



TRANSFORMING SOCIAL CARE HOMES IN UKRAINE

Proposals regarding the Slavyansk and Svyatoshinsky social care homes

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I. Executive Summary

In May 2018, an international team of Ukrainian and foreign experts, together with representatives of the Ministry of Social Affairs Office and the Department of Social Affairs of Kyiv carried out an assessment of the Slavyansk and Svyatoshinsky social care homes in Ukraine.

The visit followed earlier assessments of both social care homes (Slavyansk in December 2016, Svyatoshinsky in January 2018) that resulted in discussions with the relevant authorities with regard to the current state of affairs in both institutions and the desire to initiate a transformation process. In both cases, the relevant authorities acknowledged the shortcomings that were mentioned in the relevant reports,¹ and agreed to a follow-up visit to assess how the situation could be amended. The current report is the result of that undertaking, which took place during the week of May 7-11, 2018.

The current report is not so much an assessment as a step further: suggestions how to transform the institutions and how to create pilots in Ukraine that help transform the social care home system. We hope that the recommendations will lead to agreements with authorities regarding the terms of reference for the transformation process, and that both documents – the report and the agreements – will lead to a commitment by the Ukrainian government as well as the international donor community to commit the necessary funding to start this process of transformation.

We are grateful to the relevant authorities, both in Donetskaya oblast and in the Kyiv municipality, as well as to the Ministry of Social Affairs, for their openness, their desire to collaborate and also their wish to initiate this much needed transformation process. We very much hope that we will be able to develop a sound and tailor-made transformation program that will alter the lives of those who are now kept in these closed institutions. It is for them that we invest time, energy, and funds.

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

II. Introduction

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

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

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

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

In Ukraine there is a general understanding that the system of social care homes should be transformed into a chain of modern community-based services. However, the task is seen as so immense that hitherto no program has either been developed or started. This project is therefore the first of its kind, and focuses on piloting modern services within a Ukrainian setting before it is rolled out across the country. It is also based on the understanding that for quite a number of years two systems will exist simultaneously: the new system, that yet has to be developed, and the old system. However, it is also important that the front door to the old system is closed and that no new clients enter the system, thereby keeping it alive, as happened several decades ago in Italy.

II.a. Past Assessments

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

auspices of the Ministry of Social Affairs. In the course of a five-day trip, again four social care homes were visited: two new ones in Krivoi Rog, again the Slavyansk social care home and Svyatoshinsky social care home in Kyiv. The latter two were not only assessed, but also information was gathered to write up a transformation plan. The report will be published after the summer, at an event still to be determined.

A total of 12 persons took part in the assessment visits, all of them experts in key areas of expertise necessary to support the future transformation process. The members of the expert teams have all agreed to participate in future activities e.g. trainings, assessments, and professional support.²

III.b. The May 2018 assessment

On May 7-11, 2018, a team of international experts toured Ukraine in order to assess the situation in social care homes. It was not the first time our organization “Human Rights in Mental Health-FGIP” assessed social care homes in Ukraine. On two previous occasions our organization carried out assessments. In December 2016 four social care homes were assessed in Donetskaya, Khmel'nitskaya and Zhitomyr'skaya oblasts, and in January 2018 an assessment was carried out at the Svyatoshinsky social care home in Kyiv.

However, both previous assessments had been carried out in collaboration with the Office of the Ombudsman for Human Rights of the Verkhovna Rada. This time we decided to link up with the Ministry of Social Affairs, directly responsible for the state of affairs in virtually all social care homes in the country.³

However, that was not the only change. While at previous times we assessed the situation and provided recommendations how to improve the situation, this time in two of the four social care homes our task was to develop a concrete and tailor-made plan of action.

The authorities responsible for the two social care homes that are subject to this report – Slavyansk social care home and Svyatoshinsky social care home – have expressed their readiness to collaborate with FGIP in initiating the transformation process. Relevant agreements have or are being drawn up, and it will be mainly an issue of available finance whether we will be able to make the next steps and start the process of change that should lead to a higher quality for life for those who will at least temporarily remain in the institutions and those who will embark on the long and difficult path to return to society.

² Petri Embregts, professor in Tilburg specialized in persons with learning disabilities (NL); Gavin Garman, senior mental health nurse (UK); Dovile Juodkaite, lawyer and expert in CRPD (LT); Rob Keukens, senior lecturer in psychiatric nursing (NL); Lars-Olof Ljungberg, social worker and Director of the Swedish Personal Ombudsman program (S); Julia Pievskaya, sociologist (UA); Jos Poelmann, social worker and retired mental health manager (NL); Madeline Roache, political scientist (UK); Helen Smith, psychiatrist and mental health manager (UK); Graham Thornicroft, professor of community psychiatry (UK); Wendy Weijts, psychologist (NL) and Robert van Voren, Sovietologist (NL/LT).

³ The two social care homes visited that were not selected for future work were near Krivoi Rog and a separate report on them has been drafted.

In compiling this report, we feel a very significant step has been taken. Our proposals are concrete, not outlandish, and affordable and take all complexities into account. We very much hope that they will provide a guide in future years to those who sincerely wish to end the exclusion of people with mental illness or mental disability from society, and end the abuse of the social care home system for not fully-medical or non-medical purposes.

III. Slavyansk social care home

III.a. Introduction

As indicated in our March 2017 report, based on an assessment visit in December 2016, the social care home is designed for 300 residents but currently, due to the war, around 475 people live there.

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.

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 is 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 permitted 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. Clients could 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.

III.b. May 2018 assessment

Also this time we found staff that is willing to reform but in need of technical support. They applied to two national funds in order to develop a program that addresses the specific needs of clients and to strive for an assisted living environment that will provide more autonomy for clients and step by step work towards reintegration into society for those who are capable of doing this.

The management of the institute lies in the hands of female staff. Compared with similar institutions run by male staff, the living conditions and the general atmosphere are better and the staff recognizes the shortcomings of the system and their own substantive limitations with regard to reforms although they endorse the importance of changes. Those who lack skills often also lack the knowledge of what skills they are missing; we often don't know what we don't know.

One of the major problems with regard to step-by-step increasing freedom for residents is that formally the practitioners are liable in case something goes wrong. For instance if a client from the social care home visits the market to do some shopping and she gets an epileptic fit, the care provider is responsible and accountable and can be accused of neglect.

In order to increase the willingness to participate in reforms, activities should be organized that provide benefits for the staff, such as computer classes, English language courses, a site visit to Bulgaria for selected staff to see modern services in community based care, supported decision making models, install a Wi-Fi system (in particular for residents in order to improve their communication with the outside world) etc. The language and computer classes could be accessible for both residents and staff. On a more conceptual level it is needed to introduce a new working ethos in which input of all staff is valued.

Decision-making procedures that elicit the knowledge and wisdom of the staff produce better outcomes than those that depend on the knowledge of a few individuals.

III.c. Physical environment

The institution has a well-tended garden area where we saw many able-bodied residents outside, easily accessing internal and external space. The staff was welcoming and appeared to have good relationships with the residents. Nevertheless it still appears to be common for the staff to wear medical uniforms (white coats were also offered to the expert team upon arrival to the social care home), which represents a paternalistic and hierarchical approach, primarily focused on controlling and managing residents and declaring specific positions and responsibilities among the staff, rather than supporting the residents. The home itself was clearly overcrowded. However, despite this there was a good atmosphere with people walking around talking to each other and smiling. Bedroom spaces were uniformly overcrowded; there were often 6 beds in spaces designed for 4. This meant that each resident had very little personal bed space and storage for personal items.

In the main building, there was a lot of comfortable seating and personal art on the walls, there was a sense “feeling like a home”. Whilst we were there residents seemed to be preparing for the holiday celebrations in the big hall. People were moving freely in and out of this hall and freely out into the garden area.

Conditions were less good in the block where the most physical disabled residents were, with disabilities that included both physical and learning disabilities. There was much less space and clearly residents here had a range of complex needs. The fabric of the building was poor with bare plaster and was dark and had the feel of a basement. There was little or no seating available besides an individual’s bed. There was a limited amount of personalization of bed space but again very little space to personalize. There were at least 6 beds per room and limited space to walk between.

Following our first visit in December 2016, some improvements had been made with regard to the privacy of residents. Besides the mobile toilets in the rooms for “bed ridden” persons (in some cases even several of them), screens had been put up in each of the room nearby the bed ridden persons for privacy when making use of the mobile toilet. Yet the general toilets and washrooms remained open, and no privacy was provided. Also there are holders in toilets for persons with difficulties in movement.

In each toilet area there is separate toilet cabin for staff, which is with the lock doors. Still attitude exist that for residents closed doors are not needed?

III.d. Facilities/living environment

Some residents had personal items in their bedrooms but not everyone. When we asked about this, staff talked about concerns that residents might steal from each other. The toilets and bathrooms were clean but lacked privacy. Toilet paper was dispensed a few sheets at a time. When we asked why this was done we were told that residents would

take too much and block the toilets.

The staff kept a running register to document when every woman menstruated. We were told that this would mean that they would know if anything unusual was happening, e.g. when a resident did not menstruate when expected. The residents had to ask for female hygiene products rather than being able to have their own supply and manage this independently.

There was a pervasive sense that residents could not be trusted and that they needed staff to take responsibility away from them, just in case something goes wrong. There was little/no evidence that the staff fears were ever realized. This need to manage every aspect of these people's lives leads to people being disempowered, deskilled, and devalued, without no responsibility and hope.

There is a marked inequality between the main house and the block within it where less able residents are housed. Physical conditions, staffing, opportunities for activity are markedly different. There is a sense that these residents have less value than the more able population of residents. In our view this needs to be addressed. The needs for this group of residents requires a much better understanding to allow for more individualised care in the least restricted environments. Where people with similar needs can be grouped together to support them functioning as well as they can with the best possible quality of life. Attention needs to be paid to the fabric of the building and the overcrowding which is more prominent in this unit as a result of the lack of decent communal spaces or any activity.

III.e. Activities

We held a small focus group of residents who described being happy in the home and said that they were well cared for. However they all said, when asked, that they would like to learn new skills. These ranged from learning to play a musical instrument to singing, to cooking to reading and writing and learning new skills to gain employment or to make and mend clothes. Others spoke of wanting to care for others.

It was clear that many of the older women had a range of daily living skills from previous experience; however, they did not use them and were not encouraged to share these skills with others.

We observed limited meaningful activity but experienced a desire from residents for that to change. There were only 26 names registered for the scheduled activities at the occupational room, from the total number of 472 residents.

There is special auditorium for social and cultural activities. There are television areas available in each unit, but the space is not big enough, and in some units there are only 4-5 benches for sitting. As a result there is no space for all residents to watch TV. There are public spaces available, but those are located in the corridors, to be used for joint activities.

The housing for the most disabled residents was, in our view, inadequately staffed to meet the complex needs of its residents. We were told that there are four nursing assistants and a trained member of staff for more than 60 residents, many of whom needed the most basic personal care. When we asked we were told that residents spent time outside during the day. However, it was difficult to see how this could be achieved with the number of staff and levels of support and supervision required to achieve this goal. There was no evidence of any planned activity in this block. There were a few people doing some needlework, but the remaining women had no meaningful activity. People often seemed to eat their food in or on their beds.

We saw some evidence of compassionate care, with a nursing assistant supporting a distressed and agitated older woman in one of the bedrooms. This space was busy. Residents were dressed individually, but poorly, especially the elderly ladies.

We spoke to a woman who appeared clearly more physically able than many others in this block. She wasn't clear why she was there. We reviewed her file with the medical staff and we were made aware that she was HIV positive. Staff described that she was managed on the more disabled unit as it was easier for them to manage her treatment. They said she had hepatitis, however, it wasn't clear to us why she couldn't have had these needs as well met in the main house where she would have been mixing with other women with more similar needs.

III.f. Legal Aspects

Right to the highest attainable health care

CRPD 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. 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 requirements of CRPD art. 25, there are no specific services provided due to the disability, no interventions, no disability tailored services. No informed consent is sought from the patients. And health professionals were not being at all informed themselves, as well as they did not raise awareness for patients about human rights, dignity, autonomy and other needs of persons with disabilities within the social care home. There is no recovery approach used in the social care home. Residents are totally disempowered, their individual needs are totally neglected. There are no individualized care- and treatment plans developed for residents, even though there are such requirements from the national legislation.

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.

There is medical treatment provided, but only medical rehabilitation. No other forms of rehabilitation. Recently the social care home received a license for medical practice (issuing and giving medication). This means that doctors within the social care home can prescribe and give neuroleptics. There is a need for special license for provision of psychotropic medication, which the social care home has not received.

Undue requirements are put forward in case residents need to be hospitalized for general health conditions, hospital requests inpatient “care” to be provided (meaning that a nurse from the social care home should lead and stay with resident at the hospital). In each of the resident’ medical file there is a list of drugs and their dosages that nurses can use and give to the residents in “urgent” cases without the doctor’s approval/prescription. Or it can be given by phone. Because of such lists, there is quite a high usage of such drugs as haloperidol and aminazine in the social care home.

All incidents, cases of trauma or special needs are indicated within the register of the nursing shifts. There are no special registrars for special events.

Right to legal capacity

There are 381 resident declared as legally incapable. 119 have their guardians outside the social care home (family members), and 262 are under guardianship of the social care home administration. This means that they are totally dependent on their guardians (either relatives outside or the administration of the home).

There is one case when legal capacity was restored.

Legal incapacity and guardianship system in it essence are contradictory to the CRPD art. 12 requirements. Persons who are declared legally incapable loose all their rights, and cannot exercise their legal capacity in any area, even with very basic daily decisions. All the decisions are taken over, guardians are taking all the decisions on behalf of the person with disabilities, notwithstanding his/her own capacities, and there is no respect for the person’s will and preferences whatsoever (either on daily activities, treatment and care options, disposition of their pensions, etc.).

Even more, with respect to the Slavyansk social care home administration being the guardian for 262 residents, this obviously shows the conflict of interests, as well as undue influence on all the areas and life decisions. There is no system for regular review, since only the guardian or controlling institutions can initiate the review procedure. There is no support provided in decision making that is proportional and tailored to the person’s circumstances.

Particularly restricted is the right of persons with disabilities being under the guardianship to use their money. This contradicts with art. 12 paragraph 5, which requires that all

appropriate and effective measures should be provided to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs ...and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

There are regulations and procedures developed within the social care home to control and manage the monthly allowances of both residents with legal capacity and those without. All the legally capable residents do have their own banking cards. Nevertheless, residents are suggested to keep those cards with the administration, in the safe. In case banking cards are left at the safe, all residents sign the small paper indicating their permission and agreement to keep their banking cards with the administration. Yet, all those permissions (with names and signature) are without date, meaning that one cannot know when they have been signed and for how long this permission is valid.

Together with the banking card, the secret PIN codes are kept to make sure that the residents would not forget them. This might bring to the situations when banking cards maybe used without the knowledge or agreement of residents. Otherwise, whenever residents want to use those, they should refer to the responsible social workers, or ask social workers to purchase products they want. The financial accountancy and expenditures are registered for each and every resident.

The residents who have been declared legally incapable are not at all allowed to use their money by themselves. Also there is Custodian committee in the social care home, who discuss requests from residents for purchasing things, products, and makes decisions with regard to the requests. The Committee takes also the decision to use residents' money for purchasing needed medication, e.g. when there is a doctor's prescription for medications other than used for psychiatric illness or mental health purpose. This raises question about the availability and free of charge medicine to be provided to residents of the social care home.

There is a general registry for monthly costs and balances for each resident. Hardly any resident (and especially those with restricted legal capacity) know about the balance of their finances. Residents have quite significant amounts in their accounts, yet there is no effort within the social care home to provide support to residents to use their money independently.

Also there is money in cash kept in the safe, either of those residents, who do not spent all the amount of money per month, or who have died leaving some balance. The latter is used for covering costs of other residents in case they lack their own.

III.g. Summary and recommendations

There are enormous opportunities for substantial changes in this social care home and there seemed to be a desire by staff to change. Looking first at the main house, where the majority of the more able individuals live.

It is our view that with a change in the emphasis of the support and care these residents experience and shift to using the skills that many residents have and/or could teach others this social care home could be reformed.

1. Individual needs assessment

Each resident must have a proper needs analysis undertaken. This should include an assessment that takes account of any physical and/or any mental health need. Based on this assessment, for each person an individual recovery plan should be developed:

- a. This will ensure that people are on the right medication for the right reasons and would also allow an inappropriate prescribing to be stopped.
- b. This should also include a basic assessment of their psychosocial functioning to include daily living skills, with an equal emphasis on presence and absence of skills.
- c. Care needs to be designed and delivered to meet residents needs not the needs of staff.
- d. This should follow any other wishes and priorities, aspirations for quality life.

A much clearer system for understanding the needs and current levels of functioning for all residents would allow people with similar needs to live together and for programs to be developed. This would also give staff a better understanding of who can live more independently. In turn these residents can be supported to develop this independence and take more responsibility of themselves and the area they live in. This would also make it easier for staff to feel confident about loosening their control over resident's lives.

2. A review of safeguarding must be undertaken.

Clear policies on safeguarding in relation to issues of a sexual, emotional, physical, exploitative nature between residents, or between staff and residents must be produced and followed. This is crucial in order ensure that the institution feels safe either to work in or be cared for. In addressing this matter it is important that there is adequate training for staff on de-escalation technics, safe mechanisms for residents (and staff) to raise concerns (developing triggers and warning signs for individuals if needed) and reliable systems that deal promptly and fairly when concerns are raised.

3. Maximizing autonomy

Residents need to have the autonomy that their level of functioning allows. This could include:

- Residents taking care of their personal space, making their own beds, washing and caring for their own clothes.
- Residents managing their own menstruation and being able to access sanitary products without the need to speak to staff.
- Residents should be able to choose which habilitation/rehabilitation activities that they wish to access.
- Residents need to have access to the sorts of opportunities that women of their age have

outside the institution such as make up, fashion etc.

- People should develop budgeting skills and skills around developing a meaningful day.

4. Meaningful activities

Meaningful activity should be made available to meet people's needs.

Examples include:

- Some residents expressed a desire to care for others - perhaps a course could be designed so that residents could receive certification in this area and use these new skills to support other less able residents.
- Developing skills in music or in sewing.
- Acquiring domestic skills like cooking and menu planning.

5. Buddy system

Residents might benefit from the development of a formal buddying system. This would allow for some residents taking responsibility for helping another. This would support the development of self-confidence and confidence in supporting someone else.

6. Staff development

Attention will need to be given to staff development and support. Changes are as difficult for staff as for the residents themselves. Staff should be trained in a way that allows them to feel confident about giving up some of the control they currently have. There will be an expectation that they will be asked to behave in a way that is culturally very different for them. Some may find this easier than others. In order to maximize staff engagement, they should be involved in designing programs with their residents. This will foster a culture of people working together. If this is not done well staff may feel "done to" rather than "worked with". This may impact on the success of any intervention.

7. Differentiation

Group residents in rooms based upon how they can cope with a range of responsibilities. It would be helpful to set up meetings with staff and residents to explore what kind of responsibilities the residents are able to handle. It was striking that many of the women we saw seemed perfectly capable of spending time outside in the community and yet very few did. Many residents perceived the world outside as dangerous and frightening; this was disproportional to the reality of the situation.

8. Reconstruction

The physical structure of the building needs to change. Residents should have open access kitchens to allow them to have drinks when they would like them. This would help residents to learn how to cook and to start prepare food for themselves as well as food to share with others.

Very promising is the plan to transform an empty building on the territory into a transition home, where smaller groups of residents could be trained in life skills and in taking care of themselves. This could be the first step to a return into society. With the institution management plans were drawn up to develop two units for eight persons each, with their own kitchen, living area, class rooms and laundry, where groups of residents could be prepared for life outside. A next step should be the development of a protected living environment outside, where residents from the transition home could continue the process of rehabilitation and from where they would reintegrate into society. Such a project could be an excellent pilot for the rest of the country and deserves maximum investment both financially and politically.

9. Communication

Open Wi-Fi excess for everyone, with appropriate training and support to ensure that these residents can protect themselves from others who may exploit their vulnerability. It would also be good to establish a computer room and provide a comfortable space with several telephones for people to connect and communicate with relatives or friends in privacy.

10. Sexual needs

There was limited evidence that resident's sexual needs were being considered. It was almost as if these people did not have these needs, an example of how dehumanizing these institutions are. There seemed to be some rather ad hoc attempts to talk to women going outside the institution and contraception but these seemed to occur after they returned. There was no evidence that conversations happen with women to help them remain safe when outside the wall.

III.h. Some individual stories ⁴

Tamara 38 years.

Tamara, born in Moldova, comes from a broken family and was put in a children's' home after her father remarried. She has a long history in children's homes and from the age of 30 she lived in the social care home. She suffers from epilepsy although she hasn't had a fit in many years. She's still on medication but couldn't tell what it was for. She gave a coherent impression and there were no signs of a mental illness. Due to her stressful life she never learned a job although she likes to sew. She's religious and would like to visit a church in the community on her own but she's not allowed to do so. After some explanations about forms of assisted and protected living she believes she would fit in. Cooking, do your own shopping, participating in vocational training would be welcomed and no problem at all.

Vera 36 years.

She has no parents, her brother and sister couldn't take care of her and as a result she ended up in various social care homes. She suffers from epilepsy.

Irina, 29 years.

Her wish was to become a nurse but her life was hard and she was never able to fulfil her dreams. She lives in this social care home for almost 8 years but prior to this she lived in various other institutes after she was virtually abandoned by her parents. She still has some contact with an aunt. In case she could participate in an assisted living program, she would like to cook.

Olga, 24 years.

Olga came to the social care home at the age of 18, before that she has spent most of her life in another institute. "If I have had other parents, my life would have been different," she says. Each year her grandmother takes her a couple of days out.. She would like to learn languages. Her dream in life is to become independent and have a family. Olga is an eloquent and determined woman and has no signs of any mental problem.

Marina, 24 years.

Marina has only a few memories of her parents. She lived in an orphanage in the South most of her live and was transferred to the internat at the age of 18. She has no idea if she has brothers or sisters. She spends her days in the institute. Only once she went to a festival outside the institute. . She would like to participate in an assisted living programme and learn to cook, grow flowers (there is a vegetable garden but clients don't work there) drawing and gain autonomy. Marina gets medication but doesn't know which type and she has no clue about her medical diagnosis. Nobody told her or informs her about her alleged medical condition.

⁴ Name and data have been altered to guarantee medical confidentiality.

IV. Svyatoshinsky Social Care Home

The Svyatoshinsky social care home was subject to a separate two-day assessment in January 2018. The team then concluded that the life of residents was 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. The expert team concluded that 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, were in violation of the United Nations Convention of the Rights of Persons with Disabilities (CRPD). The team also noted that a considerable number of residents seemed 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.

The expert team recommended fundamental changes in the way that residents were cared for (or rather: kept) and the institution was managed. The report listed a considerable number of steps that could 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. The team concluded that there should be a fundamental shift from looking at disabilities to a focus on abilities.

The report on the January 2018 assessment visit formed the basis of extensive communication with the department for social policy of the city of Kyiv, which led to the decision to use the May 2018 assessment as a basis for a joint analysis of what could be done to change the current situation. The original assessment team was enlarged with representatives of Kyiv municipality and several Ukrainian and foreign experts joining the team.

IV.a. Physical environment

Important is to note that the experience of visiting this unit was quite different to that of visiting the social care home in Slavyansk. The staff attitude to us was mixed. Some were welcoming but a more pervading sense of mistrust and low-level hostility. The staff seemed to have no concept of recovery. In their perception a diagnosis equals permanent disability, which in turn equals permanent institutionalization. Staff training should be an essential component of any future transformation plans.

When we arrived we went out into an open central courtyard, where most residents that were able appeared to be. During their time outside, the door back inside was closed and doors back into people’s living space appeared locked. It wasn’t clear if there was choice about being inside or outside.

There is a large yard surrounded by a metal fence that is used for the “old building” residents. The fence was locked from the outside. The yard is not equipped with comfortable benches to sit and rest; rather, stumps and broken benches are used to sit on. The majority of ladies were lying on the ground with very thin decks. There were no

activities, residents were just sitting or lying, walking around. Some ladies seemed to be cold (as if they were kept outside for a specific time and not let back in). Some parts within the yard were not safe for people, littered with some ruins and other remains. There was one mobile toilet outside in the patio for around 100-150 residents. This was a portable toilet with bucket suspended underneath and no toilet paper. There was evidence (feces and urine) that residents were currently using this toilet. There seemed to be no freedom to go to the toilet on your own accord.

Several ladies in wheelchairs were spending time separately in the yard.

In the bedroom areas there was little or no personalization. The communal spaces on the wards were cramped and without any comfortable seating, at best wooden benches with backs. The only activity on these wards appeared to be a wall mounted TV, all were on but although residents may be crowded around them they was very little evidence that people were actually paying attention to what was on them.

There were cabinets in resident's rooms and these were often locked, the keys kept by the nursing staff. The reason given once again related to safety purposes. There was little personalization; some people had carpets on their walls. Staff described how everyone would soon have a carpet. We asked to see these and were shown a pile of carpets on a wards floor. People were suspicious of us and would not be photographed unless with their backs turned towards us.

The bathing and toilet facilities do not allow any privacy. Toilets are without doors, just with a low dividing wall between them. Mobile residents have regular access to toilet facilities, they are not closed, but there is no toilet paper available. Residents must ask for toilet paper when they want to go to the toilet.

Menstruations of residents are followed and indicated in the notebooks in each unit, that gives the staff information from one shift to another. Toothbrushes were observed only in some of the units (in new building mostly), some personal marked ones, but some were not marked. The staff explained us that residents know which is theirs.

There were a number of residents on the second floor of this home who could not easily access the external space without support. It was difficult to imagine how they would have got outside.

The canteen in an "old building" services 160 residents, and residents eat in 2 shifts. Others eat in their rooms. There is wooden fence in the canteen to prevent residents to reach windows. The fence is as if it is there for decorative purposes, but shows the very controlling and closed environment. Forks and knives are not allowed to use, only spoons. The director explained that this was "for security reasons". A second canteen is in the new building, where in 380 residents are served in 3 shifts. Kitchen equipment and hygiene is not in accordance with norms and requirements.

IV.b. Facilities/lived environment

In the courtyard there was music playing and people were wandering about and a few dancing to the music. Residents were curious as to why we were visiting and came to talk to us. As with other places we visited it was evident that the residents had very varying needs, mental health, physical health, learning disabilities and others who did not have obvious impairment. During their time outside some residents take and carry personal belongings with them in plastic bags. Many residents were not wearing personal clothes. There seemed to be an “institutional dress” of the same pattern in different colors worn over other clothing, the clothing was quite old and shabby.

Mobile toilets for the bed-ridden residents are used in the rooms, but no privacy secured (no screens available). Only metal dishes are used for the meals.

We had the opportunity to speak to a number of residents in the courtyard. They spoke about how they had come to be in the home. Explanations included stories about mental health issues, depression, anxiety, probable psychosis and families not wanting them at home any longer. Many residents talked about wishing to leave the institution and live outside with family. Although in this home and the one in Slavyansk we only spoke to a small number of residents, there was a marked contrast in how happy people seemed to stay. Later on a member of staff expressed some anger that we had listened to a story about a young woman who had said that she wanted to live with an uncle but this staff member said that the last time she had stayed with him she had broken his arm and that he never wanted her back again. Without additional information it was not possible to know the truth of the situation.

We had the opportunity to visit a corridor where there were a number of arts and crafts rooms, including a room with sewing machines. In each room there was an abundance of arts and crafts materials and displays of completed projects. We were able to meet with 2 members of staff who appeared to have responsibility for organizing these crafts. Within these rooms were a variety of people, some who appeared to have learning disabilities and some who clearly had significant arts and crafts skills. There was one individual in the sewing room altering a dress but otherwise little else being done using the sewing machines. At one level the facilities that we saw were among the most advanced that we saw on our visits, but they were open to very few people and very much based on arts and crafts.

During our visit to the old villa we had conversations with residents about why they were there. We met people who were there as a result of having nowhere else to go and others with more complex needs. We spoke with an older woman who described having a depressive illness. She described the medication regime she had had outside of the residence and said she had been unable to get the medication she wanted inside. It was interesting to meet women who had held responsible positions in society as well as bringing up families prior to being admitted. There was a sense from many that they were “resigned to their fate”.

IV.c. Legal Aspects

The right to enjoyment of the highest attainable standard of physical and mental health (Article 25 of the CRPD)

The institution provides medical treatment when necessary, but rehabilitation is fully and only of medical nature. No other forms of rehabilitation are provided. The social care home has no license for medical practice.

The medical documentation is not in compliance with requirements. No medical confidentiality is secured and medical files are signed in in a standardized form. There are major concerns about the registry of medication that has been procured. Big quantities were purchased within only a few days. No procedures for purchasing and keeping medicine were found and in May 2018 no procurement procedures had been started for the purchase of medicine for the year 2018, which indicates that a large stock is left over from the previous year(s).

Staff is not provided either with training or written information on the rights of persons with mental disabilities. They are not familiar with international human rights standards, including the CRPD.

No comprehensive individual rehabilitation plans, or any other plans for that matter, have been developed for residents. In the “old building” rehabilitation, skills training or educational targets are totally neglected.

The right to exercise legal capacity and the right to personal liberty and security of person (Articles 12 and 14 of the CRPD)

The majority of residents (606 from 657) are under the guardianship (either with director of the institution being guardian, or with one or more family members functioning as guardians). This means that they are completely limited in their rights. But even residents who are not declared legally incapable do not have any decision-making powers.

The majority of residents do not receive their pension. In case a resident is under the guardianship of a family member, this family member receives the pension. It is up to the family to decide whether they will give some money to resident concerned. Residents who are under the guardianship of the social care home (202 persons at this moment), see their money transferred to a bank account. These funds can almost never be used and most residents have no idea how much money they actually have. Money can be used only according to the decision of the Commission functioning in the social care home. They give permission to use the funds to buy medicine that is needed (and which the doctor prescribed). Other personal wishes are not at all followed. Nevertheless during the visit it became clear that there is no functioning Commission at the moment.

There is registry of legally capable residents, who agrees to give their money to social

workers. Then they can ask social worker to buy them various products. But there seems to be very low number of residents in the registry; almost all residents give their money to the administration.

There is no legal review of incapacity and guardianship cases. Also there is no control over the guardians, even in cases when there is a case of possible abuse and violations of the rights and interests of a person under the guardianship.

General regulations

The social care home does not have any basic regulations, procedures and documentation written down with regard to care and/or treatment. There are only general statutes of the institution. Residents are not provided with a document specifying their rights and house rules.

The administration is not following the legal requirements under which residents should be referred to, and accommodated in, the social care home, or conditions that determine in which unit they are housed according to their independence status and health condition. In addition, the social care home is not following the legal requirement to sign individual contracts with residents (or their guardians), to describe what services are provided for residents, and under which conditions they are treated and cared.

Registration of incidences

There is no registration of any emergencies, such as cases of acute behavior, conflicts, injuries, etc. All the information is filled in into the general staff notebook, which is handed over from shift to shift.

There is no registry for the use of restrains or seclusion. During the visit there was one lady who had been in the isolator for almost one year. There is only a register for entering and leaving the isolator, but no other activities or interventions are registered.

There is also no mechanism for complaints about violations of rights violations and there is no system of appeal to decisions made by the administration. To the contrary, the administration blocks 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.

IV.d. Summary and recommendations for change.

We were concerned about the culture of this social care home. We felt that a significant proportion of the staff we met did not really see the need for change, and resented that visitors should suggest that there might be things that could be done differently. We were frequently asked about how things were different where we came from but our sense was that this enquiry was not borne out of a desire to improve but something different and more suspicious.

1. Structural change

In our view, it is impossible to do anything constructive in an institution with 700 clients, in particular when the clientele is so diverse. In fact, we are looking at a population that could be categorized into three groups:

- Persons with dementia and other old age illnesses
- Persons with intellectual disability
- Persons with a psychiatric history or diagnosis.

We believe that the only proper approach is to divide the Svyatoshinsky social care home up into three separate institutions, each taking care of one of the above-mentioned categories. Then an environment is created that is still complex to manage, but no longer impossible. Our guess is that in the “mental health” component some 200 persons would remain, a population that is easier to deal with. This unit should get a new, young and reform minded director who is focused on rehabilitation, resocialization and recovery. For each of the units a separate development plan should be worked out, tailor-made to the needs of the specific populations.

2. Needs assessment

Following the division of the institution into three separate entities, each resident must have a proper needs analysis undertaken. This should include an assessment that takes account of any physical and/or any mental health need. First of all, this will ensure that people are on the right medication for the right reasons and would also allow an inappropriate prescribing to be stopped. Evidence based prescribing will ensure that medication is used for therapeutic benefit and not for control. Secondly, this should also include a basic assessment of their psychosocial functioning to include daily living skills, with an equal emphasis on presence and absence of skills. And finally, this will assure that care needs are designed and delivered to meet residents’ needs, and not the needs of staff.

A much better understanding of each residents’ needs will help to identify people with similar needs who could live together and will make any recovery or rehabilitation programs easier to deliver.

3. Support of personnel in a time of change

Attention will need to be given to staff development and support. Changes are as difficult for staff as for the residents themselves. Staff should be trained in a way that allows them to feel confident about giving up some of the control they currently have. There will be an expectation that they will be asked to behave in a way that is culturally very different for them. Some may find this easier than others.

We are concerned in this home that if this is not done the staff may resist rather than deliver the program of work required. As part of this staff and residents need to develop a new mission statement and associated objectives to help them to get from where they are now to where they want to be. This must be believed in and lead by the director of services.

There seems to be a fear of recrimination for staff if they change and something goes wrong. There needs to be a clear understanding of any risk undertaken, who is accountable and responsible for understanding the risk and managing the risk. The consequences of the emerging risks need to be fully and widely understood.

Staff needs to learn to trust residents in order that they can support them develop their autonomy.

4. Training of staff

Staff should be trained to support residents to live as full a life as possible in the context of any disability. We recommend a recovery based approach (as in recovery movement in European mental health and learning disability services) and solution-oriented therapy.

5. Privacy, personalization and communication for clients

Put in place support to help patient autonomy and make the space for each resident more personal. There are some relatively simple things that can be done to support autonomy and personalization. For example, it could be arranging that every resident have their own cabinet with their own key for personal belongings. Rooms could be personalized with noticeboards for pictures etc.

Residents should be allowed to have their own mobile phone if they liked and this could be safely stored in this cabinet. We would recommend installing Wi-Fi in the institution, to allow clients to access Internet and maintain contact with the outside world more easily. Residents need to be able to access the world outside the gate as their needs allow rather than a seemingly blanket ban.

6. Specific patient needs

There was very little evidence to suggest that resident's spiritual needs were being considered. This needs to be addressed.

There was no evidence that resident's sexual needs were being considered at all. It was almost as if these people did not have these needs, an example of how dehumanizing these institutions are. There was no evidence to suggest that safe guarding issues whether these issues were of a sexual, emotional, physical and/or exploitative nature either between residents or between staff and residents. In order ensure that the institution feels safe to work in or be cared for in this must be addressed, with adequate training for staff, safe mechanisms for residents (and staff) to raise concerns and reliable systems that deal promptly and fairly when concerns are raised.

IV.e. Some individual stories ⁵

Valentina, 56 years.

She claims that she comes from a rich family who abandoned her. She was sent to a mental hospital and from there to this social care home. 'Everything "turned me into a freak. I am not schizophrenic although they give me injections, I hate that. I suffer from unanswered love. If I feel low and have ideas about suicide they beat me and force me to accept injections."

Tanya, 38 years.

She came to the social care home via a psychiatric hospital after her former husband cheated on her and took all of her belongings, including her apartment. She used to work for the court. She gets medication. At one point they changed the medication without tapering and replaced it by other drugs. She ends the conversation by saying: "I really don't know what the use of my life is."

Natalya, 31 years.

At the age of 13 she was sent to a children's home, where the situation was even worse, and after that to the social care home. Abandoned by her family, she has no idea about her family. Nobody guided her in life. She just adapts to the situation and keeps quiet. In case she feels sad or has problems she keeps this to herself. She doesn't trust staff members to discuss her problems with. She feels very lonely. She would like to live independently. She likes reading but there are hardly any decent books and she would like to improve her computer skills.

⁴ Name and data have been altered to guarantee medical confidentiality.

V. Recommendations from the CRPD Committee

The CRPD Committee reviewed Ukraine 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.

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, and that persons with disabilities in rural areas have limited access to health-care facilities. 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.

