

# REVIEW OF SOCIAL CARE HOMES IN UKRAINE AND THE DEVELOPMENT OF A PLAN OF ACTION

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# I. General Observations

It's not the economic power of an individual that is an adequate indication of development, but to which extent a person can use his capacities in the system

Amartya Sen

## I.a. Introduction

Within the framework of a project financed by the Dutch Ministry of Foreign Affairs, a group of experts of the international foundation Human Rights in Mental Health-FGIP and the Office of the Ombudsman of the Verkhovna Rada visited four social care homes in Eastern and Western Ukraine in the week of December 4-10, 2016. The social care homes were chosen carefully, to have a good representation of the current situation in the facilities in the country. Our visits were unannounced. In total, we spent 54 hours on the road and covered some 2,500 kilometers. The impressions have left a permanent imprint in our memory.

In this report, we wish to provide an overview of what we have encountered, share our conclusions and also make concrete recommendations to the relevant executive authorities. In the end we also present a plan of action – how we think the immense task of reforming an outdated and inhuman system could be tackled. Because one thing is clear: this system has no place in a modern civilized world and should be ended as soon as possible. However, we also realize that change does not come as quickly as we would like and that the transformation to more human and therapeutic environments will take a long time.

## I.b. Social care homes

According to the Ministry of Social Policy of Ukraine, compared to 2013, the network of institutions for elderly and disabled patients decreased because of the military conflict, as a result of which 34 institutions found 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 for women and men.

Our assessment focused on the psychoneurological internats, in English usually referred to as “social care homes”. The official position is that social care homes are stationary socio-medical institutions, which are intended for permanent residence of citizens with psychoneurological disorders who require medical assistance, supportive care, and help in household duties. The main tasks of the institutions are to provide the appropriate living conditions for mentally disabled citizens, who are in need of outside care and assistance, and to contribute to their social integration.

The clients of the social care homes are supposed to be provided with all of the necessities according to all of the established norms:

- Housing, clothing, footwear, bedding, soft and firm equipment and tableware;
- A 4-time rational nutrition, including dietary food, given according to one's age and health condition of the person concerned, within the norms of rational nutrition (intervals between

meals should not be more than four hours, the last meal is organized in two hours before bedtime);

- Around the clock medical care, including consulting care, fixed medical treatment, as well as preventive medical care;
- Hearing devices, glasses, prosthetic and orthopedic products, dental prosthetics, special means of transportation (except motorized), drugs and vital drugs, according to the medical diagnosis;
- Public utilities (heating, lighting, installation of radio, water, etc.);
- Organization of work therapy, cultural, recreational and sports activities in the light of the age and health of those living in the institution;
- Conditions that promote the adaptation of mentally ill citizens in the new environment.

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. Physicians and the nursing staff working at the social care homes periodically upgrade their qualification, and sometimes 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.

### **I.c. Systemic aspects**

In the course of our assessment four social care homes were visited: two in the Eastern part of the country in Donetskaya oblast, and two in the Western part of the country in Khmel'nitskaya and Zhitomyr'skaya oblasts.

The four social care homes for persons with intellectual and mental disabilities are all places of residence where a significant number of people have limited capacity, are cut off from the wider community for an indefinite duration, and lead an enclosed, formally administered round of life. The life of the clients takes places 24 hours a day and 7 days a week within the same confined space with physical and psychological barriers between the social care home and the outside world and there is a clear distinction between staff and clients.

Once admitted to these facilities, the individual is disciplined to follow the rules of the institute whereby his or her identity is stripped away. The individual who endures repeatedly painful stimuli from which it is impossible to escape, learns to accept the loss of control over the outcome of a situation.

This so called learned helplessness is aggravated by the medicalization of the social, moral and existential problems of the individual. The individual in the institute is looked at through the prism of obsolete Soviet psychiatry. Thus, a person is deprived of individuality. Clients are seen by professionals as "broken apparatus" and there is no need to take them seriously. As one experienced psychiatrist put it: 'Don't believe patients stories, they are deranged and only looking for attention'.

The clients of the social care homes are provided with a persistent stamp in the form of a diagnostic category. As a result, the person living in these debilitating circumstances eventually accepts the medical definition of his or her existence and starts as a way of self-stigmatization to behave like a patient.

The problems from which the persons suffer are decontextualized. Phenomena such as sadness, loneliness and meaninglessness are attributed to neurobiological defects instead of the result of living in alienating total institutions. An individual response to individual needs is replaced by dehu-

manizing block treatment, whereas what is best for the average client, never is the optimum for a specific person. Treatment as a concept however only refers to daily routine: personal hygiene, meals, cleaning and medication. No meaningful activities nor forms of psychological support or counseling are offered so basically the clients are submitted to an endless chain of 'empty days' and a regime of control that erodes any sense of autonomy and individuality.

For the staff, who often agreed to give up meaning for the sake of the management of the institution, and lost the intuitive ability to recognize in another the same essence as in themselves, it is difficult to abandon this practice of medicalization because they are not only incapable of identifying other options for leading a high-quality and meaningful life, even with an illness, but also they assume that this is their main task. The staff in the social care homes, although often practicing with a good heart, assume that well-being and health is the absence of disease or infirmity instead of the ability to adapt and self-manage, considering the physical, emotional and social challenges of life.

Fundamental human needs are invariable. They are the same everywhere, for every person, for every culture, in every historical period, the needs have always been, and are still, the same. What changes over time and between cultures is the way these needs are met.

The needs of the clients of the social care homes, with or without an illness or a disability are the same as the needs of the staff, as the needs of people living in the community. The way their fundamental needs are satisfied in the closed institutions reveal the inequity between the deprived and neglected persons in the social care homes and the average citizens. Removal of this injustice should be a priority. Based on the collected data it can be established that within the social care homes only a few satisfiers (e.g. food, shelter) are in place to meet the fundamental human needs of the clients.

In addition, not once did we meet clients who wound up in the social care home system purely because of the fact that relatives wanted to get rid of them, for a variety of reasons, often however for economic ones e.g. obtaining (part of) a pension or expropriating an apartment or other living place.

## **I.d. Institutional aspects**

In general, the living conditions were relatively decent if you take into account the Ukrainian socio-economic context. Ukraine is ranked 81<sup>st</sup> out of 186 countries according to the Human Development Index (2015).<sup>1</sup> Partly due to the continuing conflict in the East of Ukraine, poverty has increased. The percentage of the people living under the poverty rate (under US\$5/day) increased to 5.8 percent in 2015, while moderate poverty increased to 22.2 percent in 2015.<sup>2</sup>

The social care homes on average are sufficiently heated; in itself quite remarkable considering the fact that Ukraine is a country at war with an unstable economic situation as a result. Most facilities we visited were not dirty, although the combined smell of urine, feces and chlorine together gives the institutions a penetrating odor. There is a sufficient supply of food and the clients were relatively well dressed, albeit the volume of clothing is limited.

Worrisome is the lack of privacy, which in some cases leads to the violations of dignity. Partly because of the armed conflict, the institutes in the Eastern part of the country are overcrowded and too many persons must share bedrooms and toilets and bathrooms. Often toilets and bathrooms offer no privacy.

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<sup>1</sup> <http://hdr.undp.org/en/content/human-development-index-hdi>

<sup>2</sup> <http://www.worldbank.org/en/country/ukraine/publication/ukraine-economic-update-fall-2016>

## **II. Living Conditions in institutions visited**

### **II.a. Kamyshovsky Psychoneurological Internat**

The Kamyshovsky social care home was a very distant location and almost impossible to reach. No public transport was available. Due to the road conditions (lots of snow) we could hardly reach the institution itself, and thus it is questionable what kind of services or support the institution can get in a case of emergency. Because of this, and because of the proximity of the front line, there were hardly any visits by relatives. Clients also had little chance of going outside because of the danger of minefields. Other means of communication with the outside world are very limited. Phones are taken away, and there is only possibility to call relatives or use phones for 1 hour from 9 to 10 two times a week. And this possibility is only in the general premises (in the main event hall).

The director, a top-down manager who had been at the institution for ten years, has no understanding of community-based services and therefore was unable to conceptualize which reforms are needed and achievable. To the question, of how many clients could go back to live in the society, he asked: “what society?” The facility has 4 registered nurses per 2 wards, the staff-client ratio being 1:46. During the night there is one registered nurse on duty with 2 assistant nurses. The registered nurses have had 3-4 years of training but only 2 months of education in mental health.

The facility was surrounded by high walls and with a guard watching the entrance, was designed for 260 clients but due to the displacements because of the military conflict there were currently 328 persons present, 122 of them were declared incapable. The duration of stay varied between 3 and 40 years, and once admitted to the social care home there is hardly an opportunity to return to the community. The system is based on one-way traffic and there is no continuity of care between mental hospitals and the social care home.

Because the front line was very much nearby, there should be plans for evacuation and rescue of clients. However, the director did not know of those, and was sure that there is no need for those “because nothing will happen”. When asked he indicated that in case of an emergency evacuation the facility would have 2 ambulances and one car in total for the transportation of the some 400 clients and staff.

The social care home was warm and clean, sufficient food was provided to the clients and personal hygiene was taken care of (although women are not being provided with hygienic means for their menstruation periods, as we were informed by the women residents. They are being given just old torn sheets instead). There were no visible signs of overmedication and/or physical restraint. There were 93 persons per ward, and in a room of approximately 12-15 square meters between 4 and 8 clients were accommodated. The psychiatrist oversees the allocation of clients. The windows of the rooms are barred, in order to prevent clients to jump out of the window and break their legs, according to the director.

Clients can watch TV only at evenings, the ones who can walk and go to the joint TV room.

Others stay at beds for all the days. There were only 3 wheelchairs observed. The library was locked.

All aspects of life are supervised by friendly, but paternalistic rank and file staff, such as use of telephone (which is restricted to “prevent clients to call the police and create false alarms”), en bloc

daily routine and very limited access to the community. No meaningful activities or resocialization programs. The population of this social care home has the same mix of diagnoses as in all the other social care homes: neurological problems, e.g. epilepsy and dementia paralytica (due to syphilis), mental health problems, mostly schizophrenia, alcoholism and developmental problems, e.g. Down's syndrome and Intellectual disabilities and persons who are admitted for social reasons, e.g. transferred from an orphanage at the age of 18. With adequate care and support, however, a substantial number of clients should be able to live outside the social care home and leave their demoralizing environment.

Clients had few personal belongings. Clients do not have their own personal underwear and bed linen. Bed linen is changed once a week. The winter clothes and boots were locked in a separate building, among other things they "don't need", as the director asserted. In general, there were not enough winter clothes and shoes available for all the clients. Thus, clients could not go out for a walk, and just sit in the PNI and do nothing.

There are major problems with privacy in the facility. Toilets are open, without the doors in between, just half full walls. Washrooms are in one open space. In one ward, there were no separate toilets for men and women. The doors to the rooms are without locks. Yet the wards were locked at night with no clear routines in case of an emergency.

There is registration of instances when an ambulance was called, but there is no registry on any other case of emergency, such as cases of acute behavioral crisis. According to the psychiatrist, he is then consulting the staff on the measures to take to calm down the clients. The psychiatrist, who proudly informed us that he had a career in psychiatry spanning 45 years, did not reveal what kind of measures he was having in mind. He also said that he was not going to tell us if they give additional medication or what kind of other measures they use.

There are 2 isolation rooms (with 4 beds each) that were empty during the visit, with bars on the windows, a separate toilet, and prison doors with a hatch for feeding. According to the psychiatrists, they are not used, but still being kept empty "in case of need". However, the clients claimed the isolation rooms are used quite often, the last case being two 2 weeks earlier. One can be sent to isolation room because of an acute state, or being violent, or as a punishment for bad behavior. Clients mentioned that it is up to the psychiatrist to release a person from the isolation room, but one can stay there for as long as two month or more.

One client also provided us with information about forcibly embedded gynecological spirals for women of a certain age. The spiral for her was embedded after the provision of additional psychotropic medication, without her consent. According to the same girl, it is forbidden to have relationships with males, but she was hiding her relations with one man from the same

institution. Clients also mentioned that there have been incidents of abortions made, but no further information was obtained on this.

## **II.b. Slaviansk Psychoneurological Internat**

The social care home is surrounded by high walls and with a guard at the entrance. The facility was designed for 350 people, but now, due to the war, inhabited by 586 persons. Of these 442 persons were legally incapacitated, as a result of which they are totally dependent on their guardians (either relatives outside or administration). The ages ranged from 18 to elderly women; only one male

client remained at the institution, as he hid himself when the males were transferred to another location. A doctor on duty estimated that around 30% of the clients could live in the community.

The social care home consists of 7 departments, including a special unit for clients with HIV. 8 persons share a room of approximately 22 square meters, so there is no room left for tables, chairs etc. One cupboard is shared to store clothing and few personal belongings.

With regard to the diagnostic categories, the same broad undifferentiated amalgam as in the other institutes: epilepsy, schizophrenia and intellectual disabilities (oligophrenia). No cases of suicide over the last 8 years. Many have somatic conditions as well, e.g. there are ties with a local cancer hospital. Tools such as prosthesis or glasses are provided for free. There are 3 resident doctors including 1 psychiatrist, 2 therapists and per shift 1 registered nurse and 3 assistant nurses. Main problems as identified by the doctor on duty are a lack of medical supplies, both qualitative and quantitative, absence of a dentist and the fact that many relatives no longer visit the clients since they (relatives) live in occupied territory of Donetsk oblast. A nurse pointed that out that the main challenge was how to pay individual attention to the clients given the unbalanced client/staff-ratio. It was difficult for the nurses to meet the individual needs of the clients.

Although there is block treatment, the regime is less strict. Clients can go shopping or to the church (with assistance because of the assumed risk of abuse). There is a library, a large so called clubroom with a television set and some games and smart phones and Internet are allowed 24/7. But in general, there was a lack of meaningful activities and besides some cleaning, the clients of the institute spend their endless days in hopeless idleness. Overall, staff attitudes were empathic and friendly.

Clients had their own personal belongings with them, and residents were allowed to have their telephones. All the clothes and beddings were personalized (with the names of the residents), and kept in storage. Bedding is changed every week. In the bathrooms, every resident had their own pocket with toothbrush, hairbrush, soap, etc. The general toilets and washrooms were open, and no privacy was provided. There were mobile toilets in the rooms provided for bedridden persons (in some rooms even several of those), however there was no privacy when using them - there were only a few screens. Clients were allowed to shower whenever they wanted, and every 6 days a sauna was possible.

All the rooms are kept open through the days and nights, the doors are fixed to the floor not to close them. This is total lack of privacy considering that persons spend there days and nights, together with others, and no time for being alone, in private is possible at all.

All the units are locked with the metal "gates". Within one unit, there is a room with intensive supervision. The room is kept open with one nurse assistant always being around. During the visit there were three ladies there. One was quite active and agitated, but no force was observed from the staff. Separate toilet in this room.

There are enough wheelchairs for non-walking clients (28) and a ramp existed to access the building of institution itself.

The general health conditions of all the clients are being constantly checked up with specialists outside the institution, including gynecologists. No contraceptives are given because there was no need, as only females were living in the institution, the doctor said. The hospital management was aware of the shortcomings of the institution and pointed at the lack of medication for the somatic conditions according to the medical norms, and the acute issue of overcrowding. They showed willingness to change but have a limited understanding of what to do, how to reform. There is a lack of

knowledge regarding a more community based approach and resocialization processes. The management is considering to renovate a pavilion and turn it into a ward for long term geriatric care, but were open to our suggestion to establish a halfway home where clients could be prepared to resocialize and reintegrate into the community.

For young women the only way to leave the institution was to find a man willing to marry them. There had been 4 weddings and 2 more are coming. However, apart from that there were no cases of going back to the community. The only other way out seemed to be of natural causes; there were 19 deaths in 2016.

### **II.c. Vinogradov Psychoneurological Internat**

The facility was a relatively small social care home built in 1977 with 160 clients, among them 4 male persons (living there because of family ties with other residents – brother, son). Of these, 42 had been declared incapable. Of these only 13 had a guardian outside the institution. Our visit was unexpected, late in the afternoon when clients were already preparing for dinner and subsequent sleeping.

The social care home lies in a remote area, is difficult to reach, yet a public bus goes from the district city Khmelnytsky three times per day during the summer, and 2 times per day during the winter. The social care home is of great economic value for the neighboring villages.

As in the other social care homes, the population consists of clients with mental health problems, mostly in remission, intellectual disabilities or social problems. There are 119 clients being able to move and having food in the canteen. Others are bed-ridden clients. There are only 4 wheelchairs to help clients to move around, but in general the building and the territory around is not adapted and therefore not accessible, so there is risk that non-walking clients just stay in the premises majority of time. There is no ramp to the main building, with 10 very dangerously slippery stairs.

Upon arrival, we found the clients resting in dark rooms, between 3 and 10 per room, subjected to endless boredom. An emptiness, only interrupted by the compelling rhythm of the daily schedule: hygiene, breakfast, cleaning, resting, dinner, hygiene and at 8 o'clock back to bed in a small room with 5 other ladies and wait for the new day with exactly the same routine to arrive.

There was a very bad smell throughout the whole institutions, but especially in the TV room, where there were around 40 clients sitting and watching TV at the moment of the visit. The odor of insufficiently washed bodies and clothes stuck to us and was sometimes so thick one could “cut” it.

The only form of ‘therapy’ is assisting putting bread on the table. In principle clients are allowed to assist in the kitchen to help the cooks but only after permission of the doctor; however it is a gesture that is never made. The institute is like an autarky. Clients visit the on-site church but not the church in the village. They can do some shopping, but not in the nearby community. Instead, every now and then a mobile shop comes to the social care home. The clients are not allowed to leave the institute on their own, because they get lost as a nurse said.

There is a quarantine room (with 4 beds) in the facility. It is used for new arrivals for the first 14 days to reside them, and then they are transferred to the ward to which they have been assigned. There is also an isolation room (with 4 beds). It has a separate toilet and washroom. According to the staff and director it is used in cases when someone gets sick, has flu, to prevent others getting infected as well. During our visit both rooms were empty. It is supposed that both rooms can be also used as isolation for acute state or agitated patients. No registration was seen for usage of those rooms.



Privacy is an issue. Toilets are totally open, even without any wall (half wall separations) in between. On top of that one has to take three steps to reach the toilet, which make them very inaccessible for persons with mobility issues, or for the elderly. Also in the rooms there was a lack of privacy.

The director is doing the best he can with limited resources. He's willing to reform but in the absence of a broader vision on rehabilitation his focus is on minor improvements. Nurses are on a 24-hour shift, officially without any opportunity to rest or sleep. There are 6 assistant nurses and 1 registered nurse per shift. Many of the nursing staff are appointed by the government to pay back their education. According to some nurses especially younger clients could live in the community with some support, but it never happens. Social care homes are an end station.

## **II.d. Novoborivsky Psychoneurological Internat**

This prison-like social care home is situated in a remote place, hidden in the woods. The place is not easily accessible, although it is in fact not very far from the nearest village. High concrete walls and a watchtower with guards separate the large terrain with its several dilapidated pavilions from the outside world. The first impression is more of a penitentiary institution than a socio-medical facility. Seventy stray dogs with lice wander around the grounds leaving their feces wherever they go.

In total 120 male clients, age between 20 and 80, live in this deeply sad environment, of whom 90 persons are legally incapable. They spend the remainder of their lives here, ostracized from the outside world.

According to the director, who has been 19 years in charge and has a background in agriculture, all of the clients have a mental disorder although he did not know which. There is no psychiatrist in the facility, although there is one visiting on a regular basis. The director also consults staff on the phone almost every day. There is doctor therapist around. Formally, every year each client undergoes a reassessment of his medical condition, but in reality this never happens. The staff has no license to administer medication.

The administration building is located at the very end of the territory of the social care home. It is two-floor building, having a quarantine room (with bars on the windows) on the first floor for the newly arriving clients. On the second floor nearby the director's cabinet there is also an isolation room. There was sign "isolation room" before the team entered the director's cabinet, yet for some reason within 10 minutes the sign was taken away. Upon request the room was opened. It was empty, a two-room apartment type with separate toilet and kitchen, and quite decent furniture. It is more likely that it is used for the staff or administration sleeping over then for isolating clients. Nevertheless, the example of taking away the sign because of the monitoring team seemed quite awkward.

The director stated that only few "cases" (he did not speak of persons) left the social care home to live with their relatives. Some of them came back after their situation worsened. The director claimed that maybe 5-10 persons would be able to leave the social care home at some point, however the vast majority will spend the rest of their lives within these walls. Many of the clients were put there by relatives without their consent.

In the department buildings on the territory, 6-8 clients share a room with beds but with no other furniture. In the rooms hung a clear urine smell. Many clients were lying in the beds in the dark,

waiting for dinner. Leisure is restricted to TV, a room with 5 computers with some games but no access to Internet. There is a day room, but the toilets there were locked. Staff explained that residents were allowed to use the outdoor toilet, or go to their living units to use the washroom. There is a meeting hall and a library in separate building, but it was empty during our visit. There is also a chapel on the grounds, and a priest visits the institute. Stuck on the wall the rules to which the clients must follow: No TV after 10 o'clock, no gambling, no cooking in the rooms etc.

A special ward (4<sup>th</sup> department) is a sort of prison within the prison. 28 persons live in this ward that is surrounded by high walls. Of these men it is said that they tried to escape or were abusive towards female staff. They are not let out from this closed ward, unless going to help to work. The ward is at the back of one of the buildings. To enter there you have to cross the empty room, which is supposed to be a meeting room with the relatives (just one sofa to sit on, nothing more). Subsequently one crosses the dining room, which is separate from others. All those are locked with the doors. Then there is a door to the outdoor yard, and when you cross the yard, you enter to the living unit. There are rooms with 7 beds. Clients are allowed to walk only within the territory of the unit.

Another ward was for bedridden clients. There were chemical toilets, but only two wheel chairs, and no iron nurse, and no physical therapy was available as a result of which clients were confined to their beds.

There is nothing to be occupied with in the institution. Director and staff mentioned that there are males working on the daily basis, but "they are hard to make to work". Some are preparing firewood (there were huge piles of firewood in the corner of the territory), some were doing odd jobs on the territory, and others were helping in the kitchen.

Most males walked around in military-type jackets, pants and boots, which show a lack of individualization, and the provision of institutional clothing. Nevertheless, clothing was appropriate with the season's requirements.

### **III. Conclusions**

#### **III.a. Individual level**

The assessment visit to the social care homes left us with a long lasting heavy feeling. Watching large groups of people lost in a system that takes away all individuality and provides hardly any sensible daytime activity is painful and frustrating. While the country is trying to break away from the Soviet past, these people have been left behind completely and in no way do they participate in this national revival.

The only positive things we found were the fact that the institutions were sufficiently heated, that the food provided was basic but seemed sufficient and that a roof over their head was provided. Another positive aspect was that in some of the institutions staff sincerely cared about their clients' wellbeing, however this was usually combined with a high level of paternalism that further reduced the individuality and free will of the clients.

Only in one institution did we meet a management that understood full well that the situation left a lot to be desired and that life for clients was difficult, yet did not seem to be able to see pathways to make the situation fundamentally and structurally better – understandable if one keeps in mind that the endless daily problems blocks thought about structural and long-term changes and leaves the management as institutionalized as the clients themselves. This was also the only social care home that did not have this typical all-pervasive “internat-stench”, that clings to clients, staff and visitors alike and stuck to your skin, impossible to get rid of or to flee away from. For us this smell became a symbol of the ultimate institutionalization: you smell of social care homes, they have entered your veins.

Yet even when one takes the difficult living conditions for many Ukrainians in the provinces into account, one has to conclude that the clients in social care homes have been rid of a meaningful life. The institutions provide neither physical, nor emotional securement and guarantee of personal dignity, rights and respect. Privacy is virtually non-existent, as too large numbers of clients are crammed into institutions that have no individual space available.

Many of the clients could have been activated in simple ways, either by allowing them to prepare food or cook for themselves, or to allow them to set up a vegetable garden and grow supplements to the basic and rather monotonous food provided by the institution. One woman complained about the quality of the borsch, and when we suggested that she should work in the kitchen to make sure the quality would be up to par, she visibly cheered up by the prospect. There are so many ways in which people can be activated to create their own cosy homely atmosphere and develop their individual day program that brings back meaning to their lives.

#### **III.b. Institutional level**

In spite of the fact that heating, food and a roof was provided in the social care homes visited, none of the facilities visited met the material conditions that are required. In most places, the institution was not adapted to persons with physical disability, e.g. by creating ramps, having sufficient wheel-chairs or walking aids. In some institutions, chemical toilets had been placed next to the beds of bed-ridden clients, yet the result was a lack of privacy.

Most of the institutions had created the conditions for this all-permeating “internat-stench”. Thick

carpets hang on the walls and were lying on the floors, which gather dust, dirt and “inhale” bodily odors and then permanently emit them. However well one wipes the floors and cleans the clients, the stench will not go away and immediately cling to freshly washed clothes and bed linen. The situation in the institution could quickly be improved by dealing with the above-mentioned issues.

Very disturbing were the clear signs of use of isolation cells for “agitated” residents.

In one institution the doors were the same as in a prison, with bars on the windows, while one institution had its own real-life prison on the territory, where clients were locked up for indefinite periods of time. Instead of trying to understand why clients were agitated or tried to escape, the management had resorted to repressive means. We are sure we did not see everything, and the remark of one of the psychiatrists on duty that he was not going to tell us which means he was using to get a patient back under control ringed ominously in our ears.

Most of the institutions had sizable territories that could be used much more effectively. We realize we visited the institutions in the winter and that in summer flowers and plants will leave a much more pleasant impression, but in none of the institutions was there any sign that clients had their own gardens, grew their own vegetables, were able to use their home-grown products in a kitchen that was available for private use. Many of the clients were from rural areas, where tending your own vegetable garden is an integral part of daily life, and providing such a possibility would have fundamentally altered their daily existence.

In all institutions visited, there was a lack of appropriate staffing (e.g. occupational therapists, rehabilitation experts) and staff was not trained to care for the residents in a different manner, e.g. in a person-centered manner, providing individualized services that are focused on empowerment, involving residents in household activities, stimulating residents to be more active. Multi-disciplinary teamwork and case management were basically non-existent.

### **III.c. Systemic level**

Considering the above, it should not be a surprise that in our opinion the system of social care homes in Ukraine is outdated, inhuman and should be fundamentally reformed. No civilized country should treat its citizens in this way. There are far poorer countries that do much better and provide much better care – to start with by enabling people to live within the community and by involving the community in taking care of those who need extra attention. In our view a fundamental reform is called for, with as a crucial step being the closure of the institutions to new clients. We will return to this issue when we make our recommendations in this report.

As one doctor said, some 30% of the clients should not be in the facility in the first place. Allowing them to return home, if need be with a tailor-made support program, would greatly alleviate the burden on the social care homes and allow for fundamental modifications. Quite possibly a larger percentage of the clients could live outside the social care home, either in their own social environment or in protected living environments near the social care home, with social care home staff providing the necessary guidance and support.

The current system lacks flexibility, which would allow catering for individual clients’ needs, lacks ingenuity, which would allow management to diversify groups and create environments for those who can basically take care of themselves, and lacks vision, for the simple reason that the whole concept of social care homes is focused on ostracizing people from society and disabling them,

rather than enabling them and integrating them in the community.

In our view, the system of social care homes should be abandoned and replaced by a new, innovative, flexible, resident-oriented system of care. We realize this takes time, and investments, but above all it requires an attitudinal change, both among politicians and policy-makers, and staff. However, we are convinced that if such a change would be brought about, it would not only greatly improve the quality of life for the clients, but also for the staff working in the facilities. Because working in the current social care homes must be one of the most depressing jobs one can imagine.

Last but not least, one should remember that Ukraine signed and ratified the Convention on the Rights of Persons with Disabilities (CRPD). Most of the personnel working in social care homes, and probably most of mental health professionals in general, have not heard of CRPD, let alone understand how it affects their work. In Annex 2 we have provided the most important conclusions of the CRPD Committee that reviewed Ukraine in 2015. The Committee issued its concluding observations on the initial report of Ukraine on 2 October 2015. The process of deinstitutionalization in Ukraine is at an early stage.

The first step is set, namely the adoption of a new edition of the “Standard provisions regarding neuropsychiatric social care homes”, approved by the Decree of the Cabinet of Ministers of Ukraine from 14.12.2016, No. 957, which expanded the powers of the institutions, guaranteed respect for the rights of clients, provided for the establishment of intensive and palliative care, supported living, etc. In addition, the Provision specified that the main priority for the institutions would be the creation of conditions for the participation of clients in cultural activities and complex rehabilitation services.

## IV. Recommendations to the Ukrainian authorities

As already indicated in the previous chapter, our first and foremost recommendation to the Ukrainian authorities is to take the fundamental decision to abandon the system of institutional social care. We realize that this is a decision with long-term consequences, as its implementation will not be completed within a short period of time. However, this decision is pivotal if one wishes 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.

Abandoning the system of institutional social care means 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. Alas, part of the clients in the social care homes is institutionalized to such an extent that reintegrating them into society is no longer feasible. However, even while living inside an institution their lives could be improved considerably and individuality could be returned. An important aspect would be to reduce the size of the institutions, as creating such improved living-conditions is impossible when the institution size remains unaltered. An option could be to cut the institution up into smaller individual “households” where clients live in a communal setting of maximum 10-12 persons, looked after by personnel.

A certain part of the clients will probably not be able to return to society altogether, but flexible living units either within the institution or in its proximity could help create as much a normal situation as possible. There is ample experience in other countries that show that much of the effects of institutionalization can be countered. And then a considerable part of the clients can be returned to their original communities, although in some of the cases the clients need to be trained beforehand, restoring their life skills and helping them to regain control of their lives. With these people gone, the pressure on the facilities will reduce enormously, allowing the management to start the so much needed reform.

As to the personnel, some of the staff will not be able to change their way of working. Having worked in these institutions sometimes for decades, they have become as institutionalized as the clients themselves. However, by introducing newly trained younger professionals, and by bringing about change in the management of the institution, a lot can be done and older “institutionalized” staff can function quite well when a new management with a new vision is in place.

Special attention needs to be paid to the fact that for some communities the social care home is the main or only means of employment. Closing an institution would mean that a complete community loses its livelihood, thereby seriously threatening the continued existence of these communities – possibly leading to the emptying of parts of the countryside. This can be avoided if the government develops a program for the alternative employment of the staff of social care homes.

The following recommendations are practical and easily implementable, and in our view there is no logical reason why they could not be implemented. By making these proposals we have taken the current economic and political situation in Ukraine into account. However, as indicated earlier, 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.**

#### IV.a. Individual Level

- **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, 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 activated as much as possible, e.g. by creating an as normal as possible day rhythm with household duties etc. This implies the redevelopment of basic life skills, which for at least part of the residents will also be part of the 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 revision of cases would very much help to develop individual treatment and activity plans.
- **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 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 come for nothing. It is unacceptable that the behavior of some (the issue of restriction should be regulated individually by a doctor) restricts access for all. 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..." 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.
- **Facilitate training to regain autonomy:** it is crucial that for clients a program of rehabilitation and resocialization is started. On 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 process of restoring their fundamental rights.

## IV.b. Group Level

- **Stop admission to Social Care Homes:** as indicated, a fundamental first step would be to stop new admissions to the social care homes. That means that while scaling down the social care homes both through reintegration and by natural causes, alternative systems should be set up which eventually will replace the social care homes altogether. This takes an effort, both financially and energy-wise, yet it is a crucial element in the program to end the system of social care homes once and for all.
- **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, client councils should be set up as a representative body of the clients that negotiates with the institution management. A personal ombudsman in the institution should mediate between a client with a complaint and the institution management, and by definition take the side of the client as his/her spokesperson. A model that could be used is the Swedish Personal Ombudsman system.<sup>3</sup>
- **End group rules and regulations:** the residents in a social care home 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.
- **Abolish the system of total control:** however well intentioned, patronizing is debilitating and often denigrating to the client. Clients 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 clients 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 staff "don't listen to him, he is mentally ill, you can't believe him"? Also a person with mental illness or 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.

## IV.c. Systemic Level

- **Regular evaluations of guardians and custodians:** a considerable percentage of clients are legally incapacitated and are under guardianship, either with an outside guardian (relative) or the director of the facility as guardian. 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. Pilot projects should be funded in order to stimulate and facilitate the introduction of 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.
- **Upgrade nursing training:** the training of nurses in Ukraine is insufficient, in particular when it comes to nursing for persons with mental illness or mental disability. The training of (mental

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<sup>3</sup> see <http://po-skane.org/in-foreign-languages/>



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 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.
- **Develop community based services responding to individual needs:** while closing social care homes for new clients, alternative community-based services should be developed that focus 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).
- **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 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 disability. Caring for a family member requires certain skills, that can easily be taught, and also the possibility of taking a break when the pressure is too big on the family. For the latter a sort of buddy system could be developed allowing a family to go on holiday knowing full well that somebody else will take care of the 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.

## V. Plan of Action

It is clear that in a country with 145 social care homes containing some 60,000 residents change does not happen overnight.

In our view, issues on the personal and group/institutional level as well as a reform of the current legal capacity legislation should be introduced immediately on a national level, by changing either legislation or instructions, while a systemic change should be introduced in two or three pilot regions.

One of these pilot regions should be Donetskaya oblast, for several reasons. First of all, the destruction of facilities such as the Slavyansk psychiatric hospital caused a crisis that can be seen as an opportunity, and we would strongly recommend not rebuilding that hospital but instead using the opportunity to develop community-based services. This, in combination with the fact that the management of the Slavyansk social care home seemed to be focused on reforming the institution, including the expansion of social services, and the fact that several innovative services have already been developed in the region, gives hope that a systemic change in this region would be a success.

A second pilot region could be Khmel'nitskaya oblast, where the regional administration is known to be interested in investing in mental and social health care reform.

### Level 1: immediate steps

The first phase should be used to create a basis for a fundamental shift in the current practice in social care homes. This would include:

1. **Drawing up instructions** to all social care homes that would change the institution's functioning and the rules on basis of which people are currently kept inside the facility.

The instructions should facilitate communication with the outside world; end the current paternalistic treatment of clients; terminate the rote system by which all persons are required to get up and go to bed at a certain hour; instruct social care homes to allow clients to participate in cooking, household duties, develop vegetable gardens on the territory, have access to telephone and Internet. Finally, the issue of privacy should be addressed.

2. **Establishing a commission** in each province to review the diagnosis and where appropriate facilitate the request to a court to alter the legal status of each and every client and/or to change the type of institution to stay in. This is a time-consuming and tedious job, but it is absolutely vital to get full understanding of the residents' capabilities and establish whether a person can be prepared for return into the community.

3. **Initiate trainings** for the staff of social care homes focused on clients' rights, activating clients, teaching life skills, as well as introduce the basis of multi-disciplinary teamwork and case management. For each and every client an individual treatment and activity plan should be drawn up, that is focused on empowerment rather than on restrictions and control. In addition, both management and staff should be trained in the basics of the CRPD and the provisions of Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, and how they can best introduce the consequences of both conventions within their professional setting. For this purpose, it is necessary to develop methodological recommendations on how to put these principles in practice.

4. **Terminate the use of isolation cells** and other restrictive measures, including the use of psychotropic drugs like aminazine, and teach staff in modern ways of aggression management. In addition, any prison setting such as the one in one of the institutions we visited should be ended immediately.

5. **Establish client and family councils** in social care homes and train them in negotiation skills. Also, the legal basis for the Patient Ombudsman should be established, and a selection procedure should be started to hire such persons and train them adequately.

6. **Strengthen control** over the functioning of social care homes through the Office of the Ombudsman, in collaboration with representatives of civil society, e.g. the Ukrainian Psychiatric Association and non-governmental organizations in the field of mental disability.

## **Level 2: piloting**

Two or three pilot provinces should be selected where the system of social care homes will be transformed into a multi-faceted system of social services for persons with chronic mental illness or mental disability that focuses on empowerment, inclusion and self-sustainability.

Being pilot regions, these provinces should have the possibility to experiment and see what systems work best within the Ukrainian context. Innovation should be stimulated by visits by foreign experts, e.g. through on the job training, and by site-visits to other countries where the system has been fundamentally altered.

## **Level 3: break with the past**

Preparations should be set in motion to prepare the legal and practical framework necessary to close the front door to the current social care homes, and thus have alternative ways to meet the needs of new clients, starting with those in the waiting lists for acceptance to the social care homes.

## Annex 1

### Interviews with clients

During our assessment visit to the social care homes our experts had private conversations with clients and staff. In some cases the institutions' management was visibly irritated that we were speaking to individual clients, either interfering ("they are mentally ill, don't believe what they are saying"), obstructing or by remaining around trying to listen in to what was said. In some cases we had to insist that staff members leave the room, and even physically push them out.

Because we do not wish to cause any negative effects to those who were willing to talk to us, we provide here a selection of interviews without any indication as to where the persons concerned were staying. The reason to provide this selection is to make clear that we encountered many people who should not have been hospitalized in the first place, or should have left the institution long ago.

### Interviews

**Female, 60 years:** Although she was diagnosed with schizophrenia and suffering from command hallucinations the interviewers found her coherent, well organized and without any sign of psychosis. She felt sad and had trouble sleeping for which she was prescribed medication. Her biggest wish is to recover. Her main tasks during the day were cleaning and taking care of the local church. She was admitted to the social care home because her husband found a new wife. She spoke bitterly about her guardians. She accused them of taking away her apartment. Her story revealed a structural issue, apparently there is no regular reassessment of guardians and custodians and there seems to be no complaints procedure.

**Female, 46 years:** She's in the social care home for as long as she remembers. She has epilepsy and schizophrenia and is prescribed medication for these afflictions. Sometimes her mother visits her, but she doesn't want to live with her. One son died and she could not attend his funeral.

**Female, no age.** She is already for 14 years in the institution. Came here after the stroke, when she was brought to the hospital, and then directly to the social care home. Now she is almost recovered, walks with a walker. She has daughter and was visiting her for 3-4 months for holidays. But she cannot leave, even though she wants and her daughter wants to take her, because of documents that are needed and apparently not in order or unobtainable. She was given contacts of the Ombudsman's Office to contact them and ask for support.

**Female, 40 years:** She spent the last 10 years in the social care home since her mother couldn't cope with her behavior anymore: hearing voices, not eating, running away from home. She also made a coherent impression. No signs of active psychosis. Some physical problems with her legs. She was on medication but had no say in dosages and type of drugs. 'Doctor knows best'. She impressed as a 'trained patient'; as a result of her long stay in the social care home she could not envisage an alternative life in the community, she was afraid to live by herself.

**Female, 36 years:** As an orphan she was transferred from the orphanage to the social care home at the age of 18. She has a sister in Luhansk. Her only medical condition is epilepsy. Her daily activities consist of hanging out in the clubroom and some cleaning work. She would like to live independently in the community but the pension she receives is too insufficient. At the same time, due to her long stay in the institutions, she lost confidence and she feels uncomfortable in the city where 'people look down on you'. She made a very coherent impression and winding up in the social care

home is her tragic fate. Clearly she can be relatively easily supported in her wish for rehabilitation and resocialization.

**Female, 80 years plus.** No diagnosis, according to her words, she came here totally healthy and strong two years ago. She herself is geologist (hydro geologist), and was working in this area. Came here after the death of her husband, and sent here by the son, who is well known urologic surgeon. He demanded her mother to leave all she had (apartment and other property). She also has a grown up daughter, a doctor as well. She has been visited only once. She was very emotional about her situation with regard to the children and her being in the institution. She had all her belongings brought with her (from clothes to books, photos). Now she complained about some health issues due to the dizziness, and said she will ask director for some tests and medication. Also she mentioned, that she has money in the bank, but cannot reach them, because they are not allowed to leave the institution. She said that she needs to ask the director for someone to take her to the bank to withdraw money. Observation: this lady does not have to stay in this institution, but have to have support in community and live in her own apartment.

**Female, 70 years:** She has been in the social care home for 15 years. She likes living there. She used to live with her mother. She described herself as shy and afraid of the surrounding world.

**Male, 58 years:** A nurse tried to interfere during the interview and was angry that she was turned away. Admitted to the social care home 3 years go. He lived with his brother and mother in an apartment. After his mother died his brother married and there was no room left for him, so his brother brought him to the social care home. He hopes that someday his brother will take him back. His only medical condition is dental problems but there is no dentist available. He made a sad, grieving impression, a normal reaction given the conditions in which he has to live, but no signs of a mental disorder.

**Female, 45 years:** She told us she was in the social care home for a week after the police took her there. She did not want to live here, although the food is good and it is warm. She does some sowing and reads books. She suffered from arthritis.

**Female, 60 years:** Gave an adequate presentation of herself. She sometimes feels moody and somewhat lonely because relatives stopped visiting her because of the war.

**Female, 38 years:** Admitted to the social care home 15 years ago after her mother deceased. She has a heart condition and a hearing problem. She really wants to go home but her father doesn't want her. She thinks she's capable of living on her own; she can manage the household, cook and grow vegetables. She finds the staff of the social care home friendly and is satisfied with the quality of food.

**Female, 45 years:** Claims to be in the social care home for only a couple of months. Made an incoherent impression, perhaps due to the fact she suffered from a brain tumor for which she was treated in the general hospital.

**Female, 50 years:** She was admitted by ambulance to the hospital after a nervous breakdown she experienced 10 years ago. Her husband is deceased. She has left the social care home once in the past 10 years to visit a museum. She is afraid to go into the community because she fears for her safety. When asked who is better off, her husband 'on the other side' or she, replied after some deep thinking: 'I think I am'.

**Female, 70 years:** She's been in the social care home for 10 years. She suffers from sleeping problems and feels nervous. Her son doesn't visit her not as frequent as he used to because of the war.

**Female, 56 years:** Her medical condition is schizophrenia; moreover she can't walk nor sleep. She has been in the social care home for 12 years. She sometimes visits her parent in summertime but they bring her back to the social care home after 2 or 3 weeks because it is too stressful for them.

**Female, around 65-70.** Epilepsy. For 30 years already in the institution. Has epilepsy, and takes medication from epilepsy (she mentioned Benzonal, Difinin, Fezam), the cases of epilepsy are not often. Otherwise she is satisfied with the conditions, food, has all the clothes needed. Nevertheless, she is not able to go out when wanted, to the church for instance.

## **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: Situation of risks and humanitarian emergencies (art. 11)**

22. The Committee is concerned about the reports that persons with disabilities were abandoned and could not be evacuated during the conflict in the east of the country. It is particularly concerned about the reports that there were no warning systems for deaf and blind people and that persons with multiple forms of disabilities could not use bomb shelters. The Committee is also concerned about the lack of accurate data on displacement, casualties and injuries among persons with disabilities during the conflict. Furthermore, the Committee notes alarming reports that humanitarian aid, including aid provided by international donors, is not accessible to persons with disabilities and contributes to their exclusion from relief efforts.

23. The Committee urges the State party to take all measures necessary, including at the local level, to facilitate the protection, including evacuation, of persons with disabilities who currently remain in the conflict areas of the country and ensure that its emergency response mechanisms and evacuation plans are inclusive and accessible to all persons with disabilities. It particularly calls upon the State party to prioritize persons with disabilities in its evacuation plans, including by training the personnel involved. The Committee further recommends that the State party mainstream disability in all humanitarian aid channels and involve organizations of persons with disabilities in setting priorities on aid distribution.

24. The Committee is concerned that the lack of a systematic registration process for persons with disabilities who are internally displaced hinders their access to social protection, emergency and humanitarian aid services, including shelters, medicine, benefits and pensions, which are necessary for an adequate standard of living.

25. The Committee urges the State party to take all measures necessary to systematically register internally displaced persons with disabilities and provide them with an adequate standard of living.

#### **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 disabilities, 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.



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Kingdom of the Netherlands