



Helsinki Citizens' Assembly Vanadzor

REFERENCE

Spitak Care Home

Transition from institutional system into community-based service

2017

Vanadzor

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Introduction

In September, 2010 the Republic of Armenia ratified the UN Convention on the Rights of Persons with Disabilities. Through the ratification of the Convention the Republic of Armenia, among other commitments, undertook the implementation of necessary and most complicated reforms in the field of psychiatric services.

For that purpose the Government of the Republic of Armenia adopted two documents¹ of strategic significance, which envisage deinstitutionalisation of large care institutions through introduction of community-based services in the Republic of Armenia.

On September 13, 2013 the RA Government approved the Action Plan for 2013-2017 of the Concept on Providing Alternative Social Care and Support Services to Persons with Mental Health Problems, which foresaw the implementation of the following action: “Within the framework of a pilot project to establish a 24-hour care home for persons with mental health problems in the two communities of the Republic as an alternative to Vardenis Neuropsychological Boarding Home”.

The same action was also foreseen within the scopes of the goal “Transition from the institutional manner of settling the problems in the mental health field to community-based support system” under the Action Plan for 2014-2019 Strategy of Preserving and Improving Mental Health in the Republic of Armenia.

Within the framework of implementing the aforementioned projects Spitak Care Home was established in April, 2016 to reside up to 16 persons.

The goal of the Care Home is “To prepare persons with mental health problems for self-sustainability, life skills, to develop interpersonal communications, social integration, and formation of non-discriminatory treatment against persons with mental health problems among the community members.”

In this reference the opportunities of exercising the rights of persons with psychosocial and mental disabilities through Spitak Care Home are presented. The current study is especially crucial in terms of highlighting the differences in the state of human rights protection between a large, closed type of care facility, such as Vardenis Neuropsychological Boarding Home and Spitak Care Home. The reference outlines the impact of Spitak Care Home on the life quality of its residents.

The studies published based on the previous human rights monitoring conducted by the Organization, the talks with Spitak Care Home staff and residents, as well as the data obtained as a result of observations by the Organization’s representatives during the site visits to Spitak Care Home served as a source for the production of this reference.

¹ <http://www.arlis.am/DocumentView.aspx?DocID=83190>, <http://www.arlis.am/DocumentView.aspx?DocID=85539>
<http://www.arlis.am/DocumentView.aspx?DocID=90364>

Summary

Within the framework of the reforms carried out in the field of mental health in the Republic of Armenia the introduction of community-based services for persons with psychosocial and mental disabilities as an alternative to large, closed institutions is prioritized.

In May, 2016 Spitak Care Home community-based service was introduced within the scope of the reforms. 10 persons with psychosocial disabilities reside in the community-based home, 7 of which were transferred from institutions providing care and treatment services to persons with psychosocial and mental disabilities.

The human rights monitoring conducted by HCA Vanadzor at institutions providing care and treatment services to persons with psychosocial and mental disabilities, as well as interviews with persons transferred to Spitak Care Home suggest that the rights of those persons were not protected at institutions providing care and treatment services to persons with psychosocial and mental disabilities.

Whereas, Spitak Care Home is a step in terms of taking full advantage of human rights and fundamental freedoms by its residents. It has contributed to the exercising of its residents' right to be independent and self-sustainable, as well as an equal member of the society. The residents have been given an opportunity to go out to the community, feel free inside their home and yard. Some of the residents have restored their relationship with relatives, and have established new contacts. Unlike institutions providing care and treatment services to persons with psychosocial and mental disabilities, the right of the residents to be free from ill-treatment is ensured in Spitak Care Home.

Here the residents are not subjected to labor exploitation; moreover, they visualize a perspective for a long-term recruitment by their own choice.

The receipt of the pension by the care home residents along with the chance to independently manage it is ensured. The residents are provided with decent material conditions to lead a dignified life.

It is undeniable that Spitak Care Home has only positively impacted on the provision of human rights, however, here there are still things to be done. This is contingent upon the fact that the residents of institutions providing care and treatment services to persons with psychosocial and mental disabilities are deprived of the chance to lead an independent life and do not master basic daily living skills. On the other hand, the Care Home staff members take ongoing care of the persons and show an immense desire to take care of them, due to which the residents' full inclusion in their own problems remains unsettled.

Nonetheless, the operation of Spitak Care Home has already proved the significance of such services and the progress in safeguarding and protecting of the rights of persons with psychosocial disabilities through them.

Furthermore, the introduction of community-based services in order to ensure the rights of persons with psychosocial and mental disabilities in the Republic of Armenia and the referral of persons, who receive long-term care at institutions providing care and treatment services to persons with psychosocial and mental disabilities, as well as members of the community needing care to institutions providing such services is extremely urgent.

Main challenges of the rights of persons with psychosocial and mental disabilities

Institutional challenges

As many as 50.000 persons with psychosocial and mental disabilities are registered in the Republic of Armenia.

9 psychiatric medical institutions operate, 3 of which in Yerevan, while the rest in Kotayk, Lori, Shirak, Gegharkunik, Ararat and Syunik marzes. In 4 marzes of the Republic of Armenia there are no institutions providing psychiatric services. The total number of beds in the said institutions is 1483², 600³ (over 40 %) of which are distributed in 3 institutions functioning in the city of Yerevan.

According to psychiatrists, 50% of the persons placed at psychiatric care facilities need care rather than in-patient treatment.

Long-term care facilities for adults also operate in the Republic of Armenia with a total of 570 beds⁴ at Vardenis Neuropsychological Boarding Home and "Dzorak" care center for people with mental disabilities.

In pursuance of the report on the findings of the screening tests of 438 residents of Vardenis Neuropsychological Boarding Home submitted to the RA Minister of Labor and Social Affairs, 103 (23.5%) out of the residents did not need to stay in the Boarding Home contingent upon their current clinical state and skills, 21 (4.8%) of them could reside in a care home for up to 3 persons, while 82 (18.7%) could live in a care home for up to 10 persons.

Due to the absence or insufficiency of community-based services, institutions providing care and treatment services to persons with psychosocial and mental disabilities are forced to carry out long-term “care” of persons with psychosocial and mental disabilities without a perspective for discharge from the above institutions.

The vast majority of persons receiving long-term care at institutions providing care and treatment services to persons with psychosocial and mental disabilities are also declared legally incapable by court’s ruling; they are thus deprived of their right to decision-making on their discharge from the facility (Pursuant to the report on the findings of the screening tests of 438 residents of Vardenis Neuropsychological Boarding Home submitted to the RA Minister of Labor and Social Affairs, 53.6 % of the residents are declared legally incapable by court’s ruling). Such a decision shall be made by a person's

² <http://www.arlis.am/DocumentView.aspx?DocID=90364>

³ http://nih.am/uploads/files/yerevan_2016.pdf

⁴ *Such facilities are fully populated and the RA Ministry of Labor and Social Affairs has a waiting list of people for admission to any care facility.*

guardian. Moreover, persons declared legally incapable are more often placed at institutions providing care and treatment services to persons with psychosocial and mental disabilities by a guardian out of vested interests so that to possess the ward's property or take advantage of it.

Moreover, children with psychosocial and mental disabilities residing there are also denied the chance to live outside such facilities. After turning the age of 18 they continue residing in professional orphanages or are immediately transferred to institutions providing care and treatment services to persons with psychosocial and mental disabilities for adults.

Challenges of human rights at institutions providing care and treatment services to persons with psychosocial and mental disabilities

Numerous facts on human rights violations have been recorded by Helsinki Citizens' Assembly Vanadzor through regular monitoring visits to closed institutions providing care and treatment services to persons with psychosocial and mental disabilities.⁵

It was particularly recorded,

- Facts on ill and degrading treatment, including physical and psychological abuse,
- Absence of proper care and effective treatment,
- Poor living conditions,
- Segregation from the community, isolation, away from the public eye conditioned

by:

- community inclusion,
- Self-sustainability,
- Decision-making,
- Absence of effective remedies for the protection of a person's rights

The aforementioned problems emerged not only from inadequate training of the staff and allocation of insufficient funding, but also as a result of residing in such a closed institution, isolation and institutionalization. The exercising of a number of fundamental human rights is impossible in closed institutions providing care and treatment services to persons with psychosocial and mental disabilities irrespective of the staff's professional and human qualities. Residing in such institutions itself deprives a person of the possibility to self-sustainability, decision-making, and community inclusion.

⁵ http://hcav.am/wp-content/uploads/2014/09/main_zekuyc_FINAL.pdf

The reports of the Human Rights Defender also testify about the human rights violations in the institutions providing care and treatment services to persons with psychosocial and mental disabilities.

Displays of ill, inhuman or degrading treatment

Article 16 of the UN Convention on the Rights of Persons with Disabilities stipulates freedom of a person from exploitation, violence and ill treatment.

Whereas, there is labor exploitation, physical and psychological abuse, application of physical restraints for non-medical purposes in the institutions providing care and treatment services to persons with psychosocial and mental disabilities operating in the Republic.

During the monitoring visits the Organization's staff members have witnessed cases of physical abuse against persons with psychosocial and mental disabilities.

Physical or psychological abuse in the institutions is carried out both by the staff and the residents.

Physical restraints are applied against persons with psychosocial and mental disabilities in closed institutions in order to punish, to gag a person, and establish orders in the ward. Besides, persons with psychosocial and mental disabilities either witness or take part in the application of the restraints, which also adversely affects their health.

Persons with psychosocial and mental disabilities are engaged in various types of activities in the closed facilities. The latter is presented as occupational therapy, whereas, they basically carry out the duties of the institution's staff: they are engaged in the cleaning of the institution, care of other persons, distribution of food, sometimes in construction and land management. Persons with psychosocial and mental disabilities sometimes agree to do the job in exchange for going out to the institution's yard.

Monetary remuneration is offered occasionally, in some institutions it constitutes up to 500-1000 AMD for certain jobs. However, in such institutions persons with psychosocial and mental disabilities are, as a general rule, deprived of the opportunity to independently manage even the earned 500-1000 AMD. In individual cases the staff tries rewarding through various incentives in exchange for the job, including cigarettes, food provision, and kind treatment.

The persons placed at closed institutions providing care and treatment services to persons with psychosocial and mental disabilities are in fact deprived of their right to work which is stipulated by Article 27 of the Convention. In pursuance with Article 27.1, "States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labor market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work...".

Challenges of organizing the privacy of persons with psychosocial and mental disabilities

Article 22 of the UN Convention on the Rights of Persons with Disabilities defines the respect for privacy. The Article particularly prescribes, "No person with disabilities shall be subjected to arbitrary or unlawful interference with his or her privacy, family, or correspondence or other types of communication..."

Whereas, the correspondence of the residents of closed institutions providing care and treatment services to persons with psychosocial and mental disabilities are subjected to censorship and the staff representatives are present during phone conversations.

In the institutions persons with psychosocial and mental disabilities usually do not have their personal area and belongings: cabinet, nightstands, clothing, hygienic supplies, or some of them do and to some extent.

In the meantime, the practice of checking the personal area of a person by the staff, coupled with violations of the right to privacy and confidentiality, is applied in the institutions.

In the institutions persons with psychosocial and mental disabilities are denied the chance to found a family.

Segregation of persons with psychosocial and mental disabilities and exclusion of their decision-making

Article 19 of the UN Convention on the Rights of Persons with Disabilities defines the right of persons with disabilities to live independently and be included in the community. According to Article 19, “Persons with disabilities, including persons with psychosocial and mental disabilities, shall have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement, receive personal assistance necessary for inclusion in the community.”

Being at closed institutions providing care and treatment services to persons with psychosocial and mental disabilities itself segregates them from the society. Besides, the overwhelming majority of the persons with psychosocial and mental disabilities are bound to enforced stay at the institution not having another shelter and being deprived of decision- making on discharge from the institution.

Being denied many of their rights and freedoms in the institutions, persons compare it with prison. They also use the “eternal bed” concept, which relates to persons, who spend their lifetimes in those facilities and see no hope and chance of being discharged.

In the meanwhile, the person doesn’t make decisions even for most basic matters: what to eat, what to wear, when to shower, wake up or sleep.

Denied of the chance to leave the institution, and in some of the cases also of the opportunity to have a walk in the institution’s adjacent yard, the life of persons with psychosocial and mental disabilities passes monotonous and boring.

Ways of ensuring the rights of persons with psychosocial and mental disabilities

Introduction of community-based services

Community-based services constitute an alternative to closed institutions providing care and treatment services to persons with psychosocial and mental disabilities. In a number of countries including Western Europe, USA, and Israel, the community-based services began to be introduced in 1980-ies.

The introduction of community-based services not only ensures the realization of the rights of persons with psychosocial and mental disabilities, but it also reduces the Government's funds: pursuant to studies, community-based services are less expensive.⁶

As stated in the introduction, the process of reforms in the field of mental health and particularly introduction of community-based services in the Republic of Armenia was launched after the ratification of the "Concept Paper on Providing Alternative Social Care and Support Services to Persons with Mental Health Problems" and "Action Plan for 2014-2019 Strategy of Preserving and Improving Mental Health in the Republic of Armenia" (2013 to 2014) by the RA Government.

Community-based services operating with the full funding of the state or local budget don't however function in the territory of the Republic today. Some of the operating community-based services are provided by non-governmental organizations; however, the latter have extremely limited functions and opportunities, and are centralized in the RA capital.

After the ratification of the UN Convention on the Rights of Persons with Disabilities by the RA as the main document stipulating the rights of persons with disabilities, the pilot community-based service introduced for persons with mental health problems is Spitak Care Home. It was launched in May, 2016 and is designated for maximum of 16 persons. As of April, 2017 10 persons reside there.

The total number of the personnel of the Care Home is 16. The Care Home responsible, psychologist, social worker, art therapist, psychiatrist, 2 cooks, technical assistant and 8 shift caregivers ensure the functioning of the Care Home and carry out activities with the residents. During time after acquiring and developing certain skills and capacities for self-sustainability, daily living management by the residents, it is planned to reduce the number of personnel.

The residents of Spitak Care Home actually had 2 options of choosing a place of residence: either to live in closed institutions providing care and treatment services to persons with psychosocial and mental disabilities or move to Spitak Care Home. Such a strictly limited option for decision-making itself doesn't conform to the principle set forth in Article 19 of the UN Convention. In the meantime, it is noteworthy that persons at Spitak Care Home have recorded positive changes in their lives during the recent year.

The residents of Spitak Care Home were transferred from:

⁶ <https://www.hrw.org/report/2017/02/22/when-will-i-get-go-home/abuses-and-discrimination-against-children-institutions>

- Vardenis Neuropsychological Boarding Home, 5 persons,
- “Hans Christian Kofoed” Charitable Foundation temporary shelter for the homeless, 1 person,
- "Dzorak" care center for people with mental disabilities, 1 person,
- Spitak, Shnogh, and Vanadzor communities of Lori Marz, 1 person from each community (persons receiving out-patient treatment, who need relevant support and care in the community).

Although Spitak Care Home has ensured only positive changes in terms of protecting the rights of persons with psychosocial and mental disabilities, yet, the sustainability of the service is jeopardized due to lack of state funding.

Steps directed at the decision-making by persons with psychosocial and mental disabilities and their integration in the community

The life for persons with psychosocial and mental disabilities in Spitak community and particularly in Spitak Care Home is interesting and diverse. These persons have not only established new social contacts in Spitak community, but some of them have also restored previous contacts with their relatives.

They communicate with neighbors, receive guests from both the community and other cities of the Republic as well as from overseas.

With the initiative of the personnel, persons enjoy the opportunity to freely stroll in the Home territory and also outside it given a relevant permission. During their stay at Home, the art therapist significantly helps them to spend an interesting day. Occupational means, like crosswords, embroidery and painting utensils and etc. have been acquired for occupational purposes.

The Care Home residents point out the warm relations at home and that they don't feel lonely. Their routine is filled with interest due to genuine talks with the staff and human contacts which came to replace the former controlling-controlled relations in the institutions. They also recall that the residents of their previous institutions were too many and the staff could not pay due attention to persons with psychosocial and mental disabilities. In the meantime, they also quote, “They drink coffee more than they work.”

Although one of the residents has encountered an obstacle by the family in terms of acceptance in the community, another resident has restored contacts with the family during the initial period of the latter's stay in the Care Home.

The family members of the first resident that live in Spitak community particularly did not accept him. The resident's relatives even rebuked that their former family member had been without their permission moved to Spitak, their place of residence.

With the initiative of the other resident's relatives the latter visits paternal house for overnight stay. The family members also often visit him/her, go walking and shopping together. Whereas, during the previous 16 years spent in a closed institution the family members seldom visited the person.

The problem encountered by the first resident hints on the presence of stereotypes, stigma against persons with psychosocial and mental disabilities as well as shame felt by their relatives due to their disability not only among public at large but also among specific groups of people. It is noteworthy that the inclusion of persons with psychosocial and mental disabilities in the community through community-based services is also a contributing factor to break such stereotypes.

There has been an immense positive shift in the Care Home in terms of decision-making by the residents; however, the latter have not yet reached full independence and self-sustainability.

Living in a closed type of institution for quite a long period the residents have got accustomed to decision-making on their behalf, while in Spitak Care Home they make both participatory and independent decisions.

According to the residents, Spitak Care Home endowed them with a chance to make decisions from the first day of their placement there. Furthermore, the residents do not still come up with an initiative to participate in the decision-making process. For instance, the residents don't have their participation in the making of the menu, as such. Although the residents' preferences are always taken into account, the menu is compiled by the staff. The residents find that the food is anyway varied and delicious, and their participation in the menu making is needless.

It is noteworthy that some of the residents have acquired skills to make food independently. They note that they know how to make dishes, but they have not tried it unaided.

With regard to reshuffles in the Home the residents don't either manifest independence. The residents are still under almost permanent surveillance of the staff, which also negatively affects their full comprehension over the acquisition of independence.

Some of the staff's approach that persons with psychosocial and mental disabilities "are poor and helpless" is problematic; therefore, they need being permanently taken care of. The presence of constant control by the staff is conditioned by this fact.

It is noteworthy that the residents of Spitak Care Home have started paying attention to their self-expression: particularly, the women have changed their hairstyles and refreshed their wardrobes. We can point out that if the conduct of isolation from the community and long-term residence in the institution was vivid immediately after their placement; living in the care home has entailed positive changes in this respect, too.

Exclusion of ill, inhuman or degrading treatment

Staff-resident, resident-resident relations in Spitak Care Home are warm and respectful.

Some of the residents of Spitak Care Home note they have not witnessed any acts of violence, whereas, in the institution they were personally subjected to violence. The residents state that the staff of Care Home are very attentive, "there is nothing that upsets us".

According to the residents, the overall positive and healthy atmosphere positively impacts on their inner world.

In Spitak Care Home persons with psychosocial and mental disabilities are engaged in household cleaning, gardening, which is carried out by their initiative and desire. The residents note that they should be responsible for the tidiness and good maintenance of “their room and home”.

Exercising labor right

One of the goals of Spitak Care Home is to lead its residents into an independent life, which also implies assistance with job placement.

None of the Home residents has so far got a long-term job, but they had a chance to carry out short-term jobs and after long years of inactivity they independently earned their own living. The Care Home residents particularly received an offer to carry out agricultural work and got small remuneration as compensation for the work.

One of the residents, who is a teacher by profession, but has for long years given up any teaching activities related to her profession, currently teaches one of the neighboring resident’s children in the Care Home.

One of the residents of Spitak Care Home valorizes having a job and states, “Here we are given an opportunity to enter community life and work, it was here that I realized I need a job, and that I will thereby support the society and many of my problems will be solved”.

The Care Home residents visualize a perspective for a long-term job placement.

In the Care Home the person with psychosocial and mental disabilities has the opportunity to independently manage his/her earned money and do it successfully. The residents independently decide and buy any item they want. Previously, during their stay at closed institution they were denied such a chance. However, it is worth mentioning that during the operation of the Care Home, the resident also bought goods that were harmful to their health.

Exercising of privacy

The residents of Spitak Care Home enjoy the opportunity to organize their privacy without being subjected to arbitrary or unlawful interference.

The residents of Spitak Care Home have the opportunity to make unlimited number of uncontrolled calls from the landline phone at any time, some of them also from their personal cell phones (it is noteworthy that one of the residents was not allowed to have a personal phone; even though the latter’s family member was against, he/she was provided with a cell phone in the Care Home; one of the residents was presented with a gift cell phone by the latter’s family members).

If necessary, the residents of the Care Home may send and receive letters without any censorship.

The residents delicately note that there is “nothing to hide” in Spitak Care Home and the lack of control during call making is conditioned by that fact.

Relevant material conditions have also been created to ensure the privacy of the residents of Spitak Care Home. For every two residents of the Home one bedroom with a toilet and bathroom is allocated. Each of the roommates is provided with a bed, cabinets, clothing and other articles.

The personal areas in Spitak Care Home are not checked by the staff or as one of the residents notes, “the staff member merely watches so that they do not keep unnecessary items”, “the staff member tells if you are not going to wear it, don’t keep it with you” or the personnel make sure they maintain tidiness and order.

Some of the residents of Spitak Care Home think they can found a family, and are thinking of having a personal life.

Problem of ensuring the right to equality before the law

Article 12 of the UN Convention on the Rights of Persons with Disabilities stipulates everyone’s equality before the law. Whereas, pursuant to the RA legislation, persons with psychosocial or mental disabilities may be declared legally incapable being deprived of the possibility to properly and fully exercise their rights, including decision-making and independent acting.

Some of the Spitak Care Home residents are also declared legally incapable. Furthermore, the persons transferred from Vardenis Neuropsychological Boarding Home were declared legally incapable also because it was one of the requirements for their admission into the said institution.

The fact of being recognized as legally incapable has created a number of problems for the residents and the staff in Spitak Care Home as well.

Unlike other boarding homes for adults functioning under the RA Ministry of Labor and Social Affairs, the residents of Vardenis Neuropsychological Boarding Home are legally deprived of the possibility to get pension irrespective of being declared legally capable or incapable. Although such a restriction doesn’t by force of law apply to Spitak Care Home or other similar non-governmental organizations, after their placement the persons did not have a chance to get the available pension contingent upon their legal incapacity.

On top of the problem with pension, some of the Care Home residents, declared legally incapable, encounter problems of managing their property and signing a labor contract.

Moreover, some of the staff members find such restrictions of the persons’ rights inconceivable, since the latter have a good insight of the consequences of their actions.

Recommendations

To the RA Ministry of Labor and Social Affairs

- Undertake necessary measures to allocate funds from the state budget for the functioning of Spitak Care Home.

- Introduce community-based services for persons with psychosocial and mental disabilities in other marzes and communities based on their needs.
- Revoke the decision of declaring a person legally incapable as a precondition for their admission into the institutions operating under the Ministry.
- Take measures to replace the institute of declaring a person as legally incapable with the institute of supporting decision-making.
- Widely elucidate the activities of Spitak Care Home for the increase of public awareness by retaining the right to confidentiality of personal data.

To the staff of Spitak Care Home

- Pay greater attention to the involvement of both male and female residents in the household matters, including:
 - Independent cooking in the kitchen
 - Self-service
 - Implementation of reshuffles upon necessity and desire
- Contribute to the decision-making by the residents, including:
 - Make a menu
 - Project plans during the day or week
 - Independently choose clothing, hygienic and other personal items