kyrgyz Republic in the framework of international agreements guarantee each person's freedom from non-consensual medical treatment.<sup>20</sup> These international instruments also assert rights integral to the exercise of informed consent, including the rights to security of person<sup>21</sup> and to seek and obtain information.22

<sup>&</sup>lt;sup>12</sup> Article 17 of the Law "On psychiatric care and guarantees of the rights of citizens upon its provision."

Principle 14, paragraph 1 (a, b, c, d) of the Principles for the protection of persons with mental illness and the

improvement of mental health care, adopted by the UN General Assembly 46/119 on December 17, 1991.

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>&</sup>lt;sup>15</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>&</sup>lt;sup>16</sup> Article 13, section 3 of the Constitution of the Kyrgyz Republic.
 <sup>17</sup> Article 61 of the Law "On protection of the health of citizens of the Kyrgyz Republic."
 <sup>18</sup> Article 92 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

Article 4 of the European Charter of Patients' Rights.

<sup>&</sup>lt;sup>20</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>&</sup>lt;sup>21</sup> Article 9, paragraph 1 of the International Covenant on Civil and Political Rights.

<sup>&</sup>lt;sup>22</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>23</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>24</sup> It is prohibited to conduct medical, biological and psychological experiments on people without their properly expressed and certified voluntary consent.<sup>25</sup>

In the sphere of psychiatric care this norm is articulated through the definition of conditions for voluntary and forced care,<sup>26</sup> by recognizing the right of the patient to obtain information about his or her rights, as well as information about existing mental health problems and methods of treatment in an accessible form, taking into account the patient's mental condition, and seeking the patient's preliminary consent or refusal at any stage to participate in tests of medications and treatment methods, research or educational processes.<sup>27</sup> Legal representatives act on behalf of minors under15 years of age or persons recognized as incapacitated.<sup>28</sup>

The Law on Psychiatric Care contains exclusions allowing decisions to be made without consultation with the patient or his or her legal representatives – for instance. upon application of forced methods of medical treatment or forced hospitalization (due to direct danger to the patient and to the people around him or her, inability to independently perform vital functions, or risk of considerable damage to the patient's health due to aggravation of the mental condition without psychiatric care). In these cases treatment is applied based on the decision of the commission of psychiatrists.<sup>29</sup>

Each person is guaranteed that he or she will be provided with the opportunity to familiarize himself or herself with the relevant documents, decisions and other materials concerning his or her rights and legitimate interests.<sup>30</sup> A person suffering from mental health problems or his or her legal representative is entitled to refuse a proposed treatment,<sup>31</sup> excepting in the situation of forced measures or forced hospitalization. To protect the interests of patients, there is a requirement for medical personnel to obtain written consent<sup>32</sup> or to issue the relevant medical records to allow for the opportunity of future appeal.33

### 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>34</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 hu-

Article 14, section 3, paragraph 13 of the Constitution of the Kyrgyz Republic.
 Article 73 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

 <sup>&</sup>lt;sup>25</sup> Article 19, section 2 of the Constitution of the Kyrgyz Republic.
 <sup>26</sup> Article 4 of the Law "On psychiatric care and guarantees of the rights of citizens upon its provision."
 <sup>27</sup> Part 2 of article 5 of the Law "On psychiatric care and guarantees of the rights of citizens upon its provision."
 <sup>28</sup> Part 2 of article 4 of the Law "On psychiatric care and guarantees of the rights of citizens upon its provision."

Article 29 of the Law "On psychiatric care and guarantees of the rights of citizens upon its provision."
 Article 6 of the Law of the Kyrgyz Republic "On guarantees and freedom of access to information."

 <sup>&</sup>lt;sup>27</sup> Article bo the Law of the Nyrgyz Republic on guarantees and record of access or monimum.
 <sup>28</sup> Article 12 of the Law 'On psychiatric care and guarantees of the rights of citizens upon its provision.'
 <sup>29</sup> Item 1 of article 11 of the Law 'On psychiatric care and guarantees of the rights of citizens upon its provision.'
 <sup>31</sup> Item 2 of article 12 of the Law 'On psychiatric care and guarantees of the rights of citizens upon its provision.'

<sup>&</sup>lt;sup>34</sup> Article 5 of the European Charter of Patients' Rights.

man rights instruments affirm a person's right to obtain information<sup>35</sup> and to recognition as a person before the law.<sup>36</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>37</sup> Patients also have the right to select their attending physician, to reject the participation of students in diagnosis and treatment,<sup>38</sup> and to choose a family physician and general practitioner.39

### 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 aeneral.40

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>41</sup> and a specific right to have his or her personal health data treated with confidentiality.<sup>42</sup>

The Constitution of the Kyrgyz Republic recognizes the right to protection of one's private life<sup>43</sup> and does not allow for collection, storage, use or dissemination of confidential information about a person without his or her consent, except in cases established by law.44

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>45</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>46</sup>

### THE RIGHT TO RESPECT FOR PATIENTS' TIME

Each individual has the right to receive necessary treatment within a swift and predetermined period of time. This right applies at each phase of the treatment.<sup>47</sup>

The ICESCR requires the creation of conditions that would ensure delivery of medical care to everyone in case of sickness.<sup>48</sup> The Committee on Economic, Social and Cul-

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.

Article 16 International Covenant on Civil and Political Rights.

Article 70 of the Law "On protection of the health of citizens of the Kyrgyz Republic,"
 Article 73 of the Law "On protection of the health of citizens of the Kyrgyz Republic,"
 Article 72 of the Law "On protection of the health of citizens of the Kyrgyz Republic,"

Articles 61 and 66 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>&</sup>lt;sup>40</sup> Article 6 of the European Charter of Patients' Rights.

Article 01 in the longeral charlet of Fateria Rights.
 Article 17, paragraphs 1 and 2 of the International Covenant on Civil and Political Rights.
 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>&</sup>lt;sup>43</sup> Article 14, section 3 of the Constitution of the Kyrgyz Republic.

 <sup>&</sup>lt;sup>44</sup> Article 14, section 4 of the Constitution of the Kyrgyz Republic.

Article 14, section 4 of the Constitution of the Kyrgyz Republic.
 Article 91 of the Law "On protection of the health of citizens of the Kyrgyz Republic."
 Article 91 of the Law "On protection of the health of citizens of the Kyrgyz Republic."
 Article 7 of the European Charter of Patients' Rights.

<sup>&</sup>lt;sup>48</sup> Article 12, paragraph 2 (d) of the International Covenant on Economic, Social and Cultural Rights.

tural 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>49</sup> The legislation entrusts health care facilities with the responsibility to provide timely medical care in accordance with their material and financial resources.<sup>50</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>51</sup>

### THE RIGHT TO THE OBSERVANCE OF QUALITY STANDARDS

Each individual has the right of access to high guality health services on the basis of the specification and observance of precise standards.<sup>52</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>53</sup>

In the Kyrgyz Republic, the law recognizes the right of the patient to access to guality medical care at medical facilities, including private medical practices.<sup>54</sup> The law also establishes penalties for the failure of persons that deliver health services to provide quality care.<sup>55</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>56</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>57</sup>

### 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>58</sup>

The safety of medical care is provided for through legislatively fixed procedures for health care delivery.<sup>59</sup> People responsible for delivering health care are held accountable for failure to provide such care safely.<sup>60</sup> The authorized state body responsible for health care regulates the observance of safety procedures.<sup>61</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.62

Article 34, section 2, paragraph 2 of the Constitution of the Kyrgyz Republic. Article 95 of the Law "On protection of the health of citizens of the Kyrgyz Republic?

- Article 4 of the Law "On protection of the health of citizens of the Kyrgyz Republic."
   Article 6 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>62</sup> Article 11 of the European Charter of Patients' Rights.

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 Mandatory Health Insurance fund.

<sup>&</sup>lt;sup>52</sup> Article 8 of the European Charter of Patients' Rights.

Article 12, paragraph 1 of the International Covenant on Economic, Social and Cultural Rights.
 Article 72 of the Law "On protection of the health of citizens of the Kyrgyz Republic."

<sup>&</sup>lt;sup>57</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 Mandatory Health Insurance fund. <sup>58</sup> Article 9 of the European Charter of Patients' Rights.

Article 34, section 2, paragraph 2 of the Constitution of the Kyrgyz Republic.
 Article 4 of the Law "On protection of the health of citizens of the Kyrgyz Republic."
 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.

Each person has the right to security of his or her person.<sup>63</sup> International human rights standards include recognition of the inherit dignity of all people.<sup>64</sup> Legal instruments specifically assert that no one shall be exposed to torture or cruel, inhuman and degrading treatment or punishment.<sup>65</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>66</sup>

The Constitution of the Kyrgyz Republic provides for protection from torture and inhuman or degrading punishment.<sup>67</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>68</sup> Domestic legislation further stipulates that patients have the right to be treated with a humane attitude by medical staff and attendants.<sup>69</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>70</sup>

UN agreements on human rights guarantee each person the right to effective remedy for rights violations.<sup>71</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 ombudsmen, human rights commissions, consumer forums, patients' rights associations or similar institutions should address violations of the right to health."72 The right to file a complaint is also explicitly provided for in cases of torture and cruel treatment or punishment.73

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 health care facility, as well as to corresponding state medical institutions or to the courts. The legislation establishes a thirty-day period for the examination of complaints.<sup>74</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.75

Article 9, paragraph 1 of the International Covenant on Civil and Political Rights.

<sup>64</sup> The Universal Declaration of Human Rights.

<sup>&</sup>lt;sup>65</sup> Article 7 of the International Covenant on Civil and Political Rights.

<sup>&</sup>lt;sup>66</sup> Article 1 Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.

Article 19, paragraph 1 of the Constitution of the Kyrgyz Republic.
 Article 20 of the Law "On protection of the health of citizens of the Kyrgyz Republic."
 Article 20 of the Law "On protection of the health of citizens of the Kyrgyz Republic."
 Article 20 of the Law "On protection of the health of citizens of the Kyrgyz Republic."
 Article 20 of the Law "On protection of the health of citizens of the Kyrgyz Republic."
 Article 13 of the European Charter of Patients' Rights.

<sup>&</sup>lt;sup>71</sup> Article 2, paragraph 3 (a, b, c) of the International Covenant on Civil and Political Rights.

<sup>&</sup>lt;sup>22</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).

Article 13 of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.
 Article 8 of the Law of the Kyrgyz Republic "On procedures for examination of complaints of citizens."
 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.

# **VIOLATIONS OF PATIENTS' RIGHTS** VIOLATION OF THE RIGHT OF ACCESS TO INFORMATION AND NOTIFICATION OF ONE'S RIGHTS

One of the key components of protection of the rights of people with mental health problems is the right to information regarding one's disease, diagnosis, and methods of treatment. Also important is the right to be informed about the rights that one is guaranteed by domestic legislation. A doctor is obliged to inform his or her patient who is suffering from a mental health problem about the character of his or her mental health problem, the purpose and methods of treatment, including alternative treatments, and the duration of the recommended treatment, as well as about pain, possible risks, side effects, and the anticipated results of treatment, in an accessible, comprehensible way, taking into account the mental condition of the patient.<sup>76</sup> Lack of information about one's diagnosis and applicable methods of treatment can have negative effects on a patient's health.

Sanjar (a pseudonym), a 36 year old, said:

I did not know my diagnosis and what was prescribed for me. When they gave me medicine I tried not to take it. I collected it and threw it in the trashcan. because other patients warned me that my whole body would be convulsed after I took these pills. I saw these patients and was scared to ask the doctor about this. Later on, the doctors found out that I had not taken the pills. When they started explaining to me [that I needed them], I did not trust them. Only when I read the product information for the sonopax did I understand that I had wasted time suffering from insomnia when I threw the pills out.77

During the course of conducting their survey, researchers found that patients are not informed about their rights and the procedures for realizing their rights. Patients' own passivity about their rights is explained by their experiences of being labeled for many years by behavioral stereotypes, their lack of education, and their lack of effective means of acquiring information and exercising control in their lives. None of the general hospitals provided information about the rights of patients with mental health problems in an accessible form. The text of the Law on Psychiatric Care was also not found in a place accessible to both medical personnel and patients.

One patient reported that his diagnosis had not been communicated to him even after several years of treatment. Jenishbek (a pseudonym), a 32 year old, said:

The doctor has observed me for many years already, [as a requirement] for me to be able to receive a pension. I take some pills. When I was a kid I suffered a head trauma. The doctors did not explain what it was and never gave me a diagnosis. And I am not familiar with the law [on psychiatric care], nobody told me about it.78

When the doctors fail to present patients with information about their treatment, it can cause unnecessary suffering and affect the health of the patients.

Law of the Kyrgyz Republic "On psychiatric care and guarantees of the rights of citizens upon its provision," May 25, 1999.

 <sup>&</sup>quot;Diaron" interview with Sanjar (a pseudonym), a patient, Jalal-Abad, September 2007.
 "Diaron" interview with Jenishbek (a pseudonym), a patient, Jalal-Abad, September 2007.

Taalai (a pseudonym), a 24 year old, told researchers:

I was told that I had a mental disorder and I was prescribed some drugs. I felt even worse after these drugs; I couldn't sit quietly, my body didn't listen to me, and I was scared. I couldn't even imagine that the drugs might cause such complications, since the doctors didn't warn me about this. I found out about it later on, when I read product information for the drugs.<sup>79</sup>

During conversations with doctors from the group of family doctors, researchers found differences in their attitude toward patients with mental health problems, as compared to their attitude toward other patients, such as children or those with heart problems or infectious diseases. General practitioners have little interest in those with mental health needs and pay little attention to them. Researchers also found a lack of legal education and information among the staff members of family medical centers. Doctors' lack of knowledge creates obstacles to patients' access to proper care and can foster distrust.

One family medical center doctor, a 41 year old, said:

I have a pretty big workload, a lot of paper work and a line of patients. I am not familiar with the Law on Psychiatric Care. It is possible to get it and read it through, but I have no time. I have no experience working with mental patients in my practice. When I serve patients with mental health problems, I prescribe them medicine, so as a rule I send them to a psychiatrist.<sup>80</sup>

Interviews with health care personnel in health care institutions demonstrated that these medical professionals did not take seriously the issue of discussing a treatment plan with patients and informing patients about their rights. These ideas are perceived as nave and pointless. In the majority of cases, the treatment plan is not discussed with the patient.

One family medical center doctor, Nurgul (a pseudonym), a 34 year old, said:

I have difficulties and feel uneasy when I serve patients with mental health problems, since I have no experience working with this category of patient. If I prescribe medicine, I prefer to give it to the [patient's] relatives and explain to them how to take it. I don't trust the patients themselves, because they can mess it up, or misunderstand, can't they?<sup>81</sup>

### VIOLATIONS OF THE RIGHT TO ADEQUATE TREATMENT

It was learned during the course of research for this report that appropriate treatment is not accessible to those with mental health needs. Doctors from family medical centers only write prescriptions for medication and send patients to an inpatient facility. It is clear that the majority of doctors continue to believe that in-patient treatment is the preferable method of psychiatric care.

The constant shortage in funding is cited by the staff of mental hospitals as the single and most urgent obstacle to the provision of adequate psychiatric care.

<sup>79 &</sup>quot;Diaron" interview with Taalai (a pseudonym), a patient, Jalal-Abad, September 2007.

<sup>&</sup>lt;sup>80</sup> "Diaron" interview with a family medical center doctor, name withheld at the doctor's request, Jalal-Abad, September 2007.

<sup>&</sup>lt;sup>81</sup> "Diaron" interview with Nurgul (a pseudonym), a family medical center doctor, Jalal-Abad, September 2007.

The head of a hospital department, a 50 year old, said:

Our hospital is a branch of the National Mental Hospital located in Kyzyl-Jar village, which is far (164 kilometers) from the city. For this reason, the majority of patients referred to us prefer to receive treatment here. Due to the large number of patients, we quickly run out of medicine, the wards are getting overloaded, and there may be interruptions in the medicine supply. In these cases patients have to buy the medicine themselves. There is a big workload, while staff salaries are low. The conditions in the department could be better; soft and hard equipment is worn-out, it is inadequate and it is not replaced. Office supplies are not coming in. There is a plan to open a mental health center for the province soon, where all the above-mentioned problems will be taken into account, so we hope that all these problems will be addressed.<sup>82</sup>

The disrespectful attitude of some doctors toward their patients with mental health problems, together with the low priority of this group and low quality of medical care provided to such patients in comparison with others, aggravate the discrimination and stigmatization of the mentally ill that they already experience in the broader society. The shortage in free medication is an additional burden for this group of patients.

Elena (a pseudonym), a 58 year old, said:

My daughter has been sick since childhood. I am sick and tired of going to the polyclinic: one can't get any sense out of them, there is no doctor there – the doctor is always out. And if you catch her, she is always in a hurry, she will not listen to complaints, she even says rude things. One has to waste the whole day to get a prescription for medicine, because without the prescription one can't buy it in the pharmacy. Not all pharmacies have these drugs. On top of that, they are very expensive. I spend all of my pension on the drugs for my daughter.<sup>83</sup>

The prevalence of pharmacological therapy, lack of rehabilitation programs, and limited access to free treatment force patients to buy medication themselves.

Karimjan (a pseudonym), a 29 year old, said:

I have been registered with a psychiatrist for eight years now. During this time I have not received any free treatment. I take tisercin constantly and take haloperidol decanoate monthly. I buy medicine in the pharmacies by prescription, but more often my father brings them from Andijan (a city in neighboring Uzbekistan).<sup>84</sup>

In addition, monitoring has shown that there are various difficulties preventing implementation of the principle of providing treatment that will help preserve patients' independence. Inadequate funding and medicine shortages are problems affecting all institutions. According to the information obtained from survey respondents, 70-80% of medications are bought for patients by their families, the majority of whom are poor. Health care services should be accessible to all, without distinction based on a person's economic and social status, but, in practice, medical care is not always accessible for everybody.

<sup>&</sup>lt;sup>82</sup> "Diaron" interview with the head of a department, name withheld at the interviewee's request, Jalal-Abad, September 2007.

<sup>&</sup>lt;sup>83</sup> "Diaron" interview with Elena (a pseudonym), a patient's mother, Jalal-Abad, September 2007

<sup>&</sup>lt;sup>84</sup> "Diaron" interview with Karimjan (a pseudonym), a patient, Jalai-Abad, September 2007. Haloperidol decanoate is an antipsychotic medication.

Almagul (a pseudonym), a 43 year old, said:

My husband has suffered from a mental disorder for more than 15 years. In addition, he drinks. He is [categorized as] one of the disabled of the 2nd group and he does not work. We have four children. The doctors said that he will take medicine until the end of his life. We have to take him to the mental hospital for treatment several times a year. There are certain difficulties in taking him to the hospital, buying him drugs, paying for writing up his case history, bringing him food, bedding, etc. There are few or none of the required medicines in the hospital, so we have to buy them. Sometimes it happens that there is no room in the hospital.<sup>85</sup>

<sup>85</sup> "Diaron" interview with Almagul (a pseudonym), a patient's wife, Jalal-Abad, September 2007.

## CONCLUSIONS

Although the content of the Law of the Kyrgyz Republic "On psychiatric care and guarantees of the rights of citizens upon its provision" in general is recognized by experts as being compliant with international standards, there are significant problems related to its implementation in practice.

Despite the fact that mental health is a field in which the rights of patients have long been under the steadfast observation of human rights defenders, our survey has shown that infringement of fundamental human rights is still taking place, including infringement of the right to information, the right to be informed about one's rights, and the right to adequate treatment in health care institutions in Jalal-Abad city.

Administration officials in health care institutions do not require doctors to inform their patients about their rights. Lack of systematic training of doctors and patients about the legal aspects of psychiatric care and about the development of skills needed in the provision of psychiatric care affect the quality of health care provided by medical personnel. The violations of patient's rights taking place aggravate the negligence and passivity of patients. The Law on Psychiatric Care is not made available to medical personnel and patients; there are no information materials about the content of this law provided at health care facilities.

There is no effective control over the implementation of the Law on Psychiatric Care and related normative acts on the part of the state. There is no system in place to deal with the protection of patients' rights independent of the state health care system, the establishment of which is provided for by the law. Many patients suffer from violation of their right to information and failure of medical personnel to respect rights guaranteed by domestic legislation. In addition, patients are not being informed about the opportunity to file a complaint against the actions of medical personnel.

The Ministry of Health of the Kyrgyz Republic has not undertaken the necessary measures to liberalize the procedures of psychiatric care provision, including by establishing open institutions, providing psychiatric services where patients are located, introducing a financing system for institutions based on assessments of the quality of their performance, and developing programs of community-based psychiatric care and social rehabilitation, all of which are recognized by the World Health Organization as the most effective and optimal means to ensure observance of patients' fundamental human rights.

# RECOMMENDATIONS

### TO THE GOVERNMENT OF THE KYRGYZ REPUBLIC

# • Allocate the funding necessary to implement the Law on Psychiatric Care and the national program for 2001–2010.

Full and adequate funding should be provided to allow for appropriate treatment of patients in medical institutions and also to raise the level of public assistance and forms of assistance offered outside hospital settings. Without additional funding it is practically impossible to effectively implement the Law on Psychiatric Care and the national program on "Mental health of the population of the Kyrgyz Republic for 2001-2010."

# • Establish an independent institution for the protection of patients' rights.

The government should establish an independent institution for the protection of the rights of mental health patients, as provided for by article 38 of the Law on Psychiatric Care. This agency should facilitate the protection of patients' rights, oversee the performance of psychiatric services being provided, and consider complaints by patients whose rights have been violated.

### TO THE MINISTRY OF HEALTH

### • Inform patients about their rights.

It is the responsibility of doctors to inform patients about their rights in way that is accessible and understandable. Initial steps toward the implementation of the right of access to information include wide dissemination of the Law on Psychiatric Care among medical personnel and patients, introduction of the practice of informing and discussing with patients their treatment plan and possible treatment methods, as well as providing detailed information to patients regarding the opportunity to file a complaint against any illegal actions by medical personnel. Medical institutions should receive explanations of the provisions in the Law on Psychiatric Care in order to study and learn them.

# • Establish a system to inform doctors about new programs and approaches in psychiatry.

In order to improve the observance of patients' right to information, and to improve the quality of health care being provided, it is necessary to regularly train doctors on new approaches in psychiatry. Doctors should be trained on the development of social rehabilitation programs and psychopharmacology; trainings should involve learning from the advanced experience of other countries, with a view to changing current practices.

### • Ensure the accessibility of medicine.

Psychotropic medications should be accessible to those who need them at all levels of the health care system, and especially in the primary health care network. Family doctors and psychiatrists at polyclinics should assume the responsibility for treatment of mental health problems at the primary level. Administrative officials at these institutions should undertake all possible measures to implement the state guarantees to provide medication to people with mental health problems.

### • Introduce alternative forms of assistance in the community.

It is necessary to develop alternative forms of assistance in the community, to develop special training programs and programs of social rehabilitation for people with mental health needs. The World Health Organization strongly recommends that UN member states develop various forms of assistance in the community. It is easier to guarantee patients' rights when services are offered close to where the patient is located and when they meet the main requirements of health care consumers.

It is also necessary to establish and develop self-help groups. Health care institutions and local self-governance structures should facilitate the development of patient self-help groups by providing them the premises to conduct meetings and other events.

### **TO DONORS**

- Increase the volume of financial aid and technical assistance to non-governmental
  organizations and health care institutions working with people with mental health
  problems. In particular, increase funding for programs providing direct aid to the
  organizations working on forms of assistance outside of hospital settings, on
  the development of community assistance, and to improve conditions in mental
  hospitals.
- Support initiatives to conduct public campaigns aimed at the destigmatization of people with mental health problems. Support programs aimed at the establishment of self-help groups and the legal education of patients and their relatives.

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# ANNEXES

# Annex A. Questionnaire for the recipients of HCI service (patients and their relatives)

# A. Introductory conversation:

- 1. Information about the program.
- 2. Consent.
- 3. Guarantees of protection (anonymity), opportunity to choose.
- 4. Personal information.
- 5. Name, last name.
- 6. Year of birth.
- 7. Place of residence.
- 8. Occupation. Education.
- 9. Social status.
- 10. Diagnosis and duration of the disease (voluntarily).
- 11. Availability of the group of disability. The size of monthly disability allowance.

# B. Service received: Where? When? By whom?

- 1. Evaluation of the service provided by HCI.
- 2. Frequency of HCI service received.
- 3. Evaluation of relations with the doctor, medical personnel of HCI.
- 4. To what extent does medical personnel help to address the problems related to your health, are you satisfied with the results?
- 5. Were there problems upon receiving medical services at the HCI? If yes, explain, where, when and what kind?
- 6. How did you demand that your rights be observed? How did you complain, where, to whom? What were the responses and the results?
- 7. Did you agree with the service received, or was a prescription issued without your knowledge (the matter was decided by someone else)?
- 8. Do you discuss treatment methods with your doctor?
- 9. Were there moments when the prescribed treatment did not help you, or did not have the expected result? How was the problem resolved?
- 10. How effective is the treatment that you receive? To your opinion, which factors does it depend on?
- 11. Do you know about the medicine that you take? Has your doctor informed you about the medicine, the effects and side effects?
- 12. Are prescribed medications always available? How do you buy the medicine? Do you have an opportunity to buy medicine at beneficial terms?
- 13.Did you apply to receive help (drugs, material support, etc.)? Where? When? To whom? What were the results?
- 14. Do you know which medicines you can buy on beneficial terms, about additional packages available from humanitarian aid? Which ones were provided to you for free?

- 15. Did you refer to doctors with other specializations? Where? When? To whom? What were the responses and results? Were you refused treatment? In what form?
- 16. What did you do to file a complaint about the violation? Did you lodge a complaint for refusal of treatment? Where? When? To whom? What were the results? What have been the consequences to your health?
- 17. What was the attitude of medical personnel toward you?
- 18.Do you know about your rights as a patient?
- 19. Do you know about the law on psychiatric care and guarantees of citizens upon its provision? Did your doctor inform you about this law and about your rights?
- 20. Were there concrete cases of your rights being violated upon receiving medical care at health care institutions?
- 21. Were there cases of discrimination towards you? If yes, where, when, by whom, under what circumstances?
- 22. Did you use self-treatment when you had a health problem? If yes, why? What were the results?
- 23. Would you like to change anything in the methods of treatment? What kind of care would you like to receive (rehabilitation, self-help groups, treatment at home, a crisis plan, etc.)?

Questions to the team of interviewers: \_\_\_\_\_

# Annex B. Questionnaire for the directors of HCIs in Jalal-Abad city

### A. Introductory conversation:

Official data about the director of HCI.

# B. Conditions of HCI functioning

- 1. Location:
- 1.1. Architecture.
- 1.2. The number of beds.
- 1.3. Personnel (number, training, employee turnover and etc.).
- 1.4. Condition of reception.
- 1.5. Conditions of consulting, conversation.
- 1.6. Conditions of examination.
- 1.7. General atmosphere.
- 1.8. Accessibility of the services.
- 2. Conditions of hospitalization:
- 2.1. With the availability of informed consent?
- 2.2. With the availability of consent of a legal representative?
- 2.3. Without consent (or court decision)?
- 2. Interview

- 1. Ideas regarding the types of psychiatric care and about mental hospitals?
- 2. What is your opinion regarding the need to provide psychiatric care? Your assessment of the problem?
- 3. What is the real capacity of the HCl in terms of psychiatric care provision?
- 4. What is psychiatric care in the HCI presented by? How is emergency care provided to patients?
- 5. Do you consider the services provided as adequate? Does the allocated budget cover the requirements related to psychiatric care provision?
- 6. What are the conditions needed for patients to receive free of charge or beneficial care, for patients with mental health problems?
- 7. Are there additional types of care (humanitarian aid, charity, etc.)?
- 8. Do you support the introduction of new forms of treatment for patients with mental health problems? If yes, how might these forms of treatment be implemented in practice?
- 9. Do you support the introduction of new positions (psychiatrist, psychologist, sociologist) in your HCI?
- 10. What is your evaluation of the professional level of the medical personnel? How might it be changed? Is there a need for training seminars?
- 11. What methods do you use to evaluate the performance of medical personnel (based on complaints, on the quality of treatment to the patients, based on documentation, based on the results of treatment, appreciation of the patients)?
- 12. What laws and provisions regulate your work? Are these documents accessible in the HCI?
- 13. In your opinion, is there infringement of patients' rights? In your opinion, why are these violations taking place? What needs to be done to prevent these violations?
- 14. Are you familiar with the Law on Psychiatric Care? To what extent is it applicable in your practice?
- 15. Were there cases of punishment for infringement of the rights of patients? If yes, when, for whom and what were the results?
- 16. In your opinion, who should control the implementation of the Law on Psychiatric Care? How should it be introduced in practice?
- C. Your proposals
- 1. What would you change in your work? What else would you propose to improve the service being provided?
- 2. What do you assess as positive and negative in your work? Do you have questions for us?
- 3. What are your proposals?

# Annex C. Questionnaire for doctors at HCIs in Jalal-Abad city

# A. Introductory conversation

- 1. Doctor's name, last name.
- 2. Place of employment, occupied position, work experience.
- 3. Social status.

# B. Interview

1. Employment conditions:

Do you like your work?

- Are you satisfied with your work?
- What is your salary?
- What is your work load, the total number of patients that you receive daily?
- What benefits do you receive from the state?
- What are your working conditions? Do they meet the requirements set out for your work (in terms of receiving patients with mental health problems, consulting, provision of medical care in general)?
- What is the status of the medicine supply?
- What is the condition of medical equipment?
- Do you conduct inventory?
- Have you passed your training courses? If yes, where, when, in what specialization? How do you rate the quality of the training you received in terms of your preparedness to start working?
- Would you like to update your qualifications? On what issues within the field of psychiatry? Do you have medical literature or access to a hospital library?
- Are you prepared to receive patients with mental health problems in general? And those with acute conditions? Are there adequate means and conditions (physical support, medicine) to receive such patients? If there were such cases, how were they resolved?
- Are you familiar with the Law on Psychiatric Care? If yes, how? Who controls the implementation of this Law?
- To what extent is the Law applicable in your practice? Have there been cases of violation of the Law?
- Were there cases of discrimination against patients in your practice?
- Were there cases of refusal to treat or care for a patient because of the fact that the patient had mental health problems? When did it happen, who was denied, what happened to the patient, what were the consequences to his or her health?
- Were there cases of bad, humiliating treatment of the patient on the part of relatives or medical personnel? What measures were undertaken? What were the results?
- In your opinion, do you receive adequate support from the state?
- What kind of support do you receive?
- What kind of support would you like to receive?

Did you refer to senior authorities for assistance to address problems you were having?

What was the response? What were the results?

- 2. Health care service
- Is your service accessible to patients with mental health problems? In your opinion, what factors does it depend on? Is it possible to remove factors hindering access?

How do you relate with patients with mental health problems?

- Are there difficulties during communications with patients (difficult patients)? If yes, how do you address this problem?
- Have you been confronted with the patients who created problems for you? How did you resolve them?
- How do you respond to requests by patients?
- In your opinion, do your patients know about their diseases and methods of treatment?

Do you provide your patients with information about their diseases, diagnosis, medications, and treatment?

- Is it possible to treat patients with mental health problems? Is it possible to treat people with mental health problems given your working conditions?
- How often do patients with mental health problems refer to you for care? What are their complaints (of mental or somatic character)? How do you address them?
- Do you obtain the consent of the patients upon administration of a service and do you approve the choice of the type of treatment? Does the patient participate in dealing with questions concerning his or her treatment, or does somebody else decide it (doctor, relatives)?

Do patients know about their rights? Do you provide patients with information:

- about the rights of patients?
- about the Law on Psychiatric Care?
- about possible ways to protect their rights?
- What medicine do you have available to you to treat patients with mental health problems? Are there medications issued to patients as benefits? Are there medications made available through an additional package? Are there medications issued via government grants? In your opinion, is the available medicine adequate to treat patients with mental health problems?
- Do you have the opportunity to prescribe psychotropic medicine? If yes, who buys this? Who pays for it?
- What services do you provide, apart from reception consultations and prescription of pharmacotherapy?
- Do you have any informational or educational handouts about mental health problems and mental health? What do you think, are these necessary?
- In your opinion, is it possible to introduce other types of care rehabilitation at home, work on a crisis plan? Is it necessary?
- Did you send patients with mental health problems for in-patient treatment to a general hospital? If there were problems, what kind of problems? How did you resolve them? What were the results?

How do you receive patients with mental health problems and how are house calls arranged?

- How often do you provide house calls? Are the conditions created for that (availability of vehicles, coverage of transportation costs)? If yes, how is this problem resolved?
- How are patients with mental health problems assigned for treatment in your institution? How often is the patient sent [for treatment] without his or her consent? Or without the consent of his or her legal representative?
- How is the hospitalization of a patient to an in-patient facility arranged? Do you obtain consent for that?
- How often is a patient hospitalized without his or her consent, upon court decision or upon the consent of his or her legal representative?

Were there cases of forced hospitalization without a court decision?

- Were there cases of infringement of patients' rights during provision of medical care at your institution? When, by whom, how and what were the results?
- Who oversees cases of infringement of patients' rights and the implementation of the Law on Psychiatric Care?

# C. Your proposals

# Annex D. Questionnaire for nurses at HCIs in Jalal-Abad city

# A. Introductory conversation

Information about medical personnel: name and last name.

Place of employment.

Position. Work experience.

Social status.

# B. Interview

1. Working conditions.

- 1.1. What do you think, do the conditions in your office meet the requirements for conducting your work?
- 1.2. The office of medical personnel (equipment, conditions for conducting examination, conversations, consulting, provision of information, general atmosphere)?
- 1.3. Do you like your work? What is your salary? What benefits do you receive from the state?
- 1.4. What is your work load? How many patients do you receive per day and how many home visits do you conduct? How many registered patients with mental health problems are there in your section?
- 1.5. Have you passed your training courses? Which courses? Would you like to update your qualifications? In what program? Do you have any literature on mental health problems?
- 1.6. Are you prepared to receive patients with mental health problems? Are there adequate conditions for this kind of work?

- 1.7. Are you familiar with the Law on Psychiatric Care? Who informed you about this Law? Who oversees the implementation of this Law? To what extent is this Law implemented in practice?
- 1.8. Have there been cases of violation of the Law? Were there cases of discrimination against patients? If yes, when, where, by whom? How was the problem resolved?
- 1.9. Were there cases of bad, humiliating treatment of a patient by relatives or medical personnel? What measures were undertaken? What were the results?
- 1.10. Were there cases of refusal to treat or care for a patient because of the fact that the patient had mental health problems? When did it happen, who was denied, what happened to the patient, what were the consequences to his or her health?
- 1.11. Were there cases of threats against you by patients? How did you respond to the threat? Were there cases of attack? What was your response? What means of protection are provided for in such cases? Are those means of protection accessible?
- 1.12. What difficulties are there in your work?
- 1.13. In your opinion, do you receive adequate support from the state? What kind of support do you receive? What kind of support would you like to receive?
- 1.14. Have you applied for assistance to address problems you were having? Where did you refer to, when, what was the response? What were the results?
- 2. Health care service
- 2.1. What kind of service do you provide to your patients?
- 2.2. What do you think, are your services accessible to health care consumers? On which factors does accessibility depend?
- 2.3. How do you relate with the patients? Are there difficulties during communication with patients with mental health problems (difficult patients)? If yes, how do you address them?
- 2.4. How often do patients with mental health problems refer to you? What kind of complaints do they have? What is your response to their requests? Are they always satisfied with the services received?
- 2.5. What medicine do you have to treat patients with mental health problems? Is medicine accessible to all patients? How do patients buy medicine? Do they receive medicine at a discounted price and as part of a humanitarian aid package?
- 2.6. What kind of services do you provide to your patients apart from pharmacotherapy? Do you support the introduction of new forms of treatment? Is it possible to introduce the new services given your circumstances?
- 2.7. Does a patient [typically] know about the methods of treatment he or she is receiving? Do you provide information to the patient about the treatment, about his or her disease and about medication?
- 2.8. Do patients know about their rights? Do you provide patients with information about their rights? Do you familiarize patients with the Law on Psychiatric Care and possible ways to protect their rights?

- 2.9. Do you obtain the consent of a patient to administer services upon provision of these services and do you agree with the patient on the method of treatment? Does the patient participate in the decision-making regarding his or her health and treatment? Or does another person decide for the patient (medical personnel, relatives)?
- 2.10. How is patient referral to in-patient treatment arranged at your institution?
- 2.11. Were there cases of forced hospitalization without the patient's consent? How often are patients referred to treatment without their consent?
- 2.12. How often does patient referral to treatment is happening upon the consent of his or her legal representative?
- 2.13. Were there problems when patients received care from other specialists general practitioners, neuropathologists, surgeons, ophthalmologists, etc.? Were there cases of refusal of care because of the fact that the patient had mental health problems? Where, when who denied care, what happened to the patient, what were the consequences to his or her health?
- 2.14. How often are you called to the homes of patients? Is this type of service accessible to all? Is there transportation for this type of service? If yes, how are house calls arranged?
- 2.15. Do you have any educational materials on mental health problems? Is educational assistance included in the scope of services you provide? What do you think, is there a necessity for such types of services?

### C. Your proposals

- 1. What would you change in your work? What additions would you propose to improve the service provided?
- 2. What do you assess as positive and negative in your work?
- 3. Do you have questions for us?
- 4. What are your proposals?