

Assessment of the Svyatoshinsky social care home Kyiv, Ukraine



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I. Executive Summary

II. General Observations

- II.a. Introduction
- II.b. Systemic aspects
- II.c. Institutional aspects

III. Living Conditions

- III.a. structure of the social care home
 - III.a.1. The “Old building”
 - III.a.2. The “New building”
- III.b. Personnel and treatment
 - III.b.1. Staffing
 - III.b.2. Medical service
- III.c. Daily life in the institution
 - III.c.1. Physical environment
 - III.c.2. Food
 - III.c.3. Day-time activities
 - III.c.5. Finance
- III.d. Human Rights
 - III.d.1. Communication with the outside world
 - III.d.2. The use of isolation rooms
 - III.d.3. Complaint mechanism

IV. Conclusions

- IV.a. Individual level
 - IV.a.1. Use of pensions
 - IV.a.2. Informed decision making
- IV.b. Institutional level
- IV.c. Systemic level

V. Recommendations to the relevant authorities

- V.a. Individual Level
- V.b. Group Level
- V.c. Systemic Level

VI. Svyatoshinsky social care home and the CRPD

Annex 1: Personal stories

Annex 2: Recommendations from the CRPD Committee

I. Executive Summary

In January 2018, an international team of experts, representatives of the Office of the Ombudsman for Human Rights and supporting staff carried out a two-day assessment of the Svyatoshinsky social care home in the Ukrainian capital. The social care home is the largest in Ukraine, with some 700 residents.

During the first day of their assessment, the expert team managed to speak freely with members of staff and residents alike. On the second day however, they were often hampered in their communication with residents and it became impossible to have conversations in private. Still, over the two-day visit, the experts were able to obtain a comprehensive view of daily life in the institution.

The assessment exposed a large number of human rights violations. The life of residents is restricted in many ways, resulting in an almost “totalitarian society” in which the managers of the institution exert complete power over the freedom and lives of the residents. In the course of the past 21 years, only two residents have managed to leave the institution alive – the others have remained in the home until the end of their lives.

The way in which the institution is run and the way that the residents are looked after, particularly the restrictions placed on their daily lives is a violation of the United Nations Convention of the Rights of Persons with Disabilities (CRPD), a convention signed and ratified by Ukraine. A considerable number of residents seem to have been incarcerated for other than medical reasons and attempts by the few who dare to challenge the system and try to leave are thwarted by repressive methods exercised by the institution’s director.

Considering the above, the expert team recommends fundamental changes in the way that residents are cared for and the institution is managed. The necessary transformation to a contemporary and community-based service will of course, take time, but there are many steps that can be taken immediately to significantly increase the quality of life of the residents. Daytime activities, the ability to communicate unrestrictedly with the outside world and the possibility to leave the institution to participate in social activities– these are things that cost no more than an attitudinal change. There should be a fundamental shift from looking at disabilities to a focus on abilities. It can be questioned whether such changes can be achieved without a change in leadership.

In addition, the expert team recommends that an independent investigation takes place in to how the finances of residents are administered and used.

The current situation is unclear, resulting in many questions. None of the residents we spoke to had any idea about the size of their pensions or how much money they had in their accounts.

The system of guardianship is flawed and in need of reform, especially when the institution is the guardian of such a large number of its own residents, giving the managers of the home even more power over their clients.

As noted in the report, “In the case of the Svyatoshinsky social care home it is of particular distress that such an inhumane and huge institution is functioning in the capital of a country that is seeking to be an integral part of Europe, right under the eyes of the international community. Such an institution should not exist in a European capital.”

II. General Observations

II.a. Introduction

In *Ten Days in a Mad-House*¹, a first-hand account of life at Bellevue Hospital on Blackwell's Island, the author Nellie Bly notes: 'After many questions, fully as useless and senseless, the doctor left me and began to talk with the nurse. "Positively demented," he said. "I consider it a hopeless case"'. Bly, an American journalist, and in perfect mental health, was admitted to the asylum to do some undercover reporting on the conditions there. She observes: 'The insane asylum on Blackwell's Island is a human rat-trap. It is easy to get in, but once there it is impossible to get out'.

Bly wrote her account in 1887.

In January 2018 in the Svyatoshinsky social care home (officially called a psycho-neurological internat) in Kyiv, a mentally fit woman expressed similar despair and hopelessness in the presence of a doctor, because of her stay in the institute. The doctor, with an air of undisputable authority, disqualified her lament by saying we should not pay attention to her as, due to her illness, she is a pathological liar. After all, she had been a schizophrenic since the age of 10.

Many years have passed since 1887, but there are striking similarities between the Ukrainian social care home and the American asylum. On one side, powerless patients (or presumed patients) are no longer seen as human beings but reduced to incompetent, damaged objects beyond repair. On the other side stand the powerful medical staff, watching and mastering the residents from the broken tower that is the biomedical model of psychiatry.

Our assessment visit to the Svyatoshinsky social care home in Kyiv was carried out on January 25-26, 2018, under the auspices of the Office of the Ombudsman for Human Rights of the Verkhovna Rada, enabling us to have unlimited access to the institution. The team consisted of six foreign experts, five representatives of the Office of the Ombudsman for Human Rights of the Verkhovna Rada, two local associates of Global Initiative on Psychiatry and two interpreters.

During the first day of our visit we were able to go wherever we wanted and talk to any patient without the presence of a member of the staff. The second day the atmosphere had markedly changed, and it was our impression that the director and his staff had "re-grouped" and decided to go onto the offensive. Our team members were repeatedly cornered, hampered in their activity, conversations with residents were blocked or strictly supervised and the whole atmosphere had become much more unpleasant and aggressive.

¹ Bly, N. (2017) *Ten Days in A Mad-House*. Nouveau Classics San Bernadino USA

In a way, this helped us to get a better and probably more realistic view of life at the institution.

II.b. Systemic aspects

According to the Ministry of Social Policy of Ukraine, compared to 2013, the number of institutions for elderly and disabled patients has decreased. This is because of the military conflict, as a result of which 34 institutions now find themselves in occupied Crimea and Donbass.

As of 2016, the number of social care homes was as follows:

- Homes for the elderly and disabled – 66;
- Geriatric centers and centers for veterans of war and labor – 27;
- Special boarding homes for people released from prison – 3;
- **Psychoneurological internats – 145;**
- Orphanages – 49.

Most of the institutions are separate and care for either women or men.

The official position is that social care homes are socio-medical institutions, which are intended for the permanent residence of citizens with psycho-neurological disorders and who require medical assistance, supportive care and help in household duties. The main tasks of the institutions are to provide appropriate living conditions for mentally disabled citizens in need of care and assistance and to contribute to their social integration.

The clients of the social care homes should be provided with all of life's necessities:

- Housing, clothing, footwear, bedding, soft and firm equipment and tableware;
- Four meals a day, taking into account the age and health condition of the person concerned (intervals between meals should not be more than four hours, the last meal being two hours before bedtime);
- Around the clock medical care, including consulting care, fixed medical treatment and preventative medical care;
- Hearing devices, glasses, prosthetic and orthopedic products, dental prosthetics, special means of transportation (except motorized), drugs, according to medical diagnosis;
- Public utilities (heating, lighting, installation of radio, water, etc.);
- Organization of work therapy, cultural, recreational and sports activities in light of the age and health of those living in the institution;
- Conditions that promote the adaptation of mentally ill citizens to the new environment.

II.c. Institutional aspects

The Svyatshinsky social care home is the biggest social care home in Ukraine and can house 710 residents. On January 25, 2018, the institution

had 689 residents, the oldest being 92 (according to the director the oldest resident ever recorded at the institution was 108 years of age). The number of inmates is usually between 685 and 705. Admission can be from 18 years of age.

The goal of the institution is to “care” for and – absolutely, as the director says - not to treat or cure inmates. Medical treatment can only be provided by professionals working under the jurisdiction of the Ministry of Health. When treatment is necessary the inmates can go to a general or psychiatric hospital. The partner for mental health is the Pavlov Psychiatric Hospital in Kiev.

The Social Care Department of the City of Kiev, after a court order, indicates, with the help of medical records, what kind of facility is needed and to which of the institutes the “care consumer” will go. There are in total 9 social care institutes in the Kyiv Region: for youth (boys or girls), men, women, and elderly people.

The institute has to complete an annual assessment of all inmates. Only if their condition is considerably improved can an application be made for a court order for release. Over the past twenty years, **in only two cases** has a guardian successfully applied for the release of a resident.

Of the current 689 residents, 624 persons are declared as legally incapable, with 200 being under the guardianship of the director or the administration of the institution. The other 424 are under the guardianship of their family members.

The Svyatoshinsky social care home has a dozen units, and residents are divided over them according to their diagnoses and health condition. The home is located in the city, and is easily accessible with public transport. The institution itself is surrounded by a huge fence and wall, with metal gates and a guard post at the gate. No one can enter without the permission of the director. The residents are not allowed to go out from the territory.

One of the assessment team members spent the first morning talking with the director of the institution, Dr. A.B. Tynok. Clearly the unexpected visit by our large team had a surprising effect and it took the director some time to readjust. However, he gradually became more assertive and showed his rather cynical attitude towards both his residents and the work his institution was doing. During the conversation he confirmed the claim that “once you are in, you never get out” and added that as long as he had been there (more than twenty years) only two residents had succeeded in leaving the institution. His cynicism was further demonstrated when he confirmed that “there is no predictable or reliable mechanism to safeguard a person from forced

admission at random”.

Tynok confirmed during the conversation that it was quite possible to have nuisance making people or unwanted relatives removed from society by having them locked up in the institution and added that indeed a person could be given a diagnosis of, for instance schizophrenia, simply to legalize this internment.

During the meeting the director repeatedly showed his skepticism in relation to human rights. Every person, also a resident, is subject to the law and regulations of Ukraine and can claim his or her rights accordingly, Tynok agreed. However, as

soon as one is under guardianship, part of his or her rights are passed on to the guardian, and if someone disagrees with that he or she can appeal to the court. For that reason, Tynok asserted, the institute does not need written rules or regulations to protect rights that have already been protected by Ukraine legislation. For the same reason, he believed that the institute did not need specific house rules. Instead, decisions were based on common law, the only necessary written document is a schedule to regulate the order of the day. Furthermore, Tynok believed that establishing a mechanism for residents to complain was unnecessary, as the residents were free to do what they like within their ward or outside should they want to walk around. However, he added, even though the institution provided workshops for handicraft, most inmates did not make use of this facility. “Our system creates lazy people,” Tynok concluded.

III. Living Conditions

The Svyatoshinsky social care home is divided into two units, referred to at times as the “new” and the “old” building. Each unit has its own “medical center” where medical and nursing care is based and coordinated. This is also where physically or mentally unwell patients who require isolation are housed.

III.a. Structure of the social care home

III.a.1. The “Old building”

The old building purportedly is home to clients who need more support with their activities of daily living. It is also referred to as being for clients who are bed ridden, though only a small percentage of those living there were unable to walk – most were up and about when we visited. The old building consists of 4 wards in which we found 293 women incarcerated.’

On some wards, the stench of urine and feces was barely tolerable. Some beds were wet with urine. Residents were permitted to shower or bath every

5 days. The sole activity in every ward was one television in a small room, where only a small number of patients could sit. The staff decided what program was watched, residents were offered no choice. Many patients were crying, some were screaming. One patient was tied up because of self-harming behavior. The staff told us happily that all the patients had gotten candy for New Year's Eve.

Walls in the majority of rooms were covered with mold. There was only one accessible entrance for wheelchair users. None of the residents could lock their rooms; there was no privacy at all. In rooms for residents who were bedridden or had difficulty with walking, there were one or more mobile (chemical) toilets. However, there were no covers or curtains for privacy.

In the majority of rooms there are no shelves or lockers. As a result, residents keep their personal belongings (the little they have) in plastic bags in their beds. Only a few had some personal belongings.

According to the doctor on duty the residents on the ward had dementia, strokes and schizophrenia. The youngest client was 26 years old and was described as helpless and needing full care.

The rooms had no curtains. One ward housed noticeably younger women with less mobility problems. Their main problem was said to be incontinence. We asked why such young people were incontinent and the staff said either they had schizophrenia (a dubious link) or seemed to say that they had always been incontinent, having grown up in institutions and never learned continence. They were given pampers and escorted to toilets. The wards were noisy at times with patients shouting at each other without obtaining much response from staff.

There was a large dining room used by two of the wards. We asked about special diets were told these were catered for individually. The dining hall was overrun with large numbers of bugs on the floor.

The doctor said they would like to provide more recreational and cultural activities and education. Some concerts had been held in the unit, but there was no center for occupational therapy. As to communication with the outside world, staff said there is a phone in the medical unit that clients can use.

III.a.2. The "New building"

The new building very much differed from unit to unit. Units 5,6, 8 and 9 seemed to be for the most dependent residents. The rooms in units 5 and 6 had tables, shelves and lockers, and some of the residents had personal belongings.

On Level 3, we visited three wards. These were said to contain the most mentally unwell patients. “You will see what we mean,” the staff said as we entered. The doors to all the wards were locked. Ward 9 was noisy as we entered and we were mobbed by curious clients. They were all dressed in similar, thin floral dresses that were made and provided centrally.

Most rooms had three beds, one wardrobe and one desk, though some had no wardrobe. The windows had net curtains. The wards were warm. There was a small lounge area with a television and wooden benches. There were an adequate number of bathrooms. The toilet cubicles had no doors but we heard this was normal for public toilets such as schools and hospitals in Ukraine. The clients did not suffer visually from over medication or side effects of medication.

The women had no apparent personal belongings and there were no pictures on the walls. There were rugs on the walls. There was a row of towels on pegs in the bathroom, one for each woman.

III.b. Personnel and treatment

III.b.1. Staffing

Each ward at the institution had two sanitares (also called junior nurses, however without any professional training) and one nurse on duty, all being females. The sanitares worked 24 hour shifts, the qualified nurse 12 hour shifts. Nurses brought medication to the wards and during their visit checked the residents’ cleanliness, their skin, inspected their nails and throats and assessed whether they were agitated or not. Staff said that standards indicated they should have 40 nurses, but in reality they had only 12. There should be one orderly for every 5 residents, but there was actually only one per 30 residents. During nighttime, there was one nurse on duty in each building.

As far as Continuing Medical Education (CME) was concerned, conferences were held once a month, with separate sessions for different grades of staff. Topics included first aid and acute conditions.² Staff had not been given training or written information on the rights of persons with mental disabilities. They are not familiar with international human rights standards, including the CRPD.

² Sometimes staff members upgrade their qualifications at their own expense. However, as the solvency of the personnel is quite limited, not all of the workers have such an opportunity. As a result, a considerable number of doctors and nurses do not reconfirm their certifications, or do not upgrade their qualification category.

III.b.2. Medical service

The institution had three psychiatrists, one- therapist, one – stomatologist and one gynecologist, and in addition a 0,25 position for a surgeon.

Social care homes are not licensed by the State Committee of Ukraine for Drug Control for purchasing, storing, transporting, destroying, and utilizing narcotic drugs, psychotropic substances, and precursors. Whilst some of the clients in the old building did appear to require more support than many in the new building, for some the placement seemed more arbitrary. Individual doctors in the two buildings gave different accounts of prescribing practice in their unit. A recently employed doctor in the new building said that clients were prescribed old neuroleptics and that she would like to change patients to newer atypical medications. At the same time, a doctor in the old building said many clients in that building were on the new anti-psychotics. We did not see prescription charts to verify either view.

An external consultant psychiatrist (from the Pavlov Psychiatric Hospital) was said to visit once a week and he could prescribe medication. The in-house psychiatrist does not have the power to prescribe and can only follow prescriptions from the visiting psychiatrists. In-house staff can only oversee what the Pavlov Psychiatric Hospital have prescribed, and the in-house psychiatrist is not legally able to change the prescription.

The senior nurse oversees the medications. As we noticed, some medications in the cupboard had been brought in by guardians or relatives and had patient names written on them in pen. We saw stocks of older medication such as aminazine and haloperidol. 20 clients were said to be on regular IM medication. We asked about consent and staff said that clients have the right to refuse.

III.c. Daily life in the institution

III.c.1. Physical environment

Both in the old and new buildings there are 3-5 beds in each room. Rooms are warmer or colder depending on the side of the building. The size of the living/sleeping quarters were said to be in accordance with national standards. None of the rooms, nor the sanitary facilities, offered any privacy.

Some rooms were quite cold (around 15-17 C). During our visit, we noticed that some ladies were lying in their beds, cold with just one blanket. There were no sweaters, only dresses. When we asked to bring them something warmer, staff brought another cotton dress, but no sweater. Some residents were lying with a light coat on.

We also noticed that there were fewer winter coats than residents (all being identical, marked), and they were obviously not for all the ladies living in the building. There were even less winter boots. It was safe to conclude that not all residents go out during the winter time.

All the linen and bedding was marked per person/per room.

III.c.2. Food

In the old building meals were provided in some of the rooms, other residents made use of the dining hall located between two wards. In the new building there was a canteen that could serve 300 residents (in three shifts). Breakfast starts with the first shift at 7 in the morning. Lunch is followed by an obligatory period of “quiet time”, when residents are supposed to lie in bed and either sleep or do nothing.

No safe drinking water was provided freely. Some residents had their own plastic half liter bottles, which they explained as their personal property and used to take the water from the taps to drink. In the new building there was water only in one room (the staff’s room), and everybody had to go to this room for water. During the first half of the visit there were no cups seen to be used. Later staff showed us how they provide water in public spaces with individual cups available.

Only the more active residents have their own dishes (cups) in their rooms. There are refrigerators available in the units within the new building. However, they are located in the staff’s room, and are only available with the permission of staff (residents have to ask to put in or take things out of the fridge).

III.c.3. Day-time activities

The facility does not in any way provide a welcoming, comfortable, stimulating environment conducive to active participation and interaction. There are no conditions that allow residents to enjoy a social and personal life. To the contrary, they are totally isolated from the community and locked up in an institution that looks at best at them as patients, and not as persons with abilities, wishes and human rights.

There is only one television area available in each unit, the space is not big enough, and in some units there are only 4-5 benches for sitting. There are no other communal spaces on the wards available for activities. No means are provided for joint activities. Instead there was an obligatory “quiet time” (from 2 to 4 pm), when all the residents were ordered to go to their rooms to sleep or just to stay there.

In the old building there are no regularly scheduled, organized activities. Even though there are 4 rehabilitation specialists employed at the social care home, none of them visit the old building. As a staff member said, “there is no point for them to come since there are no residents able to do any activities”.

The “Occupational Therapy Unit” in the new building has three workshops, staff said it was used all day, but when we were there, at one time there were three residents and later only one. The excuse was that two instructors were allegedly both on vacation (Patients also said this and did name the staff who were on vacation so it appeared true). It is the doctor who decides who can use the occupational therapy area. Staff said that in summer, more activities take place in the yard.

We also saw an auditorium with a screen for projections. The medical director said they do groups there and there is a weekly film. They once held a beauty contest. There was a tuned piano on the stage. There was a safe in the room, which was said to also act as a ballot box; the medical director said those who are capable may vote in national elections.

There was no evidence of comprehensive individual rehabilitation or care plans.

Rehab and skills or educational targets are totally neglected. There was nothing that would show any resident involvement and participation in the planning of their care.

III.c.5. Finance

Of the disability pensions, 75% covers the costs of the institute: staff salaries, food, maintenance of the buildings, costs of (medical) care. The remaining 25% percent is given to the resident, or in cases of legal incapacity, to the legal guardian. For those whom the institution and its director is the guardian, the funds are put in a bank account on behalf of every individual resident. A Guardianship Committee (or “board of trustees”) supervises the management and use of this money. When an inmate wishes to make use of her money the resident, or a member of staff in her name, needs to apply for use of the pension, providing the reason and the costs involved. For those whom the director is the guardian, he judges the necessity of the desired purchase. The application is then, with the director’s advice, forwarded to the Guardianship Committee to decide.

However, this Guardianship Committee is not independent. It consists of staff-members, a member of the institute’s administration as well as of administrations of other institutes and is presided over by the deputy head of the relevant social care administration (in this case Kyiv municipality). The di-

rector objects that none of these members have any knowledge of “patients”, as he calls the residents.

As a result, residents have no allowance, not even a small one, and there is actually no opportunity to spend it, as there is no shop or kiosk on the site. Sometimes family visitors bring cigarettes or candy; sometimes a staff-member shares a cigarette. But smoking is not encouraged, as the director said during his meeting with one of our team members “it is killing, just like jumping out of the window. Some want nicotine, some want to jump out of the window. Everyone has certain wishes, which is no reason to meet them all.”

III.d. Human Rights

It became quickly clear to the assessment team that the residents have their human rights severely limited. The home is a closed institution, from which hardly anybody ever leaves, with residents who are purposely frightened about the world outside (being told “there are drug addicts, you can be raped or molested”, etc.) and thus they very rarely leave the institution, if ever. Some residents are permitted to go on vacation, for which they must be picked up by their guardian. During our visit 6 residents were outside on vacation.

On the inside of the institution residents also see their movement severely restricted, with doors to wards being locked and only being allowed for a walk in the courtyard for one hour a day. The institution has no specific place for religious practice. According to the staff, the priest visits once a month and mass is provided in the public hall. In the corridor, outside the closed unit, residents can smoke (or in the toilets). But smoking is only possible when staff light the cigarettes, as residents are not allowed to have lighters or matches.

Needless to say, the rights of residents to participate in political and public life and to exercise freedom of association is fully neglected. We could not escape the very depressing feeling that we were looking at nothing else but a concentration camp with no therapeutic or rehabilitation-related value.

III.d.1. Communication with the outside world

Only one mobile phone was observed in the old building. It was given to a lady, whose given name day was on the day of our visit: she was given the opportunity to call someone. Otherwise there were no mobile phones allowed.

In the new building, a few residents had possession of a mobile phone. One

of the residents we spoke to was a 23-year old girl who had been in the institution for two years and who had used a mobile phone to communicate with the outside world that she wanted to see her legal capacity restored and leave the institution. Because of this, her mobile phone had been removed, she had been held incommunicado for many months and was now on medication. When we informed the director that we would provide this resident with a mobile phone so she could exercise her right to communicate with the outside world, the director did not object. However, when after our visit the phone was delivered by the resident's lawyer, the director refused permission to hand the phone over. One other resident who communicated with us during our visit and continued to do so after our visit as she had access to a mobile phone, was punished by having the electric socket in her room disconnected, thus making it much harder for her to charge the battery of her phone.

The residents can receive visitors, but in the old building there is no specific place for receiving them. Instead, there were a few tables with chairs in the corridors, outside the closed units. The visiting times are indicated in the rules. The visiting times are Wednesday, Saturday and Sunday from 10 to 17. In the new building there is a room for visitors. There are a few tables in the room and a separate toilet. There is a registry for visitors. Staff said the visiting room was used by up to 50 people daily, but the register did not have anywhere near this number of recorded visitors.

III.d.2. The use of isolation rooms

During his meeting with one of our team members, the director stated in relation to aggression or violence the institution had no legal means to hold or to restrict people. That meant that in case of an uncontrollable situation, the staff would call the psychiatric hospital for consultation or for a temporary transfer. However, he asserted, the staff are trained to deal with aggression.

The institution does however have an isolation area consisting of two rooms with separate bathrooms. During the visit there were 2 persons kept in separate rooms in isolator. One lady was, according to the doctor, very agitated and aggressive. Another lady was sitting on her bed, she was very lightly dressed, although it was cold in the room, and the small window was opened.

The rooms had no window panel in the doors so staff who sat outside could not see what the client is doing, which is unsafe. The observing nurse was wearing a face mask. The rooms had no curtains and there appeared nothing to do. We saw the aggressive and agitated lady who was said to be in isolation after removing another patient's eye out in the delusion that she was an eye surgeon. She had been referred to but refused by the Pavlov Psychiatric

Hospital. Staff said there had been a judgement of constitutional court to allow the isolation. The client has a guardian, her mother. They had tried to reintroduce her to the wards but this had failed.

In the nurses' room, we saw the records of the lady in isolation, which contained legal documents and a few pages of handwritten notes. She had been in the Pavlov Psychiatric Hospital in 2014 and 2015, and twice in 2016. (I suspected this may have prompted their subsequent refusal to take her back.) She was prescribed Haloperidol IM twice daily.

There was no separate register on the use of isolation (recording why it was used, when and how often monitored).

III.d.3. Complaint mechanism

We found no evidence of a systematic use of de-escalation methods and no evidence of cooperating with residents. Safeguards are not in place to prevent torture or cruel, inhuman or degrading treatment and other forms of ill-treatment and abuse.

During the visit one of the residents had her hands tied behind her back. Staff said that it was because she herself and her guardian asked for this, since otherwise she would self harm.

Residents have no access to legal representation. There is no information available on rules or rights. When asked if there was a complaints procedure, staff said that guardians can complain on behalf of patients.

IV. Conclusions

IV.a. Individual level

IV.a.1. Use of pensions

Most of the residents are under guardianship (either of the director or a family member as guardian). This means that they are severely limited in their rights. Even residents who are not declared as legally incapable do not have any decision-making powers.

There are very few persons who have been given the opportunity to go outside the social care home. Others, even those who are legally capable, do not have this right.

Most residents do not receive their pension (money) and have no idea how large their pension is and how much they have in their “account”. In the case of residents who are under guardianship of a family member, the pension is received by the relevant family member, who often withholds information about the size of the pension. It is then up to this family member to decide whether they bring money to their relative under guardianship. Other residents who are under the guardianship of the social care home and its director see their money transferred to a bank account managed by the institution. These funds are almost inaccessible. These funds can only be used after agreement from the Guardianship Commission. e.g. for the purchase of needed medication (if prescribed by the doctor). Other personal wishes are not often followed.

Residents should have the right to spend their pension funds as they choose, unless the resident is not capable to do so. Then the guardian should be an advisor. The guardian, or the Guardianship Commission, that looks after the funds should be fully independent. That means that employees of the institute or of the department of Social Care should not be on the board.

IV.a.2. Informed decision making

There are no procedures and safeguards are not in place to prevent detention and treatment without free and informed consent. ***All the decisions are made by doctors.***

Staff interaction with residents is very much paternalistic, power-based, and there is very limited recognition of the ability of residents to make decisions and choices. In discussing residents, staff members constantly used degrad-

ing references such residents being "bredovaja" (delusional), or being a slozhnij sluchai" (difficult case), or "gluboko defektivnyje" (deeply disturbed). One doctor asked a resident to come closer to show us what a difficult and severe cases she had in her unit.

None of the residents seemed to have any information about their diagnosis, their treatment, their personal situation, and the size of their pension. There was no evidence of opinions or comments by residents in their medical files.

There are no procedures and rules provided for any of the interventions (which was confirmed by the director in his conversation with one of our team members, as he considered such rules to be unnecessary).

There is only one registry – a notebook used to register all the events during the shift. There was no separate registry for emergencies or incidents. Residents rights were violated at every level, and rules and regulations were not to be found.

IV.b. Institutional level

The director of the social care home was initially clearly disturbed by our visit. However, that did not last long. Soon he became hostile and uncooperative. At our final meeting he said that he just wanted more staff and more resources without explaining how the residents would benefit from that. He is clearly a man without any vision and little concern to the well-being of his clients, wanting only to maintain a calm workplace. We had the impression that the chief doctor was caring but did not seem to have much influence over the way the institution was run.

Perhaps as a result of the lack of staff, the inactivity among the residents was appalling. Although we have seen a workshop center in the main building, we met with the reality of hardly any participation in activities. In addition, some of the few activities we encountered had more resemblance to production, for instance the production of camouflage nets, without any payment to the residents concerned.

We encountered major legal gaps. To name a few of the most striking ones:

- There is no register of incidents. There is no registration of any emergencies, such as cases of acute behavior, conflict, injuries, etc. All the information is entered on a general staff notebook which is handed over from shift to shift. There is no registry for the use of restraint or seclusion.
- There are no rules and procedures on the use of the personal finances

of residents. There is a registry of legally capable residents, who agree to give their money to their social workers. Then they can ask the social worker to buy them various products. There were only 17-19 recorded in a register who gave their finances to the administration. All the receipts are kept, and there is a registry of those expenses. It is problematic that social workers, after purchasing products for residents, give them to the staff of their unit. There is then no formal procedure as to demonstrate that the products are given to residents.

- There seem to be a very low number of residents in the registry. According to testimonies, however, all residents from 1 unit give their money to the administration. It is unclear how much money (in cash) in total is kept in the administration, and in general there are no rules for maintaining financial records.
- The Administration is not following the requirements of the law in that residents should be referred and accommodated in the social care home and in particular units of the social care home that correspond with their independence status and health conditions.
- Also, the social care home is not following legal requirements for signing individual contracts with residents (or their guardians), to describe what services are provided for residents, the conditions under which they are treated and cared for.
- There are no legal reviews of incapacity and guardianship cases. Also there is no control over the guardians, even in cases when there is possible abuse and violations of the rights and interests of persons under the guardianship.
- There are no rules and regulations for specific procedures in the social care home. There are only general statutes of the social care home. No rights and rules are provided in writing to residents.
- There is no mechanism for complaints in cases of rights violations and no appeal mechanisms against decisions made by the administration.
- There are no clear regulations on the administration's decision-making criteria for the use of personal money. There are no regulations in place for the disposal of personal money after the death of persons being declared as legally incapable.

IV.c. Systemic level

The analysis presented in the *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (2017)*³ summarizes adequately the fundamental shortcomings of the system of social care homes. The report puts the finger on the sore spots of mental health practices and concludes that the history of mental health care is marked by an endless series of rights violations performed in the name of (reductionist biomedical) psychiatry. This obsolete model, of which many of its basic concepts are not supported by scientific research, has contributed to: 'The exclusion, neglect, coercion and abuse of people with intellectual, cognitive and psychosocial disabilities, persons with autism and those who deviate from prevailing cultural, social and political norms' (2017)⁴.

The report also notes that the decision-making power is concentrated in the hands of these biomedical gatekeepers and that their overwhelming monopoly prevents contemporary humanistic services of mental health care to flourish. This fundamental power imbalance, often based on laws that compel the mental health professionals to take coercive action, reinforces paternalism and violations of human rights of service users and erodes their right to make decisions about their own health and life.

It would be too easy to put the blame with regard to the embarrassing shortcomings on the medical staff alone. They have been exposed for many years to officially authorized rhetoric beyond reproach and discussion, about the 'true' nature of human suffering. That is, endlessly repeated mantras that the origin of madness can be found in biological substrates in the human body that eventually lead to a substandard existence that has to be controlled by experts. This undisputed truth legitimizes the actions of the isolated medical professionals and their extended arms, the unprepared nurses and auxiliaries on the ward, who are ignorant of contemporary knowledge about mental health care and not trained in critical skills. To a certain extent they are also trapped in the human rat-trap and in order to cope with their daily stress they seek shelter in the status provided by the biomedical model and its accompanying vocabulary.

The rhetoric not only leads to a vulnerable position of professionals and service users – an inappropriate term in this context since it falsely suggests the position of a consumer who can choose from a plethora of possibilities. It often results in a process of self-stigmatization which occurs when residents of

³ Human Rights Council. (2017) *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*. United Nations New York USA

⁴ Idem ii

the social care home internalize public attitudes and the diagnostic approach of medical staff. Residents then suffer negative consequences, such as the worsening of the cause of their affliction because of the harm of the internalized experience *per se*. Staff that are pessimistic about the possibilities and capacities of the residents feed self-stigmatization that undermines feelings of self-worth and the hope that personal goals can be achieved.

Some residents refuse to resign to this process of negative labelling and continue to express their individuality. Unfortunately these signs of a rebellious but clear mind are seen as symptoms of the underlying pathology, whereas in reality the so-called symptoms are not expressions of problems but in fact an answer to the problems and difficulties. Symptoms are not a sign of madness, but a coping strategy, a continuous dynamic restructuring of reality in order to survive. Patients who struggle to keep their 'persona' alive find themselves in a reversed version of the infamous *Catch 22* from Joseph Heller's homonymous novel. The protagonist in Heller's book, fighter pilot Yossarian, wants in vain to escape combat by pretending to be insane but his commanders interpret his desire to get out of the war as a sign of perfect sanity.

The system, in this case the Government, should create or sharpen legislation concerning psycho-neurological institutes. They must open-up this stifling system of confinement of people without fault or crime.

Staff of the institute seem to accept the system as a matter of course. They say the inmates cannot be released because they have no place to go outside the institute and are not able to take care of themselves.

What the system requires is a chain of facilities that offer and take the inmates by the hand to gradually restore their relationship with society. It should be mentioned, that Ukraine has been reviewed by the CRPD Committee in 2015. The Committee has issued Concluding observations on the initial report of Ukraine on the 2 October 2015. The Committee raised in particular concerns with regard to issues related to the institutionalization of people, especially people with intellectual and psychosocial disabilities. The Committee also indicated the need of provision of support to families, in order for children with disabilities to be guaranteed the right to grow up in a family environment (for more information see appendix 2).

V. Recommendations to the relevant authorities

In December 2016, the foundation “Human Rights in Mental Health-FGIP” carried out an assessment of four social care homes in Ukraine, two in the Eastern part of the country, two in the West. The final report was published in March 2017, and in this report the first and foremost recommendation to the Ukrainian authorities was to take the fundamental decision to abandon the system of institutional social care. In the view of the assessment team, many of which members also participated in the current assessment of the Svyatoshinsky social care home, it was high time to fundamentally alter the system and provide vulnerable Ukrainian citizens with a system of care and services that respects their human dignity, individuality, strengthens their self-reliance and participation in the community to which they belong.

The March 2017 report also pointed out that abandoning the system of institutional social care meant that there should be a transformation period (quite a long one) during which a diverse and consecutive chain of community-based services should be developed with a person-centered approach. During this period two systems will exist in parallel. Because some of the clients in the social care homes are institutionalized to such an extent that reintegrating them into society is no longer feasible, life inside should be improved considerably and individuality should be returned.

In the case of the Svyatoshinsky social care home, the situation is no different. During our assessment we met a considerable number of women who should never have been incarcerated in this institution in the first place and who could easily live outside in the community. Even the staff (including the director) admitted that some of the diagnosis were in fact fake and only used to give a legal rubber stamp to the hospitalization. However, those residents who wished to leave the institution were discouraged to do so, sometimes by further restricting their means of communication with the outside world and even through forms of punishment, while the residents were discouraged to even think about expressing such a wish by false stories of “drug addicts, molesters and rapists” who would be waiting for them outside.

Many of the members of staff have become just as institutionalized as the residents, and some might no longer be able to change their way of working. However, it was our clear impression that much of the repressive atmosphere in the institution was caused by the director. A first and essential step would be removing him from his position and replacing him with a young, new and trained director who understands his task is not to lock up persons for the rest of their lives but to try to do his or her utmost to assist residents to return to society or at a minimum lead a full and meaningful life within the institution. The assessment team does not see any way in which the current director could be retained.

Some of the staff will not be able to change their way of working. However, by introducing newly trained younger professionals, a lot can be done and older “institutionalized” staff can function quite well when a new management with a new vision is in place.

The following recommendations are practical and easily implementable, and in our view there is no logical reason why they could not be implemented. We have taken the current economic and political situation in Ukraine into account. However, there are countries that are much poorer than Ukraine, or that also find themselves in complex political situations, that provide much better care to vulnerable groups. **The political and economic situation can never be a reason not to return human dignity to the citizens of the country.** In the case of Svyatoshinsky social care home it is of particular distress that such an inhumane and huge institution is functioning in the capital of a country that is seeking to be an integral part of Europe, right under the eyes of the international community. Such an institution should not exist in a European capital.

V.a. Individual Level

- **Maximize freedom of choice:** residents 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 the social care home, the rejection of total control and strict regulation of the lives of clients during the day.
- **Provide meaningful activities:** instead of spending days in emptiness the residents should be as active as possible, e.g. by creating as normal as possible daily routine with household duties etc. This implies the redevelopment of basic life skills, which for at least some of the residents will also be part of their preparation to reintegrate into society.
- **Assessment of residents' needs:** in our view, a multi-disciplinary team of mental health professionals should review all cases. We have serious doubts about some of the diagnoses and feel that a review of cases would very much help to develop individual treatment and activity plans. We would not be surprised if many of the diagnoses of schizophrenia would not stand during such a revision.
- **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.

- **Ensure the right to the Internet and means of communication without restrictions:** there is no logical reason why residents should not be allowed to use the internet and mobile phones. It is unacceptable that access to a mobile phone is used as a means of punishment or reward. Communication with the outside world is absolutely essential for integration and inclusion into society.
- **Individual assessment of a person to determine if he or she can leave the institution by him/herself:** also in this case restrictions are imposed based on the idea “what if...” and enforced with false stories about the dangers outside. Many of the residents 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.
- **Facilitate training to regain autonomy:** it is crucial that for clients a program of rehabilitation and resocialization is started. On the basis of an individual assessment for each client an individual rehabilitation program should be developed, either to prepare the client for return into society or to maximize the individual's autonomy within or under supervision of the institution.
- **Regular assessment of possibility of developing skills:** a mechanism should be developed to monitor progress of each individual client and when possible add training programs to improve or sophisticate skills.
- **Review all the cases of all incapacitated clients and clients with limited capacity** in order to start the process of restoring their fundamental rights.

V.b. Group Level

- **Establish client counsels (self-governance) and a Personal Ombudsman system:** clients should be involved in the management of the institution. In order to facilitate this, a “resident council” should be set up as a representative body of the residents that negotiates with the institution management. A personal ombudsman in the institution should mediate between a resident with a complaint and the institution management,

and by definition take the side of the resident as his/her spokesperson. A model that could be used is the Swedish Personal Ombudsman system.⁵

- **End group rules and regulations:** the residents should cease to be treated as a group but be treated as individuals with individual needs and wishes and with full respect for a person's human dignity. Individualization of care should be key. Residents should also know their rights, and they should be made available throughout the building and explained to those who cannot read or need help to understand them.
- **Abolish the system of total control:** however well intentioned, patronizing is debilitating and often denigrating to the resident. Residents should be treated as equal human beings with equal rights. Patronizing behavior should be combatted with all means and at all levels.
- **End parental attitudes to adult residents:** equal to the above, treating adult residents as children who cannot decide for themselves or have no voice of their own is a fundamental "no go". How often did we hear from the staff "don't listen to him, he is mentally ill, you can't believe him"? Also a person with mental illness knows what he or she wants, is able to voice his or her views and even though the message might come across garbled there is always a basis of truth to a resident's complaint or voiced desire.

V.c. Systemic Level

- **Regular evaluations of guardians and custodians.** The system of guardianship is fundamentally debilitating and paternalistic, and prone to misuse. As a first step towards ending the system of guardianship, as is required by the CRPD, all cases of guardianship should be reviewed and subsequently be subject to regular reviews. At the same time, a system of supported decision-making should be introduced. Svyatoshinsky social care home could be designated as a pilot project to introduce a person-centered approach in empowering and supporting persons in their decision making, in accommodating and meeting their wishes and individual choices, and foster respect of those by all the others. However, it is highly questionable whether that would be possible with the current leadership.
- **Upgrade nursing training:** the training of nurses in Ukraine is insufficient, in particular when it comes to nursing for persons with mental ill-

⁵ see <http://po-skane.org/in-foreign-languages/>

ness or mental disability. The training of (mental health) 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.

- **Upgrade 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 Svyatoshinsky social care should be trained in psychiatric rehabilitation to support recovery. Also, they 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. In addition, family-members of those living in the social care home 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 promoted, protected and defended.
- **Develop community based services responding to individual needs:** it would be important to develop a plan that includes the closing of the front door of the Svyatoshinsky social care home and simultaneously develop the system of community-based services. These should be focused on keeping individuals in the community and provide tailor-made services to support independent living. In extreme cases supported living should be made available (see the next point). Svyatoshinsky could become an example of how this transition could be achieved. It is important to allow sufficient time to implement this process with care and without haste to avoid complications or mistakes that could have a negative effect on the reputation of the program or jeopardize it altogether.
- **Develop affordable housing for persons who can live independently:** a variety of living environments should be developed, ranging from individual housing with mobile care programs assisting the person concerned where needed, to protected living environments where residents live as independently as possible in small groups (preferably mixed male and female).
- **Put mechanisms in place for family support:** in most cases, except when a family has been the cause for institutionalization (e.g. a parent or spouse put away because of being “too bothersome”), the family is a crucial resource of support for a person with mental illness or mental dis-

ability. Caring for a family member requires certain skills, that can easily be taught, and there should be the possibility of taking a break when the pressure is too big on a family. For the latter a sort of buddy system/ respite care could be developed allowing a family to go on holiday knowing full well that somebody else will take care of their relative in the mean time.

In addition, family members should be stimulated to join family councils, which would be consulted on a regular basis on issues regarding life in the institutions, thereby strengthening outside control, family involvement in the well-being of their relatives and links between clients and their families.

- **Appreciate personal differences:** “unification” is a well-meant violence to individual differences. 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.

VI. Svyatoshinsky social care home and the CRPD

The monitoring visit to Svyatoshinsky social care home revealed not only prolonged and extremely harmful practices, but also grave violations of the human rights of residents.

Since Ukraine has ratified the UN Convention on the Rights of Persons with Disabilities (CRPD, it must meet its requirements with regards to the rights of people with disabilities. The main articles of CRPD that are violated either directly by the Svyatoshinsky social care home, or through systematic violations within the social care system can be indicated: articles 5, 12, 14, 15, 16, 19, 25, 26 and art. 28.

Article 5

Art. 5 of the CRPD regarding 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. Residents in social care home are discriminated against on the basis of their disability and are denied equal and effective legal protection against discrimination. Patients being referred to social care homes are already discriminated against because such a referral is discriminatory in its nature. We have heard of few cases where patients are able to challenge their need to live in an institution.

Article 12

Equal recognition before the law (art. 12) requires that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life, providing them with access to the support they may require in exercising

their legal capacity. Safeguards should be put in place to ensure that measures relating to the exercise of legal capacity **respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances**, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.

The guardianship system in its essence is contradictory to the CRPD art. 12 requirements. With regards to persons being declared as legally incapable they lose these rights and cannot exercise their legal capacity, even with regard to very basic daily decisions. All decisions are taken over and there is no respect for the individual and their preferences. Even more, with respect to Svyatoshinsky social care home, as the administration is the guardian for a large number of its residents, this creates a conflict of interests, as well as undue influence on all the areas of life decisions. There is no system for a regular review of clients' needs, since only the guardian or controlling institutions can initiate the review procedure.

Service users' preferences are not the priority in decisions on what treatments they receive or activities they would like.

Article 14

Liberty and security of the person (art. 14) require that persons with disabilities are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

Living in the social care home and not being able to leave it is a deprivation of liberty. Due to their disability, persons are referred to the institution with only the input of their guardian, in the majority of cases against their personal wishes.

There is no procedures in place for people to appeal their treatment or detention within the facility. No legal representation is provided, in fact the administration prevents residents from meeting and speaking to their legal advisor (if they have one). There is no evidence of any legal support being offered from outside the institution.

Article 15

Freedom from torture or cruel, inhuman or degrading treatment or punishment: no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

From the institution's practice, service users may be subjected to seclusion or restraint, in an isolation room. There are no less restrictive alternatives used in consultation with the service user concerned, in order to identify the triggers and factors he or she find helpful in diffusing crises and to determine the preferred methods of intervention when a crisis occurs. There is not a clear process to record the use of isolation and no possibility to appeal.

Such “treatment” or “care” leads to degrading or ill-treatment t, and thus clearly violates art. 15.

Article 16

Art. 16 indicates that there needs to be in place 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. Countries should ensure that all facilities and programs designed to serve persons with disabilities are effectively monitored by independent authorities.

There must be very clear mechanisms for monitoring institutions, with legal support for persons in case of violence and abuse. No such mechanisms indicate that there is non-compliance with art. 16.

Article 19

Living independently and being included in the community (art. 19) recognizes the equal right of all persons with disabilities to live in the community, with choices equal to others. Countries shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that: Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement; Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

Being admitted into an institution such as the Svyatoshinsky social care home is a violation of art. 19, since there are no community services available to persons to meet their support needs. Also they do not have any choice about where and with whom they live, they are obliged to live in a particular 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 in 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.

Article 25

Health (art. 25) indicate that persons with disabilities should be provided with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs. Also, there should be provided health services needed by persons with disabilities specifically because of their disabilities, including early identification and in-

tervention as appropriate, and services designed to minimize and prevent further disabilities.

Health services should be provided as close as possible to people's own communities.

Health professionals must provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training.

Considering the requirements of CRPD art. 25, Svyatoshinsky social care home does not provide an adequate level of health care services. Also there were no specific services provided specifically due to a type of disability, no interventions and no disability tailored services. No informed consent is sought from the patients. Health professionals are not well informed and able to raise the awareness of their patients about their human rights, dignity and autonomy.

Article 26

Habilitation and rehabilitation (art. 26) establish 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**. Shall organize, strengthen and extend comprehensive habilitation and 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.

In the Svyatoshinsky social care home it was apparent that there are no rehabilitation services (except medical ones) that maximize independence and physical, mental, social and vocational abilities, with the full inclusion and participation of the patients. Patients were totally disempowered, their individual needs were totally neglected. There were no vocational or educational programs provided for patients. Patients' skills (even the ones they had prior to coming to social care home) were disappearing while they live in the institution.

Article 28

Adequate standard of living and social protection (Art 28) recognize 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, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

Conditions in Svyatoshinsky social care home in terms of food, clothing and housing were far from being satisfactory and thus violate art. 28.

Annex 1

Personal stories

Client 1 is a 40 years old lady who lives for 10 years in the social care home. She lives in a small, clean room, that she shares with a roommate she has not chosen herself. She makes a faded, tired impression. She tells us she was brought to the social care home because of mood swings and loss of memory. She now suffers from infections and describes her health as bad. Her days are long and empty and constantly follow the same, boring routine. Early rise, some cleaning, food, mandatory rest as if they are toddlers and twice a week an hour in the yard of the fenced social care home. There is hardly an opportunity to leave the institute. All patients are being told that the outside world is extremely dangerous full of rapists and drug addicts who are out on their honor and money so they are kept behind closed doors for their own security. Many of the patients seems to have internalized this fear and therefore prefer to stay inside. There is no possibility for client 1 to escape from this rigid block treatment, no individuality is allowed and no possibility to exercise her hobbies, playing the piano and singing. She's convinced that, should she have the opportunity, she could have a job, for instance in a sewing studio. The quality of life often lies in small things. She likes reading, but her glasses are broken and although she asked the staff for replacement, but so far to no avail. The antenna from her small television set is broken but no one is able to repair it. She longs for more attention and affection from the staff. If residents don't comply to the rules and regulations they are sometimes threatened with the use of straightjackets or tying to a bed. According to the psychiatrists they are not allowed to apply such means.

Client 2 is approximately 35 years of age. She's limited in her expression, probably because of intellectual disability. Her aunt has arranged for the admission to the social care home, but her only wish is to go back home. Like all other residents Sonja is subjected to the rigid block treatment.

Client 3 has been in the social care home since 2011 although she has no medical condition. She's 38 years of age and was left by her mother in the institute. She owned an apartment which is now probably in the hands of her relatives. She works on average twenty hours per week in the social care home, sewing. She does not receive money for her labor. One of her sisters is her guardian and manages her benefit. She doesn't know on how much money she's entitled to. She complains about the food, it's tasteless and little varied.

Client 4, 40 years old. She was transferred from an orphanage to the social care home at the age of 18. She makes the impression of being a normally gifted person who has to spent her days between fellow 'patients' many of

whom have intellectual disabilities. Her telephone is broken and is not replaced.

Client 5, 32 years old. To keep sane she stays as much as possible away from the other residents and staff. Everybody here lives on an island, every woman for herself. I assume, she says, that the vast majority of people living here is lonely. She's prescribed medication (*note editor: prescription is for a drug for epilepsy although the doctor claims she suffers from schizophrenia*) but has no idea why. She suffers from side-effects such as a feeling of weakness, drowsiness and sometimes she becomes agitated. Contact with staff is characterized as mutual avoiding of face to face relations, everyone retires to their own domain which makes it possible for the staff to objectify the other person.

Client 6 is an educated woman of 42. She studied at university level and ended up in the social care home via a mental hospital. She was hospitalized because as the result of an abusive husband she started to drink. She feels very lonely and during her stay in the social care home she gradually accepted her situation and is silted up in a situation of learned helplessness. The doctor told her she suffers from a form of "depressive schizophrenia" but did not explain what this is about. According to client 6 people in the social care home easily accept their diagnosis without asking questions and doctors nor nurses give any form of psychoeducation whatsoever. She experiences side effects from the medication. Prescriptions are hardly re-evaluated over the years. She sees no future, but if there is an opportunity she thinks with support she'll manage to live outside the social care home.

Client 7, 57 years old. She likes it in the social care home. After her mother died she was via the Pavlov psychiatric hospital transferred to the social care home, she can't remember how long ago this happened. The marriage of her parents was bad. Her stepfather was an evil man who stabbed her mother and tried to rape her. She complains about the junior nurses, they are mean and often admonish her, which makes her offended since she tries to work hard and do her utmost. Her aunt is her guardian but she doesn't know how much money she's entitled to. Often she has no money to buy cigarettes.

Client 8, 46 years of age. She lives in the social care home for four years, before that she was treated in the Pavlov psychiatric hospital. Conflicts within the family led to her hospitalization and she got the short end of the stick. Her family is not interested in her and since they are her guardians she's stuck in the social care home because without their permission she's unable to leave. A disturbing story that we not only heard from her is that it is apparently possible to arrange a psychiatric diagnosis from psychiatrist on the grounds of which someone can be put under guardianship of stakeholders and locked up in an social care home without legal possibilities to challenge

this course of events. She made a depressive impression, not so much because of her medical condition as well as a result of the hospitalization itself.

Client 9 said she had been put here for financial reasons five years ago. She said she had no money and did not know what happened to her pension.

Client 10 said she should have been at a research foundation but was sent here instead when her relatives went abroad. The women on this ward looked to be in their forties, one showed me a picture of her son. Clients eat four times day and can smoke on the balcony of the ward. The lady had no money. She had a custodian and said she didn't know what happened with her money. Visitors are allowed and there is a telephone they can use any time. No one had a mobile phone. This lady said that at times the sanitares 'bound them'

Annex 2

Recommendations from the CRPD Committee

Ukraine was reviewed by the CRPD Committee in 2015. The Committee has issued Concluding observations on the initial report of Ukraine on 2 October 2015. Here are some of the significant parts of the Committee's report.

Regarding: Equal recognition before the law (art. 12)

26. The Committee is concerned that persons deprived of their legal capacity by decision of the courts lose all their rights, including the right to challenge their status before a court, and that the State party's legislation does not provide for supported decision-making mechanisms for such persons.

27. The Committee calls upon the State party to replace its guardianship and mental health law with supported decision-making mechanisms and abolish all deprivation of legal capacity both fully and partially in relation to all persons with disabilities. The Committee also recommends that the State party fully harmonize its provisions with article 12 of the Convention, as set forth in the Committee's general comment No. 1 (2014) on equal recognition before the law (art. 12) and recognize the full legal capacity of all persons with all types of disability.

Regarding: Freedom from torture or cruel, inhuman or degrading treatment or punishment, exploitation, violence and abuse (arts. 15 and 16)

32. The Committee is concerned about the various forms of abuse, including those that can amount to cruel, inhuman or degrading treatment against persons with disabilities, particularly boys and girls in conditions of institutionalization.

33. The Committee recommends that the State party evaluate the impact and effectiveness of its training programs for the prevention and absolute prohibition of torture and ill treatment in accordance with the concluding observations of the Committee against Torture (see CAT/C/UKR/CO/6, para. 18 (e)). These training programs should incorporate, explicitly, the prevention of cruel, inhuman or degrading treatment against persons with disabilities.

Regarding: Living independently and being included in the community (art. 19)

36. The Committee notes with concern that the State party continues to practice the institutionalization of persons with disabilities and provides very limited support, especially to persons with intellectual and psychosocial dis-

abilities, to enable them to live independently in their respective communities.

37. The Committee urges the State party to adopt measures for deinstitutionalization and to allocate sufficient resources for the development of support services in local communities that would enable all persons with disabilities to choose freely with whom, where and under which living arrangements they live.

Regarding: Respect for home and the family (art. 23)

42. The Committee is concerned about the reports of pressure on families imposed by public officials and professionals to place their children with disabilities in institutions and deny the right of persons with disabilities to a family life.

43. The Committee recommends that the State party take measures to provide the support necessary to families with children with disabilities in order to guarantee children with disabilities the right to grow up in a family environment and the right to have a family life.

Regarding: Health (art. 25)

46. The Committee is concerned about reports that persons with disabilities face difficulties accessing health care, particularly in accessing medicines and rehabilitation services. The Committee is furthermore concerned that women and girls with disabilities have restricted access to information on sexual and reproductive health and family planning.

47. The Committee calls upon the State party to ensure that all persons with disabilities have access to timely and quality health-care services both in rural and urban areas, including by providing access to medicines and rehabilitation services and providing information and services on sexual and reproductive health and family planning, especially to women and girls with disabilities.

Regarding: Habilitation and rehabilitation (art. 26)

48. The Committee is concerned about the lack of rights-based habilitation and rehabilitation services and programmes for persons with disabilities in the State party which promote their physical, mental and social development.

49. The Committee urges the State party to create accessible, comprehensive, habilitation and rehabilitation services and programs, such as early intervention, providing comprehensive, multidisciplinary and individualized support for persons with disabilities and their families.

Regarding: Adequate standard of living and social protection (art. 28)

52. While noting the difficulties that the State party is facing as a consequence of the ongoing conflict, the Committee is nevertheless concerned that the disability pension is extremely low and is not sufficient to meet the basic needs of a person, including food, medical and social needs.

53. The Committee calls upon the State party to review its budgetary allocations and increase the disability pension in order to provide persons with disabilities with adequate standard of living. The Committee also recommends that the State party ensure that resources for persons with disabilities are not adversely affected by inflation, budget cuts or any forms of crisis.

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