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ASSESSING SOCIAL CARE HOMES IN UKRAINE

REPORT ON SOCIAL CARE HOMES IN THE KRYVYI RIH AREA
(DNEPROPETROVSKAYA OBLAST)

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I. Executive Summary

In May 2018, an international team of Ukrainian and foreign experts, together with a representative of the Ministry of Social Affairs, carried out an assessment of two social care homes in Dnepropetrovskaya oblast in Ukraine. Both social care homes are located near the city of Kryvyi Rih.

The visit followed earlier assessments of social care in December 2016 and January 2018 that resulted in discussions with the relevant authorities with regard to the current state of affairs in both institutions and the desire to initiate a transformation process. In both cases, the relevant authorities acknowledged the shortcomings that were mentioned in the relevant reports,¹ and agreed to a follow-up visit to assess how the situation could be amended. Whereas earlier assessment visits took place under the auspices of the Ombudsman for Human Rights of the Verkhovna Rada, the May 7-11, 2018, visit took place under auspices of the Ministry of Social Affairs, the ministry responsible for social care homes.

During the May 2018 visit we concentrated on two groups of social care homes: two institutions we visited earlier and where we agreed to support a transformation process in collaboration with local authorities, and two new institutions that had not been visited before. This report focuses on the two new institutions, one for women and one for men, near Kryvyi Rih.²

Whereas the social care home for women was found to be a fairly humane institution with caring staff doing their best with the limited resources available, the daily reality in the male institution consisted of structured abuse, inhumane and degrading treatment, extensive use of medication, slave labor and an unusually high death rate. Quite shocking was the fact that the institution was run by a director who demonstrated little expertise or awareness of his responsibilities but who had no problem using his residents as forced labor in his garden and farm. We believe that this institution needs a fundamental overhaul and a detailed review of current practices and that only through a change in leadership can a structural improvement be accomplished.

We are grateful to the Ministry of Social Affairs, for its openness, desire to collaborate and also the wish to initiate this much-needed transformation process. We hope our report will form the basis for measures to improve the standard of living and quality of care at the institutions and eradicate the abuses that we uncovered during our assessment visit.

¹ Review of social care homes in Ukraine and the development of a Plan of Action, FGIP, February 2017; Assessment of the Svyatoshinsky social care home, Kyiv, Ukraine, FGIP, February 2018.

² The report on the other two institutions in Slavyansk and Kyiv will be published separately and focus on recommendations and suggestions how to initiate the transformation process.

II. Introduction

Over the past years the Federation Global Initiative on Psychiatry has become actively involved in the issue of social care homes in Ukraine, in which 41,000 adults and 6,000 children are kept in virtually total isolation from society.

It is important to note that by all international standards the system of social care homes should not exist. The system is in violation of international human rights standards and contradictory to the key concepts of the UN Convention of the Rights of Persons with Disabilities (CRPD), which Ukraine has signed and ratified.

In December 2017, the Council of Europe made several recommendations that are very relevant in this respect:

- People with disabilities should be more involved in decision-making when transitioning from institutional to community-based care;
- People need to be able to autonomously decide where to live;
- The scale and number of existing residential institutions must be reduced, and affordable and high-quality community-based solutions developed.

In Ukraine there is a general understanding that the system of social care homes should be transformed into a chain of modern community-based services. However, the task is seen as so immense that hitherto no program has either been developed or begun. This project is therefore the first of its kind, focusing on piloting modern services in one part of Ukraine before rolling out reform across the country. It is also based on the understanding that for a number of years, two systems will exist simultaneously: the new system (yet to be developed) and the old institutions. However, it is also important that access to old institutions is closed and no new clients enter and maintain the old system, as happened several decades ago in Italy.

II.a. Past Assessments

Over the past two and a half years, three assessment visits have been conducted, providing a wealth of information essential to understanding the current situation of the social care system and possible avenues for reform. In December 2016, an assessment was carried out under the auspices of the Office of the Ombudsman for Human Rights of the Verkhovna Rada. Four social care homes were visited: two in Donetskaya oblast (Slavyansk and Kamishovska), one in Khmelnytskaya oblast and one in Zhitomyrskaya oblast. A report was published and presented at the Ombudsman's Office in March 2017. In January 2018, a two-day assessment was carried out in the Svyatoshinsky social care home in Kyiv, again under the auspices of the Ombudsman's Office. Svyatoshinsky is the largest social care home in the country with 700 beds. A report was published and presented at a press-conference in April 2018.

III.b. The May 2018 assessment

From May 7-11, 2018, a team of international experts toured Ukraine in order to assess the situation in social care homes. Four social care homes were visited: two in Kryvyi Rih that had not previously been assessed, with return visits to the Slavyansk social care home and Svyatoshinsky social care homes in Kyiv. In addition to an assessment, our purpose in visiting the latter two homes was to gather information to inform a transformation plan that will be published separately.

A total of 12 people took part in the assessment visits, all of them with expertise in key areas of the future transformation process. The members of the expert teams have all agreed to participate in future activities e.g. trainings, assessments, and professional support.³

While previous assessments had been carried out in collaboration with the Office of the Ombudsman for Human Rights, this time we sought to work with the Ministry of Social Affairs as they are directly responsible for virtually all social care homes in the country.

The social care homes near Kryvyi Rih were chosen randomly from a list provided by the Ministry. This change to working with the Ministry of Social Affairs removed the ability to visit institutions unannounced, as had been possible during earlier assessments under the auspices of the Ombudsman for Human Rights. The fact that institutions knew about our arrival did not appear to significantly affect our findings. The institutions had four or more days to clean their buildings and remove things that they did not want us to see; for example to try and eliminate the worst institutional smells or to shave and improve the presentation of their residents, but this merely created a superficial veneer under which it was quite easy to detect daily reality and the true state of affairs.

³ Petri Embregts, professor in Tilburg specialized in persons with learning disabilities (NL); Gavin Garman, senior mental health nurse (UK); Dovile Juodkaite, lawyer and expert in CRPD (LT); Rob Keukens, senior lecturer in psychiatric nursing (NL); Lars-Olof Ljungberg, social worker and Director of the Swedish Personal Ombudsman program (S); Julia Pievskaya, sociologist (UA); Jos Poelmann, social worker and retired mental health manager (NL); Madeline Roache, political scientist (UK); Helen Smith, psychiatrist and mental health manager (UK); Graham Thornicroft, professor of community psychiatry (UK); Wendy Weijs, psychologist (NL) and Robert van Voren, Sovietologist (NL/LT).

III. Zelenopilskyi social care home (for women)

III.a. Introduction

With a capacity of 123 places, the institute at the time of our visit housed 119 residents in two wards (4 residents had been transferred for treatment to a local hospital). One ward provides care for 30 bed-ridden persons. Many of these residents have a form of intellectual disability (such as Downs syndrome) and or neurological problems (such as Parkinsons). This ward is in need of 'high low' adjustable beds.

A total of 54 residents are under guardianship, with 4 residents being under the guardianship of the social care home's administration. The remaining 50 have family members as their guardians though half of these no longer have contact with people from outside the social care home. The vast majority of residents come to the institution from other facilities and no-one leaves the home before their death. Staffing ratios are one nurse for every 40 residents. On the ward for bed-ridden patients there is one nurse per 10 residents. The nurses work in shifts of either 8 or 24 hours.

The home is the main employer for the local area but reports they find it extremely difficult to attract well trained staff. Nurses and social workers do not choose to work there because of the low salaries (approximately 105 Euros per month for a 42 hour working week). As a result, many of the staff are untrained assistants with a good heart but limited skills.

We found the atmosphere to be caring. Staff were doing what they could with limited means and resources.

III.b. Physical environment

Despite its status as a home for women, there were at least 3 male residents. These men had a separate room on the same corridor as the female dormitories.

The home was clean but there were some basic problems with the fabric of the building, for example trip hazards on corridor floors in the older building. There was a modern dining space with a karaoke machine which residents said was used regularly and the atmosphere felt relatively relaxed. The home had a fire alarm system.

People were using the outside space, playing with some dogs who also lived at the home. There was reasonable privacy for those using the toilets and showers. There was toilet paper available and people had their own soap and toothbrushes. There was also a bin of sponges, not personalized, which we were told were disinfected after use.

Dormitories were fairly uniform with little personalization. The social worker showing one of our teams around shared a folder of art work done by residents. This was kept in her office rather than being used to decorate residents' personal spaces.

III.c. Facilities/lived environment

Residents looked mostly to be dressed as individuals and able to exercise personal choice in how they looked. A number of the more able residents looked fashionable and akin to peers living outside the institution. One resident was allowed to cut the hair of others and this meant that a few had modern hair styles.

We spoke with different residents and they described a variety of difficulties. Their main complaint was the lack of opportunity to engage in activities that they wanted to pursue. It appears that there is limited meaningful activity on offer for residents. The social worker showed us a packet of pencils that individuals may use and we were shown a library that consisted of about 30 books in a cupboard, many of which were religious in nature. There was no program of activities available and people had no useful structure to their days, bar fixed bed and mealtimes. Only 25 residents were accessing some form of occupational program.

Residents were allowed to take limited responsibility for their personal space or activities of daily living. However, as is common in social care homes, staff routinely infantilize the skills of residents. For example, one resident asked to assist in the dining room but this was not allowed as staff felt she might burn herself with the food. This culture and attitude prevents residents from developing skills of daily living and fosters a dependency on staff that is unhealthy and hampers any move out of the institution.

A few residents have chosen to take care of residents far less able than themselves. This is very much like a buddying system and there should be opportunities for further development of this informal system of support, with appropriate safeguarding measures in place.

III.d. Legal aspects

Since Ukraine has ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), it must follow its requirements, including in services provided by social care homes.

Responsibility is shared both by the government, public institutions (such as social care homes), professionals and specialists, since they all are required to act in conformity with the Convention. The social care home system in Ukraine systematically violates articles 12, 14, 15, 16, 19, 23, 25, and 26 of the CRPD.

Article 5 of the CRPD (on equality and nondiscrimination) requires that all persons are recognized as equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law. The overwhelming majority of residents in the care homes visited came to the home via other facilities and none leave before their death. This constitutes discrimination based on disability, because residents are referred to the social care home with no option to choose to receive services elsewhere or to challenge their situation.

Admission into the institution is a violation of art. 19, as there are no alternative community services available to meet the residents' needs. In addition, residents do not have any influence over the decision where and with whom they live and are obliged to live in a specific living arrangement (e.g. the social care home with all its regime, rules and conditions). Residents of the social care home are totally isolated and have no possibility to be included into society. The services in the social care home do not meet the individual needs of residents and are not striving to support them in living outside the institution. This represents systematic violation of art. 19.

Article 25 indicates that persons with disabilities should be provided with the same range, quality and standard of free or affordable health care and programs that are provided to other persons, including in the area of sexual and reproductive health and population-based public health programs. There should be health services to care for their specific disability, including early and appropriate identification and intervention and services designed to minimize and prevent further disabilities.

In relation to CRPD article 25, the social care home did not provide health care services equivalent to others. Also, there were no specific services tailored to meet the needs of specific disabilities. No informed consent is sought from the residents. Health professionals were not well trained or informed on human rights and they did not raise the awareness of patients regarding their human rights and rights to dignity and autonomy.

The social care home has no license for the provision of psychotropic medication. There is, however, quite a large amount of psychotropic medication purchased in advance (for the whole year) and stored in the social care home. This raises the question of adequate prescription, management and storage of medicine. Such drugs as haloperidol and aminazine appear to be the most frequently used and the social care home maintains at least a three month supply.

Article 26 of the CRPD points out that countries shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. The government should organize, strengthen and extend comprehensive rehabilitation services and programs, particularly in the areas of health, employment, education and social services, in such a way that these services and programs begin at the earliest possible stage and are based on the multidisciplinary assessment of individual needs and strengths.

It was obvious that the social care home did not provide rehabilitation services (other than medical rehabilitation) that would maintain maximum independence, and facilitate full physical, mental, social and vocational ability, and full inclusion and participation of the patients. Patients were disempowered, their individual needs were neglected. There was no possibility of employment and no education programs were provided for patients.

Despite the fact that individual rehabilitation plans were being developed as required by Ukrainian legislation, the plans do not focus on recovery and do not ensure that the will and/or preferences of the residents are ensured.

Almost half of residents are declared as legally incapable. This means that they are totally limited in their rights.

The majority of residents do not receive their pension or benefits. When a resident is under the guardianship of a family member, the pension is received by this family member. It is then up to the family whether they bring some money to the resident or not, which is unacceptable.

For residents who are under the guardianship of the social care home, their pension is transferred to a bank account. Each month nursing staff go to the city to withdraw money from bank cash machines and purchase any items that residents have requested. The remaining money is kept either by the residents themselves (if capable) or by the administration. Full documentation is maintained by the administration with regard to the use of the residents' pensions. All legal documentation is held by the administration.

IV. Kryvyi Rih social care home (for men)

"I am not a human, I am a resident"

IV.a. Introduction

The Kryvyi Rih social care home is an institute for up to 326 male patients and 136 staff. At the time of our visit there were 285 residents, 20 had been transferred for treatment for tuberculosis and 4 to a local psychiatric hospital. The institution is run by a director who has been in post since 1977. During our short meeting with the director, it was evident that he had difficulty answering our questions and seemed to have little understanding of the needs of his residents. He gave the general impression of having little interest in his job. He appeared disheveled and out of touch with the requirements of someone in his position. We were concerned that he did not have the necessary knowledge or attitude to adequately lead his complex institution.

We noted that mortality rates seemed high and there was significant physical and mental health morbidity. There was tuberculosis in the institution and two quarantined wards. We were handed face masks as we arrived, initially it seemed to be as some sort of protection from infection but it quickly became more apparent that this was to help mask the institutional stench.

On checking the register, we found that in the course of seven years, 147 inmates had entered the home; as the size of the social care home did not change this means that in the same period some 147 must have died – a death rate of 5-6%. Looking at the birth dates we concluded that this was not due to old age: the oldest person in the institution was born in 1941. Most were born in the 1960s and onwards. Residents who managed to escape the controlling restrictions of the management and speak to one of our team members confirmed our fears. They spoke of high dosages of medication, punishment with neuroleptics and physical abuse. It became apparent that some fitter residents were working as forced labor in the lands surrounding the institution. They were being paid a wage for this, however those who refused to give up this wage to staff within the institution were punished. We heard stories of residents being beaten, chained naked to a radiator for long periods of time and others undergoing other forms of degrading treatment amounting to torture.

Residents rooms were uniformly non-descript, stripped of everything that might have made them feel personal or homely. Many people were just hanging around, walking in circles, some talking to themselves, some looking sedated and others looking bored and listless. There seemed to be no planned activity, leaving people to endure endless empty days. The institution seems to be stuck in a time warp.

We heard about and saw evidence of sexually inappropriate behavior, agitated and aggressive behavior, psychosis and marked sexual safeguarding concerns. We wondered what the role of alcohol was in firing some of these abnormal behaviors

IV.b. Physical environment

We were met on arrival by staff and residents. After meeting with the senior management team, we went out into the social care home to meet staff and residents. One team was accompanied by a female deputy director who avoided answering all our questions by saying she was not a psychiatrist and therefore did not know the answers. The other team was accompanied by the psychiatrist. We understood he attended for 3 hours per day, 5 days a week. At other times, he worked at the psychiatric hospital in the local town. We noted no positive interaction between this doctor and the people we were meeting during our tour. He did not appear to have any interest in building relationships with this population.

The institution consisted of 5 separate units across several buildings, one of which had been quite recently constructed by a German development organization. The fabric of the older buildings was poor. Every dormitory bedroom should have contained a working sink. However, no sink appeared to have any tap fittings and in other rooms the sink itself had disappeared and only piping remained. This had clearly been a longstanding problem for many years. The psychiatrist said this was going to be repaired soon. However, we were unable to confirm this.

Bathroom and toilet facilities were at best inadequate, with too few for the population they were serving. There was no privacy, doors were without handles, the showers were in a very poor condition, and the (French, squatting style) toilet stalls were dirty with no toilet paper. We could not be sure if there were problems with the water supply or pressure, but we noticed that many residents seem to have dirty hands and feet and dirty nails.

The overall fabric of the building was poor, the flooring was in poor condition as was shelving and other trimmings. Beds were of poor quality with thin mattresses. Each had a blanket, cover and a pillow. Beds and linen were dirty. They were uniformly and tidily made up, but there was no personalization of rooms.

In the old building in the corridors the doors had bars, and all rooms had bars on the windows.

Keeping in mind that our visit was known of in advance and that the institution had probably four days or more to prepare for our visit, one could only imagine what the institution would have looked like if we had been unannounced. One of the residents told us that he and other residents had been shaved just two days ago. This appeared to have been done hastily and many had small wounds from the razor blade on their chin and cheeks.

IV.c. Facilities/lived environment

We looked in communal wardrobes and found plastic bags of dirty, smelly clothing. Staff showed us that residents clothing was kept in a communal store room. This washing was neatly laundered. We did not see evidence of any toothbrushes, toothpaste, towels, soap or shampoo.

Residents everywhere had institutional clothing, some dressed in uniform brightly colored tee shirts that looked brand new and had probably been handed out in preparation for our visit. All the residents wearing these uniform tee shirts were close to the special unit which we were told accommodated residents with tuberculosis, raising the suspicion that these residents with tuberculosis were being marked out by their clothing. Other residents wore identical black sweat shirts or army fatigues.

Food was cooked in a central kitchen, taken and served in each block. There appeared to be 3 meals a day. The dining space was small so meals were taken in shifts.

There appeared to be no program of activities available to any resident. People were just sitting around, some alone and other talking to themselves or to each other. Again the population was mixed, with people with mental health problems, some with learning disabilities and others with physical health problems.

It was very striking to observe the behavior of staff during our visit. There was very little positive interaction between any staff and the residents, we did not see anything we could call compassionate interaction. There was no communication between patients and doctors. A number of staff permanently wore face masks, even when not in direct contact with residents. When we asked why this was, we were told it was because of “the stench”. It seemed perfectly acceptable for staff to protect themselves from this but no consideration was given to the effects of the stench on the residents. The staff seemed to tolerate their jobs and did not take much pride in their work. One of the cooks in a block described working there for several years and she described how well fed everyone was.

Observing the residents, there was a stark contrast in how people looked. There were some who had clearly been out in the sunshine with obvious suntans and others who looked grey and sick as though they never saw the light of day. It was the more able individuals (mentally and physically) who seemed more likely to have been in the sunshine.

We spoke to many residents, often accompanied by our psychiatrist. People told their stories of why they were resident. Some said their families had left them there as they were no longer able to care for them and others that they came from local psychiatric facilities.

In the middle of the outside area we found “the Arbor”, apparently built by a Canadian faith group. This was essentially a metal cage in the yard of the institution, with a toilet in the corner and a door at one end. It was filled with residents, many of them appeared agitated. High on one wall was a TV, it was switched on but few were watching. Staff explained that the TV is taken from one of the units and brought to the outside Arbor, as during the day residents spent the majority of their time there. We were aware of a constant low level of agitation and aggression in this space. In contrast to those outside, these residents looked grey and unhealthy. Many were scratching themselves and had drawn blood. People looked underweight in some cases and dentition was uniformly poor, with yellowed or missing teeth. Residents came up to speak to us and whilst it is difficult to accurately understand what was happening, we thought it likely that many were experiencing symptoms of severe mental illness. There was an atmosphere of paranoia.

Interpersonal conflict was being constantly managed by resident peers or by a member of nursing support staff sited within this space.

We wondered whether it was normal for these people to be free to walk outside or if they might normally spend more time locked inside and had been let out in connection with our visit. We also noted that the external wall was quite low and easily scalable if someone wanted to leave. We asked about people escaping and were told that this never happened. In light of the people we spoke to and some of their unhappiness about being there, we were puzzled by this. We wondered if the answer was truthful on one hand or whether actually the residents at risk of escaping were locked up more often than appeared.

We were surprised to see female residents mingling amongst the men. When we tried to talk to an elderly woman, it was evident that her thinking was dominated by delusional beliefs. She looked vulnerable and out of place in this institution. We came to understand that some of the women share rooms with males. This is not acceptable, an alarming situation which must be changed immediately. Women are vulnerable day and night within this institution. We had no sense that staff gave any consideration to the risks their environment posed to the physical and sexually safety of their residents.

There was little evidence of this being a caring environment for anyone using it, irrespective of that individual's needs, with even the most basic needs not being met. In our professional view this institution does not provide the right therapeutic environment for any individual suffering from a major mental health problem, or indeed for those with physical health problems or a learning disability. It is hard to see how anyone, male or female, could recover in such a hostile and uncaring space - far safer to stay wrapped up in your delusional beliefs.

This is perhaps best summed up in a conversation we had with an elderly resident in the grounds. This conversation started well, we had a humorous exchange about his previous life and the women he had known and the children he may have fathered. The tone changed considerably when we asked about what he would like for his future, his response was stark and encapsulated everything we had seen: "That thinking is for humans, I am not a human, I am a resident".

We consider that this institution has a number of fundamental failings and radical action is required to address the harm that residents are suffering there.

IV.d. Legal Aspects

As outlined earlier, Ukraine ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) and must follow its requirements. The social care home in question violates articles 12, 14, 15, 16, 19, art. 23, 25, 26, and 28. The most grave violations were found with regards to articles 14, 15 and 16 of the CRPD.

Residents of the social care home are deprived of their liberty and security of person (art. 14 CRPD), because they are staying in an institution against their will and are not allowed to leave. There are no procedures in place for people to complain or appeal against their staying within the facility. No legal representation is provided. No evidence was found of any person who left the institution except by their death.

According to Art. 15 CRPD, no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. Specifically, no one shall be subjected to medical or scientific experimentation without his or her free consent. There should be effective legislative, administrative, judicial or other measures to prevent persons with disabilities from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

Under international law, according to the UN Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, the term "torture" means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him, or a third person, information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.⁴

At least four essential elements are reflected in the definition of torture provided by article 1, paragraph 1, of the Convention against Torture: an act inflicting severe pain or suffering, whether physical or mental; the element of intent; the specific purpose; and the involvement of a State official, at least by acquiescence (A/HRC/13/39/Add.5, para. 30). Acts falling short of this definition may constitute cruel, inhuman or degrading treatment or punishment under article 16 of the Convention (A/63/175, para. 46).

Whether an act qualifies as "torture," "cruel and inhuman treatment or punishment," or "degrading treatment or punishment" depends on several factors, including the severity of pain or suffering inflicted, the type of pain and suffering inflicted (i.e. physical or mental), whether the pain and suffering was inflicted intentionally and for an improper purpose, and whether the pain and suffering is incidental to lawful sanctions.

Cruel and inhuman treatment or punishment can be intentional or unintentional and with or without a specific purpose, while torture is always intentional and with a specific purpose.

⁴ UN Convention against torture and other cruel, inhuman or degrading treatment or punishment http://legal.un.org/avl/pdf/ha/catcidtp/catcidtp_e.pdf

Article 2 prohibits torture, and requires parties to take effective measures to prevent it in any territory under their jurisdiction. This prohibition is absolute and non-derogable. The prohibition on torture applies to anywhere under a party's effective jurisdiction inside or outside of its borders, including health care industries, schools, day care centers, detention centers, embassies, or any other of its areas, and protects all people under its effective control, regardless of nationality or how that control is exercised.

The European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment established a European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment ("the Committee" or 'CPT'). The Committee shall, by means of visits, examine the treatment of persons deprived of their liberty with a view to strengthening, if necessary, the protection of such persons from torture and from inhuman or degrading treatment or punishment.⁵

According to the report by UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment certain forms of involuntary treatment and confinement and inhuman and degrading treatment, may sometimes constitute torture.⁶ The UN Special Rapporteur is well aware of the power of identifying such situations as inhuman or degrading treatment, as this falls within an absolute prohibition under leading human rights documents (including the European Convention on Human Rights). Torture "presupposes a situation of powerlessness, whereby the victim is under the total control of another person," and that "deprivation of legal capacity and deprivation of liberty are such circumstances." Persons who are deprived of their liberty or deprived of their legal capacity are very much exposed to the will of third parties, are highly vulnerable to the arbitrary and unprincipled exercise of power.

According to the Special Rapporteur, "medical treatments of an intrusive and irreversible nature, when lacking a therapeutic purpose, may constitute torture or ill-treatment when enforced or administered without the free and informed consent of the person concerned." This is particularly the case when intrusive and irreversible, non-consensual treatments are performed on patients from marginalized groups, such as persons with disabilities, notwithstanding claims of good intentions or medical necessity.

A social care home is a place (a closed institution) where people are detained against their will. From the institution's practice we know that clients may be subjected to restraint and being confined or secluded in an isolation room (sometimes as punishment, as we heard from the residents). The Krivyi Rih institution has a special isolation section for people diagnosed with tuberculosis. This unit consisted of 48 residents in a separate building, residents wear uniform T-shirts and have a separate walking/resting area. It was obvious to us that residents were agitated, and were restricted in their movement.

There is also an isolation room with three metal beds in one of the regular units. During the visit the room was empty, but smelt strongly of urine, as if someone had been kept there for a long time. The beds had no mattresses, nor any bed linen. There was no separate

⁵ <https://rm.coe.int/16806dbaa3>

⁶ Document A/HRC/22/53 dated February 1, 2013

register recording the use of isolation (e.g. for what reasons, when, how often, for how long and how monitored).

There are no consultations with residents to find less restrictive alternatives to identify the triggers and factors that they find helpful in diffusing crises and to determine their preferred methods of intervention in times of crisis. There is no set of criteria in place (who decides and for how long a measure is taken and how this is recorded, who is responsible for reporting, etc.), and there is no possibility of appeal. There is no complaints mechanism in the social care home. Doctors stated that all conflicts or issues are told to staff and the staff find a solution.

There is restriction on free movement (e.g. going for walks outside the facility). People living in different units seem to have limited movement within the territory of the social care home and there are separate walking/sitting areas for different residents.

Article 16 of the CRPD, states that parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects. All appropriate measures should be taken to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. The state parties should assure that protection services are age-, gender- and disability-sensitive are in place.

However, in the social care home, four women live in the male institution alongside the men, which obviously raises the risk of exploitation, violence and abuse. The institution does not have any measures to prevent such exploitation, violence and abuse by ensuring appropriate forms of gender- and age-sensitive assistance and support. To the contrary, the staff did not see the risks inherent in this situation, and explained that those women “are not an object of possible sexual abuse from the male residents because of their condition (severe intellectual disability)”.

With regards to Art. 25 and 26 on health and rehabilitation, the social care home did not provide health care services adequate to others. Also there were no specific services provided due to the residents’ disabilities, no interventions, and no disability tailored services. No informed consent was sought from the patients.

Health professionals were not well informed themselves about issues of human rights, dignity, autonomy and the needs of persons with disabilities within the social care home, and were thus unable to inform their clients accordingly. Also there were no rehabilitation services (except of a medical nature) that would maintain maximum independence and facilitate inclusion and the development of full physical, mental, social and vocational abilities. Patients were totally disempowered, and their individual needs were neglected. There were no employment possibilities and no education programs were provided for the residents.

At least some of the residents were forced to work without due remuneration, and some residents may be subject to forced labor and exploitation which constitutes a violation of Article 16 of the CRPD.

Article 28 of the CRPD recognizes the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions. The institution should take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability. The conditions in the Kryvyi Rih male social care home regarding food, clothing and housing were far from being satisfactory and thus violate this article in all respects.

V. Recommendations for change

V.a. Organizational issues

V.a.1. A change in management: as indicated in our report, the current management of the institution is incompetent, disinterested and abusive. As long as the current management stays in place, abuse will continue. It is also important that when the director is replaced, the current post holder is not allowed to continue in his current residence: it is located right next to the institution with an open gate leading to his land, facilitating the use of residents as forced labor.

V.a.2. Individual assessment of residents to determine if he or she can leave the institution by him/herself: Institutions base restrictions on incidents that may happen ('what if') rather than individualizing care. Most of the clients are fully able to go into the community with or without assistance, and stimulating this enhances the quality of their lives, improves the working conditions for staff and also has a de-stigmatizing effect: a society that does not see people with mental disability or chronic mental illness is not used to having them in their midst, one of the main causes for stigma in the first place.

V.a.3. Provide meaningful activities: instead of spending days in emptiness the residents should be activated as much as possible, e.g. by creating an as normal as possible daily routine of work and leisure activities and household duties. This implies the redevelopment of basic life skills, which for many of the residents will constitute a part of their preparation to reintegrate into society.

V.a.4. Maximize freedom of choice: clients should be provided with the ability to plan, organize and independently carry out their activities (life) in the social care homes according to their interests and needs. This requires fundamental changes in the functioning of social care homes with the rejection of total control and the strict regulation of the lives of clients.

V.b. Quality of life

V.b.1. Ensure privacy in all aspects of life: every individual has the right to privacy, either to meet personal needs (e.g. sexual) or just because a person should be able to be alone when he/she wishes to do so. Sanitary facilities should be adapted to provide more privacy. The current facilities are based on the desire for total control, which is therapeutically detrimental and seriously jeopardizes the clients' human dignity.

V.b.2. Ensure the right to Internet and means of communication without restrictions: there is no logical reason why residents should not be allowed to use internet and mobile phones. The main reason for limitation we heard was the fact that some clients call the police, who then attend when not needed. It is unacceptable that the behavior of some restricts access for all. Restrictions should be based on individualized assessments. Communication with the outside world is absolutely essential for integration and inclusion into society.

V.b.c. Abolish the system of total control and appreciate personal differences: Patronizing behavior from staff is debilitating and denigrating to the client. Clients should be treated as equal human beings with equal rights. People are different, with different needs, wishes, and peculiarities. Everything should be done to allow these differences to exist, thereby assuring the desired quality of life. Staff should receive training on human rights and the respectful, lawful treatment of the disabled. Institutions must review their practice and remove unnecessary blanket rules and degrading regimes.

V.b.d. Abolish mixed sex sleeping accommodation. Sleeping accommodation and dormitories must be single sex and housed in separate areas that are not accessible by the opposite sex. Each gender should have their own toilet and shower rooms and a separate lounge area. Residents should have opportunities to meet and form relationships with members of the opposite sex in a way that maintains safety. These should include joint therapeutic and rehabilitative activities.

V.c. Training

V.c.1. Improve nursing training: the training of nurses in Ukraine is insufficient, in particular when it comes to nursing people with mental illness or a mental disability. The training of nurses should be brought to a European level, and in daily work nurses should be given an equal voice in a multi-disciplinary team, with their own professional responsibilities and ability to make decisions. The training should especially focus on rehabilitation and providing recovery-focused care. Also on the professional level, paternalism should be brought to an end, as it hampers good functioning of staff and violates the professional dignity of staff members.

V.c.2. Improve and stimulate training of other professionals: there is a clear lack of well-trained professionals, and some professionals – rehabilitation experts, occupational therapists, social workers – are virtually absent in the system. All professionals working in the social care home system should be trained in psychiatric rehabilitation to support recovery. Also, all personnel should be educated in issues of human rights and the provisions of the UN Convention on the Rights of Persons with Disabilities, and Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. Also, family-members of those living in social care homes should be involved in such training, as they too lack adequate knowledge on the rights of their family members, and ways how they should be protected and defended.