



REPORT

FROM THE VISIT TO THE

*Special Institution in
Demir Kapija*





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Publisher:

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Authors:

Tona Kareva Taleska and Aleksandra Trajanovska

Graphic design:

Hamid Arif

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Introduction

This report was prepared within the framework of the project “Strengthening human rights and services for children and vulnerable persons at risk in closed institutions”. The main objective of the project is to contribute to the improvement of services for target groups through a human rights-based approach. The specific objectives are aimed at improving conditions and protecting human rights, strengthening the capacities of staff and encouraging cooperation between local activists, institutions and the community. Within the first part of the project activities – monitoring and visit – a visit was carried out to The Special institution in Demir Kapija and the housing units.

The monitoring of the Special institution in Demir Kapija and the housing units was conducted by a team consisting of: Tona Kareva Taleska and Aleksandra Trajanovska from the Helsinki Committee for Human Rights, as well as from external collaborators: Prof. Dr. Liljana Ignjatova, psychiatrist, and Bojana Jovanovska, social worker.

During the visit, interviews were conducted with the institution's staff, including the acting director, who is also a special educator, two social workers, three coordinators of organizational units, two nurses, one laboratory assistant, and more than twelve caregivers.

The visit was conducted based on a previously developed methodology, and the goal of the monitoring was to obtain a comprehensive picture of the current living conditions, healthcare, staff capacity, organizational practices and the degree of implementation of the deinstitutionalization process in the institution, with the aim of developing recommendations for improving the quality of services and protecting the rights of beneficiaries.

Findings from the monitoring visit

GENERAL INFORMATION

The Special Institution in Demir Kapija is the oldest institution for persons with intellectual and combined disabilities in the country, with a long history of institutional care, spanning several decades. Initially established as a closed institution, the Institution has for years been a central institution for long-term and, in many cases, permanent residential care for persons with severe and profound intellectual disabilities. The deinstitutionalization process, formally launched in 2008, was supposed to mark the gradual abandonment of large institutions and the establishment of small, shared forms of care. However, its implementation in the following years was slow and with limited results, mainly due to insufficient financial support, staffing deficits and the system's unwillingness to implement a comprehensive reform.

Only after a decade, the process was re-intensified through the adoption of new strategic documents and transformation programs, with the support of international partners, when the first transfers of beneficiaries to small group homes began. At that time, a significant step was taken towards the practical application of the community-based care model, with some of the former beneficiaries of the Institution being transferred to small group homes, most often in rented apartments in Demir Kapija and in surrounding towns, such as Negotino. Small group homes were conceived as a temporary solution and a transitional form towards family or supported independent care.

The team engaged in each housing unit consists of: 4 caregivers, 1 coordinator, 1 social worker, as well as one nurse and one head nurse from the Demir Kapija Special institution. The caregivers work in two 12-hours shifts, with 2 days off after the shift.

The housing units operate within the framework of support from the institution, which provides hygiene products, medicines and food. The nurse visits once a week and delivers the necessary therapy to the beneficiaries, and the psychiatrist comes twice a month.

Each facility is equipped with a kitchen, washing machine, bathroom and toilet, bedrooms, living room and terrace. Users have their own wardrobes, and clothes and bedding are washed twice a week or more often, as needed. Bathing is done by the caregivers.

Unfortunately, stray dogs are observed in Demir Kapija,¹ which restrict safe movement and walks outside the housing units. Additionally, architectural barriers such as stairs and unpaved paths restrict the movement of wheelchair users.

The main building of the institution has not undergone renovation for years, due to the ban on new accommodation and the expected move to the new facility, the so-called Dependance, which has been completed but is still non-functional due to technical problems with the heating and cooling system. Employees and beneficiaries have been waiting for a long time for intervention by the Ministry of Social Policy, Demography and Youth, so that the move can finally be carried out. Preparatory activities have begun for the transformation of public institutions for the provision of social services in the community, with funds provided from IPA 3 funds for the complete renovation of the old facilities, which will also involve the relocation of beneficiaries to the new building.

¹These are dogs owned by neighbors or stray dogs, especially in a single housing unit that has an unpaved path, which makes things somewhat more difficult.

Capacity

According to information received from the director of the institution, the total number of beneficiaries cared for in the Institution and in small housing units is 117 people, of whom 54 are placed in the Institution and 63 in housing units in the community.

Two beneficiaries are foreign citizens without an ID number, one person is unknown and one person does not have regulated citizenship. For these persons, the costs are covered privately.

Staffing

The institution employs:

- 10 nurses
- 2 head nurses
- 4-5 caregivers in each housing unit)
- 1 laboratory assistant
- 2 physiotherapists
- 1 instructor
- 3 social workers (one is a coordinator)
- 4 special education teachers
- 1 director

Non-medical personnel:

- 2 lawyers
- 2 economists
- 1 bookkeeper
- 1 archivist
- 2 warehouse workers
- 6 kitchen employees (2 chefs and 4 kitchen assistants)
- 5 employees in the laundry.

The number of medical staff is below the minimum standards. Staff leave the institution more often than new people are hired. Although salaries are higher compared to other social institutions, the job is not considered attractive.

An additional factor is the emigration of the population from the city and the region. (The institution has already submitted a request for the employment of 2 nurses.)

Only two nurses are present during night shifts.

The staff has attended training on how to deal with aggression, but there is a lack of continuous training, especially on how to deal with emergency medical conditions

Handling cases of aggression

Aggression is present among users, but also towards staff. Around 20 users manifest pronounced aggressive behavior.

In cases of aggression, a protocol is followed. The practice described by the staff includes:

- physical restraint of a person in order to prevent injury,
- removal from the environment where the conflict occurred,
- walking and calming down,
- giving water,
- administering therapy after consultation with a doctor

Mechanical restraint is not used. Staff physically restrain the user to prevent injury. The only form of restraint used is a wheelchair restraint belt, with a caregiver present at all times.

There have been cases of attacks on staff. One user is being treated at the Psychiatric Hospital Skopje and some receive depot antipsychotic therapy.

But it often happens that two female staff members deal with the aggression that occurs. They describe a situation that happened that morning, with an aggressive user, and how they dealt with him – first they physically hold him and squeeze him, then they give him plenty of water to drink, take him outside the environment where the conflict occurred, if the situation allows it, walk him and give him medication on the recommendation of a doctor, after the nurse communicates with the doctor.

There was a case where a caregiver was attacked by a user, who has been treated at the Psychiatric Hospital "Skopje" on several occasions and is placed on a depot preparation (an antipsychotic in the form of a depot monthly injection). The caregivers use only a wheelchair safety restraint, as a protection for the user from falling out of the wheelchair, with one caregiver constantly next to the user.

The institution does not have a soft (sensory) room for dealing with a crisis situation; it is planned to create one in the building, which is under reconstruction.

Living conditions

The material conditions in the institution are below acceptable standards, with the presence of dampness, mold, and unhygienic conditions, especially in Ward C, where beneficiaries with the most severe behavioral challenges are housed. Section A currently houses 18 people. The bedrooms and the common room are in relatively good condition, but the remaining sanitary and auxiliary rooms are dilapidated. In Section B, where 14 people are housed, the conditions are very poor. Damaged walls with holes to adjacent rooms, cracked glass on the doors have been noted. Section C, which houses 20 people, is the most worrying section, in which the condition is below human living standards and requires urgent intervention. The plasterboard walls are damaged, and the mattresses are old and torn.

The main building of the institution has not undergone renovation for years, due to the ban on new accommodation and the expected transfer to the new facility, which has been completed, but is not yet functional due to technical problems with the heating and cooling system. Employees and beneficiaries have been waiting for a long time for intervention from the Ministry of Social Policy, Demography and Youth, so that the move can finally be implemented.

Preparatory activities have been initiated for the transformation of public institutions for the provision of social services in the community, with funds provided from the IPA 3 funds for the complete renovation of the old facilities, which will also take place in parallel with the relocation of beneficiaries to the new building.

The facility has no elevator and is not accessible to persons with physical disabilities, so staff are forced to improvise and make do.

Nutrition

Beneficiaries receive three meals and two snacks per day. The following is provided:

- diet for people with diabetes,
- pureed diet for people who cannot consume solid food.

The menu also includes fruits and vegetables.

Clothing

In the housing units, the users use personal clothing. In the institution, the clothing after washing can be used by different users

Hygiene

Hygiene in the institution is at a low level, unlike the housing units, where the condition is good.

There is an unpleasant odor in several wards, especially Ward C.

Clothes are washed daily, and bed linen twice a week (in the housing units up to three times a week).

For users who cannot control their sphincters, diapers and protective underpads are used, but some users do not tolerate them and remove them, especially in Ward C.

At the time of the visit, In Section B there were insects and cats roaming around the premises. Disinsection is carried out as needed, but the problem recurs. There were no insects in the housing units.

All the users in the institution are not regularly taken out to fresh air.

Leisure activities

Leisure activities are limited, although there is a positive practice with the picking and selling of lavender. There is an established practice for organizing the leisure time of the beneficiaries from the Institution and from the housing units for their socializing, joint activities, birthday celebrations, holiday activities, joint activities with children from the local school and kindergarten, organized meetings in a local bar – the last one was for Easter.

Health care

Out of 117 beneficiaries, 115 have a family doctor. A systematic examination was performed a year ago (blood count, glycemia and biochemical analyses). No tests for hepatitis B and C were performed. No chest X-ray screening has been performed. There is no registered person positive for TB. The most common health problems are respiratory infections, bronchitis and there are 4 people with COPD (chronic obstructive pulmonary disease).

A psychiatrist is hired on a contract basis and visits the facility twice a month, but is available 24/7. Records are kept of therapy (antipsychotics, anxiolytics, and antiepileptics). Some of the beneficiaries receive depot antipsychotic therapy (monthly/injection every 21 days).

Common psychiatric conditions are self-harming behaviour, aggression towards others and destructive behavior.

A large number of users have been diagnosed with epilepsy, but no EEG is performed. Also, no ECG is performed – although there is a device in the facility, It is not in use. The laboratory is not operational at the time of the visit, however, laboratory findings are made every day, if necessary.

About a dozen users have anemia.

Family doctors conduct assessments approximately once a month. When an indication is determined by a family doctor, beneficiaries are sent to some health institutions. Although in most cases beneficiaries are admitted and examined, the staff reports that there have been cases where some of them have been returned from some health institutions without being examined.

For women under 50 years of age, contraception is used with the consent of a guardian.

In the event of a deceased beneficiary, the primary care physician and emergency medical services are notified to diagnose the death. Autopsies are not performed in the event of death.

A physiotherapist is hired twice a month and provides services at the institution. Beneficiaries also receive shoes and insoles in collaboration with some companies. Dental services are available primarily for tooth extraction; prosthetic rehabilitation is not provided.

Contacts with the outside world

Four beneficiaries, for whom it is appropriate, move outside the institution freely and without restriction, go to a store or in the immediate vicinity of the institution and return, i.e. their freedom of movement is not restricted.

Visits are allowed, but a small number of beneficiaries have regular contact with their families. Most often, visits are 1-2 times a year. A larger number of beneficiaries have no visits. A report is prepared for each visit by a nurse or social worker.

The beneficiaries have guardians (family or officially appointed). Some of the beneficiaries have not been deprived of their legal capacity

Staff suggestions

The director and some of the staff believe that the working conditions in the housing units have improved compared to the previous period, but are still not sufficient to fully and qualitatively meet the needs of the users. In this regard, they propose the development and improvement of the following services and activities:

- Establishment of a Day Care Center in Demir Kapija.
- Organizing training for users on creative work and establishing creative workshops.
- Utilizing the institution's existing resources (grape plantations) to encourage self-sustainability and work engagement of beneficiaries who are capable of it.
- Continuation and improvement of good practices for harvesting and selling lavender.

They stated that these services are scheduled to begin with the reconstruction, which has begun to refurbish and renovate the new building.

Findings from the visit to the housing units in Demir Kapija

Housing unit 1

This housing unit accommodates five residents, three men and two women, one of whom is immobile. A caregiver and the unit coordinator were present during the visit. Medications are stored and distributed according to a list, and meals are prepared by the caregiver, with occasional assistance from the residents. Residents have the opportunity to participate in daily activities such as washing and folding clothes, and are also taken out for fresh air and sometimes for a walk outside the unit.

Housing unit 2

This unit accommodates five users, two men and three women, one of whom is blind and one is immobile. The caregiver and the coordinator were present. The hygiene in the premises is satisfactory, and the users are dressed in clean and their own clothes. There is a list in the unit with the names of the users, the medications they use and the time they are given to the users. One user receives an antibiotic by injection in the hospital, while the others receive therapy according to the schedule. The users sometimes participate in preparing meals and in other activities according to their abilities, and going out for fresh air is provided within the unit. During the visit, lunch was prepared for the users, and in addition to the main meal, they had a dessert.

Housing unit 3

This housing unit accommodates six residents, one male and five females. The caregiver and coordinator were present. Two of the residents are anemic, with marked pallor. The unit is located on the first floor. From the house and the stairs limit going outside, although the terrace allows partial movement. The terrace is equipped with a table and chairs. Hygiene is satisfactory, and there is a bath chair in the bathroom. The users are dressed in clean clothes and participate in the preparation of meals.

Housing unit 4

This unit accommodates six beneficiaries, three men and three women. The caregiver and the coordinator were present. The housing unit is spacious, and has a terrace equipped with chairs, where beneficiaries can go out into the fresh air. However, the unit is on a floor with stairs, which makes it inaccessible to the yard and outside the yard. However, according to the employees, the rent is very affordable. Hygiene and conditions are satisfactory, and beneficiaries are dressed in clean clothes. Meals are prepared with the help of the staff and sometimes beneficiaries participate in its preparation

Housing unit 5

The unit accommodates five users, two men and three women. The caregiver and the coordinator were present. One user is anemic, and one user has epilepsy, psychosis and diabetes. His blood sugar has not been checked for more than seven months and he does not receive a special diet. Humidity was noticeable in one room and hygiene is not satisfactory, although all users are dressed in clean personal clothing.

Housing unit 6

This housing unit accommodates six beneficiaries, two men and four women. The caregiver and the coordinator were present. One of the beneficiaries has epilepsy and receives regular therapy. Additionally, some medications, such as vitamin D for osteoporosis, are provided by family members. Hygiene is satisfactory, and the beneficiaries' clothing is clean.

Housing unit 7

This unit accommodates five users, three men and two women. One male caregiver and the coordinator were present. The users are bathed by a female caregiver. The housing unit has a small terrace, but going outside is limited due to space, although the users wish to do so. There is dampness and mold in the rooms, and hygiene is not at a satisfactory level. One of the users is a smoker. The users have their own lockers and clothes, and they are all dressed in clean personal clothing. One user who was wearing diapers was noticed to have leaked her diaper, and after we pointed it out, we were told that each user only has three diapers per day and they must be saved.

Housing unit 8

This housing unit is home to five beneficiaries, two men and three women. The caregiver and coordinator were present. One room accommodates one young beneficiary and one adult beneficiary together; this is the room that was the day care, but since they both stay later to watch TV, they are accommodated in that room. The unit is located on the ground floor and beneficiaries are free to go out. The villagers do not stigmatize the beneficiaries and they are involved in activities such as collecting and selling lavender. One of the beneficiaries is friends with young people from the village, he goes to them and they come. The staff report that this unit is a positive practice. Some of the beneficiaries are involved in an activity of collecting lavender, which they sell at a fair in Negotino, they collected money and one of the beneficiaries reports that they bought a necklace with the money.

This beneficiary has intellectual disability. Although the institution does not accept people with that categorization, he freely leaves and returns to the housing unit, makes friends with some young people from the village, and was also the most successful in selling lavender at a fair, so he received a necklace as a gift from the money he earned. Hygiene in the unit is at a satisfactory level. All users are dressed in clean, appropriate and their own clothes

Findings from the visit to the housing units in Negotino

Housing unit 1

This housing unit accommodates five users, three of whom are male and two are female. Two users are immobile (one male and one female). Only one user has developed speech, and one user has sphincter control. One of the users can independently go to the store and shop with funds provided by his brother. The nurses are organized so that each bathes one user. Hygiene in the unit is at a satisfactory level. Users use clean, appropriate and personal clothing. Laundry is done regularly, as well as whenever necessary.

Housing unit 2

Five beneficiaries are cared for in this housing unit, one of whom was transferred from the Demir Kapija Special Institution and four from the Topansko Pole Institution. During the visit, it was noted that one beneficiary was spitting blood, which is why he was taken to the hospital in Kavadarci. None of the beneficiaries have sphincter control and all use diapers. Four people have no developed speech, while one person communicates through gestures. All beneficiaries receive therapy prescribed by a psychiatrist, which is given to them by the caregivers. The psychiatrist makes regular visits, as well as additional visits as needed. Hygiene in the unit is satisfactory. Users use clean, appropriate and personal clothing, and laundry is done regularly and as needed.

Housing unit 3

Five beneficiaries, two males and three females, are cared for in this housing unit. During the visit, one of the beneficiaries was sleeping. Only one beneficiary has developed speech, while the others are receiving therapy in accordance with the recommendations of a psychiatrist. Access to the toilet is via stairs, but an access ramp is also provided. Users have the opportunity to go out for fresh air in the yard of the unit, where an access ramp is also installed. Hygiene is at a satisfactory level, and all users are dressed in clean, appropriate clothing. Laundry is done regularly and as needed.

Housing unit 4

This housing unit accommodates five users, one male and four female individuals. It has been noted that there are no wheelchairs, and one user, who is immobile, lies on a mattress placed on the floor. One of the users displays aggressive and hyperactive behavior. In the recent period, she has developed a closeness with a male user, during which she shows physical closeness (kissing). She receives psychiatric therapy, as well as contraception. Hygiene in the unit is at a satisfactory level. Users are dressed in clean, appropriate and personal clothing.

Concluding observations

The Special Institution in Demir Kapija is an institution with the longest history of institutional care for people with intellectual and combined disabilities in the country. Its decades-long role as a central closed institution has left a strong institutional model of functioning that, despite the formally initiated deinstitutionalization process in 2008, has not yet been fully overcome. In the past decade, certain steps have been taken through the opening of small group homes and the transfer of some of the beneficiaries to the community, but the transformation process remains partial and structurally unfinished due to insufficient financial support, staffing deficits, systemic unpreparedness and the absence of continuous institutional investment. The material conditions in the main building, especially in Department B and Department C, are below the minimum standards for a dignified life, with the presence of damp, mold, damaged walls, dilapidated equipment and a low level of hygiene, and the insufficient staffing support and the presence of aggression create an environment that does not meet the needs of the beneficiaries. It is particularly worrying that the newly built, which was supposed to be a key step in the transformation of the institution, has not yet been put into operation, which deepens the structural inefficiency of the institution and limits the possibility of transferring beneficiaries to better conditions.

The visit to the housing units in Demir Kapija and Negotino indicated that life in small group homes allows for greater inclusion, individualized care and participation of beneficiaries in daily activities. In most units, beneficiaries participate in preparing meals and maintaining hygiene, and they are also free to go out in the fresh air, while in some units access to the outside space is limited due to architectural barriers. Hygiene and equipment in the housing units are generally satisfactory, although problems with humidity and partial inaccessibility for people with limited mobility are noted. In some cases, health care, especially for chronic conditions such as anemia, epilepsy or diabetes, is not regularly monitored². In some units, positive practices are observed, with beneficiaries actively involved in local activities, such as collecting and selling lavender, which contributes to their autonomy and social inclusion. In all units, beneficiaries are dressed in clean, personal and appropriate clothing, and staff provide support and care in accordance with their needs.

In summary, the Special institution is in a state of transition between a traditional institutional model and an initiated but unfinished transformation. Despite positive practices in the housing units, the institution remains faced with structural and systemic challenges that limit the full realization of the right to a dignified life and integration of the beneficiaries into the community.

² Note from the institution: All examinations are performed continuously and daily and appropriate therapy is provided in accordance with the guidelines of primary care physicians and specialist doctors

Recommendations

Based on the established factual situation, the conversations conducted and the direct insight, the recommendations are grouped into the following thematic areas:

RECOMMENDATIONS RELATED TO THE TRANSFORMATION OF THE INSTITUTION AND THE NEW FACILITY SO CALLED DEPENDANCE:

- *To ensure the immediate commissioning of the new building by overcoming the existing technical obstacles (heating and cooling system), with clearly defined deadlines and responsibilities by the competent Ministry.*
- *To develop a clear operational plan for the relocation of beneficiaries in the new building, which will determine the phases of relocation, the criteria for selecting beneficiaries, and the necessary personnel and logistical support.*
- *When putting the new building into operation, priority should be given to beneficiaries housed in Section C, given that the conditions there are below the minimum standards for a dignified and safe life and pose a high risk to the health and well-being of beneficiaries.*
- *To ensure that the new building is fully compliant with accessibility standards, including elevators, ramps, adapted restrooms, and spatial solutions for people with severe and combined disabilities.*
- *To prevent the repetition of the institutional model in the new facility, by limiting the number of users per housing unit, providing privacy, personalized space, and daily activities oriented towards community life.*

- *To ensure adequate staffing before and during the move to the new building, with additional hiring and training of staff to work in a transformed care model.*
- *To establish regular external monitoring of the process of putting the new building into operation, with the participation of independent bodies and civil society organizations, with the aim of transparency and protection of the rights of the beneficiaries.*
- *To establish a clear status of the new building as a transitional, rather than permanent, form of accommodation, with parallel investment in the development of community services (supported living, family care, individual apartments).*

HEALTH CARE:

- *To put the existing medical resources (ECG - device and laboratory equipment) into operation and to provide professional staff for their use. – There is a laboratory technician who constantly performs his duties in accordance with the instructions of the doctors regarding all laboratory analyses.*
- *To establish a practice of regular systematic examinations (ECG, EEG, laboratory analyses), with proper medical records. – For each beneficiary there is a medical file that includes all medical analyses and examinations.*
- *Establish regular screening for infectious diseases (including hepatitis B and C) and periodic fperiodic chest X-ray screening in accordance with public health standards.*
- *To establish regular glycemic control among users with diabetes and to ensure an appropriate diet. – An appropriate diet is continuously provided in accordance with the recommendations of doctors and regular glycemic control is performed.*
- *To provide ongoing dental care, including prosthetic rehabilitation, when medically indicated.*
- *To conduct regular reviews of psychiatric therapy, especially for minors, by a child psychiatrist.*

- *To provide regular assessment by a physiatrist and individualized physical therapy plans. – We have a consulting physiatrist with whom we have continuous cooperation and wheelchairs, commodes, orthopedic shoes are provided for the beneficiaries in accordance with the recommendations of the physiatrist.*

HUMAN RESOURCES CAPACITIES AND TRAINING:

- *Measures should be taken to attract, retain and appropriately value professional staff, by improving working conditions.*
- *Increase the number of medical personnel, especially on night shifts.*
- *Establish a continuous staff training program, including: handling emergency medical conditions, de-escalation techniques, working with people with complex needs , as well as prevention of professional burnout.*

HANDLING CASES OF AGGRESSION AND PROTECTION FROM INAPPROPRIATE TREATMENT:

- *Estblish or improve a protocol for managing aggressive behavior, with a clear focus on de-escalation and minimizing physical interventions.*
- *To introduce mandatory written records for every incident of aggression and every form of physical restraint, with regular internal and external audit. (There is a daily logbook, in which any incidents and injuries are noted.)*
- *To provide and put into operation a soft and sensory room as an alternative calming measure in a crisis situation.*

INDIVIDUALIZATION OF SUPPORT AND QUALITY OF LIFE:

- *To establish individual support plans for each beneficiary, with regular review by a multidisciplinary team. (There are individual plans for each beneficiary.)*
- *To strengthen organized daily activities and work engagement in accordance with the abilities of the beneficiaries. (There are already well-organized daily activities and work engagement of beneficiaries who are able to participate.)*
- *To ensure regular and organized fresh air for all users.*
- *To continue and intensify the process of deinstitutionalization and development of community services.*

RECOMMENDATIONS FOR HOUSING UNITS:

- *When selecting housing units, ensure full physical accessibility, especially taking into account the mobility of the users. It is recommended to use ground-level buildings or buildings with adequate access (without architectural barriers), with solid and quality construction, as well as conditions that guarantee the absence of moisture and mold.*
- *Appropriate measures should be taken regarding the presence of stray dogs in the area, in cooperation with the competent services, in order to ensure safe and unhindered movement of users outside the housing units.*
- *To establish regular glycaemic control in users with diabetes, who should be provided with an appropriate diet in accordance with their health condition and medical recommendations.*
- *To conduct a professional review of the therapy for minors by a child psychiatrist, in order to assess the appropriateness, effectiveness and the possible need for modification or adaptation of the therapeutic approach.*



