



BRIEFING NOTE

THE HUMAN RIGHTS SITUATION OF PERSONS WITH INTELLECTUAL AND PSYCHOSOCIAL DISABILITIES IN UKRAINE

1 February 2022

SUMMARY

In line with the principle to leave no one behind defined in the Sustainable Development Goals 2030 and its unequivocal commitment to end discrimination and exclusion, the UN Human Rights Monitoring Mission in Ukraine has been monitoring the human rights situation of persons with intellectual and psychosocial disabilities. The briefing note presents the results of this work, describes human rights violations and concerns affecting persons with intellectual and psychosocial disabilities in Ukraine and provides recommendations. The briefing note focuses on two major concerns affecting the rights of persons with intellectual and psychosocial disabilities – institutionalisation and denial of legal capacity – and analyses the impact of these and other concerns on the range of human rights provided in the Convention on the Rights of Persons with Disabilities and other universal international human rights instruments applicable in Ukraine.

Persons with intellectual and psychosocial disabilities are the group that is most represented in institutions in Ukraine. They continue to be placed in long-term care facilities, which remain almost the only option for accommodation and social care. Many facilities accommodate over a hundred residents, without the capacity to provide individualised social services and support. Persons living in such facilities are cut off from local communities, the social and medical services provided there, and official employment. Only in rare examples can they return to living in the community. Most of the persons are trapped in long-term care facilities for life. Grave human rights violations, such as torture, ill-treatment, involuntary medication, forced labour and deprivation of personal liberty occur in such institutions. Denial of the right to private life and family life, as well as the right to sexual and reproductive health, is another pervasive human rights concern in long-term care facilities.

A decade after Ukraine ratified the Convention on the Rights of Persons with Disabilities, no measures have been taken to start the implementation of article 12, on equal recognition before the law. Denial of legal capacity continues to be widespread in Ukraine and more than 40 thousand people are not allowed to make decisions about their own lives. A human rights violation *per se*, the denial of legal capacity of persons with intellectual and psychosocial disabilities also affects other human rights. The law explicitly prohibits incapacitated persons to vote in elections and referendums, establish or join civil society organizations and political parties, dispose of their property and social payments.

A complete move away from institutionalising persons with intellectual and psycho-social disabilities and amending the civil legislation on legal capacity could take years or decades. An important start to this process are the efforts of the Government of Ukraine to develop access to social services in the community, which are the precursors of these two major reforms. The briefing note contains recommendations to address the human rights concerns outlined in the paper, including for deinstitutionalisation of persons with intellectual and psycho-social disabilities and reform of the system that regulates legal capacity, and suggests possible directions for cooperation between government, international partners and civil society.

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Introduction

1. The United Nations Human Rights Monitoring Mission in Ukraine (HRMMU)¹ monitors the human rights situation of individuals and groups in marginalized and vulnerable situations, in line with the realization of the 2030 Agenda for Sustainable Development and UN commitment to leave no one behind.

2. In this note, HRMMU examines the human rights situation of persons with intellectual and psychosocial disabilities in Ukraine, including those residing in institutions and those deprived of legal capacity, by focusing on violations of their right to equal recognition before the law and other rights closely interlinked with it and guaranteed under the UN Convention on the Rights of Persons with Disabilities (CRPD).² The briefing note describes the human rights situation of persons with intellectual and psychosocial disabilities living in the territory of Ukraine under control of the Government. It makes recommendations to the Government of Ukraine to help bring legislation, policy and practice in compliance with its international obligations under the Convention and other human rights treaties.

3. The exact number of persons with intellectual and psychosocial disabilities in Ukraine is unknown. According to the Government of Ukraine, as of 1 January 2020, there were 40,327 persons deprived of legal agency³ and 1,357 persons with limited legal agency. At that time, 14,596 persons with removed legal agency resided in long-term care institutions in Ukraine.⁴

4. In September 2015, in its Concluding Observations on the initial report of Ukraine, the Committee on the Rights of Persons with Disabilities (hereinafter – Committee) strongly recommended that Ukraine adopts a human rights based approach to disability in all its laws, policies and decisions.⁵ In particular, the Committee called on Ukraine to revoke national legislation that discriminates against persons with disabilities, including to abolish all forms of deprivation of legal capacity in relation to all persons with disabilities, as well as deprivation of liberty on the basis of disability. These, as well as many other recommendations made by the Committee in 2015 are yet to be implemented.

5. In its Concluding Observations on the 8th periodic report of Ukraine in March 2017, the Committee on the Elimination of Discrimination against Women (CEDAW) stressed its concern about the lack of public policies and measures to protect the rights of women and girls with disabilities, including their rights to inclusive education, healthcare, employment, housing and participation in political and public life, as well as the absence of mechanisms to protect women and girls with disabilities from intersecting forms of discrimination and from violence and abuse.⁶

6. By eliminating discrimination against persons with intellectual and psychosocial disabilities, Ukraine would also contribute to the implementation of the Sustainable Development Goals (SDGs), such as SGD 3 on access to healthcare, especially for those most vulnerable; SDG 4 that guarantees equal and accessible education by building inclusive learning environments and providing the assistance for persons with disabilities in obtaining an education; SDG 5 on achieving gender equality and empowering all women and girls, including those with disabilities; SDG 8 on promoting inclusive economic growth, full and productive employment allowing persons with disabilities to fully access the job market; SDG 10 emphasizing the social, economic and political inclusion of persons with disabilities; SDG 11 on creating accessible cities and water resources, affordable, accessible and sustainable transport systems, providing universal access to safe, inclusive, accessible and green public spaces, and SDG 16 providing for improved access to justice and public services.

7. Between October 2020 and October 2021, HRMMU made 47 monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities and 6 monitoring visits to psychiatric hospitals, located in 11 different regions of Ukraine. HRMMU teams conducted 411 semi-structured confidential interviews with 209 men and 202 women, mainly persons with intellectual and psychosocial disabilities, their relatives, representatives of organisations of persons with disabilities and other human rights organizations advocating on their behalf, long-term care facilities and psychiatric hospitals. In February 2021, HRMMU also conducted an online survey among 226 relatives of persons with intellectual and psychosocial disabilities.

¹ HRMMU was deployed on 14 March 2014 to monitor and report on the human rights situation throughout Ukraine and to propose recommendations to the Government and other actors to address human rights concerns. HRMMU implements the Office of the High Commissioner for Human Rights (OHCHR) mandate to protect and promote human rights in Ukraine.

² Ukraine ratified the Convention without any reservations or declarations on 16 December 2009. See the Law of Ukraine No. 1767-VI of 16 December 2009, available in Ukrainian at: <https://zakon.rada.gov.ua/laws/show/1767-17#Text>.

³ Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency). Deprivation of one of the elements leads to denial of the legal capacity. According to civil legislation of Ukraine, only persons with chronic intellectual and psychosocial conditions can be deprived of legal agency.

⁴ Information provided by the Ministry of Social Policy on 20 November 2021 upon HRMMU inquiry.

⁵ Committee on the Rights of Persons with Disabilities, *Concluding Observations in relation to the initial report of Ukraine*, 4 September 2015, available at <http://daccess-ods.un.org/access.nsf/Get?Open&DS=CRPD/C/UKR/CO/1&Lang=E>.

⁶ Committee on Elimination of All Forms of Discrimination against Women, *Concluding Observations to the eighth periodic report of Ukraine*, 9 March 2017, available at https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CEDAW/C/UKR/CO/8&Lang=En.

HRMMU also analysed national legislation, case law, internal regulations of social institutions, and open-source information, including reports of national human rights institutions and civil society organizations.

HRMMU MONITORING ACTIVITIES



Creation Date: 15 January 2022 Source: HRMMU

8. The briefing note is divided into two parts. The first part focuses on Ukraine’s obligation to ensure equal recognition of persons with disabilities before the law (under article 12 CRPD). It presents international human rights standards and analyses the compliance of Ukraine’s legislation, policy and practices with the CRPD and other international human rights instruments. The second part examines the situation with other rights of persons with intellectual and psychosocial disabilities under the CRPD, including access to justice (article 13), the right to independent living and inclusion in the community (article 19), liberty and security (article 14), freedom from torture or cruel, inhumane and degrading treatment or punishment (article 15), respect of integrity of a person (article 17), privacy (article 21), home and family (article 22), education (article 24), health (article 25), work (article 26), habilitation and rehabilitation (article 27) and adequate standard of living and social protection (article 28). The note concludes with recommendations to the Government, local authorities in Ukraine and international partners.

I. Violations of the right to equal recognition before the law

9. Ukrainian legislation and legal practice continue to utilize removal and restriction of legal capacity of persons with disabilities, which is not in line with international human rights conventions ratified by Ukraine. HRMMU observed that restoration of legal capacity presents a major challenge for persons with disabilities, who according to HRMMU's analysis succeed in only around 22 per cent of cases.

A. International standards on the right to equal recognition before the law for persons with disabilities

10. Apart from the general human rights standards on equal recognition before the law defined in article 16 ICCPR, article 12 of the CRPD requires that persons with disabilities have the right to recognition everywhere as persons before the law and shall enjoy legal capacity on an equal basis with others in all aspects of life. At the same time, it guarantees persons with disabilities access to the support they may require in exercising their legal capacity and 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.⁷

11. In the interpretation of the Committee and the Special Rapporteur on rights of persons with disabilities (Special Rapporteur)⁸, implementation of article 12 of the Convention requires States to:

- abolish all laws and practices providing for denial of legal capacity of persons with disabilities, including on the basis of a medical condition or impairment (status approach), on a person's decision considered as having negative consequences (outcome approach), or deficient decision-making skills (functional approach);⁹
- Introduce supported decision-making to provide persons with disabilities the support they may require in exercising their legal capacity, and abolish substitute decision-making when all decisions are taken for a person with a disability by a guardian or trustee. Supported decision-making shall be guided by the principle of the "best interpretation of the will and preference", instead of the "best interest" principle intrinsic to substitute decision-making arrangements.¹⁰

B. Legislation on legal capacity and substitute decision-making

12. Ukraine's legislation does not comply with article 12 of the CRPD and provides for removal and restriction of the legal agency of persons with intellectual and psychosocial disabilities based on a combination of status and functional approaches. As a result, persons with disabilities who have their legal agency restricted or removed cannot enjoy their civil, political, economic, social and cultural rights guaranteed under international human rights treaties.

13. The basic rules on the legal capacity of natural persons and its limitations are laid down by the Civil Code of Ukraine, which distinguishes between legal standing and legal agency within the overarching concept of legal capacity. Legal standing is described as the ability to hold civil rights and obligations inherent to all human beings from birth.¹¹ The Civil Code defines legal agency as the ability to acquire civil rights by one's own actions, exercise them independently, create and perform civil obligations and bear responsibility.¹² Legal agency depends on the ability of a person to perceive and control their actions, and as a rule, a person enjoys full legal agency from the age of 18. The Civil Code provides that adults can have their legal agency removed or restricted by a court. The court "may restrict the legal agency of natural persons with mental disorders that severely affect their ability to perceive and (or) control their own actions".¹³

⁷ See article 12, p. 3 and 4.

⁸ The same approach on the legal capacity of persons with disabilities was later included in the *International Principles and Guidelines on Access to Justice for Persons with Disabilities*, available at: https://www.ohchr.org/Documents/Issues/Disability/SR_Disability/GoodPractices/Access-to-Justice-EN.pdf.

⁹ See *A/HRC/37/56 Report of the Special Rapporteur on the rights of persons with disabilities*, para 14-15. See also *Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014) on equal recognition before the law*.

¹⁰ See *A/HRC/37/56*, para. 26-28.

¹¹ See article 25 of the Civil Code. Available in English at: http://teplydim.com.ua/static/storage/filesfiles/Civil%20Code_Eng.pdf. Ukrainian legislation on legal capacity is aligned with definitions of the Committee on the Rights of Persons with Disabilities. The Committee defines legal capacity as the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency). Removal of one component would amount to a violation of the right to equal recognition before the law.

¹² *Ibid*, article 30.

¹³ Apart from the restriction of legal agency on the basis of mental disorder, the court may also restrict the legal agency of a person if they abuse alcohol, drugs, or gambling, which has a negative impact on their economic situation or economic situation of their family.

14. An adult person whose legal agency is removed is unable to take any legally-relevant actions or decisions and such persons do not bear civil responsibility for their actions. The court may remove legal agency and deem a person incapacitated if they are not able to perceive and/or control their actions due to a “chronic and stable mental disorder”. A guardian appointed by the court takes all legally-relevant actions and decisions on behalf of a person whose legal agency has been removed, acting in the person’s best interest.¹⁴ A person deemed as incapacitated is not authorized to challenge the guardian’s actions made on their behalf or independently request the court to change the guardian unless their legal agency is restored.

15. A person with restricted legal agency is allowed to make major civil transactions only with the consent of a trustee appointed by the court, but can challenge decisions of their trustee in the court and bears limited civil responsibility.

16. Both guardianship and trusteeship constitute different forms of substitute decision-making incompatible with article 12 of the CRPD because they provide for the transition of the individuals’ faculty to make deals to their trustees or guardians, not for the support of persons with intellectual and psychosocial disabilities in decision-making in relation to their rights.¹⁵

17. Based on the Civil Code, persons with removed legal agency cannot participate in civil transactions to exercise their property and non-property civil rights. On top of that, the concept of an incapacitated person is included in Ukraine’s Constitution and widely used in legislation, and leads to denial in the realization of other rights. Ukrainian legislation explicitly prohibits persons deemed as incapacitated to vote in elections and referendums,¹⁶ create or join civil society organizations and political parties,¹⁷ get married,¹⁸ join the civil service,¹⁹ independently cross the state border,²⁰ and apply to a court.²¹

18. HRMMU notes with regret that in the absence of any supported decision-making arrangements, removal of legal agency and assignment of a guardian remains the only legal mechanism enabling relatives to provide legal support to persons with severe and profound intellectual and psychosocial disorders. According to HRMMU’s online survey, the majority of relatives of persons with intellectual and psychosocial disabilities who requested the court to remove legal agency had decided to do so either to protect the property rights of their loved ones or to provide assistance with the disposal of their property rights (see infographic below). The vast majority of respondents decided to apply for removal of legal agency upon recommendations of the disability evaluation board, social workers, doctors or human rights defenders. The online survey also indicates that in almost half of the cases where relatives decided not to request the removal of legal agency, such decisions were made to retain enjoyment of social and economic rights and voting rights. Moreover, parents of adult persons with intellectual disabilities told HRMMU that they did not apply for the removal of legal agency to prevent stigmatization in light of numerous restrictions of rights resulting from the removal of legal agency.

19. HRMMU is concerned that the Ukrainian official translation of the CRPD, in particular, the translation of the term “legal capacity” in article 12, is not in line with the English text of the CRPD. It narrows the scope of equality before the law to equal enjoyment of legal standing, not legal agency. This implies that removal or limitation of legal agency by the court is not prohibited by the Ukrainian official translation of the Convention.²²

¹⁴ See article 55 of the Civil Code.

¹⁵ HRMMU interviews with parents of persons with intellectual and psychosocial disabilities, 14 January 2021.

¹⁶ See article 70 of the Constitution of Ukraine, available in English at: <https://rm.coe.int/constitution-of-ukraine/168071f58b>.

¹⁷ See articles 7 and 8 of the Law of Ukraine "On Civil Associations", available in Ukrainian at: <https://zakon.rada.gov.ua/laws/show/4572-17#Text>.

¹⁸ See article 39 of the Family Code of Ukraine, which deems void a marriage with a person deemed as incapacitated. Available in Ukrainian at: <https://zakon.rada.gov.ua/laws/show/2947-14#Text>.

¹⁹ See article 19 of the Law of Ukraine “On Civil Service”, available in Ukrainian at: <https://zakon.rada.gov.ua/laws/show/889-19#Text>.

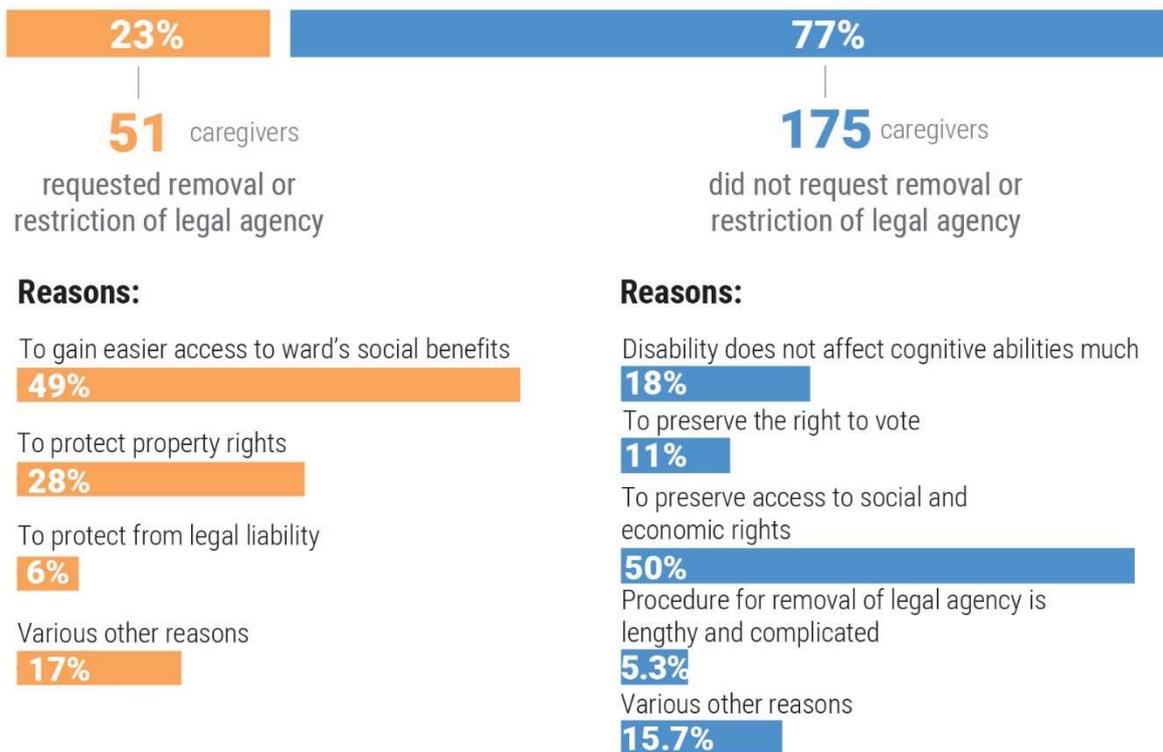
²⁰ Persons deemed as incapacitated can leave Ukrainian territory only upon motion of their guardians or court order. See article 10 of the Law of Ukraine “On the Procedure of Ukrainian Citizens Entry in Ukraine and Departure from Ukraine”, available in Ukrainian at: <https://zakon.rada.gov.ua/laws/show/3857-12#Text>.

²¹ Except for cases concerning the restoration of legal agency.

²² For more information on this please see the Ukrainian translation of General Comment No. 1 of the Committee prepared by UN Human Rights Monitoring Mission in Ukraine, available at: <https://ukraine.un.org/en/133050-general-comment-no-1-article-12-equal-recognition-law>.

POSITION OF CAREGIVERS ON REMOVAL OF LEGAL AGENCY

According to the online survey of HRMMU among 226 caregivers of persons with disabilities



Creation Date: 28 January 2022 Source: HRMMU

C. Fair trial concerns in cases of removal or restoration of legal agency

20. HRMMU is concerned that Ukrainian procedural legislation and jurisprudence fail to protect individuals in practice, leading to removal of legal agency even in cases where persons with intellectual and psychosocial disabilities can effectively exercise their rights without extensive services for supported decision-making, which are not available in Ukraine. Restoration of legal agency presents a stiff challenge for persons with disabilities since the courts deny the applications in around 80 per cent of cases. Major concerns that infringe the enjoyment of the right to equal recognition before the law are (1) the lack of a review procedure for decisions on the removal of legal agency rendered before 2017; (2) violations of the right to be present during court hearings; (3) the heavy reliance of court decisions on the results of psychiatric examinations, which lack a specified methodology; and (4) insufficient access to legal aid.

21. In October 2017, changes were made to the Civil Procedure Code to provide the right of legally incapacitated persons to apply independently for restoration of their legal agency.²³ In addition, the changes introduced a mandatory two-year periodic review of all court decisions on the removal of legal agency taken after December 2017 when the amendments entered into force.²⁴ If neither of the parties concerned applies to the court for an extension of the removal of legal agency, the relevant court decision expires and the person's legal agency will be automatically restored.²⁵

²³ In May 2013, the European Court of Human Rights (ECtHR) concluded that the absence of the right to apply independently for the restoration of legal agency breaches article 6.1 of the European Convention on Human Rights. See *Case of Nataliya Mikhaylenko v. Ukraine*, application 49069/11. HRMMU notes that it took the Government four and a half years to amend the law and enshrine the right of persons with disabilities to apply independently for the restoration of their legal agency. On 3 October 2017, Parliament adopted Law No. 2147-VIII, which provided for the total revision of the Civil Procedure Code of Ukraine, available in Ukrainian at: <https://zakon.rada.gov.ua/laws/show/2147-19#n2972>.

²⁴ See article 300.6 of the Civil Procedure Code.

²⁵ According to article 300.7 of the Civil Procedure Code, a guardian or representative of the guardianship body should file an application for extension of the period for the removal of legal agency at least 15 days before the expiration of the previous court decision.

22. HRMMU is concerned that the requirement of a periodic review applies only to court decisions rendered after relevant amendments to the legislation entered into force on 15 December 2017.²⁶ Thus, a large number of people whose legal agency was removed before that date are excluded from the review requirement, including individuals whose legal agency was removed much earlier, under the Soviet civil and civil procedure legislation,

“It is easy to deem [a person] as legally incapable. But it is much harder to get legal capacity back.”

– Person with intellectual disability on restoring his legal capacity.

before it was replaced by modern Ukrainian laws in 2003 and 2004. HRMMU has identified cases of persons with disabilities who have continued to be legally incapacitated since 1982. The removal of legal agency of these individuals does not expire and it is not subject to any periodic review.

23. Although positive from the perspective of safeguarding human rights, the review procedure creates enormous emotional and financial pressure on guardians, mostly relatives, who shoulder the responsibility of arranging the review every two years and cover all expenses in relation to this, including for legal services to prepare the application to court and gathering documents, and for transportation.²⁷ Court proceedings on the review usually last 6-8 months, which forces guardians to commence preparations for the review procedure barely a year after a decision on the removal of legal agency is rendered. In cases where persons with intellectual and psychosocial disabilities are not granted lifetime disability status, their relatives bear the responsibility of arranging a periodic review of their relative’s disability status every two years, in addition to the biyearly review regarding legal agency.²⁸ The guardians complained to HRMMU that they are constantly occupied with one or the other procedure.

24. Women with caring responsibilities for persons with disabilities are particularly affected because, according to HRMMU’s online survey, they constitute 95 per cent of those who serve as guardians for their children or relatives with disabilities. Families residing in rural areas often encounter greater difficulties arranging transportation to the courts and hospitals conducting forensic psychiatric examinations, which are mandatory in such proceedings.

25. The 2017 legislative changes to the civil procedure also allowed for the presence of affected persons in the courtroom in cases regarding removal of their legal agency, although it is not obligatory.²⁹ However, HRMMU is concerned that in the overwhelming majority of cases it analysed, the removal of legal agency was adjudicated in the absence of the affected individuals.³⁰ Of even greater concern is that legally incapable persons are not informed at all about the cases and may only become aware of decisions years after they have been rendered.³¹ HRMMU observed cases when courts reviewed applications on the restoration of legal agency in the absence of the affected individuals, in particular those residing in institutions. Although such practice may prevent unnecessary stress for persons with severe and profound intellectual and psychosocial disabilities, it may amount to a violation of the right to access to justice contained in article 13 of the CRPD.³²

26. HRMMU received reports from human rights defenders and social workers that judges tend to review such cases *pro forma* and rely heavily on the conclusions of the forensic psychiatric examinations, ordered by the

²⁶ Law No. 2147-VIII entered into force on the day the new Supreme Court commenced its operations on 15 December 2017. Before the adoption of the Civil Code in 2003 and the Civil Procedure Code in 2004, Ukraine used relevant laws of the Ukrainian Soviet Socialist Republic of 1963 with amendments.

²⁷ Some guardians complained to HRMMU that their expenses may reach up to 10 thousand UAH (360 USD). This compares with the average monthly wage in Ukraine.

²⁸ In Ukrainian legislation, disability is defined as a degree of loss of health in connection with disease, injury (its consequences) or congenital conditions that in interactions with the environment may lead to restriction of activity of a person. Based on the degree of health-loss, the legislation provides for three groups of disability, which are assigned to a person by the disability evaluation boards (medical and social examination commissions). Disability status is usually assigned for a period from 1 to 3 years (usually for 2 years). To extend disability status, a person should undergo reexamination. In cases of congenital conditions and irreversible impairments, the disability status may be assigned for life.

²⁹ Article 240.1 of the Civil Procedure Code states that courts have to decide on the necessity of the presence of persons subjected to the procedure on the removal of legal agency on a case-by-case basis.

³⁰ HRMMU documented nine cases of persons with intellectual disabilities who complained that the courts rendered decisions on the removal of their legal agency in their absence. HRMMU conducted a sample analysis of the 2016 case law on the removal of legal agency. Out of 50 court decisions on removal of legal agency analyzed by HRMMU, in only two cases were persons subjected to the removal of their legal agency present at the court hearings.

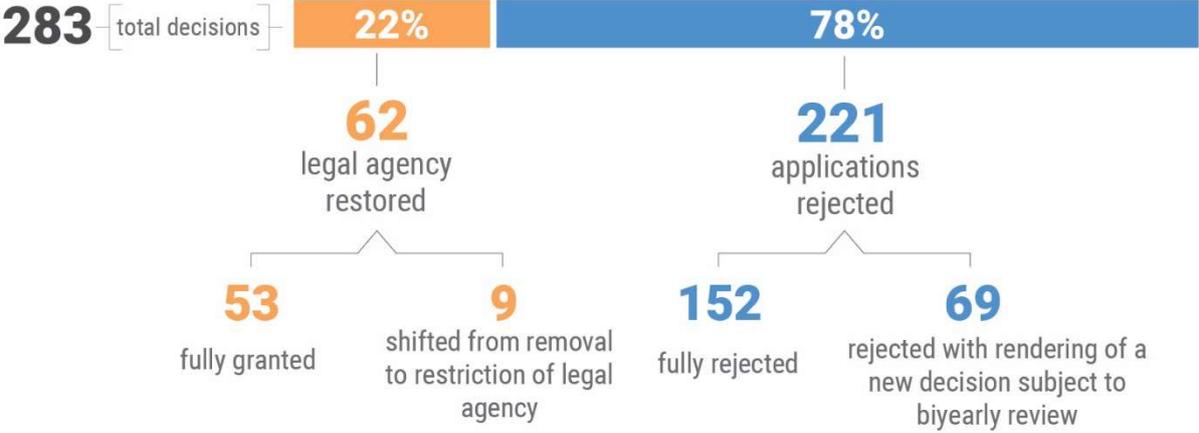
³¹ HRMMU interview, 27 November 2020.

³² “States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.”

court in such cases in accordance with the law.³³ According to HRMMU’s analysis of 117 court decisions in cases where parties requested the restoration of legal agency in 2020-2021,³⁴ courts ruled in only 22 per cent of cases (62 in total) to restore legal agency. Most of the cases for restoration of legal agency were filed by the directors of long-term care facilities or relatives, who claimed that the condition of persons with disabilities had significantly improved and provided clinical records.³⁵ Yet, in all these examples, courts rejected the cases based on the negative conclusions of state forensic psychiatric examinations.

COURT DECISIONS ON RESTORATION OF LEGAL AGENCY

in 2020-2021



Creation Date: 28 January 2022 Source: According to the unified court register

27. HRMMU has reasonable grounds to believe that the state’s monopoly on forensic psychiatric examinations and limited opportunity to obtain alternative examinations are among the major barriers for restoration of legal agency. According to the legislation, forensic psychiatric examinations are conducted by experts of specialized forensic psychiatric institutions of the Ministry of Health, namely 28 municipal psychiatric hospitals and three specialized expert institutions.³⁶ The legislation does not permit private hospitals and psychiatrists to conduct forensic psychiatric examinations, which implies a state monopoly in this domain and limits individuals the opportunity to present alternative evidence in court.³⁷ Human rights defenders complained to HRMMU that forensic psychiatric examinations in cases on the restoration of legal agency are assigned to the same hospitals which conducted the examination for the earlier removal of legal agency.³⁸ In such cases, experts tend not to change their previous conclusions.

³³ Moreover, human rights defenders also told HRMMU that judges and jury members adjudicating cases on the removal of legal agency are not fully familiarised with international human rights standards on equal recognition before the law and the peculiarities of the behavioural and cognitive abilities of persons with different forms of intellectual and psychosocial disabilities. HRMMU analysed court decisions on restoration of legal agency in 2020-2021 and did not see any decisions referencing article 12 CRPD.

³⁴ Based on information from the Unified state court register.

³⁵ By virtue of the law, long-term care facilities are obliged to conduct comprehensive medical examinations of the mental health of all their residents once a year. Positive results of such examination are usually used by the facilities to request the court restore the legal agency of their residents. Some applicants claimed that the removal of legal agency was an extreme and inappropriate measure and their wards could return to independent living in the community if adequate support was provided. For example, applicants told judges that a person with a disability, who had been deprived of legal agency, “can write, count, use money and dispose of property”; or “is a student at a university in his fourth year”; or “can take care of himself and is adapted to the social environment; wants to undergo computer training”; or “is an employee”.

³⁶ HRMMU also notes that with the introduction of the review procedure for court decisions on removal of legal agency, the workload of the psychiatric experts has significantly increased. Experts also complained to HRMMU about low salaries. HRMMU interviews, 29 January 2021.

³⁷ In this regard, HRMMU notes, that the ECtHR provided a critical assessment of such a system for forensic psychiatric examinations in a case on involuntary admission to a psychiatric hospital. See *Anatoliy Rudenko v. Ukraine*, 17 April 2014, no. 50264/08, para. 113.

³⁸ Usually, each region has only one psychiatric hospital conducting forensic psychiatric examinations.

28. HRMMU also notes the complaints of psychiatrists that it interviewed about barriers in being able to practice forensic psychiatry³⁹ and the lack of a unified methodology for forensic psychiatric examinations. The legislation does not describe the methodology but provides only for the number of methods used in such examinations. Reportedly, every institution develops and uses its own methodology, including a set of questions to define cognitive skills and socialization of persons with disabilities. In this regard, human rights defenders and persons with disabilities complained to HRMMU about inadequate questions, which experts asked persons undergoing procedures for the restoration of their legal agency. For example, persons with disabilities were reportedly asked “[w]hat is a cache-pot?” or “[H]ow do you use an ATM”.

“...the doctors cannot admit their own mistake... And the courts simply agree with the doctors.”

- Director of long-term care facility on low number of cases on restoration of legal capacity.

29. HRMMU documented an emblematic case of a man with an intellectual disability who struggled to get his legal agency restored. The man had been residing in a long-term care facility for children since his early childhood. When he turned 18 in 2010, a court rendered a decision on the removal of his legal agency. In March 2019, upon the man’s request, the director of the facility applied to the court to restore his legal agency. Two psychiatric examinations commissioned by the court came to different conclusions in relation to the severity of his disability and ability to perceive and/or control his actions. The man complained to HRMMU that during the examinations he had been asked questions about geography, which he could not answer because he had not received a proper education in the long-term care facility for children where he was raised. The court denied the application for the restoration of his legal agency. However, after the intervention of the Ombudsperson’s Office upon referral from HRMMU, in August 2021 in yet another proceeding, the court restored the man’s legal agency following the positive conclusion of a psychiatric examination produced at another hospital in a different region.⁴⁰

30. HRMMU is also concerned that not all persons with intellectual and psychosocial disabilities can enjoy free legal assistance in court proceedings on removal and restoration of their legal agency. According to Ukrainian legislation, all persons are entitled to secondary free legal aid in such court proceedings. Positively, 20 out of 46 directors/staff of long-term care facilities interviewed by HRMMU concluded memorandums on cooperation with local free legal aid centres in order to facilitate access to free legal aid for individuals in their institutions. Directors of 19 long-term care facilities confirmed to HRMMU that representatives of free legal aid centres conducted regular visits to provide legal information and legal advice. However, HRMMU is concerned that free legal aid centres did not have printed information materials in a language and format accessible for persons with intellectual and psychosocial disabilities, which presents an effective impediment to the right to free legal aid.⁴¹

31. Human rights defenders complained to HRMMU that attorneys providing secondary free legal aid in some cases neglected their duties and some did not even visit their clients in long-term care facilities before proceedings started. In one emblematic case documented by HRMMU, the lawyer of a woman with an intellectual disability objected to her application for the restoration of her legal agency because she “*did not have particular plans for the future*”.⁴²

32. HRMMU also notes that enjoyment of the right to equal recognition before the law of persons with intellectual and psychosocial disabilities living in facilities very much depends on the facility administration’s position regarding the legal agency of its residents. The average number of persons with removed legal agency in the facilities visited by HRMMU was 53 per cent. However, the situation was particularly dire in 7 facilities where more than 90 per cent of residents had their legal agency removed.⁴³ While some directors whom HRMMU interviewed considered the removal of legal agency necessary in cases of severe and profound disabilities, others found it completely inappropriate and inconsistent with human rights standards. Directors of 7 long-term care

³⁹ According to the legislation, to become a forensic psychiatric expert, a person should acquire a “forensic psychiatric examination” speciality, which is a separate medical specialization of higher education, like cardiology or surgery. Psychiatry and psychotherapy are defined as separate specializations. Given that, medical professionals with psychiatry or psychotherapy university degrees cannot become psychiatric experts without additional education. Reportedly, because of this requirement, many highly-regarded psychiatrists prefer not to engage in forensic expert activities.

⁴⁰ See Decision of the Bilopilskyi court of Sumy region of 2 August 2021, available at <https://reyestr.court.gov.ua/Review/98829161>.

⁴¹ There can be no effective access to justice if the buildings in which law-enforcement agencies and the judiciary are located are not physically accessible, or if the services, information and communication they provide are not accessible to persons with disabilities. See CRPD/C/GC/2, para. 37, available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/033/13/PDF/G1403313.pdf?OpenElement>. States parties must also ensure that persons with disabilities have access to legal representation on an equal basis with others. See CRPD/C/GC/1, para. 38.

⁴² See Decision of the Pereiaslav-Khmelnytskyi district court of Kyiv region in case 373/1027/19 of 14 February 2020, available in Ukrainian at <https://reyestr.court.gov.ua/Review/87598164>.

⁴³ HRMMU monitoring visits to Antunskyi (99 per cent), Bilopilskyi (99 per cent), Baraboiskyi (99 per cent), Velykorybalskyi (93 per cent), Hrabarivskyi (93 per cent), Sviatoshynskyi (92 per cent) long-term care facilities.

facilities visited told HRMMU that they had never applied for the removal of legal agency of their clients. Moreover, directors of 9 facilities told HRMMU that they simply refused to file applications on restoration of the legal agency of the residents despite their request, when they believed that the procedure would not lead to the restoration of legal agency.

D. Human rights concerns in relation to guardianship

33. HRMMU documented complaints about the poor performance of guardians of persons with intellectual and psychosocial disabilities whose legal agency had been removed. Reportedly, while some guardians are not motivated to perform their duties well due to the absence of reward or other compensation, others acquired guardian functions to gain control over the property and social benefits of their wards. Additional concerns are the insufficient number of guardians available for persons with disabilities and the assignment of guardian functions to long-term care facilities, permitted by law.

34. HRMMU is concerned that guardians may neglect to protect and ensure the rights of persons with intellectual and psychosocial disabilities due to the absence of reward for their work. Even though the Civil Code entitles guardians and trustees to a state reward for performing their duties, they are not able to obtain it as the Cabinet of Ministers of Ukraine has never adopted the necessary regulations on it.⁴⁴ Relatives of persons with intellectual and psychosocial disabilities complained to HRMMU that the lack of reward violates the rights of guardians and trustees when they bear expenses for performing their duties and makes them reluctant to become guardians or trustees or to perform their functions with due diligence.⁴⁵

35. Directors and social workers of 21 long-term care facilities and persons with intellectual and psychosocial disabilities complained to HRMMU about the systematic defective performance of some guardians.⁴⁶ In particular, HRMMU was told that guardians initiated the removal of legal agency of their wards to obtain control over their real estate⁴⁷ and social benefits, did not devote wards' social benefits to the fulfilment of their needs, initiated their placement in institutions against their will, failed to facilitate the provision of healthcare services outside of the facility or accompany their wards to hospitals, failed to visit them for long periods of time or were not reachable for the administration when their consent for certain actions were needed.⁴⁸

36. HRMMU visited eight facilities in the Donetsk and Luhansk regions which accommodated up to a dozen legally-incapacitated residents each, whose guardians resided in armed group-controlled territory. Directors and social workers of the facilities told HRMMU that such guardians could not fully exercise their functions due to problems crossing the contact line.⁴⁹

37. Reportedly, administrations of long-term care facilities for persons with intellectual and psychosocial disabilities may fail to ensure individual guardian protection for residents where the guardian status is assigned to the facilities, in accordance with the law. HRMMU established that in some long-term care facilities, directors exercise guardian functions for more than half of the residents who have had their legal agency removed. In 11 facilities, this was for more than 150 persons.⁵⁰ In this regard, human rights defenders and persons with disabilities complained that directors acting as guardians and as managers of the facilities are able to perform their guardianship functions only *pro forma* and do not pay attention to the individual needs of particular wards. Persons with disabilities in long-term care facilities complained to HRMMU that directors failed to address their requests for transfer to other facilities, did not file applications on the restoration of their legal agency and did not use their wards' pensions to buy what they had requested.

38. Human rights defenders complained to HRMMU that in some cases, judges failed to establish guardianships and appoint a guardian after they ruled on the removal of legal agency, either due to shortcomings in the applications or due to the absence of persons willing to become guardians (for persons not living in

⁴⁴ See article 73 of the Civil Code of Ukraine.

⁴⁵ HRMMU interviews with human rights defenders, 19 October and 23 October 2020.

⁴⁶ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

⁴⁷ HRMMU received numerous complaints from human rights defenders, social workers and psychiatrist about cases of illicit appropriation of property of persons with intellectual and psychosocial disabilities. Reportedly, the removal of legal agency and assignment of a guardian is used by fraudsters and abusive relatives to appropriate real estate of persons with intellectual and psychosocial disabilities. Such abuse is particularly prevalent in big cities, where prices for real estate are relatively high. The lack of sufficient legal protection for the property rights of persons with intellectual and psychosocial disabilities is one of the key factors contributing to their homelessness. – HRMMU interviews with human rights defenders, 19 October, 18 November, 25 November, 10 December and 24 December 2020.

⁴⁸ Usually, consent for providing specific healthcare services. In this regard HRMMU also notes complaints by directors that some guardians were inaccessible or refused to give consent for COVID-19 vaccination of their wards. HRMMU interview, 2 August 2021.

⁴⁹ In the majority of these cases, the facilities applied to court to acquire guardianship functions to ensure better protection of the rights and interests of persons with intellectual and psychosocial disabilities.

⁵⁰ HRMMU interview, 3 February 2021. HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

institutions).⁵¹ HRMMU notes that out of 40,327 persons whose legal agency had been removed who resided in Ukraine as of 1 January 2020, only 32,285 had guardians, which leaves more than 8,000 persons without effective protection of their rights and makes them particularly vulnerable to violations of their property rights.⁵²

II. Violations of other rights of persons with intellectual and psychosocial disabilities

A. Right to live independently and be included in the community

“Our residents are not likely to be discharged. Usually they die here.”

- Director of long-term care facility on how often residents are discharged.

39. Persons with intellectual and psychosocial disabilities continue to be deprived of the right to live independently and be included in the community due to the lack of available mental health and social services in the community, including support services, and the lack of available social housing. Long-term care facilities for persons with intellectual and psychosocial disabilities (boarding houses or so-called “psychoneurological internats”) and psychiatric hospitals remain the only place where mental health and social services are provided on a daily basis to persons with intellectual and psychosocial disabilities, although without due individualisation. Violations of the rights to liberty, to control one’s everyday life and to choose a place to live are widespread within the institutional system, which is not compatible with requirements of article 19 of the CRPD.

40. Through interviews with persons with disabilities, social workers and human rights defenders, HRMMU established that the lack of accessible housing and community-based social and mental health services remain the key obstacles to the de-institutionalisation of persons with intellectual and psychosocial disabilities. Moreover, HRMMU observed cases where the lack of community-based social and mental health services have led to institutionalisation of persons with disabilities who had housing and relatives providing some support. Directors of long-term care facilities confirmed to HRMMU that most of the residents, especially those without relatives, would live in facilities their entire lives. As an illustration of this, HRMMU documented cases of persons with disabilities who have lived in facilities since the 1950s.⁵³

41. HRMMU is concerned that the system of long-term care facilities for persons with intellectual and psychosocial disabilities, which includes 145 facilities in different regions, prevents their residents from participating in community life due to the remote and isolated locations of such facilities. HRMMU visited facilities located on the outskirts of remote villages and even some facilities located several kilometres from the nearest villages.

42. HRMMU observed that the shortcomings in the institutional system prevent persons with intellectual and psychosocial disabilities from receiving individualised social services and support, as prescribed by article 19 (b) of the CRPD.⁵⁴ 42 out of 46 facilities visited by HRMMU accommodated more than 100 people,⁵⁵ meaning that individualised support was *a priori* not available.⁵⁶ Of greater concern is that HRMMU visited 5 facilities which accommodated more than 400 persons.⁵⁷ The lack of staff in these facilities also contributes to the unavailability of individualised social and medical care for persons with disabilities. Reportedly, the issue is caused by inflexible legislative staffing table regulations in facilities, low salaries and difficult working conditions, which does not allow facilities to recruit professional and motivated staff. In regard to the latter, HRMMU received complaints about the insufficient number of orderlies and nurses per residents⁵⁸ and difficulties with recruiting medical professionals in rural areas. HRMMU notes with concern complaints from employees in 44 facilities about low salaries and that they had to work in two, or even three jobs, to earn a living.⁵⁹

⁵¹ HRMMU interviews with human rights defenders, 19 October and 24 December 2020.

⁵² See CRPD/C/UKR/2-3, para. 167. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fUKR%2f2-3&Lang=en.

⁵³ HRMMU monitoring visit to long-term care facility for persons with intellectual and psychosocial disability.

⁵⁴ See para.28 CRPD/C/GC/5.

⁵⁵ Two facilities accommodated more than 600 persons each at the moment of the monitoring visits.

⁵⁶ See Committee’s approach to large-scale institutions in Hungary in CRPD/C/HUN/IR/1.

⁵⁷ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

⁵⁸ HRMMU observed that in most of the facilities, one orderly and nurse are usually responsible for providing care to 30 residents.

⁵⁹ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

43. In relation to the right to choose one's place of residence, HRMMU notes with concern that during its monitoring visits to 14 facilities, persons with intellectual and psychosocial disabilities complained that their requests to be transferred to other facilities were either not processed by the directors of the facilities or not granted by the social security bodies. Persons with disabilities wanted to be transferred either to live in the same facilities as their loved ones or friends or to be closer to their relatives.⁶⁰ In this regard, HRMMU also observed that the staff members of facilities usually discouraged residents from independent living, persuading them that they would not be able to live outside the facility without assistance.

"It is hard to be here. This is a dead end."

- Resident of long-term care facility on living there.

44. HRMMU is concerned about violations of the right to have control over one's everyday life in long-term care facilities where enormously rigorous daily schedules are imposed on residents. While all the facilities visited by HRMMU had daily schedules for residents, nine long-term facilities enforced the schedules in an abusive manner. In one facility, HRMMU observed that residents were not allowed to stay in their rooms during the time of the day allotted for walking outside and other activities. In 21 facilities, HRMMU observed that residents under increased supervision were only allowed to walk outside, eat, bathe and engage in daily activities in groups and during the scheduled time.⁶¹

45. HRMMU welcomes the practice of creating departments for supported living inside long-term care facilities for persons with intellectual and psychosocial disabilities. HRMMU visited four facilities where residents in such departments enjoyed full control of their lives. Although the current arrangements in such departments are not fully in line with standards of independent living, expanding the number and capacity of such departments in long-term care facilities for persons with intellectual and psychosocial disabilities may gradually prepare people living there for fully independent living.⁶²

46. Apart from the lack of accessible housing and community-based social and mental health services, the institutionalisation of children with disabilities is among the major reasons leading to institutionalisation of persons with disabilities as adults. Through interviews with persons with disabilities and human rights defenders, HRMMU established that children with intellectual and psychosocial disabilities are particularly vulnerable to institutionalisation in adulthood, due to their lack of education, socialisation, habilitation and rehabilitation in children's institutions,⁶³ and lack of social housing for persons with disabilities discharged from long-term care facilities for children. Ukrainian legislation allows care facilities for children with intellectual and psychosocial disabilities to create adult departments to which persons are transferred after reaching the age of majority, so that they may stay in one facility over their lifetime.⁶⁴

47. HRMMU notes that the reform of deinstitutionalisation of children may decrease the number of adult persons with intellectual and psychosocial disabilities in long-term care facilities in the future. In August 2017, the Government adopted a Strategy for deinstitutionalisation of children for 2017-2026 and a relevant action plan.⁶⁵ One of the key points of the Strategy provided for the cessation of placing children under the age of three in long-term care facilities, starting from 2020. However, in January 2021 the Government came up with amendments to delay the implementation of this point to 2026.⁶⁶ Although the amendments to the Strategy have not been adopted, this situation demonstrates how little progress has been achieved in the implementation of the reform process.

⁶⁰ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

⁶¹ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities. HRMMU interviews with human rights defenders, 25 November and 24 December 2020.

⁶² Small group homes and even individual homes cannot be called independent living arrangements if they have other defining elements of institutions or institutionalization, such as obligatory sharing of assistants, lack of choice over whom to live with, identical activities in the same place for a group of persons under a certain authority; supervision of living arrangements; or a disproportion in the number of persons with disabilities living in the same environment. See CRPD/C/18/1, para.16.

⁶³ HRMMU interviews, 19 October, 28 October and 27 November 2020.

⁶⁴ HRMMU visited one such facility where all the residents were deprived of legal agency when they reached the age of major.

⁶⁵ See Order of the Cabinet of Ministers of Ukraine "On the National Strategy to the Reform of the Institutional Child Care System in Ukraine and Action Plan for the Implementation of Stage I" of 9 August 2017, available in Ukrainian at: <https://zakon.rada.gov.ua/laws/show/526-2017-%D1%80#Text>.

⁶⁶ See draft Resolution of the Cabinet of Ministers of Ukraine "On amending the National Strategy for the Reform of the Institutional Child Care System for 2017-2026", available in Ukrainian at: <https://www.msp.gov.ua/projects/645/?fbclid=IwAR1czjPPqFVWZdwDsNmO3msj9khwXs7uyuxwuL6pQgd8LNieEuOfU9AuO60>. According to many human rights defenders, including the Commissioner of the President on the Rights of the Child, the Strategy's provision to cease the placement of children under the age of three in long-term care facilities is one of the Strategy's key points. Suspension of this provision will affect the whole reform process. Moreover, the draft Resolution did not include specialized boarding schools in the institutions expected to be cut down. On 30 June 2021, several Special

48. HRMMU is concerned that the implementation of the healthcare reform process has deprived persons with intellectual and psychosocial disabilities discharged from psychiatric hospitals of housing, social and mental health services. On 1 April 2020, the Government launched the second phase of the healthcare reform process and changed the funding model for in-patient treatment.⁶⁷ As a result of the reforms, the National Health Service of Ukraine provides funding for the treatment of cases of mental health disorders (30 days of in-patient care per person at a time) and not hospital beds, as was the case in the past. This drove psychiatric hospitals to discharge patients who had resided there for years and needed mostly social services rather than in-patient psychiatric treatment. Hospitals that accommodated many long-term patients and did not receive additional funding for them had to discharge them almost immediately after the beginning of the reform process.⁶⁸

49. HRMMU remains concerned that many persons with intellectual and psychosocial disabilities continue to live in psychiatric hospitals permanently due to the lack of available social housing and social care services elsewhere, which also amounts to a violation of their right to independent living and being included in the community. HRMMU made monitoring visits to 3 psychiatric hospitals which continued to provide permanent accommodation to persons with intellectual and psychosocial disabilities.⁶⁹ HRMMU notes with concern the emblematic case of a woman who has been in a psychiatric hospital in the Kharkiv region for 28 years.⁷⁰ Reportedly, due to a lack of habilitation and rehabilitation services in psychiatric hospitals, many of the patients have lost their basic self-care and social skills and cannot reintegrate into their communities without due support.

B. Respect for liberty and freedom from torture, violence and abuse

“It is clear that many of them want to go and live in society... but where would we let them go? A month or two and they would be back – or in a hospital.”

- Director of long-term care facility on reintegration of the residents into the local community.

50. All the long-term care facilities and psychiatric hospitals visited by HRMMU violated the right to liberty of persons with intellectual and psychosocial disabilities by imposing restrictions on freedom of movement, either inside the institution or in relation to outside visits. Such restrictions were even imposed on legally-capable persons. Of further concern, HRMMU documented credible allegations about torture and ill-treatment of persons with intellectual and psychosocial disabilities by staff of the institutions, as well as physical and psychological violence between residents.

51. The arbitrary denial of the right of all or some of the residents with intellectual and psychosocial disabilities to leave the facilities, even during the day, is one of the major concerns observed by HRMMU. Decisions to allow residents to leave the facilities for a few hours during the daytime, after their written application, were often made by psychiatrists based on the mental conditions of the residents. While in some facilities only persons with legal agency were allowed to leave the facilities during the day, in other facilities, all residents, including those with full legal agency, were denied the right to go outside. 42 facilities allowed residents to go outside accompanied by staff members, usually in groups. Such groups mostly left the facility to visit specific places in the community – such as shops, churches or public institutions. The possibility to leave the facilities in a group was strictly dependent on the availability of accompanying staff. HRMMU notes that most of the facilities it visited tightened these restrictions due to the COVID-19 pandemic and continued applying them even when pandemic-related restrictions for the general population were relaxed.

Procedure mandate-holders expressed concern to the Government of Ukraine that the suspension of the deinstitutionalization of children would constitute a significant and worrisome step backwards towards ending institutionalization. The document is available at: <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gId=26477>.

⁶⁷ The reform provided for a shift from input-based funding toward output-based purchasing. Before the reform, psychiatric hospitals were funded based on the number of ‘in-patient beds’ (namely, a standard number of patients to whom hospitals can provide in-patient healthcare services). The reform implies that hospitals receive funding based on the number of patients to whom the hospital provides packages of services (according to the principle that “money follows patients”). Tariffs for package of psychiatric services is set at 7406,4 UAH (approx. \$265). The tariff was calculated with regards to WHO’s recommendations that in-patient psychiatric services should be provided for no longer than 30 days.

⁶⁸ According to HRMMU’s observations, decisions to continue providing accommodation for long-term patients were made based on the portion of such patients in the hospital, extent of provided social and medical care, and number of staff in the hospitals, availability of other sources of funding, availability of places in long-term care facilities, to where persons with disabilities could be transferred. HRMMU also observed that in parallel to discharging long-term care patients, hospitals usually cut down the number of staff.

⁶⁹ HRMMU monitoring visit to a psychiatric hospital.

⁷⁰ HRMMU monitoring visit to a psychiatric hospital.

52. HRMMU also notes that 21 facilities practised restrictions in relation to residents' freedom to move inside the facility. HRMMU observed that residents, mostly those under enhanced supervision, were not allowed to leave the premises of their departments and move freely around the long-term care facilities. Moreover, HRMMU notes with concern that residents of 22 long-term care facilities⁷¹ were restricted to fenced areas during their daily outdoor exercises. Such areas with high or concrete fences resembled exercise yards in detention facilities. Apart from the violation of the right to liberty, such practice amounts to degrading treatment.⁷²

53. Directors of long-term care facilities could not explain to HRMMU the legal grounds for the restrictions of the right to liberty they imposed, including in relation to persons with removed legal agency, but referred to their personal duty to protect the life and health of the residents, which is provided in the legislation.⁷³ Most of them also referred to the lack of staff responsible for supervising the residents (mostly, orderlies) as an excuse for restrictions on free movement inside the facility and to leave the facilities.⁷⁴

54. HRMMU also observed similar concerns in relation to the right to liberty in all the psychiatric hospitals it visited. Hospitals did not allow even voluntary patients to leave their departments or territory unaccompanied, referring to such restrictions as a part of mental health treatment. In this regard, the administration of the hospitals confirmed to HRMMU that every voluntary patient was free to go once they withdrew their consent for hospitalisation and treatment.

55. In 10 long-term care facilities for persons with intellectual and psychosocial disabilities and 2 psychiatric hospitals, residents confidentially complained to HRMMU that they or other residents had been subjected to torture or cruel, inhuman or degrading treatment or punishment.⁷⁵ Most of the complaints pertained to violations perpetrated by the orderlies and nurses of the facilities, who reportedly verbally abused, pushed, shocked with a taser, beat with hands or sticks, or choked residents because they did not comply with their orders or because of personal animosity towards the residents. Although directors and chief officers of the facilities and hospitals informed HRMMU about strict policies and measures had been introduced to prevent such cases, the residents in 8 long-term care facilities stated that the perpetrators continued to work there, even after the violations they committed were reported to the administration.

56. Numerous reports by human rights defenders and the National Preventive Mechanism (NPM),⁷⁶ also describe beatings, cruel treatment, sexual violence, psychological violence and excessive application of isolation and physical restraint measures against residents of long-term care facilities in different regions.⁷⁷ Together with HRMMU's findings, such reports illustrate that the institutional system is far from immune to human rights violations.

57. Physical and psychological violence against persons with intellectual and psychosocial disabilities was perpetrated not only by the staff of institutions but also by other residents, whom the staff did not stop, and in some cases, even instrumentalised to subjugate other residents.⁷⁸ Inter-resident violence was also often accompanied by thefts.⁷⁹ In regard to the former, residents and directors of the long-term care facilities also complained to HRMMU that alcohol abuse was among the major concerns which triggered violence in facilities.

58. HRMMU remotely documented three cases of ill-treatment of residents in facilities it had visited before. HRMMU brought the cases to the attention of the directors of the facilities and later learnt that the perpetrators were dismissed. At the same time, HRMMU is deeply concerned that although other staff members should have seen or otherwise become aware of those three incidents, they have not reported them and the incidents were

⁷¹ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

⁷² See e.g. *Stanev v Bulgaria* 36760/06 [2012] ECHR 46. HRMMU notes that the staff treated the residents of these departments almost as convicts.

⁷³ See para. 71 of the Model statute of the psychoneurological long-term care facility, adopted by a Resolution of the Cabinet of Ministers on 14 December 2016, available in Ukrainian at: <https://zakon.rada.gov.ua/laws/show/957-2016-%D0%BF#Text>.

⁷⁴ Deprivation of liberty on the basis of impairment or health conditions in mental health amounts to a violation of article 12 of the Convention. See Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities, para.15/; available at: <https://www.ohchr.org/Documents/HRBodies/CcRPD/14thsession/GuidelinesOnArticle14.doc#:~:text=Article%2014%20of%20the%20Convention%20is%20in%20essence%20a%20non.on%20disability%20in%20its%20exercise>.

⁷⁵ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

⁷⁶ Special Report of the Ukrainian Parliament Commissioner for Human Rights "State of Implementation of the Istanbul Protocol in Ukraine as a Tool for Effective Documentation of Torture and Other Types of Ill-Treatment", sections 4-5, available in English at: <https://ombudsman.gov.ua/ua/page/npm/provisions/reports/>. See also Special Report of the Ukrainian Parliament Commissioner for Human Rights "State of Implementation of National Preventive Mechanism in 2019", sections 5-6, available in English at: <https://ombudsman.gov.ua/ua/page/npm/provisions/reports/>.

⁷⁷ For more information, see CPT/Inf (2018) 41, CPT/Inf (2020) 1, Human Rights in Mental Health-FGIP Review of Social Care Homes in Ukraine and the Development of a Plan of Action, available at: www.gip-global.org/files/final-eng-report-internats-2.pdf.

⁷⁸ HRMMU interviews with human rights defenders, 19 October, 28 October, 9 November and 25 November 2020. HRMMU notes that it received complaints about violence between residents mostly in long-term care facilities for men.

⁷⁹ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

disclosed only because the residents or temporary workers recorded them on their phones. Of further concern, residents of three facilities complained to HRMMU over the phone that staff members of the facility intimidated them to make them stop contacting HRMMU.

59. In 13 long-term care facilities HRMMU received complaints that staff confined residents in isolation rooms, transferred them to other departments (mostly, for enhanced supervision) or referred them to psychiatric hospitals as forms of punishment for not complying with their orders. In a long-term care facility for men with intellectual and psychosocial disabilities, residents were transferred to an isolation room with no furniture and had to sleep on the floor if they were not present twice a day for a regular check of their presence.⁸⁰ Although such violations were denied by the administrations of long-term care facilities, the number and coherence of such complaints give reasonable grounds to believe that such practice exist in the facilities.

C. Right to respect for physical and mental integrity

“Even prisoners are released at some point. So, here it is worse than in a prison.”

- A resident of long-term care facility
on possibility to leave the facility.

60. Ukrainian legislation continues to allow involuntary admission to psychiatric hospitals and treatment there without the consent of persons with psychosocial disabilities, which runs contrary to standards set in articles 14, 15 and 17 of the CRPD that prohibit forced treatment by psychiatric and medical professionals and states that persons with disabilities shall be allowed to make decisions about their treatment at all times, including in crisis situations. HRMMU is particularly concerned about the involuntary medication of persons with intellectual and psychosocial disabilities in psychiatric hospitals and long-term care facilities.

61. Ukrainian legislation regulating psychiatric care does not effectively prohibit involuntary admission to psychiatric hospitals and treatment without consent. Article 14 of the law On Psychiatric Aid allows for involuntary admission to a psychiatric hospital of a person with a severe psychosocial disorder if the person has acted or has shown intentions to act in a manner that is dangerous to themselves or others or the person cannot meet their basic needs. The hospital has 24 hours either to apply to the court to get an order for involuntary admission or to discharge the person. The law allows psychiatric hospitals to start treatment of persons before applying to the court. Psychiatrists from three hospitals confirmed to HRMMU that they usually started the treatment in most of these cases in line with the decisions of the commissions of psychiatrists in the hospital. However, after such treatment within the first 24 hours, persons usually gave their consent for further hospitalisation and only in rare cases were applications to the court needed. HRMMU notes that despite the safeguards described above and regular review of the relevant medical records by law-enforcement authorities, the mere possibility for involuntary hospitalisation or medical treatment is contrary to human rights principles set by the CRPD.

62. Procedural legislation on involuntary admission to a psychiatric hospital does not provide for mandatory participation of a lawyer in such proceedings or for free legal aid centres to be informed about such cases. Given that involuntary admission will restrict the right to liberty, this may amount to a violation of the right to legal counsel.⁸¹ HRMMU received allegations from a woman that the staff of a psychiatric hospital did not allow her to contact a lawyer or the Ombudsperson’s Office before a court hearing concerning her involuntary admission. A psychiatrist also told HRMMU that lawyers, if they are appointed by courts, rarely visited patients before the hearings.⁸²

63. HRMMU is particularly concerned about information gathered regarding medication of persons with disabilities without their knowledge. In one long-term care facility and one psychiatric hospital, staff members confirmed to HRMMU that they or other staff members had mixed neuroleptics and other medications into residents food or drinks because they had refused to take them.⁸³ In this regard, HRMMU notes complaints received from three human rights defenders about the medication of persons with intellectual and psychosocial disabilities in long-term care facilities and psychiatric hospitals without either their consent or knowledge.⁸⁴

⁸⁰ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

⁸¹ Ukrainian legislation provides that secondary free legal aid centers should be informed about cases of detention and arrests.

⁸² HRMMU monitoring visit to a psychiatric hospital.

⁸³ HRMMU monitoring visits to psychiatric hospitals and long-term care facilities for persons with intellectual and psychosocial disabilities. HRMMU also notes that the interlocutors withdrew their statements during later conversations, probably when they realized that such practice amounts to human rights violations.

⁸⁴ HRMMU interviews with human rights defenders, 9 and 25 November, 10 December 2020.

D. Respect for privacy and family life

“No, you cannot have a rest [in the bedrooms] during the daytime. What if a [monitoring] commission comes?”

- Resident of long-term care facility about day schedule and access to bedrooms.

64. According to HRMMU’s observations, persons with intellectual and psychosocial disabilities in institutions lack privacy in bedrooms and bathrooms, and staff interfere with their privacy.

65. 44 of the long-term care facilities for persons with intellectual and psychosocial disabilities visited by HRMMU did not allow for privacy in bedrooms, which accommodated more than two, and usually four to six, residents. Moreover, in 19 long-term care facilities, bedrooms did not have doors, locks on the doors or had inspection windows or holes or staff members did not allow residents to close the doors of their bedrooms. There was a lack of doors in cabins in shared toilet rooms and shower rooms. HRMMU also witnessed and documented complaints by the residents that they were watched by staff members while taking showers.⁸⁵ Among other violations of the right to privacy in the facilities, HRMMU witnessed the denial of the right of residents to have and use mobile phones all the time and the lack of lockers in bedrooms.⁸⁶ HRMMU also notes with concern that in 5 long-term care facilities and psychiatric hospitals, staff members inspected residents’ parcels from relatives and interfered with residents’ written or oral communications.⁸⁷

66. In relation to the right to develop and cultivate personal identity, HRMMU observed that in two long-term care facilities, residents were provided by the administrations with the clothing of the same style, regardless of the residents’ preferences. Moreover, residents also complained to HRMMU that the staff members in the facilities made them cut their hair in a particular way or to shave.⁸⁸ The lack of possibility of meeting a romantic partner, which is particularly acute in same sex facilities, and to maintain family relations with relatives outside the facilities are among major concerns in relation to the right to family. HRMMU notes with regret that 23 out of 46 long-term care facilities visited accommodated only residents of the same sex. Living in such long-term care facilities makes it almost impossible for heterosexual persons with intellectual and psychosocial disabilities to marry or form a family, in violation of article 23 of the CRPD. In some mixed facilities, couples were not allowed to live together, even after years of being in a relationship. Moreover, HRMMU found that directors or staff members of 32 facilities treated the residents in a paternalistic manner in relation to their family rights by discouraging them to have a family life and sexual relations or not giving their consent to date persons inside or outside of the facilities.

67. Amidst the COVID-19 pandemic and enforcement of quarantine restrictions by the Government, long-term care facilities for persons with intellectual and psychosocial disabilities introduced restrictions in relation to family visits. Long-term care facilities limited the number and duration of visits, banned overnight stays of relatives and prohibited residents from visiting their relatives. Persons with disabilities with relatives residing in territory controlled by armed groups suffered even more, because their relatives could not travel to visit them due to crossing restrictions imposed by self-proclaimed ‘Donetsk people’s republic’ and self-proclaimed ‘Luhansk people’s republic.’ Although intended to protect residents from COVID-19, the restrictions clearly demonstrate that individualised decisions were not being made in such facilities and that people in facilities were disproportionately affected by the restrictions. In addition, some facilities visited by HRMMU continued to employ the same restrictions even when the Government eased quarantine measures, following improvement of the epidemiological situation.

68. In 25 facilities HRMMU received complaints from the residents that they had lost contact with their relatives or friends completely. In this regard, persons with intellectual and psychosocial disabilities noted the lack of support from social workers in establishing or maintaining contacts with their loved ones, e.g. finding their mailing address or phone numbers, or assisting with writing letters.

⁸⁵ HRMMU notes with concern that in facilities for men, female nurses and orderlies watched over male residents when they were in the shower. In this regard HRMMU notes complaints of the facility administrations that they could not hire male nurses or orderlies due to low salaries, which were not competitive with salaries for manual work usually performed by men.

⁸⁶ In this regard resident of 7 facilities complained to HRMMU that their belongings had been stolen, reportedly by other residents.

⁸⁷ HRMMU monitoring visits to psychiatric hospitals and long-term care facilities for persons with intellectual and psychosocial disabilities.

⁸⁸ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

E. Right to health, including sexual and reproductive health and related rights

69. HRMMU is concerned that persons with intellectual and psychosocial disabilities in long-term care facilities have limited access to health services in the community. At the same time, many long-term care facilities cannot ensure access to the full range, appropriate standards and quality of specialised health services inside the facilities, mainly due to the lack of staff.

70. 42 out of 46 long-term care facilities for persons with intellectual and psychosocial disabilities visited by HRMMU were licenced to provide different types of general and specialised medical services, including psychiatric, surgical, dental and gynaecologic services, and in-patient care. Moreover, residents of the facilities had signed declarations with family doctors enabling their access to general and specialized medical services outside the facility.

71. However, HRMMU observed that the quality and scope of medical services provided in the long-term care facilities for persons with intellectual and psychosocial disabilities was insufficient in facilities in rural areas, to a great extent due to the unavailability of medical personnel and social workers. In this regard, directors and staff members of 29 long-term care facilities complained that low salaries, difficult working conditions and the remote locations of the facilities led to a lack and high turnover of medical staff and even the impossibility of contracting certain health specialists,⁸⁹ especially in rural areas, which affected the right to the highest attainable standard of health of persons with disabilities in such facilities.⁹⁰

72. Likewise, the shortage of funding for psychiatric hospitals that emerged in the context of the second stage of the medical reform process has affected the right of persons with intellectual and psychosocial disabilities to access health care in such hospitals.⁹¹ Chief medical officers of 6 psychiatric hospital complained to HRMMU about understaffing and high turnover of the staff due to low salaries and difficult working conditions, which affects the quality of healthcare services provided to persons with psychosocial disabilities.⁹² Among other related concerns, psychiatrists and human rights defenders mentioned the lack of access to outpatient psychiatric care, inaccessibility of modern neuroleptics provided free of charge,⁹³ and unclear procedures for providing general medical services to persons admitted to psychiatric hospitals.

73. HRMMU is concerned about the arbitrary requirement of hospitals and ambulances that long-term care facilities for persons with intellectual and psychosocial disabilities provide a nurse to accompany residents of the facilities during their hospitalisation or medical visits. Although most of the facilities visited by HRMMU managed to comply with the requirement to ensure residents' access to healthcare services, at least 26 facilities had struggled to spare nurses to accompany their residents in some situations.⁹⁴ In this regard, HRMMU notes with regret the case of a woman in a long-term care facility in the Kharkiv region, who had skin cancer and reportedly could not undergo five months of radiation therapy in a hospital due to the unavailability of accompanying staff.⁹⁵ The woman died on 17 May 2021.

74. Persons with intellectual and psychosocial disabilities in long-term care facilities, especially women, face different limitations and violations in relation to sexual and reproductive health and related rights. These include the right of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education and to have access to health care and programmes in the area of sexual and reproductive health.

75. Of greater concern is the practice of giving hormonal contraceptives to female residents in long-term care facilities for persons with intellectual and psychosocial disabilities. HRMMU found this practice in three facilities it visited. Staff members of the facilities reported that they had the consent of all women given such medication. However, HRMMU notes that some female residents gave such consent under threat of being transferred to facilities accommodating only women (consequently separating some of them from their partners) if they refused to accept the contraceptive. HRMMU has also been told that some women suffered physical pain and strong side-effects from the hormonal shots, but continued to provide consent for the above reasons. Such consent cannot be seen as free and informed from the perspective of international human rights standards and amounts to violation of the right to respect for physical and mental integrity, reproductive health and respect for family. Female

⁸⁹ Including psychiatrists, psychologists, gynaecologists, urologists and dentists.

⁹⁰ HRMMU notes that most of the nurses and orderlies in the facilities received only a minimum salary and usually worked another part or fulltime job to meet their needs.

⁹¹ According to available reports, funding for psychiatric hospitals dropped by 25-50 per cent after April 2020. See, e.g. Ukrainian mental health services and World Psychiatric Association Expert Committee recommendations, September 2020, available at [https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(20\)30344-8/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(20)30344-8/fulltext).

⁹² HRMMU monitoring visits to psychiatric hospitals.

⁹³ In this regard, HRMMU received complaints that lack of outpatient psychiatric care and access to modern medication were mentioned by psychiatrists as being among the major causes for relapse of psychosocial conditions.

⁹⁴ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

⁹⁵ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

residents' privacy was also compromised by "menstruation cycle diaries" – monthly recordings and verification checks of women's periods.⁹⁶

76. Most of the persons living in long-term care facilities lack access to sexual education and information on health rights in relation to reproductive health. Only 16 out of 46 facilities visited by HRMMU provided residents access to sexual education on a regular or periodic basis.⁹⁷

F. Education, habilitation and rehabilitation services

"Of course you can get an education. But not here. They only teach how to draw."

- Resident of a long-term care facility on vocational education and rehabilitation services.

77. Poor access to inclusive education, including pre-school, basic, vocational and higher, as well as to individualised habilitation and rehabilitation services both in long-term care facilities and in the community continues to be a major obstacle to the independence, the development of full physical, mental, social and vocational abilities of children and adults with intellectual and psychosocial disabilities and hinders their inclusion and participation in all aspects of life.

78. Long-term care facilities visited by HRMMU provided limited access to quality adult education and lifelong learning, mainly limited to access to basic life skills education, access to the Internet, basic computer skills training, libraries and audio libraries. These only catered for persons who already had a basic education. HRMMU observed no coherent programs in the facilities to provide a basic education for residents, even though some facilities accommodated up to 25-30 per cent of illiterate residents. In some facilities, social workers sporadically taught some residents writing and reading skills.⁹⁸ Such education is a key factor in supporting deinstitutionalisation and promoting independent living.

79. Through monitoring visits, interviews with social workers and human rights defender, HRMMU documented that the lack of good quality education and access to community-based social services for children with intellectual disabilities is a major cause for their institutionalization in adulthood. Children with intellectual and psychosocial disabilities in general do not have access to inclusive basic education and can only access special education in the long-term care facilities where they live.⁹⁹ Children with severe and profound intellectual disorders are usually neglected or even excluded from the learning process.¹⁰⁰

"I could study to become a tiler, a train host or a chef. But you cannot do it here."

- Resident of a long-term care facility on vocational education and rehabilitation services.

80. HRMMU notes a lack of options for vocational education or other higher education for persons with intellectual and psychosocial disabilities. Persons with intellectual and psychosocial disabilities in institutions only have access to a few vocational specializations, usually shoe repairing, sewing or house painting.¹⁰¹ A woman with an intellectual disability complained to HRMMU that the administration of a long-term care facility for children where she lived had offered her only two options for vocational education – to be trained to sew garments or to paint houses, neither of which she had really liked.¹⁰² In eight long-term care facilities visited by HRMMU, persons with disabilities also complained about the lack of any vocational education in or outside the facilities. On the other hand, HRMMU also observed positive examples, namely that two facilities visited did facilitate attendance of vocational education outside the facilities for several residents.¹⁰³

⁹⁶ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

⁹⁷ This included lectures about safe sex, sexuality and reproductive health, talks with psychologists, access to reading materials.

⁹⁸ In this regard, human rights defenders complained to HRMMU that the Government has failed to put in place comprehensive programs for providing basic education to adults in long-term care facilities.

⁹⁹ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities

¹⁰⁰ HRMMU interviews with persons with disabilities and human rights defenders, 28 October, 25 and 27 November, 10 December 2020.

¹⁰¹ HRMMU interviews, 25 November and 10 December 2020.

¹⁰² HRMMU interview, 27 November 2020.

¹⁰³ HRMMU monitoring visits to a long-term care facility for persons with intellectual and psychosocial disabilities.

81. The Government introduced a comprehensive framework on habilitation and rehabilitation services for persons with disabilities in 2005.¹⁰⁴ The law provides for rehabilitation (habilitation) services for persons with disabilities based on an individual programme for rehabilitation,¹⁰⁵ technical and other equipment for rehabilitation and targeted social payments. Rehabilitation and habilitation services can be provided at the place of residence (including in long-term care facilities) and in rehabilitation centres.

82. HRMMU is concerned that long-term care facilities for persons with intellectual and psychosocial disabilities provide very limited and poor quality habitation and rehabilitation services, which fail to match residents' individualised needs. All long-term care facilities for persons with intellectual and psychosocial disabilities visited by HRMMU provided various types of rehabilitation and habilitation services. Those included social therapy sessions (including art therapy, group therapies, aroma therapy and others), self-care, cooking and handiwork courses, sports activities, organisation of leisure activities (dancing, singing, and celebration of holidays) and ergotherapy. However, lacking social therapists and psychologists, 33 facilities provided only a limited number of habilitation and rehabilitation services. HRMMU also observed that residents did not attend habilitation and rehabilitation courses and groups because they were not interested in them, which was mainly explained by the lack of an individualised approach to the residents' needs and their lack of usefulness or attractiveness (for example, repetitive drawing classes).

83. HRMMU is particularly concerned about the lack or limited access to rehabilitation and habilitation services for persons with intellectual and psychosocial disabilities in psychiatric hospitals. Such social services are no longer covered by the National Healthcare Service within the package of psychiatric service, having stopped since the second stage of the medical reform process, which prompted psychiatric hospitals to cut down on the number of psychologists and social therapists. Psychiatrists complained to HRMMU that implementation of reforms thus deprived individuals of an important aspect of psychiatric aid.

84. Parents/caregivers of children and adults with intellectual and psychosocial disabilities complained to HRMMU about the lack of habilitation and rehabilitation services in the communities for their children. The situation is particularly dire in rural areas, where the lack and limited access to day-care, rehabilitation and habilitation services (due to location of those services mainly in regional capitals, or cost of transportation, distance, etc.) makes persons with intellectual and psychosocial disabilities stay in their homes all the time.¹⁰⁶ Human rights defenders providing habilitation and rehabilitation services to persons with intellectual and psychosocial disabilities also complained to HRMMU about the lack of support from the Government and local authorities (planning and budgeting of such services is decentralised to the local level, however, the authorities often do not prioritise such services). Relatives of persons with intellectual and psychosocial disabilities seconded such complaints and noted that civil society organizations presented the only option for their adult relatives with intellectual or psychosocial disabilities to access such services regularly.

G. Freedom from exploitation and the right to work and employment

“The administration does not want us to leave, because we do work here. If only seriously ill residents were left, who would do the work?”

- Resident of a long-term care facility
on forced labour.

85. HRMMU notes with concern that persons with intellectual and psychosocial disabilities are subjected to forced labour and exploitation in institutions. HRMMU also documented complaints about the lack of opportunities for formal employment for persons with intellectual and psychosocial disabilities, both living in institutions and in communities.

86. In 12 long-term care facilities for persons with intellectual and psychosocial disabilities, HRMMU observed practices that may amount to forced labour. In particular, residents told HRMMU that staff members compelled the residents to perform work¹⁰⁷ under threats of physical violence or restraints or by promising them

¹⁰⁴ See the Law of Ukraine “On Rehabilitation of persons with disabilities in Ukraine” of 6 October 2005, available in Ukrainian at: <https://zakon.rada.gov.ua/laws/show/2961-15#Text>.

¹⁰⁵ Individual rehabilitation programs are developed by the disability evaluation boards.

¹⁰⁶ In this regard HRMMU notes complaints of a social therapist and mother of a person with intellectual disability, who said that such situations create enormous stress for relatives of persons with disabilities, and particularly women, who usually bear responsibility to take care of their loved ones.

¹⁰⁷ Taking care of other residents, carrying different things, renovating premises, cleaning halls and toilets, working in farms and gardens.

additional benefits.¹⁰⁸ HRMMU also observed that residents of long-term care facilities were engaged, either voluntarily or without their full and free consent, in taking care of other residents. Reportedly, residents feed other persons with disabilities, changed their clothes or diapers and walked with them outdoors. HRMMU also noted that in six facilities residents were distributed among the departments so as to allow for such care to be provided.¹⁰⁹

87. HRMMU observed that in 12 long-term care facilities for persons with intellectual and psychosocial disabilities, in practice residents performed regular part-time jobs disguised as ergotherapy sessions, unpaid and not covered by labour legislation.¹¹⁰ 23 facilities visited by HRMMU had agricultural land and animal farms, where part of the residents worked regularly during ergotherapy sessions. Although such work in most cases was voluntary and limited by maximum hours of ergotherapy, the lack of remuneration, as well as protection under labour and social legislation, may amount to a violation of the right to work of persons with intellectual and psychosocial disabilities.¹¹¹

88. On the other hand, directors, social therapists and residents of long-term care facilities for persons with intellectual and psychosocial disabilities told HRMMU that many residents would like to work more in their facilities: beyond the hours set aside for ergotherapy sessions, on different jobs or on a more regular basis, and to be paid for it. In 16 long-term care facilities, HRMMU received complaints about the lack of standard employment opportunities inside and outside the facilities.¹¹² Directors of long-term care facilities told HRMMU that the legal framework prevents facilities from creating social businesses in the facilities, which would ensure remuneration and other labour guarantees for persons with intellectual and psychosocial disabilities. On a positive note, HRMMU observed good practice in five long-term care facilities for persons with intellectual and psychosocial disabilities, which provided part-time employment for their residents.¹¹³

89. Human rights defenders and directors of long-term care facilities told HRMMU that it is virtually impossible for persons with intellectual and psychosocial disabilities to obtain formal employment in the community because of stigmatization. Moreover, ambiguous labour legislation is silent about specific labour guarantees and proceedings in relation to persons with intellectual and psychosocial disabilities, such as support services at the workplace. Although legislation provides for a mandatory quota for the employment of persons with disabilities, employers are keen to employ persons with physical impairments in need of minimal reasonable adjustment at the workplace, rather than persons with intellectual and psychosocial disabilities.¹¹⁴ Removal of legal agency presents another challenge for employment due to the stigmatization of individuals with this status. Moreover, while the law does not explicitly prohibit persons with removed legal agency to enter into contracts of employment,¹¹⁵ it provides for termination of the status of unemployed persons if their legal agency is removed, which results in the lack of access to employment services and indicates that legally incapacitated persons cannot apply for employment. Reportedly, apart from entrepreneurs running a social business, only a few major companies in Ukraine are ready to consider the employment of persons with intellectual and psychosocial disabilities.

¹⁰⁸ Such as additional food, tea, sweets, cigarettes or allowing residents to do certain things, usually prohibited in the facilities. In one facility, residents complained to HRMMU that orderlies distributed residents' cigarettes to them only if the residents had worked.

¹⁰⁹ HRMMU noted that residents who could provide such care were put in departments for residents who were in need of such care.

¹¹⁰ Types of work performed during ergotherapy sessions were usually dictated by the needs of a particular facility. Residents clean premises and yards, renovate the facility, help employees of the facilities with their daily tasks, etc.

¹¹¹ HRMMU notes that such work falls under indicators of employment relations defined in para. 13 of the ILO Employment Relationship Recommendation, 2006 (No. 198).

¹¹² In long-term care facilities for persons with intellectual and psychosocial disabilities, especially in rural areas, many residents of the facilities moonlight in local communities.

¹¹³ Residents were employed as janitors, and to do laundry and carry out handiwork.

¹¹⁴ According to article 19 of the Law of Ukraine "On the fundamentals of social security of persons with disabilities", all employers are obliged to ensure four per cent of their workforce is made up of people with disabilities or one person with disabilities if the total number of staff ranges from 8 to 25 persons.

¹¹⁵ HRMMU notes that the law does not explicitly prohibit persons without legal agency to enter into employment contracts. In this regard HRMMU notes the judgement of the Supreme Court of 24 June 2015 in case No. 6-530/15 where the Court concluded that provisions of the Civil Code on invalidity of the contracts are not applied to employment contracts. This implies that the removal of legal agency of an employee cannot be used to claim the invalidity of an employment contract and thus cannot be a barrier to enter into employment contracts. At the same time, HRMMU notes that the legislation provides for termination of one's unemployment status and associated employment services and social benefits in case of removal of legal agency. Employment legislation does not provide for specific rules on safety at the workplace of persons with intellectual and psychosocial disabilities, their disciplinary liability and liability for damages. Absence of such rules in the context of the status of legally-incapacitated persons, which implies a lack of control over one's own actions, may be seen as a major obstacle for concluding an employment contract with a person with intellectual or psychosocial disability.

H. Adequate standard of living and social protection

“I have no father, no mother, no brother, no sister, where would I go?”

- Resident of a long-term care facility on why he continues to stay in the facility.

90. The lack of accessible and affordable housing, including social housing, continues to be a major concern affecting the human rights of persons with intellectual and psychosocial disabilities. Many only continue to live in institutions due to the lack of available housing. Individuals discharged from institutions may find themselves at risk of homelessness. The issue became acute during the second stage of the medical reform process, when psychiatric hospitals had to discharge their long-time patients. In long-term care facilities, HRMMU documented concerns in relation to poor living conditions in buildings, poor food and lack of access to social benefits in long-term care facilities. Guardians of persons living in communities complained to HRMMU about problems with acquiring disability status associated with certain social benefits.

91. The lack of accessible and affordable housing is a major obstacle preventing persons with intellectual and psychosocial disabilities from living independently. Although legislation provides for the right of persons with disabilities to social housing, in practice, almost no social housing is provided to meet their needs, including for those raised in children’s institutions.¹¹⁶ Residents of 29 long-term care facilities for persons with intellectual and psychosocial disabilities or psychiatric hospitals complained to HRMMU that they continued to stay in those institutions only due to a lack of housing¹¹⁷

92. HRMMU is concerned that persons with intellectual and psychosocial disabilities who have resided in psychiatric hospitals are particularly vulnerable to homelessness. Human rights defenders told HRMMU about several cases where persons with intellectual and psychosocial disabilities were discharged from psychiatric hospitals after the launch of the second stage of the medical reform and had no place to live. This was of particular concern since some of them needed regular medical care.¹¹⁸ Some psychiatric hospitals introduced a social service of in-patient care to accommodate persons with disabilities for longer periods.¹¹⁹ Despite being positive for preventing homelessness, in the long term, such a practice may lead to protracting the institutionalisation of persons with intellectual and psychosocial disabilities.

93. HRMMU observed poor living conditions in 19 long-term care facilities for persons with intellectual and psychosocial disabilities and four psychiatric hospitals visited. Among major concerns were the lack of living space in bedrooms, dilapidated bedrooms and halls, poor conditions of bathrooms, toilets and related equipment, lack of doors in toilet rooms and bathrooms, unsanitary conditions in toilets, bathrooms and kitchens, and poor-quality beds that contributed to bedridden residents being prone to bedsores.

94. In 7 long-term care facilities for persons with intellectual and psychosocial disabilities and 4 psychiatric hospitals, HRMMU documented complaints relating to the food provided. Persons with intellectual and psychosocial disabilities complained to HRMMU about the lack of food, poor quality of food and spoiled products, lack of meat, fish, eggs, and vegetables in the food and lack of dietary variety.¹²⁰ In three psychiatric hospitals, HRMMU observed that patients had to eat their own food, usually brought by their relatives, due to the lack of food provided in hospitals.

¹¹⁶ Social housing is a special category of subsidized housing usually owned by the State at central or municipal levels. Social housing is allocated to tenants on the basis of special lease agreements typically concluded for an indefinite period. See the Law of Ukraine “On the Housing Fund for Social Purposes” of 1 January 2007, available in Ukrainian at: <https://zakon.rada.gov.ua/laws/anot/en/3334-15/>.

¹¹⁷ Directors of the long-term care facility also told HRMMU that they must indicate a new place of residence in the documents discharging a person. They said that they would not discharge a persons who has no place to go, as this would place such persons in jeopardy.

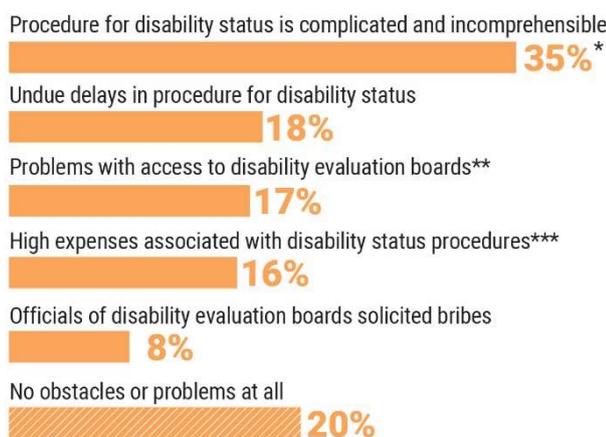
¹¹⁸ Reportedly, this situation was mainly observed in large cities, where long-term care facilities have no places available for newcomers. HRMMU also documented such a case and reported it in *OHCHR Report on the human rights situation in Ukraine, 1 February to 31 July 2021*, para 102.

¹¹⁹ HRMMU observed such practice in Kyiv.

¹²⁰ HRMMU notes that residents of the long-term care facilities cannot choose the menu or influence it in any way.

95. Through interviews with human rights defenders and relatives of persons with intellectual and psychosocial disabilities, HRMMU documented concerns in relation to access to disability status, and therefore, social benefits associated with it.¹²¹ In particular, interlocutors complained about significant delays in examinations and extortion of bribes by members of disability evaluation boards. Many relatives were disappointed that the disability evaluation boards did not assign a lifetime disability status for their relatives with profound and irreversible conditions and they have to undergo regular examinations to extend the disability status, usually every two years.¹²² Many interlocutors also complained that the disability evaluation boards tend to attribute a lower disability group in comparison to expectations of the persons based on their diagnosis. These findings are corroborated by the HRMMU online survey, which shows that 92 per cent of respondents encountered problems during examinations (see infographic).

OBSTACLES IN RELATION TO ACCESS TO DISABILITY STATUS
According to the online survey of HRMMU among 226 caregivers of persons with disabilities



Creation Date: 28 January 2022
Source: HRMMU

*Portion of respondents. Respondents could choose several answers.
** Problems with transportation from remote locations, long waiting lists to disability evaluation boards.
*** Expenses for transportation, accommodation and stay in locations with disability evaluation boards.

96. HRMMU is also concerned about access of persons with intellectual and psychosocial disabilities to their social payments. Ukrainian legislation provides that persons living in institutions are entitled to dispose of 20 or 25 per cent of their social payments provided in relation to their disability status.¹²³ HRMMU also notes that legally incapacitated persons in institutions can dispose of their social payments only through special boards.¹²⁴ In this regard, persons with intellectual and psychosocial disabilities in ten long-term care facilities complained to HRMMU that the boards did not take into account their wishes on the distribution of funds and usually purchased the same goods or items for all the residents.¹²⁵ HRMMU observed that in five long-term care facilities this practice also affected persons with legal agency, who had to request staff members to buy food and goods for them due to a lack of shops in the vicinity of the facilities located in remote rural areas.

III. Conclusions and recommendations

97. Persons with intellectual and psychosocial disabilities are the most neglected group among persons with disabilities in Ukraine. This is due to their systematic institutionalisation, stigmatization, and lack of guarantees of protection. Besides institutionalisation, the removal of legal agency of persons with intellectual and psychosocial disabilities presents another significant factor hindering their access to the full set of rights provided by the CRPD and contributing to violations of their fundamental human rights. For the past decade, the Government of Ukraine has only implemented fragmentary measures to reform its legislation and social policy in relation to the rights of persons with intellectual and psychosocial disabilities, and thereby failed to significantly advance Ukraine towards the fulfilment of its international obligations enshrined in CRPD and to achieving related SDGs.

98. Ukrainian legislation continues to allow for the removal of legal agency of persons with intellectual and psychosocial disabilities, which contributes to discrimination, social isolation and deprivation of human dignity, as it limits them in accessing their rights and entitlements associated with participation in the life of society. Shortcomings in procedural legislation and legal practice allow for the removal of legal agency even when persons with disabilities are able to make decisions about their lives with no or minimal support. Many persons with

¹²¹ Ukrainian legislation links the right to social protection for persons with disabilities with their disability status. The scope and amount of social payments, social benefits and social services depend on the disability group.

¹²² Paragraph 22 of the Resolution of the Cabinet of Ministers No. 1317 of 3 December 2009 provides, that re-examinations are to be conducted every 1-3 years. Reportedly, in the majority of case the re-examinations are held every two years.

¹²³ Persons with disabilities are entitled to dispose 25 per cent of their pensions/social aid. Persons with disabilities who are not entitled to a disability pension or social aid for persons with disabilities from childhood receive state aid and can dispose of 20 per cent of their social aid. The remaining 75 or 80 per cent goes to the institutions, who must use this funding to improve residents' living conditions. See article 48 of the Law of Ukraine "On Mandatory State Pension Insurance" of 1 January 2004, article 13 of the Law of Ukraine "On State Social Aid to Persons Disabled from Childhood and Disabled Children" and article 10 "On State Social Aid to the Persons not Eligible for Pension and Disabled".

¹²⁴ According to legislation, such boards consist of at least five persons and may include staff members of the facilities, representatives of civil society organizations or local guardianship bodies. See Order of the Ministry of Social Policy No.1173 of 17 September 2018.

¹²⁵ HRMMU monitoring visits to long-term care facilities for persons with intellectual and psychosocial disabilities.

removed legal agency could be reintegrated into communities if the relevant social services, including housing, were available. Flaws in legislation and practice on guardianship and the absence of any arrangement of supported decision-making continue to be major human rights issues.

99. Due to the lack of services allowing for independent living, specialized long-term care facilities remain the only place of residence for persons with intellectual and psychosocial disabilities. Given that such facilities usually accommodate more than a hundred persons, individualised social services and care are a priori not available there. Children with intellectual disabilities are particularly vulnerable to institutionalisation in adulthood due to a lack of education and individualised support in long-term care facilities for children. Of major concern are the grave human rights violations occurring in such facilities, including torture, ill-treatment, forced medication, deprivation of liberty, and forced labour, all of which continue to be reported by the Ombudsperson and human rights defenders throughout the country. Respect for personal liberty, right to private and family life, sexual and reproductive health are also a matter of concern.

100. Persons with intellectual and psychosocial disabilities residing in the community lack access to social services, habilitation and rehabilitation, employment, and education. The situation is particularly dire in rural areas, where the complete absence of such services confines persons with intellectual and psychosocial disabilities in their homes. Civil society organizations including associations of parents, which provide such services or access to employment, suffer from a lack of governmental support and funding.

101. The Government of Ukraine must immediately launch consultations with persons with intellectual and psychosocial disabilities and their organisations to develop plans and programs to ban substitute decision-making arrangements. Supported decision-making mechanisms should be introduced as soon as possible. In the summer of 2019, the Government of Ukraine launched a comprehensive reform of civil legislation. This reform presents an opportunity to repeal rules on the removal of legal agency and introduce rules on supported –decision-making arrangements, and harmonise necessary amendments with other provisions of the new Civil Code, to bring Ukraine’s legislation in line with CRPD.

102. Support and technical assistance from the international community, organizations of persons with disabilities and other civil society organizations will accelerate reforms to provide social services for adults with intellectual and psychosocial disabilities in communities, and thus move Ukraine closer to the deinstitutionalization reforms needed. HRMMU notes that assistance to projects and programs piloting best practices on supported living arrangements, social services in the community, employment and education for persons with intellectual and psychosocial disabilities are needed.

103. In order to eliminate the systemic discrimination and violations of rights of persons with intellectual and psychosocial disabilities that exists in law and practice, HRMMU recommends that the Government of Ukraine, regional and local authorities:

104. On the right to equal recognition before the law:

a. The Parliament to repeal the legislation allowing for removal or restriction of legal agency, and instead introduce arrangements for supported decision-making in line with requirements defined in article 12 CRPD and General Comment 1 of the Committee, in consultations with persons with intellectual and psychosocial disabilities and their organisations;

b. In the meantime, in consultations with persons with intellectual and psychosocial disabilities and their organisations, amend civil procedure legislation to provide for better protection of the rights of persons with disabilities in proceedings on removal or restoration of legal agency, in particular:

- The Parliament to allow persons with removed legal agency to apply to court independently and on an equal basis with others;

- The Parliament to expand the procedure for review of the removal of legal agency to cover individuals whose legal agency was removed before 2017;

- The Parliament to adjust the procedure for review of the removal of legal agency of persons with irreversible intellectual and psychosocial disabilities living with relatives in the community, e.g. by reducing the periodicity of such reviews/expanding the validity of removal;

c. The Cabinet of Ministers and central executive authorities to ensuring better application of international standards on the right to equal recognition before the law by providing training for legal, social and medical professionals;

d. The judicial authorities to cease the practice of adjudicating cases on the removal or restoration of legal agency in absence of persons with intellectual and psychosocial disabilities and without questioning them;

e. The judicial authorities to refer to the article 12 Convention on the Right of Persons with Disabilities to enhance protection of the rights of persons with disabilities from removal of legal capacity;

f. The Cabinet of Ministers and central executive authorities, in consultation with organizations of psychiatrists, to introduce unified standards and methodology for forensic psychiatric examinations, to eliminate any arbitrariness;

g. The Cabinet of Ministers and central executive authorities to introduce and support initiatives and programs aimed at raising the public's awareness on inclusiveness, deinstitutionalization and supported decision-making.

105. On the right to independent living:

a. The Cabinet of Ministers and central executive authorities to enhance efforts to implement the deinstitutionalisation of children reform process and, in consultations with persons with disabilities and their organisation, begin to develop a policy and plan for the deinstitutionalisation of adults, including adults with intellectual and psychosocial disabilities;

b. The local authorities, social protection and healthcare bodies and institutions to start developing services for independent living and cease all programs and plans providing for the construction of new long-term care facilities for children and adults with intellectual and psychosocial disabilities;

c. The local authorities, social protection and healthcare bodies and institutions to enhance efforts to enable accessible housing and community-based social and mental health services for persons with disabilities.

106. On the rights to liberty and security of persons

a. The local authorities, social protection and healthcare bodies and institutions to conduct prompt and effective investigations into all reports and complaints about torture, ill-treatment, forced medication, deprivation of liberty, forced labor and other violations of human rights in long-term care facilities and psychiatric hospitals;

b. The Ombudsperson to enhance efforts on monitoring, identifying and documenting human rights violations in long-term care facilities for persons with intellectual and psychosocial disabilities, in particular, through regular confidential interviews with the residents, providing them unimpeded and confidential access to a complaint mechanism;

c. The Parliament to amend the legislation on psychiatric aid to abolish involuntary admission of persons with intellectual and psychosocial disabilities to psychiatric hospitals;

d. The Cabinet of Ministers and central executive authorities to enhance efforts in regards to deliver training on the prevention and absolute prohibition of torture and ill-treatment in psychiatric hospitals and long-term care facilities for persons with intellectual and psychosocial disabilities;

e. The local authorities, social protection and healthcare bodies and institutions to cease the practice of giving hormonal contraceptives to women living in long-term care facilities for persons with intellectual and psychosocial disabilities without their free and informed consent based on information about other options and impact on their health, including reproductive health;

f. The Parliament to amend the law to enhance safeguards against involuntary treatment and forced medication of persons with intellectual and psychosocial disabilities, including in long-term care facilities.

107. On the respect for privacy and family

a. The local authorities, social protection and healthcare bodies and institutions to cease all practices in long-term care facilities which amount to violations of the right to privacy, such as paternalistic treatment, observance of residents in rooms, showers and toilets by staff of the opposite sex, seizure of mobile phones, interferences in private conversations.

108. On the right to health

a. The local authorities, social protection and healthcare bodies and institutions to ensure access of persons with intellectual and psychosocial disabilities to healthcare services in the community, in particular, through eliminating additional requirements for personnel accompanying persons at general hospitals;

b. The Cabinet of Ministers and central executive authorities to enhance the quality and scope of psychiatric care by improving access to outpatient psychiatric care, and providing adequate funding for psychiatric hospitals, which would allow persons with psychosocial disabilities to access adequate psychiatric treatment, medication, habilitation and rehabilitation services, as well as enjoy decent living conditions in these hospitals;

c. The local authorities, social protection and healthcare bodies and institutions to ensure access of residents of long-term care facilities for persons with intellectual and psychosocial disabilities to information on sexual and reproductive health in accessible formats and technologies.

109. On the right to education, habilitation and rehabilitation

a. The local authorities, social protection and healthcare bodies and institutions to continue to work towards enabling inclusive quality education for persons with intellectual and psychosocial disabilities, including children in specialized institutions;

- b. The local authorities, social protection and healthcare bodies and institutions to ensure access to education, including primary, secondary and higher education, for persons with intellectual and psychosocial disabilities, including those residing in institutions;
- c. The Cabinet of Ministers and central executive authorities to create accessible comprehensive habilitation and rehabilitation services and programs accessible to persons with intellectual and psychosocial disabilities residing both in the community and institutions;
- d. The local authorities, social protection and healthcare bodies and institutions to extend full cooperation and provide support to civil society organizations and parents' organizations providing habilitation and rehabilitation services to persons with intellectual and psychosocial disabilities.

110. On the right to work and employment

- a. The Parliament to provide additional guarantees for employment of persons with intellectual and psychosocial disabilities in legislation, such as supported services and specific quota for employment;
- b. The Cabinet of Ministers and central executive authorities to create and support programs and services for persons with intellectual and psychosocial disabilities at the workplace; introduce legislation to protect and guarantee labour rights of persons with intellectual and psychosocial disabilities working in long-term care facilities;
- c. The local authorities, social protection and healthcare bodies and institutions to limit the use of ergotherapy only to rehabilitation purposes and enhance control over its use in long-term care facilities;
- b. The Cabinet of Ministers and central executive authorities to provide benefits and support to entrepreneurs and businesses as incentives for employing persons with intellectual and psychosocial disabilities.

111. On adequate standard of living and social protection:

- a. The Cabinet of Ministers and central executive authorities to ensure access of persons with intellectual and psychosocial disabilities to independent use of their social payments.