



# “WE ARE LIKE DEAD SOULS”

LIFE WITHOUT LEGAL CAPACITY IN KAZAKHSTAN

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**Cover photo:** Nikolai Klochkov looking out of the window of the flat he shares with other beneficiaries of a sheltered housing project run by the Association of Psychoanalysts in Almaty  
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# GLOSSARY

## PSYCHOSOCIAL AND INTELLECTUAL DISABILITIES

The convention on the rights of persons with disabilities does not define disability, but in Article 1 it does offer a basis for understanding to whom the CRPD applies and was intended by the drafters to serve as a baseline for states in defining disability for various purposes in legislation. We are using these terms to refer to what is commonly referred to as “mental health conditions”. Various official documents use different terms, such as “mental disabilities”.

## LEGAL CAPACITY

Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency). It is the key to accessing meaningful participation in society.<sup>1</sup>

## MENTAL CAPACITY

Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors.<sup>2</sup>

## GUARDIANSHIP

Adults deprived of legal capacity in Kazakhstan are placed under guardianship and a guardian makes all or some decisions on their behalf. Plenary guardianship refers to a system where the guardian takes all decisions on behalf of the person under guardianship.

## INCAPABILITY

Persons deprived of their legal capacity are referred to as being “incapable” under the law in Kazakhstan.

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<sup>1</sup> Committee on the Rights of Persons with Disabilities, General comment No. 1, Article 12: Equal recognition before the law, UN Doc. CRPD/C/GC/1, 19 May 2014, Eleventh session 31 March–11 April 2014, para. 13

<sup>2</sup> *Id.*

# EXECUTIVE SUMMARY

At least 16,000 persons with psychosocial and intellectual disabilities in Kazakhstan have been recognised as “incapable,”<sup>3</sup> deprived of legal capacity, and a guardian has been appointed to make all decisions about their lives for them. This guardianship regime is incompatible with the Convention on the Rights of Persons with Disabilities (CRPD)’s human rights-based approach to disability. Its consequences are devastating as it stigmatizes persons with psychosocial and intellectual disabilities by preventing them from exercising their human rights. It is a relic of a system that condemned persons with disabilities to a life in institutions hidden from the public gaze.

Kazakhstan is one of several countries in the post-Soviet region where discriminatory guardianship regimes continue to define the lives of people with disabilities. Kazakhstan’s guardianship regime should be replaced by one which allows persons with psychosocial and intellectual disabilities exercise of their rights as equal members of society.

Under current laws, persons with psychosocial and intellectual disabilities can be declared “incapable” by a court and put in the care of a guardian (often a close relative). From that moment on, they are no longer able to make decisions about their lives nor exercise their rights. Once a person is declared “incapable” by a court they are deprived of the right to make any decisions about their lives – for instance, to control their finances, to marry, to study or to work. Doctors no longer need their free and informed consent for medical treatment and can treat and hospitalize them with the consent of their guardian.

While the ostensible aim of the guardianship regime is to “protect” persons with psychosocial and intellectual disabilities, in practice it often exposes them to exploitation at the hands of self-seeking or inadequate guardians who fail to act in their best interest or seek to take advantage of their property. The “one size fits all” system allows no flexibility in the application of purported protection measures and cannot be adapted to individual needs. Once declared “incapable” persons with psychosocial and intellectual disabilities are trapped in a vicious circle: they are dependent on the will of a guardian who may not have their best interests at heart, yet they cannot apply to a court to restore their legal capacity or change their guardian because they are “incapable”. If they are in an institution they have little hope of ever leaving.

The law does not provide for an automatic review of “incapability” decisions and legal capacity can only be restored if the person is judged to have been “cured” or if their guardian or Prosecutor General’s office applies to restore it. In practice, it is very rare for legal capacity to be restored and most people will remain under guardianship for life. Those who attempt to regain their legal capacity with the help of others face demeaning and absurd tests of their mental capacity.

The criteria for depriving people of legal capacity are vague and set a very low threshold considering the overwhelming consequences of such a step. The law merely stipulates that a “person who cannot understand the meaning of his actions or cannot control them as a result of mental illness or weak-mindedness” may be declared incapable by a court. Experts interviewed by Amnesty International for this research have failed to explain the criteria or even point to a source where these are clearly outlined.

Vadim Nesterov is one of a group of young adults interviewed by Amnesty International who have been transferred out of state residential psychiatric facilities<sup>4</sup> and are now taking part in an NGO-supported community living project. Their example demonstrates that they are indeed able to lead a normal life outside of state institutions. During Vadim’s childhood he was given a diagnosis of “mental retardation” and moved

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<sup>3</sup> The term “legal capacity” (Rus. pravospobnost), in line with the Convention on the Rights of Persons with Disabilities encompasses the term “legal agency” (Rus. deesposobnost). In Kazakhstan these two terms are used separately.

<sup>4</sup> The Russian term is *medico-social institution*.

to a juvenile psychiatric institution. At the age of 18 he was transferred to an adult state residential psychiatric facility, deprived of his legal capacity without his knowledge, and the director of the facility became his guardian. Parents of adult children with disabilities are often told by social services officials to apply to courts to have their children deprived of their legal capacity when they turn 18 and to become their guardians in order to continue receiving state benefits on their behalf.

Kazakhstan ratified the Convention on the Rights of Persons with Disabilities (CRPD) in 2015, and the government has made some progress towards improving support services in the community. It has opened additional, state-funded day care centres<sup>5</sup> for children with disabilities throughout the country, has amended legislation<sup>6</sup> to allow NGOs to provide government funded services, and has introduced legislation on additional “special social care”. However, Kazakhstan needs to go further if it is to fully comply with its obligations as a state party to the CRPD, including examining recent reforms such as those above to ensure they comply with the CRPD. Article 5 (1) of the CRPD requires that state parties recognize that all persons are “equal before and under the law”. This means that persons with disabilities not only have rights on an equal basis with others, but that they are able to exercise those rights themselves.

The next task for the Kazakhstani government will be to lay out a timetable to replace the guardianship system for adults with an adequate system of support for persons with psychosocial and intellectual disabilities. This system should be based on the actual capacity of the person concerned and be tailored to their needs. The support system should enable persons with psychosocial and intellectual disabilities to exercise their rights as equal members of society without fear of exploitation or coercion, and not take away their legal capacity – and with it their rights. The Kazakhstani authorities should also explore best practice by consulting closely and actively with persons with disabilities including children, and with their representative organizations, and by working with experts from other countries.

While the report refers explicitly to persons with psychosocial and intellectual disabilities, the rights discussed pertain to all persons with disabilities, as set out by the CRPD.

## METHODOLOGY

In preparing this report Amnesty International visited Kazakhstan in February and August 2018 and carried out in-depth interviews with 15 individuals with psychiatric diagnoses, parents of children with disabilities, psychiatrists, NGO workers, lawyers and human rights defenders, as well as employees of the Ministry for Labour and Social Protection, the Ministry of Health, and the Ombudsman’s Office. Amnesty International delegates visited Almaty, Astana, and Uralsk. We were introduced to most of the interviewees by NGOs who had supported them in various ways, including in assisting them to regain their legal capacity. Psychiatric hospitals and hostels are closed facilities in Kazakhstan and require official permission to visit. With the assistance of the Ministry of Foreign Affairs, we were able to interview residents in one psychiatric home, and we met psychiatrists working in the mental health centres in Almaty, Astana and Uralsk. Amnesty International is very grateful for the cooperation and openness shown by the Kazakhstani authorities.

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<sup>5</sup> These centres offer physiotherapy, occupational therapy and various activities.

<sup>6</sup> The Law “On state social contracts, grants and awards for non-government organizations in the Republic of Kazakhstan” was introduced in 2005.

## NIKOLAI KLOCHKOV



*Nikolai Klochkov*

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### NIKOLAI KLOCHKOV

Amnesty International met Nikolai Klochkov in February and August 2018. He is working in a training café as part of an NGO project run by the Association of Psychoanalysts. Nikolai Klochkov, spent at least part of his childhood in state institutions, and when he joined the project he was living in an adult psychiatric hostel. At some point in his life he was deprived of legal capacity, probably when he was admitted to the psychiatric hostel.

This means that he cannot work, he cannot enrol in a place of education, marry, apply to a court to defend his rights or vote in elections. He has a diagnosis of “medium mental retardation” which seems to be because he has difficulty communicating; he is partially deaf and never received support to enable him to communicate either with sign language or by lip-reading. Despite these barriers, he is able to live independently with minimal assistance. Through a mixture of basic sign language and speech, he explained to Amnesty International delegates that he would like to work and live independently. He is very good at mending mobile phones and hopes that in the future he might be able to work in a mobile phone repair shop. When Amnesty International met him in February he was hopeful that he would be able to regain his legal capacity, start a family and be employed on an official employment contract. All those hopes were dashed when he “failed” the forensic medical examination in August 2018. A psychiatrist who took part in the panel examining him informed the NGO that he did not show any evidence of “improvement” and there was no reason to question the past medical reports. On 17 September a court ruled that there was no “improvement in his mental state” and he therefore required guardianship. Many people told Amnesty International that psychiatrists fear to contradict an existing diagnosis because that would imply that somebody had made a mistake.

# INTRODUCTION

Kazakhstan ratified the CRPD in 2015, and it submitted its first state report in June 2017 which has yet to be considered by the UN Committee on the Rights of Persons with Disabilities, the expert body that monitors the implementation of the Convention by states parties. The adoption of the CRPD in 2008 marked an important shift in the way states regarded persons with disabilities. They can no longer be regarded as recipients of aid, or medical treatment, but must be regarded as rights holders, and it is the responsibility of states to ensure that they can exercise their rights on an equal basis with others. The CRPD requires states parties to combat harmful practices and stereotypes concerning persons with disabilities. All states parties have taken on the commitment to abolish systems of guardianship and replace them with systems that support the capacities of persons with disabilities. This is a challenging but necessary undertaking for states which requires a complete review of legislation to ensure compliance with CRPD standards as well as the introduction of new support measures. Article 12 of the CRPD requires that states must recognize that persons with disabilities, including psychosocial and intellectual disabilities, are equal before the law.

## PUBLIC SERVICES FOR PERSONS WITH DISABILITIES IN KAZAKHSTAN

Currently, most people who seek mental healthcare are treated as in-patients in psychiatric hospitals or state residential psychiatric facilities. There are 31 such institutions for adults in Kazakhstan, and in 2017, around 18,000<sup>7</sup> persons with psychosocial and intellectual disabilities – both children and adults – were reportedly institutionalized in Kazakhstan.

Persons with disabilities are treated very much as recipients of medical treatment rather than rights holders. Instead of being treated with equality they are often viewed from the point of view of their medical diagnosis. They are categorized as having “mild”, “moderate” or “severe” disabilities based on a medical diagnosis and the amount of support they need. Persons with disabilities receive a state disability pension graded according to disability that ranges from approximately \$75 per month (equivalent to minimum wage) to double that amount in cases where more support is required.

In recent years, Kazakhstan has taken steps to reform its mental health services. In 2008, the Law on Specialised Social Services was passed. Since the passing of the law, Kazakhstan more than doubled the availability of in-home care for persons with disabilities, introduced the profession of social workers and set up a system for financing these services. During the next stage of reform of its mental health services (2018 – 2021) the government plans to deinstitutionalize most of the residents of the large psychiatric hospitals, and to increase the number of day centres offering care in the community. There are also increasing moves towards inclusive education, and several positive initiatives which aim to increase the inclusion of persons with psychosocial and intellectual disabilities in society by offering them employment. The state-run Mental Health Centre in Astana has established a Psychiatric Rehabilitation Centre on the grounds of the psychiatric hospital. It is a large building with workshops and training rooms providing technical labour training for 100 people and capable of providing for 80 more people. Persons with psychosocial and intellectual disabilities are engaged in woodwork – making items from recycled timber, sewing and other crafts. While these are important steps towards compliance with the CPRD, these measures need further reassessment and

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<sup>7</sup> The population of Kazakhstan is 17.9 million.

development to comply fully with the CRPD and move towards a rights-based approach rather than a medical or charity model approach to disability.

## STIGMATIZATION OF DISABILITY

“Society despises them. They can work, but only in isolation so that they don’t traumatise people,” psychiatrist quoted by the mother of a young man with cerebral palsy.

According to the still to be considered state report to the CRPD, Kazakh national legislation does not contain any provisions that are discriminatory towards persons with disabilities, and the Constitution guarantees that “everyone is equal before the law and before the courts”.<sup>8</sup> This statement contradicts the reality for persons with psychosocial and intellectual disabilities who face stigma and discrimination on a daily basis. According to a study carried out by Aigul Shakibaeva,<sup>9</sup> doctors at maternity hospitals continue to advise mothers of babies with disabilities to leave the child in state care. She gave birth to a son with Down syndrome in 2010 and was under pressure to leave her child in state care. She found little support from doctors:

“I was amazed by their coldness and indifference. They just kept saying to me, ‘what have you decided. Are you going to take your son home or not? We need to draw up the documents for the children’s home.’”

### AIGUL SHAKIBAeva



*Aigul Shakibaeva and her son Asad*  
© Amnesty International

Other mothers of children with disabilities told Amnesty International that they experienced rudeness and discrimination in public, such as some mothers telling their children not to play with children with disabilities. Maira Suleeva, the director of the NGO Kenes, that runs a day centre and a kindergarten told us that when the kindergarten was initially opened to children with disabilities, other parents stopped sending their children to the kindergarten.

This stigmatization is re-enforced by a system that requires people to prove that they are not registered (на учёте) with a psychiatrist to enter some colleges of higher education, to drive, or be employed in certain jobs whether or not they have been declared “incapable”. Anybody applying for a driving licence must apply to their nearest psychiatric clinic to be issued with a certificate confirming that they are not registered. Such a requirement is discriminatory and not in line with the requirements of the CRPD.

<sup>8</sup> Kazakhstan First State Report to the CRPD, Advance unedited version in Russian, June 2017, paras. 118 and 119, [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fKAZ%2f1&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fKAZ%2f1&Lang=en)

<sup>9</sup> Unpublished report.

# LEGACY OF SOVIET PSYCHIATRY

Psychiatrists interviewed by Amnesty International acknowledged that the country has not fully overcome the legacy of punitive psychiatry. Soviet Psychiatry developed in a closed society where there was little contact with international psychiatric practice.<sup>10</sup> By the 1960s in the USSR the abuse of psychiatry to imprison dissidents had become widespread. The legacy of Soviet psychiatry continues to be felt and Amnesty International has intervened in a number of cases in the former Soviet Union where people who criticize the regime or denounce injustice continue to be subjected to psychiatric diagnosis and involuntary treatment in psychiatric hospitals. In March 2018,<sup>11</sup> psychiatrists we spoke to were very conscious of the need to be aware of international practice and frequently quoted the World Health Organization's International Classification of Diseases (ICD).

## LEGAL CAPACITY

One of the biggest challenges facing Kazakhstan is to comply with the requirements of Article 12 of the CRPD (Equality before the law) which will require it to abolish the guardianship regime for adults and introduce measures to facilitate assisted decision making for persons with psychosocial and intellectual disabilities. Currently, in Kazakhstan, persons with psychosocial and intellectual disabilities are denied the ability to take key decisions or actions. They are deprived of legal capacity by a court and a guardian is appointed to make decisions on their behalf. Kazakhstan's first report to the Committee on the Rights of Persons with Disabilities, which has yet to be considered, states that all "citizens" are equal before the law, but that "citizens with mental illness or feeble-mindedness who cannot understand or control their actions" may be deprived of their legal capacity by law and a guardian can be appointed to control their affairs.<sup>12</sup> Guardianship in Kazakhstan has no flexibility and once declared "incapable" by a court, individuals are deprived of the right to make any decisions about their lives, to control their finances, to marry, to study or to work. There are no systems for review and it is very rare for the status to be reversed.

Many people interviewed by Amnesty International during the preparation of this report explained that guardianship is essential to protect individuals who are perceived at risk in Kazakhstan from possible exploitation. Psychiatrists at one psychiatric hospital in Almaty told Amnesty International delegates that at least four of their patients in recent years had been "tricked into giving up their homes". Amnesty International recognises the need to protect all people from exploitation, however, this can be done in a manner which does not strip them of all decision-making and legal capacity. The CRPD requires that states take appropriate measures to provide persons with disabilities with the support they need to make their own decisions. The current approach is not compatible with Kazakhstan's obligations as a state party to the CRPD and other international human rights law and standards.

According to information provided to Amnesty International by the Ministry for Labour and Social Protection in the period 2014 to 1 April 2018, 16,000 individuals who had been deprived of legal capacity were receiving "special social services" from the Ministry. In reality, the number of people under guardianship may be much higher, because this figure does not include those who may be deprived of legal capacity, but are not receiving support from social services. For example, in August 2018 a medical practitioner informed Amnesty International that in 2017, in Almaty alone, 78 people were deprived of legal capacity because of dementia, and these people may not have been receiving "special social services" from the Ministry. In June 2018, Amnesty International requested complete figures for those under guardianship from the Department for Legal Statistics and Special Reports at the Prosecutor General's Office, but at the time of finalizing this report had not received an answer.

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<sup>10</sup> Soviet psychiatrist, Andrei Snezhnevsky, developed the theory of "sluggish schizophrenia", according to which schizophrenia was much more widespread than previously thought because it could be present with minor symptoms and develop later. Such people might overestimate their own importance or suffer from delusions such as "grandiose ideas of reforming society", or a "mania for persecuting authorities". This diagnosis was used to imprison many critics of the government, and the Serbsky Institute in Moscow (which has since changed its name) was the leading centre for the use of punitive psychiatry. See: [http://www.europarl.europa.eu/RegData/etudes/etudes/join/2013/433723/EXPO-DR01\\_ET\(2013\)433723\\_EN.pdf](http://www.europarl.europa.eu/RegData/etudes/etudes/join/2013/433723/EXPO-DR01_ET(2013)433723_EN.pdf)

<sup>11</sup> During a trial held on 27 March in her absence, a judge at Abay District Court in Shymkent ruled that Ardak Ashym should be placed in a psychiatric hospital pending trial because she had suffered from "episodic paranoid schizophrenia" since 2015 and was "not in a condition to understand the danger to society of her actions". See: <https://www.amnesty.org/en/documents/eur57/8298/2018/en/>, <https://www.amnesty.org/en/documents/eur57/8378/2018/en/>

<sup>12</sup> Kazakhstan First State Report to the CRPD, Advance unedited version in Russian, June 2017, para. 217, [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fKAZ%2f1&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fKAZ%2f1&Lang=en)

## VADIM NESTEROV



Vadim Nesterov  
© Amnesty International

“I need to do my best to show that I am able to do what’s needed, that I am “capable”, Vadim Nesterov.



### MOVING TOWARDS INDEPENDENT LIVING

#### Training Café, the Association of Psychoanalysts

“We are demonstrating that all people are worthy of respect and love. They mustn’t be classified by their diagnosis. What we are doing is fighting against the prejudice and stigma in society”, Anna Kudiyarova, Founder of the Association of Psychoanalysts.

In 2011, the Association of Psychoanalysts started working with young people who had grown up in orphanages and were living in closed psychiatric institutions. Initially they set up a club house and invited the participants to the club for counselling. In 2015, they embarked on the second part of the project and set up the first Training Café with grants from the Soros Foundation and later from the Kazakh government. The young people taking part in the project underwent training and learnt to cook and to work in the Cafes. However, the young people were still living in the psychiatric institutions and were required to return every evening by 6pm. In order to increase their independence and make it easier for them to take part in the project, the Association of Psychoanalysts started a third project to provide sheltered housing. The government provided them with a number of flats in Almaty and the participants in the project live either alone or in groups with a supervisor on site. Almost all the participants of the project were deprived of legal capacity when they entered the adult psychiatric system, and the Association of Psychoanalysts has employed a lawyer to assist them in reclaiming their legal capacity. According to Anna Kudiyarova, judges were astonished when they first started applying: “The judges almost fell over, their jaws fell and they said: ‘What is this? For 25 years we have been taking away legal capacity and suddenly you are asking us to return it!’” One of the project participants has regained their legal capacity, but two more did not pass the psychiatric examination (the first step in regaining their legal capacity). According to Anna Kudiyarova this is due to educational neglect more than anything else. They received sub-standard education, if any at all, in the institutions they were living in and have poor writing skills and little general knowledge.

The **Künde Café** at the Nazarbayev University in Astana is the idea of Maulen Akhmetov, a 21-year-old literature student at the University. He employs persons with psychosocial and intellectual disabilities, who are trained first at the Psychiatric Rehabilitation Centre before moving to work in the Café.

These types of work trainings and moving out of large institutions are positive steps, however, to comply with the CRPD persons with disabilities, and in this case psychosocial and intellectual disabilities, need to be able to live independently in the community (CRPD Article 19) and have their right to work on an equal basis as others respected (CRPD Article 27).<sup>13</sup>

<sup>13</sup> For more information on CRPD Article 19, Living independently and being included in the community, and what would not constitute compliance with this article, see: Committee on the Rights of Persons with Disabilities, General comment No. 5, Article 19: Living independently and being included in the community, CRPD/C/GC/5, 27 Oct. 2017.

# COMPLIANCE WITH INTERNATIONAL LAW AND STANDARDS

**“Equal recognition before the law is central to human rights. Often described as the “right to have rights”, it articulates the right of every person to be a holder of rights and obligations under the law, which is a necessary precondition for the exercise of all other human rights and fundamental freedoms.”**

UN Special rapporteur on the rights of persons with disabilities.<sup>14</sup>

Article 5 of the CRPD requires states parties to recognize that all people are “equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.” This requires a fundamental shift in the way states treat persons with psychosocial and intellectual disabilities. To this day, throughout the world persons with psychosocial and intellectual disabilities continue to be denied their legal capacity in contravention of the standards set out in the CRPD. Their legal capacity is usually restricted because of a medical diagnosis, because they are perceived to have poor judgement or to be incapable of making decisions about their life. They are placed under “guardianship” - a substitute decision-making regime - where a legal representative (often a relative) will make decisions on their behalf. The impact of being deprived of legal capacity is grave and means that persons with disabilities are no longer able to make decisions about their lives ranging from where they want to live to whether they want medical treatment or not. In effect, they lose the ability to exercise their rights.<sup>15</sup>

Article 12 of the CRPD requires that persons with disabilities should be recognized as legal personalities who have the right to own or inherit property, to control their own financial affairs, to marry and to take part in the social and political life of their communities. In other words, they should be able to retain their legal capacity and exercise their rights. Guardianship regimes or substituted decision-making are not compatible with the CRPD and must be abolished. The UN Committee on the Rights of Persons with Disabilities has explicitly stated in General Comment No.1 to the CRPD:

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<sup>14</sup> See: Report of the Special Rapporteur on the rights of persons with disabilities, Catalina Devandas Aguilar, presented at the 37th session of the Human Rights Council 2018, [http://www.embracingdiversity.net/files/report/1519639659\\_report-legal-capacity-web.pdf](http://www.embracingdiversity.net/files/report/1519639659_report-legal-capacity-web.pdf)

<sup>15</sup> Report of the Special Rapporteur on the rights of person with disabilities, p 4

“Historically, persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner under substitute decision-making regimes such as guardianship, conservatorship and mental health laws that permit forced treatment. These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others. Article 12 of the Convention on the Rights of Persons with Disabilities, however, makes it clear that “unsoundness of mind” and other discriminatory labels are not legitimate reasons for the denial of legal capacity (both legal standing and legal agency). Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.”<sup>16</sup>

## ALTERNATIVES TO GUARDIANSHIP

In place of guardianship regimes, Article 12 (3) instructs states to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.” The UN Committee on the Rights of Persons with Disabilities has highlighted: “‘Support’ is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication. The type and intensity of support to be provided will vary significantly from one person to another owing to the diversity of persons with disabilities. This is in accordance with Article 3 (d), which sets out “respect for difference and acceptance of persons with disabilities as part of human diversity and humanity” as a general principle of the Convention. At all times, including in crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected.”<sup>17</sup>

Several states have started to introduce supported decision-making in place of guardianship regimes. In the United Kingdom persons with psychosocial and intellectual disabilities may set up a network of people with whom to consult and discuss issues known as a Circle of Support.<sup>18</sup> In Sweden there is a Personal Ombudsman, who can assist in making decisions.<sup>19</sup> There are assisted living schemes in some countries including in Australia.<sup>20</sup> In Finland there is an early intervention treatment in cases of psychosocial and intellectual disabilities called Open Dialogue which has been promising.<sup>21</sup> In other cases, people can draw up advance directives for temporary situations in which they may not be able to make decisions about their lives.



### LEGAL REFORMS IN RUSSIA AND GEORGIA

In Russia and Georgia, which have very similar guardianship regimes to Kazakhstan, there have been legal challenges to the implementation of guardianship. In a February 2009 decision, the Russian Constitutional Court considered an application by three individuals who had been declared “incapable” and who complained of their lack of appeal against the decision.<sup>22</sup> While Russia still maintains unacceptable restrictions on the rights of persons with psychosocial and intellectual disabilities, the Constitutional Court has at least acknowledged that constitutional rights are inherent and belong to everybody from birth, and that there are no grounds in the Russian Constitution to restrict the rights of people who have been declared “incapable” beyond the ban on voting and being elected. The applicants complained that they had not been present at the hearings to deprive them of legal capacity, and the court found:

<sup>16</sup> Committee on the Rights of Persons with Disabilities, General comment No. 1, Article 12: Equal recognition before the law, UN Doc. CRPD/C/GC/1, 19 May 2014, Eleventh session 31 March–11 April 2014, paras 7 and 13, [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fGC%2f1&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fGC%2f1&Lang=en)

<sup>17</sup> Committee on the Rights of Persons with Disabilities, General comment No. 1, Article 12: Equal recognition before the law, paras 17 and 18.

<sup>18</sup> Circle of Support (UK), [https://youtu.be/w6RX\\_WQmSf4?t=54](https://youtu.be/w6RX_WQmSf4?t=54)

<sup>19</sup> Personal Ombudsman system (Sweden), <https://www.youtube.com/watch?v=xqma4wK8sC0&feature=youtu.be>

<sup>20</sup> Independent living schemes (Australia), <https://www.youtube.com/watch?v=3QSEBG3gLqQ>

<sup>21</sup> Open Dialogue (Finland), <https://www.youtube.com/watch?v=ywtPedxhC3U&feature=related&app=desktop>

<sup>22</sup> Russian Constitutional Court, Ruling of 27 February 2009, on the constitutionality of Articles 37, 52, 135, 222, 284, 286 and 279 of the Civil Procedural Code, and Part 4 Article 28 of the Law of the Russian Federation on Psychiatric Assistance and Guarantees of the rights of citizens who receive it, in connection with the complaints of Yu.K. Gudkova, P.V. Shtukaturov, and M.A. Yashina.

“The failure to give the individual in question the possibility to personally, or via a representative defend their position, prevents a full understanding of the circumstances of the case, prevents the hearing of the explanations of all interested parties, and the collection of other essential evidence.”<sup>23</sup> The Court also found that people who were not present at the hearing were rarely informed of the appeal dates, and therefore effectively were deprived of the right to appeal. The Russian Federation has since reviewed its legislation and made changes to ensure that people undergoing “incapability” hearings are present except in exceptional circumstances. It has also changed its legislation to allow those declared “incapable” to appeal against such decisions even if the initial appeal period had passed. The Court also found it was incompatible with Russia’s obligations under the European Convention on Fundamental Freedoms and Human Rights to subject those who had been declared “incapable” to medical treatment on the request of their guardian without their consent or a court order:

“(According to) Articles 5 and 6 of the Convention for the Protection of Human Rights and Fundamental Freedoms, in their interpretation by the European Court of Human Rights everyone’s right to liberty and security of person implies that mentally ill persons may not be deprived of liberty and put in detention in a manner other than within a procedure prescribed by law”.

More recently, Russia has introduced partial guardianship for persons with psychosocial and intellectual disabilities and this is gradually being implemented. Partial guardianship regimes do not involve depriving the individual concerned of legal capacity and provide for flexibility in the type of decisions that will be taken by a guardian. While these measures are not in compliance with the CRPD, they do constitute measures of moving away from guardianship.

In Georgia, following a Constitutional Court decision in October 2014 in the case of *Irakli Kemoklidze and David Kharadze v. the Parliament of Georgia*<sup>24</sup>, the entire incapacity system was changed in the light of Georgia’s obligations under the CRPD, which it ratified in 2013. In March 2015, a package of laws was passed which set up a new system for determining the needs of persons with psychosocial and intellectual disabilities. The previous system of depriving a person of legal capacity completely and without flexibility was abolished and a new system based on the principles of flexibility, maximum preservation of legal capacity, and proportionality was set up. The needs of a “support recipient” are assessed and a support system is established which is tailored to the individual’s particular needs. A “support recipient” maintains the right to appeal to a court to reverse or change the decision. While the Public Defender’s Office has found numerous shortfalls in the new system, such as a lack of clarity during the transitional phase when a person is being assessed, and the failure to protect that person’s right not to be subjected to medical experimentation without their informed consent, the new system is an important step towards ensuring the rights of persons with psychosocial and intellectual disabilities.<sup>25</sup>

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<sup>23</sup> As above

<sup>24</sup> Citizens of Georgia – Irakli Kemoklidze and David Kharadze versus the Parliament of Georgia, N2/4/532,533 Batumi, 8 October 2014, <http://www.constcourt.ge/en/legal-acts/judgments/citizens-of-georgia-irakli-kemoklidze-and-david-kharadze-versus-the-parliament-of-georgia.page>

<sup>25</sup> *Legal Capacity – Reform without implementation*, <http://www.ombudsman.ge/en/reports/specialuri-angarishebi/legal-capacity-reform-without-implementation.page>

# SAFEGUARDS

**“We need to have the possibility to declare somebody “incapable”. There must be a way of protecting defective patients,”**

Psychiatrist speaking during a meeting between psychiatrists at the Centre for Mental Health in Almaty and Amnesty International staff in February 2018

Article 12 (4) of the CRPD requires governments to “ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.”

The Committee UN Committee on the Rights of Persons with Disabilities has elaborated on these safeguards, stating that they also include the right to take risks and make mistakes.<sup>26</sup>

## LACK OF FLEXIBILITY

In Kazakhstan, the law does not allow for any flexibility in the imposition of substitute decision making. There are legal provisions for partial guardianship, but that option is only available for drug users and those dependent on alcohol. There are further provisions for custody (Article 127 of the Code on Marriage and Family), which would allow the person to hand over responsibility for certain decisions to a custodian on the basis of a contract. Custody can be ended at the request of the person under custody and does not entail the loss of legal capacity in all other matters.

These provisions are not available to persons with psychosocial and intellectual disabilities. In cases of psychosocial and intellectual disabilities, the only option is to deprive a person of legal capacity in all spheres of life for an indefinite period of time.

## ABSENCE OF REGULAR REVIEW

The CRPD requires that all measures relating to appropriate and effective safeguards with regard to legal capacity should be for the shortest time possible and be subject to regular review by a competent, independent and impartial authority or judicial body. In Kazakhstan, the law does not provide for an automatic periodic review of the appointment of a guardian or of the need for a guardian at all. Unless a third party, or the actual guardian or the Prosecutor General’s office, applies to a court on behalf of the person under guardianship they are likely to remain under guardianship for life.

Amnesty International interviewed R. Kh, a patient in the psychiatric hospital in Akzhaik, who had been in psychiatric institutions for 30 years and whose guardianship status had never been questioned nor undergone any type of review. He told Amnesty International that he had worked as a steward on Atlantic liners sailing from Odessa. In 1995 he experienced an “emotional crisis” and started to hear voices. He was placed in a psychiatric hospital at this point. He told Amnesty International that he no longer heard the voices.

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<sup>26</sup> Committee on the Rights of Persons with Disabilities, General comment No. 1, Article 12: Equal recognition before the law, UN Doc. CRPD/C/GC/1, 19 May 2014, Eleventh session 31 March–11 April 2014, para. 22.

# CONFLICT OF INTEREST

Chapter 17 of the Code on Marriage and Family describes in detail who cannot be a guardian or custodian and the responsibilities of the guardian or custodian, but it noticeably omits to consider the interests of the person over whom guardianship is granted. The law does not provide any guidance on conflict of interest.

Article 122 of the Code on Marriage and the Family lists who can be appointed a guardian and specifies who cannot be appointed a guardian or a custodian. A guardian or custodian can only be appointed if they agree to take on the duties prescribed by the Code, but the Code does not require the agreement of the person to be placed under guardianship. Guardians must not have been declared “incapable”, have been removed from the position of guardian because of failure to carry out their responsibilities, or who cannot carry out the responsibility for reasons of health, those without a fixed place of abode, or with a criminal record, or unmarried men (in the case of children). The Code specifically states that in the case of people in institutions, the administration of the institution will take on the role of guardian. This is potentially a conflict of interest as the institution has a financial interest in keeping people in their care and is unlikely to put that in jeopardy by reinstating the legal capacity of those in its care.

For persons who live in state-run psychiatric institutions, 70% of their pension is put towards their care in the institution and 30% is put aside for their own use. However, at least in the psychiatric facility that Amnesty International visited, patients did not have access to their funds. Psychiatric institutions are required to report on the use of funds, but “voluntary contributions” towards the needs of the home by patients are permitted.

There is a certain level of oversight and reporting requirements, but these do not go far enough nor are they strictly enforced to protect those under guardianship. For instance, there are provisions which aim to protect the property of people under guardianship. Article 129 of the Code on Marriage and Family states that it is forbidden for guardians to exploit guardianship for monetary gain, yet there are no mechanisms in place to prevent this. Any property or income belonging to the person under guardianship can only be disposed of by the guardian in the interests of the person under guardianship and with the permission of the Custody and Guardianship Department that oversees guardianship. This includes jointly owned family property. Article 128 states that guardians cannot sell or rent property of a person under guardianship, nor can they reduce that persons’ property. The Custody and Guardianship Department oversees how the assets are used.

There are reporting requirements, but these do not provide adequate protection, and do not question the need for a guardian or possible conflict of interest. Guardians are required to report at least twice a year to the Custody and Guardianship Department on how they are carrying out their duties as a guardian. The Custody and Guardianship Department in Uralsk told Amnesty International that they periodically visit the homes of those under guardianship, however, the reporting requirements mentioned by parents of adults with disabilities appeared to concern only financial expenditure on behalf of the person under guardianship. They do not go far enough in protecting the welfare of those under guardianship.

As can be seen from the case of Vasily Novoselov, individuals under guardianship cannot apply to a court to defend their interests in the case of exploitation by guardians. Margarita Luchenkova was deprived of her legal capacity on the request of her brother. She told Amnesty International that her brother is living in a flat that she owns and has not paid her any rent for over a year. Having been deprived of legal capacity she cannot apply to a court to defend her interests or to change her guardian. Vasily Novoselov (see text box on p. ) has attempted to challenge his mother’s will, but has not been able to do so because the very person who he believes has profited from the situation is his guardian. His repeated attempts to challenge the appointment of a guardian on the grounds of conflict of interest have been frustrated.

# BARRIERS TO REINSTATEMENT OF LEGAL CAPACITY

**“In legal practice in Kazakhstan the legal possibility to return capability on the basis of a cure or an improvement in a person’s condition is hardly ever used. This is a particular problem for orphans and people living in specialized closed institutions. These children have been abandoned by their mothers like Cuckoos and are practically condemned to spend their whole lives in closed institutions.”**

Karlygash Kuzhagarieva, lawyer representing the participants in a community-living project.

Article 26 of the Civil Code provides for a person to regain their legal capacity if a court judges that they have been “cured” or “their health has significantly improved”. The application, while inappropriately relying on medical diagnoses for a determination of rights, can be made to the local Custody and Guardianship Department by the guardian of the person in question or a medical professional. In practice, this article of the law is rarely used. According to statistics provided to Amnesty International by the Ministry of Social Welfare and Labour: in the period 2014 – 1 April 2018, only 14 people regained their legal capacity.<sup>27</sup> As in the case of Nikolai Klochkov, (text box on p.) this places people in the absurd position of having to prove that they are capable of exercising their rights.

The current guardianship system in Kazakhstan allows for no flexibility and is not tailored to the particular needs of the individual concerned. The law gives the courts no option but to deprive persons of their legal capacity in all areas and to hand over all decision making to a family member or another individual. The Kazakhstani authorities must abolish the guardianship system currently in place, conduct a thorough overhaul of all laws related to it, and comply with their international human rights obligations.

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<sup>27</sup> Unfortunately, despite Amnesty International’s requests, the government has not supplied statistics on the number of people deprived of legal capacity per year.

# PROCEDURES – THE RIGHT TO A FAIR TRIAL

**“She just wants a quiet life. She just wants to live the way she likes,”**

Yulia Sycheva explaining why her grandmother deprived her of legal capacity.

According to Article 26 of the Civil Procedural Code a “citizen who cannot understand the meaning of his actions or cannot control them because of mental illness or weak-mindedness” may be declared “incapable”<sup>28</sup> by a court. An application to declare an individual “incapable” can be made by relatives, Guardianship and Custody Departments of municipalities, or by municipal psychiatric hospitals (mental health centres). The Supreme Court clarifies in its commentary on the Civil Procedural Code that an application can also be made by a psychiatric institution “in order to protect the rights and interests of mentally ill people.”<sup>29</sup> Article 324 of the Law requires that an application to declare an individual “incapable” should contain “evidence of the presence of a mental illness or mental disability, weak mindedness or other mental illness as a result of which the person cannot understand the actual nature and meaning of their actions or control them.” If this requirement is satisfied the court will call for a forensic psychiatric examination to be carried out. The examination is carried out by a forensic psychiatric commission convened by the Ministry of Justice.<sup>30</sup>

As a state party to the International Covenant on Civil and Political Rights (ICCPR), Kazakhstan is obliged to ensure that “All persons shall be equal before the courts and tribunals. In the determination of any criminal charge against him, or of his rights and obligations in a suit at law, everyone shall be entitled to a fair and public hearing by a competent, independent and impartial tribunal established by law.” As elaborated by the Human Rights Committee (HRC), the body of independent experts that monitors implementation of the ICCPR by its state parties, these guarantees in Article 14(1) not only apply to criminal cases, as further sections of Article 14 do, “but must also be respected whenever domestic law entrusts a judicial body with a judicial task”.<sup>31</sup>

The European Court of Human Rights<sup>32</sup> has found in numerous cases that hearings to determine “incapability” did not conform with international fair trial standards, in particular, Article 6 of the European Convention for the protection of Human Rights and Fundamental Freedoms.<sup>33</sup>

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<sup>28</sup> The Russian term *nedeeposobny* translates as ‘incapable of action’.

<sup>29</sup> Commentary on the Civil Procedural Code of the Republic of Kazakhstan, June 2017, [http://sud.gov.kz/system/files\\_force/verstka\\_poslednyaya.pdf?download=1](http://sud.gov.kz/system/files_force/verstka_poslednyaya.pdf?download=1)

<sup>30</sup> Despite numerous enquiries Amnesty International was unable to clarify the criteria for these examinations, and those undergoing examination for the restoration of their legal capacity reported being tested on general knowledge and basic educational skills.

<sup>31</sup> Human Rights Committee, General Comment No. 32, Article 14: Right to equality before courts and tribunals and to a fair trial, CCPR/C/GC/32, 23 August 2007, para. 7.

<sup>32</sup> While Kazakhstan is not a member of the Council of Europe, Council of Europe standards are recognized as recommended standards.

<sup>33</sup> In the case of *Shtukaturov v. Russia* the European Court of Human Rights found that it was indispensable for the judge to see the applicant in person, in order to judge for themselves whether Pavel Shtukaturov understood “the nature of his actions” as required by the

Article 13 of the CRPD requires that states parties “ensure effective access to justice for persons with disabilities on an equal basis with others.” This means that persons with disabilities must be able to defend their rights in a court of law, which is denied to people who have been declared “incapable” in Kazakhstan. The Committee on the Rights of Persons with Disabilities notes that state parties must ensure that persons with disabilities have access to justice on an equal basis with others. “The recognition of the right to legal capacity is essential for access to justice in many respects.” States must ensure “that persons who experience interference with their right to legal capacity have the opportunity to challenge such interference — on their own behalf or with legal representation — and to defend their rights in court.”<sup>34</sup>

Given the drastic effects of being deprived of legal capacity, anybody subjected to an “incapability” hearing in a court of law should have procedural safeguards such as the right to defend themselves in person or through legal of their own choosing, pending the abolition of guardianship. The current procedures to determine “incapability” in Kazakhstan do not provide persons subjected to the process with fair trial rights in line with Kazakhstan’s international human rights and domestic obligations.

## YULIA SYCHEVA



Yulia Sycheva  
© Amnesty International

“I am a very creative and musical person and like all creative people I get carried away and need to create. Being creative means that you think in a non-standard way, but that doesn’t mean that I am mad,” Yulia Sycheva

## LACK OF FAIR HEARINGS

The European Court of Human Rights has stated that for the proceedings to be considered fair it is the judge who must make the final determination:

“[...] it is the judge and not a physician, albeit a psychiatrist, who is to assess all relevant facts concerning the person in question and his or her personal circumstances. It is the function of the judge conducting the proceedings to decide whether such an extreme measure is necessary or whether a less stringent measure might suffice. When such an important interest for an individual’s private life is at stake a judge has to balance carefully all relevant factors in order to assess the proportionality of the measure to be taken.”<sup>35</sup>

Psychiatrists that Amnesty International met insisted that they were not the ones who make the final determination and that it was up to the court to decide, but the practice of “incapability” hearings suggests that judges almost always follow the advice of psychiatrists even when there is other opposing testimony.

Yuliya Sycheva was declared “incapable” by a court on 30 November 2017 on the application of her grandmother. Her grandmother told the court that she wished Yuliya to be declared “incapable” so that she could be placed in a psychiatric hospital permanently. Her mother testified to the court that she believed Yuliya’s grandmother had caused all her problems, and recalled that she and Yuliya had been driven out of the flat they shared with her when Yuliya was a baby and as a result she had had to place Yuliya in a

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law. The court ruled that the fact that the judge decided to hold the hearing in absentia on the basis of documentary evidence alone was a violation of the principle of adversarial hearings as required by Article 6.

<sup>34</sup> Committee on the Rights of Persons with Disabilities, General comment No. 1, Article 12: Equal recognition before the law, UN Doc. CRPD/C/GC/1, 19 May 2014, Eleventh session 31 March–11 April 2014, para. 38.

<sup>35</sup> Case of X and Y v. Croatia, *Application no. 5193/09*, 3 November 2011, <http://hudoc.echr.coe.int/eng?i=001-107303>

children's home after which she was adopted by her grandmother. Yuliya's mother opposed declaring Yuliya incapable. The court decision also notes that Yuliya offered clear testimony concerning her situation and asked not to be declared "incapable". The state appointed lawyer also supported her position. However, the psychiatrist's report stated that she had been diagnosed with schizophrenia, and a psychiatrist explained to the court that Yuliya was able to express herself clearly because she was currently in "remission". The court found that "she could not understand the consequences of her actions". Yuliya appealed against the decision and in February 2018, when Yuliya went to the court room with members of the NGO that had supported her, the NGO workers were able to explain to Yuliya's grandmother what the consequences of being declared "incapable" were, and she agreed to allow her legal capacity to be restored. When Amnesty International visited Kazakhstan in August 2018, Yuliya Sycheva was again being treated as an in-patient at the psychiatric hospital against her will.

## HEARINGS IN ABSENTIA

**"All this was imposed on me without my knowledge or participation in a formal and illegal way: disability, incapability, guardianship etc. with no way out. How can that be according to law? Despite this they agree that I am capable of work, I am not aggressive, I can live independently, educate myself, I am calm, self-controlled and capable of self-analysis...."**

Vasily Novoselov, in a letter to a human rights group.

Once a person has been declared "incapable" by a court they have the right to appeal against the decision if they do so within a month of the final decision. Once the decision becomes final the person declared "incapable" can no longer apply to a court on their own behalf and must depend on their guardian, a prosecutor or a physician to apply on their behalf.

The right to be present is of vital importance in "incapability" hearings, so that the judge can see for themselves whether the person in question is "capable of understanding their actions and controlling them". It also allows for the person in question to know that the hearing is occurring, something that often does not happen. According to Article 326 of the Civil Procedure Code the person about whom the application has been made "should be called to the court hearing" if the person's presence "does not present a danger to their life or health or the life or health of others". Furthermore, Article 326 states that in cases where the person might be a danger to themselves or others, the hearing can be conducted where the person is located, such as in a psychiatric hospital. The presence of the person in question is therefore not obligatory, and in practice many "capability" hearings are conducted in his or her absence even when the presence of the person could, and should, have been made possible.

Margarita Luchenkova, was declared "incapable" by a court in October 2014 on the application of her brother who declared himself her guardian. Despite having been declared "incapable" she works as a small-scale businesswoman, lives independently, manages her own financial affairs and cares for her 75-year-old mother with a disability. She was not present at the hearing and she only found out about the court decision some months later by chance. By that time, the appeal deadline had passed. Margarita successfully applied to have the appeal deadline extended, however, her brother arranged for her to be hospitalized which meant that she missed the extended deadline for appeal. In the second half of 2015, again in her absence, a court upheld the decision to declare her "incapable". Margarita was therefore unable to appeal the decision to a court and unfairly discriminated against because of her brother's application declaring her "incapable".

## MARGARITA LUCHENKOVA



Amnesty International researcher and  
Margarita Luchenkova  
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“I believe that depriving someone of legal capacity should not depend on what a person is diagnosed with,” Margarita Luchenkova.

Natalia Pereverzina was declared “incapable” by a court in the village of Darinsk in August 2017, on the application of the local social services branch. She feared the involvement of her grandmother’s friend, who she suspected wanted to take possession of her house. She told Amnesty International that on the day of the hearing the police came to tell her to come to court, but as she had not received any warning she refused to go at such short notice. The court decision states that she did not attend for “reasons of ill-health”.

## INADEQUATE DEFENCE

The law gives people undergoing “incapability” hearings the right to present their position in person or through a representative (Article 236(1)). As has been shown above, in the case of Margarita Luchenkova, “incapability” hearings are often held in the person’s absence. Furthermore, people who have been declared incapable are prevented from presenting arguments in their own defence on the grounds of “incapability.”

Under Article 12 of the CRPD and Article 16 of the ICCPR, all persons have a right to recognition under the law. These articles ensure that all human beings are respected as having legal personality.

The HRC makes clear that “the right to equality before courts and tribunals also ensures equality of arms” and that “that each side be given the opportunity to contest all the arguments and evidence adduced by the other party”.<sup>36</sup>

People undergoing capability hearings have the right to a state-funded lawyer to represent their interests (Article 325). However, very few lawyers appear to argue against “incapability” decisions in defence of their clients. The state lawyer who represented Natalia Pereverzina supported the decision to deprive her of legal capacity and agreed with the psychiatrists’ report that she “suffered from weakmindedness”.



### A LEGAL CHALLENGE TO “INCAPACITY”

The human rights NGO, the Kazakh International Bureau for Human Rights has taken up the case of Vasily Novoselov in order to challenge guardianship legislation:

“We took up the case to establish the fact that he should have the right to apply to a court on his own behalf and defend his interests. The main point is not whether he has been defrauded or not but that he has a right to receive documents and to apply to a court to defend his rights,” Yevgeny Zhovtis.

Vasily Novoselov is a 60-year old man who has been diagnosed with schizophrenia in 1991 and had been treated as an inpatient regularly. Vasily Novoselov found out after the death of his mother that he had been declared “incapable” in approximately 2006 without his knowledge, and a distant relative

<sup>36</sup> Human Rights Committee, General Comment No. 32, Article 14: Right to equality before courts and tribunals and to a fair trial, CCPR/C/GC/32, 23 August 2007, paras 8 and 13, [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CCPR%2fC%2fGC%2f32&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CCPR%2fC%2fGC%2f32&Lang=en)

had been appointed as his guardian. After his mother's death in 2013 he found out that his guardian's son had inherited half of his mother's apartment while he and his brother, who had cared for his mother until her death had been granted a quarter share each. Vasily Novoselov cannot apply to a court to challenge the will because he is "incapable". The only person who can apply to a court on his behalf is his guardian who has a clear conflict of interest. Vasily Novoselov first tried to get a copy of his mother's will from the notary, but this request was refused because he is "incapable". With the help of the Kazakhstan International Bureau of Human Rights and Rule of Law, Vasily Novoselov was able to view the will in January 2018 and discovered discrepancies which he thought put in question the authenticity of the document. He then started to discuss the possibility of changing his guardian and applied to the Custody and Guardianship Department in the local Akimat (local government office) to replace his guardian. In February 2018, the Bureau applied to the Almalinsky Akimat to request a change of guardian, but that request was declined. The Bureau then appealed to the Almalinsky District Court, but that appeal was denied on 26 July 2018 on the grounds that the Human Rights Group did not have the right to apply to a court on behalf of Vasily Novoselov. Only his guardian, a doctor or the Prosecutor General's office could apply on his behalf. An Amnesty International delegate was present and witnessed the judge refusing a request from the NGO lawyer to allow Vasily Novoselov to present his own case on the grounds that he was "incapable". The Bureau appealed against this decision in August 2018 and that appeal was denied. They then applied to a court to bring the matter before the Constitutional Council,<sup>37</sup> but that was also declined.

Pending the abolition of guardianship and the introduction of other measures to respect, protect and fulfil the rights of persons with psychosocial and intellectual disabilities, the Kazakh authorities must ensure that those who have been declared "incapable" have the right to apply to courts to reinstate their legal capacity or to change their guardians. The law must state unequivocally that the presence of the person in question is obligatory and judges should be instructed that such individuals have the right to present their case. Furthermore, such people should have the assistance of a lawyer of their choosing.

## MENTAL HEALTH CENTER IN ALMATY



*A corridor in the Mental Health Centre in Almaty*

*© Amnesty International*

<sup>37</sup> This body replaced the Constitutional Court in 1995. It does not accept applications from citizens and the only route is to apply to a court to bring a matter before the Constitutional Council.

# ARBITRARY DEPRIVATION OF LEGAL CAPACITY

General Comment No. 1 to the CRPD highlights the difficulty of determining when to deprive somebody of legal capacity and the risk of doing so arbitrarily. Under guardianship regimes the decision to deprive somebody of legal capacity is commonly based on a diagnosis of an impairment known as a status approach, on the assessment that a person has made a poor decision or an outcome approach, or when a person's decision-making skills are considered to be deficient (functional approach):

“This approach is flawed for two key reasons: (a) it is discriminatorily applied to people with disabilities; and (b) it presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not pass the assessment, it then denies him or her a core human right — the right to equal recognition before the law.”<sup>38</sup>

In Kazakhstan, the criteria for depriving persons of legal capacity are vague (“citizen who cannot understand the meaning of his actions or cannot control them because of mental illness or weak-mindedness”) and set a very low threshold considering the devastating consequences of depriving a person of their legal capacity. As a result, persons with a psychiatric diagnosis are at risk of being deprived of legal capacity on the basis of a diagnosis which may be inaccurate. The fact that they are deprived of their rights based on a medical diagnosis is squarely at odds with the CRPD. They can also fall victim to relatives and third parties who want to lay claim to their assets, or simply find them inconvenient.

Amnesty International met psychiatrists in Almaty, Uralsk and Astana, some of whom were sitting on the forensic psychiatric boards that carry out the psychiatric examinations in legal capacity cases, but nobody was able to elaborate on the criteria for declaring somebody “incapable” beyond the vague provisions in the law. Staff at the Republican Centre for Mental Health could only say that the criteria were “in any text book from the Serbsky Institute in Moscow”. All the court decisions that Amnesty International viewed quoted the vague phrasing of the law.

In a country where psychiatric practice is just emerging from the very closed world of Soviet psychiatry there is a risk of misdiagnosis. Psychiatrists that Amnesty International met frequently quoted the WHO ICD. This is an internationally recognized list of diseases including psychosocial and intellectual disabilities, however, it has come under criticism including from the UN Rapporteur on the Right to Health as an example of the over-expansion of diagnostic categories to medicalize human experience.

“Diagnostic tools, such as the International Classification of Diseases and the Diagnostic and Statistical Manual of Mental Disorders, continue to expand the parameters of individual diagnosis, often without a solid scientific basis. Critics warn that the overexpansion of diagnostic categories encroaches upon human experience in a way that could lead to a narrowing acceptance of human diversity.”<sup>39</sup>

Amnesty International found that psychiatrists in Kazakhstan sometimes used the ICD rigidly and inconsistently. We were told by one psychiatrist that autism is a childhood condition, and that when a child with autism becomes an adult “they will be diagnosed as schizophrenic”.

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<sup>38</sup> Committee on The Rights of Persons With Disabilities, General Comment, no. 1 (2014, para. 15, [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/download.aspx?symbolno=crpd/c/gc/1&lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/download.aspx?symbolno=crpd/c/gc/1&lang=en))

<sup>39</sup> Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Human Rights Council, Thirty-fifth session, 6-23 June 2017, p.5, [https://www.dgsp-ev.de/fileadmin/user\\_files/dgsp/pdfs/Wissenschaftliche\\_Artikel/UN\\_Kritik\\_Puras.pdf](https://www.dgsp-ev.de/fileadmin/user_files/dgsp/pdfs/Wissenschaftliche_Artikel/UN_Kritik_Puras.pdf)

# MISUSE OF THE SYSTEM

## NATALIA PEREVERZINA



*Natalia Pereverzina and her partner in Darinsk in February 2018*

*©Amnesty International*

“The laws aren’t right, but nobody cares. We are like dead souls,” Natalia Pereverzina in an interview with Amnesty International

Amnesty International interviewed Natalia Pereverzina at her home in the village of Darinsk outside Uralsk in February 2018. She was living independently with her partner. She had been treated at the local psychiatric hospital, but could not say if she had been diagnosed with a psychosocial or intellectual disability. When Amnesty International raised the case with the psychiatrists in Uralsk they told us that she was prone to “excessive drinking” and led a “disordered life”. She had inherited the house in the village after her grandmother died in 2016 and was deprived of legal capacity in August 2017, possibly with the involvement of a friend of her grandmother’s. She told Amnesty International that she believed that person wanted to claim the house by becoming her guardian, placing her in a psychiatric hospital, and controlling her assets. Her grandmother’s friend had taken all the deeds to the house and her grandmother’s will. An official at the local government office (Akimat) told her that she would be placed in the local psychiatric hospital. However, in August 2018 she was still in possession of the house because the local government authorities had not appointed a guardian.

## “ON THE CONVEYOR BELT”

**“This system is like a conveyor belt and until we break the machine it will just keep on forever,”**

Karlygash Kuzhagarieva, lawyer representing six beneficiaries of an NGO independent living project.

In February 2018, Amnesty International interviewed six people who had spent their childhoods in state care and then were transferred to an adult psychiatric hostel when they turned 18. All of them had been deprived of legal capacity without being informed. Almost all of them had a diagnosis of “light or medium mental retardation”.

Vadim told Amnesty International that his mother left him in the maternity hospital, and he spent his whole childhood in orphanages. During his childhood he was given a diagnosis of “mental retardation” and moved to a children’s psychiatric hospital. He attended school and completed 9 grades, but told Amnesty International that that he was badly taught. In 2011, shortly before he turned 18, he was moved to the adult psychiatric hostel in Almaty on Kablukova Street because of his age. Shortly after the move he found out that he had been declared “incapable”:

“I went to the bank with a social worker and was given some money. Then I heard them call me “incapable”. I went to the director and asked: “Why did you do that? Am I an invalid?” He said: “No it is not because of that. It is because you are living at the state’s expense and you are given everything you need.”

Since 2017, Vadim has been living with three others in a sheltered housing project run by the NGO, The Association of Psychoanalysts. The NGO is applying to take over guardianship as a first step towards assisting him to regain his legal capacity.

When we visited a new-style state-run small psychiatric institution, Akzhaiksky Centre for Special Services, in Akzhaik outside Uralsk we were told that all the residents had been deprived of legal capacity, most of them upon admission, and the director was their guardian. When we asked if it would be possible to be a resident of the facility and retain legal capacity, the director was surprised by the question. This attitude shows that it is established practice to automatically deprive those entering residential care of legal capacity. As our interviews with the beneficiaries of the Training Café project have shown, this is usually done without their knowledge.

## TURNING PARENTS INTO GUARDIANS

**“So, this means, until now we have been parents, but now we are supposed to become guardians!”**

Sapar Sabitov, father of a son with Down syndrome.

Amnesty International met a group of parents of children with disabilities in Uralsk in February 2018, many of them had been told by the district department of social services that they had to apply to deprive their children of legal capacity in order to continue receiving the disability pensions on behalf of their children once they turned 18. This is not a legal requirement and ignores existing provisions that make it possible to have pension payments delivered to the homes of recipients.

Sapar Sabitov’s son, Kazbek (25) has Down syndrome, and Sapar was wrongly informed by the district department of social services that unless he became his son’s guardian he would lose the benefits he receives. He now reports twice yearly to the local Guardianship and Custody Department but has just learnt that he can’t sell his car because guardians cannot dispose of joint property that could potentially be inherited by those under guardianship.

# CONSEQUENCES OF “INCAPACITY”

**““Being “incapable” in its current form is equivalent to civil death,”**

From a report by the Kazakhstani International Bureau of Human Rights.<sup>40</sup>

## VIOLETIONS OF ECONOMIC, SOCIAL AND CULTURAL RIGHTS

Once a person has been declared “incapable”, they lose the power to make decisions about their own life and are excluded from society. They are immediately deprived of the right to work, to enjoy family life, and to participate in the political life of their society.

The CRPD aims for the “full and effective participation and inclusion in society” of persons with disabilities. This includes the right to marry and found a family, the right to education and to the full development of their “human potential and sense of dignity and self-worth”, the right to work on an equal basis with others, the right to participate in the political life of their society, and the right to control their own financial affairs. Currently in Kazakhstan persons with psychosocial and intellectual disabilities who have been declared “incapable” are prevented by law from enjoying any of these rights.

## THE RIGHT TO WORK

Article 27 of the CRPD requires that states parties recognize the right of persons with disabilities to work, on an equal basis with others. This includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. Furthermore, Article 27 prohibits discrimination on the basis of disability, which includes persons with psychosocial and intellectual disabilities.

In Kazakhstan, the law directly discriminates against persons with psychosocial and intellectual disabilities and prevents individuals who have been declared “incapable” from being employed. The Labour Code (Article 57) states that employment contracts drawn up with “incapable” individuals are invalid and if a person is declared “incapable” their employment contract will be terminated.

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<sup>40</sup> *Analysis of international and national legislation relating to the recognition of individuals as incapable* (in Russian), by Aigul Shakibaeva, [https://bureau.kz/novosti/sobstvennaya\\_informaciya/okazavshiesya\\_v\\_zone\\_porajeniya/](https://bureau.kz/novosti/sobstvennaya_informaciya/okazavshiesya_v_zone_porajeniya/)

In effect, this provision of the law means that people are denied the right to work based on their disability, without a reasonable and objective justification in violation of Kazakhstan's obligations under the CRPD.

For Vadim Nesterov and Nikolai Klochkov who are currently working in the training cafes run by the NGO the Association of Psychoanalysts in Almaty, the right to work is a very important reason why they seek to regain their legal capacity. For them it is the way towards an independent life. When we asked Vadim if he would like to work somewhere else he said:

"No, I can't because I am "incapable" and as an "incapable" person I can't be employed anywhere."

For the time being the beneficiaries of the community living project in Almaty receive their salary as a grant, but if they are to be truly part of society and find official work outside the project, the Kazakhstani authorities will need to remove this discriminatory provision of the law. In addition to removing the discriminatory provision of the law, the authorities will need to "promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment" as well as the other requirements found within Article 27 of the CRPD.

## RIGHT TO FAMILY LIFE

Article 23 of the CRPD requires that states parties take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, and that person with disabilities are able to marry and found a family on the basis of free and full consent.

However, those declared "incapable" in Kazakhstan are prevented by law from marrying. Article 11 of the Code on Marriage and the Family specifically prohibits marriage with people who have been declared "incapable" in violation of Kazakhstan's obligations under the CRPD.

### **"I WANT TO FOUND A FAMILY, LIVE LIKE EVERYBODY AND FIND GOOD WORK."**



*AI researcher and Nikolai Klochkov in August 2018*

*© Amnesty International*

Amnesty International researcher and Nikolai Klochkov reading his statement for the psychiatric board.

In his statement for the psychiatric board Nikolai Klochkov wrote: "I want to found a family, live like everybody and find good work."

The discriminatory legislation in Kazakhstan currently prevents him from realizing his dreams. The psychiatric board wrote a negative report after meeting Nikolai and recommended that he should not regain his legal capacity. On September 17 2018 a court followed the recommendations of the psychiatric board and ruled not to restore Nikolai's legal capacity.

## THE RIGHT TO PARTICIPATE IN PUBLIC AFFAIRS

In Kazakhstan people who have been declared “incapable” are expressly forbidden to vote. Article 33 of the Constitution states that those declared “incapable”, along with convicted criminals cannot vote, participate in referenda or be elected. The CRPD requires states parties to guarantee that persons with disabilities can fully participate in political and public life on an equal basis with others. States should ensure that voting procedures, facilities and materials are should be easy to understand and accessible.

The Kazakhstani authorities must review and amend these laws which directly discriminate against persons with psychosocial and intellectual disabilities and are incompatible with the CRPD.

## VIOLATIONS OF CIVIL AND POLITICAL RIGHTS

Individuals who are deprived of their legal capacity in Kazakhstan also face violations of their Civil and Political rights. As mentioned in Section 4 of this report, once declared “incapable” persons with psychosocial and intellectual disabilities no longer have the right to appeal to a court of law which means that they have no legal recourse against violations of their rights and possible exploitation. They become vulnerable to other violations as they can no longer have control over their own lives.

## LACK OF INFORMED CONSENT AND INVOLUNTARY HOSPITALIZATION

Article 14 of the CRPD (the right to liberty and security of the person) states that persons with disabilities must not be deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty must be in conformity with the law and that the existence of a disability shall in no case justify deprivation of liberty. Furthermore, the right to liberty and security of the person is guaranteed under Article 9 of the ICCPR.

The UN Committee on the Rights of Persons with Disabilities has emphasised that the detention of persons with disabilities in institutions against their will equates to arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention:

“The denial of the legal capacity of persons with disabilities and their detention in institutions against their will, either without their consent or with the consent of a substitute decision-maker, is an ongoing problem. This practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention. States parties must refrain from such practices and establish a mechanism to review cases whereby persons with disabilities have been placed in a residential setting without their specific consent.”<sup>41</sup>

The UN Committee on the Rights of Persons with Disabilities has repeatedly made recommendations to states parties to ensure that any hospitalization is based on informed consent. In its concluding observations on Spain in 2011 the Committee expressed concern that laws allowed for the institutionalization of persons with psychosocial and intellectual disabilities which only contained *post facto* safeguards for the affected individuals and asked the government to review laws that allow for the deprivation of liberty on the basis of disability, “including mental, psychosocial or intellectual disabilities, and to repeal any provisions that authorize involuntary detention based on an apparent or diagnosed disability.”<sup>42</sup>

In Kazakhstan, the Code on Public Health and the Health System (Article 94 part 2) allows doctors to carry out medical procedures without seeking the informed consent of people who have been declared “incapable”. There is no requirement for doctors to seek any input from the concerned person - it is sufficient for them to seek the consent of their guardians. In the case of persons in residential care, the guardian will be the administration of the institution in which they are living. If no guardian can be found then a decision will be taken by a commission of medical workers, and if that is not possible then the doctor themselves will make the decision and inform the guardian.

Forced placement in a psychiatric institution in Kazakhstan requires a court order, but once a person has been declared “incapable” they can be placed in a psychiatric institution against their will on the decision of the Custody and Guardianship Department following the conclusions of a medical commission.<sup>43</sup>

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<sup>41</sup> General Comment 1, para 40.

<sup>42</sup> Concluding Observations of the Committee on the Rights of People with Disabilities, Spain, Committee on the Rights of Persons with Disabilities, Sixth session, 19–23 September 2011,

[https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD%2fC%2fESP%2fCO%2f1&Lang=en](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD%2fC%2fESP%2fCO%2f1&Lang=en)

<sup>43</sup> Code of the Republic of Kazakhstan on the health of the population and the health system, Article 129. Justification for placing individuals in psycho-neurological organizations.

In addition to undermining the right to informed consent and against forced treatment, this process also risks violations of a range of other rights because of the wide scope of abuse it allows. Many of the individuals interviewed by Amnesty International had been repeatedly hospitalized for lengthy periods of time, at the request of their guardians, usually following arguments or conflict of some kind. In the case of Vasily Novoselov, his guardian resorted to hospitalization to prevent him from challenging her guardianship.

Vasily Novoselov, (see text box on p. 28) is currently dependant on a guardian, a distant relative, who he believes has forged his mother's will in order to lay claim to his inheritance. He has attempted to challenge the will but is denied the right to apply to a court on his own behalf. He was most recently hospitalized in January 2018, the NGO assisting him, the Kazakhstani International Bureau of Human Rights, believes that the timing and evasiveness of the local authorities suggests that it may have been an attempt to prevent him from challenging his distant relative's status as his guardian. As an incapable person he had no opportunity to appeal against the hospitalization. On 30 January 2018, Vasily Novoselov was due to come to the NGO offices to discuss the possibility of changing his guardian. When he didn't turn up to the meeting the Bureau tried to locate him. The Custody and Guardianship Department of the local Akimat denied any knowledge of his whereabouts. The Bureau found out later that Vasily Novoselov had been forcibly hospitalized on 30 January and had arrived at the psychiatric hospital accompanied by his guardian. The Bureau wrote to the local prosecutor's office questioning the procedures under which Vasily Novoselov was hospitalized and suggesting that he had been arbitrarily detained in violation of Kazakhstani law. The Almaty City Department of Health responded to an enquiry from the Bureau in a letter dated 13 February 2018 stating:

"When he arrived at the department during the doctor's inspection he was expressing hallucinatory ideas about relationships and theft. He declared that "they wanted to hospitalize him to take away his flat." He linked all previous hospitalizations to the illegal actions of his guardian. The patient was prescribed drug therapy."

At the time of writing Vasily Novoselov continues his battle to change his guardian and claim his inheritance.

The cases that have come to Amnesty International's attention fail to comply with international human rights standards on the treatment of persons with psychosocial and intellectual disabilities. Adults declared "incapable" and subjected to forced placement in a psychiatric hospital have no possibility to appeal against their forced treatment, and they cannot apply to a court on their own behalf. Their guardians could apply on their behalf, but as can be seen from the examples above, there may be a conflict of interest between the guardian and concerned person.

The Kazakhstani authorities must immediately review legislation relating to placement in a psychiatric hospital and ensure that "incapable" persons have the possibility to appeal against their involuntary treatment.

## **MEDICAL EXPERIMENTATION**

Article 180 part 9, point 5 of the Kazakhstani Code on Public Health and the Health System forbids the carrying out of drug tests or medical-biological experiments on people who have been declared "incapable" "with the exception of clinical research of medical technology and medications aimed at treating psychiatric disorders".

This provision of the law is in violation of Article 7 of the ICCPR which bans torture and other ill-treatment explicitly states that "no one shall be subjected without his free consent to medical or scientific experimentation".

Article 15 of the CRPD requires that all appropriate measures be taken to prevent persons with disabilities from being subjected to torture or cruel, inhuman or degrading treatment or punishment, and that no one must be subjected to medical or scientific experimentation without his or her free consent. Article 16 requires that all measures be taken to protect persons against and prevent all forms of exploitation, violence and abuse.

Pending the abolition of plenary guardianship, the Kazakhstani authorities must make the necessary changes to relevant laws to ensure that there is no discrimination in the treatment of persons with psychosocial and intellectual disabilities within the health system. Article 180, part 9, point 5 of the Code on Public Health and the Health system must be immediately removed as it violates Kazakhstan's international human rights obligations relating to torture and other ill-treatment.

# CONCLUSIONS

The current guardianship regime for adults with psychosocial and intellectual disabilities in Kazakhstan is incompatible with the CRPD's human rights- based approach to disability. It discriminates against persons with psychosocial and intellectual disabilities and subjects them to the ultimate form of stigmatization by depriving them of legal capacity thus preventing them from exercising their human rights and isolating them from society. It is a relic of a system that condemned persons with disabilities to a life in institutions hidden from the public gaze.

While the ostensible aim of the guardianship regime is to “protect” persons with psychosocial and intellectual disabilities, it actually exposes them to exploitation at the hands of self-seeking or inadequate guardians. The “one size fits all” system allows for no flexibility in the application of protection measures and cannot be adapted according to the individual needs of persons with disabilities. The absence of regular review means that once a person has been deprived of legal capacity it is very unlikely to be restored. Those who do attempt to restore their legal capacity, with the assistance of others, face demeaning and absurd tests of their mental capacity. Guardianship is applied on the basis of vague criteria via an arbitrary process which exposes people to the risk of being arbitrarily deprived of their rights. Furthermore, by depriving individuals of the right to apply to courts on their own behalf, they have no recourse to protect their rights, or to challenge the guardianship under which they have been placed.

Kazakhstan has demonstrated its intention to respect the human rights of persons with disabilities by ratifying the CRPD and making progress towards inclusivity by increasing accessibility and working with NGOs to offer support services within the community. Kazakhstan must now take the next step towards building a truly inclusive society by recognizing that the current guardianship regime is not compatible with the CRPD. As a first step, the government must conduct a thorough review of legislation in the light Article 12 of the CRPD, in order to remove all those provisions that are incompatible with the Convention. As a priority the government must remove all provisions that directly discriminate against persons with disabilities, and specifically as is the case in this report, persons with psychosocial and intellectual disabilities.

The next task will be to lay out a timetable for the establishment of an adequate system of support for persons with psychosocial and intellectual disabilities that require such support to replace the guardianship system. These measures should be based on the actual capacity of the person concerned and be tailored to their needs. They should make it possible for persons with psychosocial and intellectual disabilities to exercise their rights as equal members of society without fear of exploitation or coercion, and without losing their legal capacity. In doing this the Kazakh authorities can benefit, and indeed must, consult closely and actively with persons with disabilities, including children with disabilities, through their representative organizations; the experience of other countries will also be beneficial in the process.

# RECOMMENDATIONS

Amnesty International makes the following recommendation to assist the government of Kazakhstan in ensuring the rights of persons with psychosocial and intellectual disabilities are fully respected, protected and fulfilled.

## ABOLITION OF GUARDIANSHIP

- Fully explore alternatives to plenary guardianship for adults and devise a timeline for the establishment of an alternative system based on best practice, in accordance with the CRPD, by closely consulting with and actively involving persons with disabilities, in particular persons with psychosocial and intellectual disabilities, including children with disabilities, through their representative organizations, and experts and practitioners both within Kazakhstan and from other countries.

## TRAINING AND AWARENESS RAISING

- Take all appropriate measures, including increasing public campaigns to raise awareness about psychosocial and intellectual disabilities, to overcome customs and practices that discriminate against persons with psychosocial and intellectual disabilities and perpetuate negative stereotyping;
- Ensure that staff of the Guardianship and Custody Departments of local government branches are fully informed about the human rights implications of depriving individuals of legal capacity and ensure that they are informed about alternative solutions for persons with psychosocial and intellectual disabilities and parents of children with psychosocial and intellectual disabilities, and always suggest such alternative solutions that are grounded in a human rights approach that respect the legal capacity of persons with psychosocial and intellectual disabilities and comply with the CRPD;
- Ensure that lawyers representing clients subject to deprivation of legal capacity are fully informed about the rights of persons with psychosocial and intellectual disabilities, including the right to retain their legal capacity;
- Ensure that judges are fully informed about the consequences of “incapability” decisions and that they understand the right of persons with psychosocial and intellectual disabilities to retain their legal capacity and ensure that they exercise their duty to hear all parties in the decision including the person in question.

# INTERIM MEASURES

Pending the abolishment of plenary guardianship and the introduction of assisted decision-making measures, Amnesty International makes the following recommendations to mitigate the human rights violations:

- Make the necessary changes to legislation to ensure that individuals who have been declared “incapable” have the right to apply to courts to defend their rights, to reverse “capability” decisions and to change guardians;
- Take effective and appropriate measures to ensure that persons with psychosocial and intellectual disabilities are not discriminated against in matters concerning respect for the home and family, including amending Article 11 of the Code on Marriage and the Family which forbids marriage for individuals declared “incapable” to comply with Article 23 of the CRPD;
- Amend, in line with Article 27 of the CRPD, Article 57 of the Labour Code which prevents individuals declared “incapable” from being employed;
- Amend, in accordance with Article 29 of the CRPD, Article 33 of the Constitution which prevents individuals declared “incapable” from voting and standing for election;
- Review the procedures governing consent in the health care system to ensure that individuals who have been declared “incapable” must give their free and informed consent to medical treatment and cannot be hospitalized without their consent, in particular Article 94 part 2, and of the Code on Public Health and the Health System;
- Remove the exception to the ban on medical experimentation which allows for testing of medical technologies and medicines for treatment of “mental disorders” on persons with psychosocial and intellectual disabilities in Article 180 part 9, point 5 of the Code on Public Health and the Health System.

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# “WE ARE LIKE DEAD SOULS”

## LIFE WITHOUT LEGAL CAPACITY IN KAZAKHSTAN

Currently at least 16,000 persons with psychosocial and intellectual disabilities in Kazakhstan have been deprived of legal capacity and a guardian has been appointed to make all decisions for them. This guardianship regime subjects persons with psychosocial and intellectual disabilities to discrimination and is the ultimate form of stigmatization. It prevents them from exercising their human rights and isolates them from society. It is a relic of a system that condemned persons with disabilities to a life in closed institutions hidden from the public gaze.

Once declared “incapable” by a court, individuals are deprived of the right to make any decisions about their lives, and doctors no longer need their free and informed consent for medical treatment. There is no automatic review of “incapability” decisions and legal capacity can only be restored if the person is judged to have been “cured” or if their guardian or a prosecutor applies to restore it. In practice, it is very rare for legal capacity to be restored and most people who have been declared “incapable” will remain under guardianship for life. Kazakhstan must ensure that persons with psychosocial and intellectual disabilities can exercise their rights fully as equal members of society by putting in place a system of support for persons with psychosocial and intellectual disabilities to replace the guardianship system.