PECULIARITIES OF THE TRANSFORMATION'S PROCESS MANAGEMENT OF MEDICAL INSTITUTIONS OF CHILDREN'S INSTITUTIONAL CARE AND UPBRINGING INTO AN INCLUSIVE ENVIRONMENT FOR CHILDREN WITH DISABILITIES

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Abstract. The effective implementation of the deinstitutionalization and transformation reform of institutions of children's institutional care and upbringing is currently one of the priorities of the state's social policy, because the future renewal of the country's human resources potential and further prosperity and well-being of Ukraine depends on the ability to socialize children and provide quality social, medical, educational services for children and families with children and their harmonious development. In accordance with the principles of deinstitutionalization and decentralization reform, local governments have to ensure the development of all types of health care, development and improvement of the medical institutions network, determining the need and forming orders for staff for these institutions, provision in accordance with the legislation of privileged categories of the population with medicines and medical devices, including families with children with disabilities (Article 32 of the Law of Ukraine "On Local Self-Government in Ukraine"). At the same time, the health care institutions network should be formed taking into account the needs of the population in medical care, the need to ensure the proper quality of such services, timeliness, accessibility for citizens, efficient use of material, labor and financial resources (Article 16 of the Fundamentals of the Legislation of Ukraine on Health Care). Adhering to the above principles in the Lviv region to comply with the order of the head of the Lviv regional state administration № 719/0/5-19 from 05.07.2019 "On conducting a comprehensive assessment of the municipal institution of the Lviv regional council" in "Orphanage № 2 for children with central nervous system disorders and mental disorders" in the period from July 22 to October 21, 2019 was carried out a comprehensive assessment process in order to further transform this institution. The results of this assessment and medical statistics provided an opportunity to analyze the need of Lviv region for inclusive medical rehabilitation services for children and families with children.

Keywords: public administration, children, social services, medical services, deinstitutionalization, inclusion, institutional institution, medical institution, evaluation, reform, decentralization.

JEL Classification: J13, J18, I18, H83, H75, H72, H51, H52, Z18

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Introduction. According to the report of the Center for Medical Statistics of the Ministry of Health of Ukraine on children with disabilities under the age of 18 living in the area of treatment and prevention facilities, orphanages or boarding schools, at the end of 2019 there were 163 thousand children with disabilities. 100% of these children need medical rehabilitation services. After all, according to current legislation, every child with a disability has Individual Rehabilitation Program (IRP) for Persons with Disabilities, which determines a set of optimal types, forms, amounts, timing of rehabilitation measures with determination of the order and place of their carrying out, aimed at restoring and compensating for impaired or lost body functions and the ability of a particular person to perform activities, defined in the recommendations of the medical and social expert commission [1].

When comparing statistics for recent years, there is a tendency to increase the number of children with disabilities by about 1.5-2% per year. On average, about 16,000 new cases of child disability are registered in Ukraine every year [1].

In addition, a significant number of children are registered each year who do not have the status of a disabled child, but have vital activity limitations in need of rehabilitation care. These include children of the first year of life who were born with various health disorders or have pathological conditions that occur in the perinatal period (which are well amenable to rehabilitation treatment and do not always lead to disability); children who have received injuries that require a long-term rehabilitation process (these conditions are not grounds for disability assignment), etc.

However, the existing network of institutions that can provide medical rehabilitation services does not provide rehabilitation assistance to the entire number of children in the country who need it. Today in Ukraine there are 54 institutions in the health care system that provide rehabilitation assistance to children. The average number of children undergoing rehabilitation treatment per year is about 37 thousand people. Moreover, it should be understood that some of these institutions specialize in providing medical rehabilitation services only for acute and subacute pathological conditions, and children with disabilities need long-term, sometimes lifelong, rehabilitation care [2].

There are also 2 institutions (Poltava, Chernihiv), subordinated to the Ministry of Social Policy of Ukraine and a number of institutions of the Ministry of Education and Science of Ukraine, which provide some services related to the system of medical rehabilitation. But the total capacity of all these institutions is still not enough. There are no exact statistics on the number of children in need of medical rehabilitation services, but even if we take into account only children with disabilities, which is 163,886 people, the powerful capacity of existing institutions does not cover 30% of the need [3].

At the same time, Ukraine is currently undergoing a nationwide health care system reform and a children's institutional care and upbringing system reform (DI deinstitutionalization reform), which provide for a radical change in the health care financing system and a number of significant changes in the health sector as a whole. Today, health care institutions have to enter into agreements with the National Health Service of Ukraine (NHSU) for the provision of certain medical services. But for each type of service there are approved special requirements for the availability of appropriate staffing, logistics and other support. However, not all medical institutions that provide rehabilitation care meet the required requirements, which will also lead to an even greater shortage of this type of service.

In any case, medical reform is reformatting the existing children's medical rehabilitation system, inherited from the Soviet era, with large centers that are more suitable for spa treatment, which does not fully address the problems of rehabilitation and integration into society of children with disabilities. At present, it takes about a year from the moment a child is referred to a rehabilitation center and to the beginning of treatment - valuable time is lost, the child's condition deteriorates, and rehabilitation takes much longer and less effectively than if the child began receiving

care immediately after the problem detection. This is especially true of rehabilitation measures for young children, which, when started in time, give high functional results and avoid further disability of the child and, in particular, to prevent parents from abandoning children due to health problems. After all, most children are sent to boarding schools due to health problems. This is especially true for young children, ie babies. Exactly congenital malformations, diseases of the nervous system, musculoskeletal system exactly are the main reasons for the admission of children to orphanages, which are boarding schools for the youngest children. The creation of a wide range of quality and affordable medical rehabilitation services for children and their families within territorial accessibility of their place of residence will reduce the percentage of institutionalization of children and ensure their upbringing in a family environment, which is one of the key tasks of institutional institutions reform, which is also currently taking place in Ukraine. Thus, the task of creating and developing local services for children with disabilities and their families, which would improve the child's health, help parents in caring for the child, socialize the child for its future life and avoid its placement in boarding school, meet the common principles of health care reform, decentralization reform and deinstitutionalization reform.

But it is important in the regions (territorial communities) to research in advance what medical services families need to provide their children with adequate medical care, to make an inventory of available services in order to avoid duplication, and only then to identify ways to develop necessary services in the territorial accessibility of the place of residence of families.

Literature Review. Today such scientists as: A. Dakal, J. Bordiyan, V. Sobchenko, O. Radchenko, V. Moskalenko, V. Skurativskyi, O. Paliy, M. Obikhod, E. Libanova study the issues of protection of children's rights and social protection. Such Ukrainian researchers as L. Volynets, N. Komarov, O. Antonova-Turchenko, I. Ivanova, I. Pesha, A. Kapska, I. Pinchuk, S. Tolstoukhova, M. Lukashevych, I. Myhovych and others are engaged in researches of problems of reforming and improvement of osocial services system in general and services for children and families with children in particular. However, reviewing the scientific works of the above authors, it should be noted that the current state of scientific development of reforming the children's institutional care and upbringing system in the activities of public authorities in Ukraine is insufficient, as the spheres of social protection, education, medicine and children's rights are in transformation procces. The processed sources of the conducted research concerned mostly certain aspects of the functioning of the social security system and work with children, namely: the history of formation and development, directions and forms of social families with children.

Aims. Attempt to analyze data from open sources on the need of Lviv region for medical rehabilitation services for children and their families and determine the feasibility of introducing these services in the pilot municipal institution of Lviv Regional Council "Orphanage N^{Ω} 2 for children with central nervous system and mental disorders".

Methods. Conducting statistical analysis of children with disabilities at the regional level. Determining the socio-demographic situation of children in the Lviv

region who have disabilities and forecasting medium-term trends in their numbers. Comprehensive assessment of the municipal institution of the Lviv Regional Council "Orphanage N^{\circ} 2 for children with central nervous system disorders and mental disorders".

Results. At the end of 2019, there were 484,905 children aged 0 to 18 living in the Lviv region. According to the official statistics of the Center for Medical Statistics of the Ministry of Health of Ukraine, in recent years there has been a slight increase in the number of children in the region. The number of children in the region has increased by about 2,000 in the last five years. But at the same time, there is a negative trend in the birth rate, on average 6-8% fewer children are born annually compared to the previous year. In 2019, for 6,000 children less were born in the Lviv region than five years ago, accounting for about 2.5% of the total child population. When comparing statistics for the last five years, there is a tendency to increase the number of children with disabilities - by about 2% per year. On average, more than 1,000 new cases of child disability are registered annually in the Lviv region [1].

While maintaining such negative trends, we can predict that in 5 years in the Lviv region there will be about 17 thousand children with disabilities, and if the birth rate does not increase, the total number of children in the region will decrease by about 6-8 thousand people, which will increase the percentage of children with disabilities in the total child population of the region twice - almost to 5%, and this will also increase the preferential burden not only on the state budget but also on the local budget through providing the decentralization reform, which provides for the transfer of most powers to local authorities, in particular, to address the needs of persons with disabilities. Determining the needs of children in the region in medical rehabilitation services primarily involves identifying the most common diseases and pathological conditions in children that lead to disability and their division into groups of nosologies (diseases) that require a convergent set of rehabilitation services.

According to the Center for Medical Statistics of the Ministry of Health of Ukraine, the main causes of disability of children in Ukraine are diseases of the central nervous system, musculoskeletal system, congenital malformations, mental and behavioral disorders, diseases of vision and hearing. In the Lviv region, these groups of diseases also occupy leading positions as a prerequisite for the emergence of disability [1].

Currently in the Lviv region there are more than 3.5 thousand children with disabilities with congenital malformations, almost 2 thousand children with diseases of the central nervous system and mental and behavioral disorders, half a thousand children with musculoskeletal disorders, which together amount to 67% of all diseases that caused disability. Other diseases that led to disability (tuberculosis, HIV, tumors, diseases of the visual and auditory organs, blood, endocrine system, etc.), all together amounted to 33% (3756 cases) [1].

Each of these groups of diseases requires its own, clinically proven list of medical rehabilitation services, which is aimed at the most effective elimination of clinical manifestations of the disease and restoration of the patient's functional state.

Thus, for the medical rehabilitation of children with diseases of the central nervous system, it is generally accepted to use such rehabilitation services as medical treatment, hardware physiotherapy, Bobath concept therapy, Vojta's method of reflex locomotion therapy, hydrotherapy, therapeutic exercise, therapeutic massage, occupational therapy, kinesiotherapy, reflexology, mobilizing gymnastics and the list of services used in diseases of the musculoskeletal system includes rehabilitation therapy, reconstructive therapy, physical rehabilitation, wax and paraffin applications, as well as therapeutic massage, occupational therapy and kinesitherapy, etc. Medical rehabilitation of congenital malformations includes a range of services that depend on the type of pathology and severity of the child's health, for example, congenital malformations of the intestine may involve the following rehabilitation services-biofeedback-therapy, rectal electrical stimulation, the appointment of daily cleansing enemas in one and the same time of day, therapeutic gymnastics, diet therapy, hydrotherapy, correction of hypovitaminosis and malnutrition. Mental and behavioral disorders in children have their own list of medical rehabilitation services, which is based on the use of rehabilitation techniques such as psychotherapy, game therapy, art therapy, fairy tale therapy, animal therapy (hippotherapy, dolphin therapy), sensory therapy, socio-psychological adaptation and correction, etc.

Medical rehabilitation services are also needed by children who do not have a disability status but have a disease or health condition for which rehabilitation measures are indicated. At the end of 2019, according to the Center for Medical Statistics of the Ministry of Health of Ukraine in the Lviv region, there were about 5,000 such children. In particular, these are children under 1 year of age with diseases of the nervous system (1123 children), diseases of the musculoskeletal system (68 children), diseases of the eye and appendages (1238 children), ear diseases (946 children), certain conditions, which arose in the perinatal period (1468 children) or children who received injuries, poisonings and other consequences of external causes, the number of which in 2019 was 113 people [4].

Today in the Lviv region in the health care system there are 6 institutions that provide medical rehabilitation care to children, including 3 state institutions:

- sanatorium "Velykyi Liubin" (60 beds) provides rehabilitation of children with cerebral palsy (CP);
- municipal institution of the Lviv Regional Council "Orphanage №1 for children with central nervous system disorders and mental disorders" (75 beds);
- municipal institution of the Lviv Regional Council "Orphanage N2 for children with central nervous system and mental disorders" (60 beds) carry out rehabilitation of children with central nervous system and mental disorders, congenital malformations, premature babies, etc.

As well as 3 private institutions:

- LLC "Kozyavkin International Rehabilitation Clinic" (100 beds) - rehabilitation of children with disabilities due to cerebral palsy, correction of vertebrogenous pathology, rehabilitation of patients with the consequences of diseases and injuries of the musculoskeletal system, etc.;

- LLC "Elita Rehabilitation Center" (outpatient reception) rehabilitation of cerebral palsy and the effects of organic lesions of the nervous system, rehabilitation program for premature infants and early rehabilitation for children under 1 year, rehabilitation of patients with diseases and injuries of the musculoskeletal system, etc.;
- LLC "Innovo Medical Center for Physical Therapy and Pain Medicine" (outpatient reception) physical rehabilitation, which includes physical therapy, developmental therapy, "hand" therapy, sensory therapy. There are also three rehabilitation departments at the Lviv Regional Children's Clinical Hospital "OHMATDYT", the regional children's hospital and the city children's clinical hospital, but they provide rehabilitation assistance to children mainly in acute and subacute conditions and have a small bed stock.

At the same time, there are institutions in the region that are not health care institutions, but also provide some services related to medical rehabilitation, namely:

- municipal institution of the Lviv Regional Council "Lviv Regional Center for social rehabilitation of disabled children" (26 beds) physical rehabilitation of children with cerebral palsy, musculoskeletal disorders, post-traumatic conditions;
- municipal institution of the Lviv Regional Council "Lviv City Rehabilitation Center" (Children's training and rehabilitation center "Dzherelo") (outpatient reception) physical rehabilitation of children with musculoskeletal disorders, mental retardation and/or intellectual disorders, genetic defects, autism spectrum disorders (ASD);
- municipal institution of the Lviv regional council "Educational and rehabilitation center "Lewenia" (200 beds) medical and psychological rehabilitation of children with visual impairments;
- municipal institution of the Lviv Regional Council Educational and Rehabilitation Center "Mriya" (200 beds) medical and pedagogical rehabilitation of children with intellectual disabilities, mental retardation, severe speech disorders;
- municipal institution of Lviv Regional Council Educational and Rehabilitation Center "Svitanok" (200 beds) medical and pedagogical rehabilitation of children with musculoskeletal disorders in combination with severe systemic speech disorders and mental retardation [4].

All rehabilitation institutions of the Lviv region of state subordination are designed for a total of 195 beds, their total capacity to provide medical rehabilitation services to children is 850-1000 children per year.

The capacity of private medical institutions is:

- LLC "Kozyavkin International Rehabilitation Clinic" 800 people/year;
- LLC "Elita Rehabilitation Center" 500 people/year;
- LLC "Innovo Medical Center for Physical Therapy and Pain Medicine" 500 people/year.

Institutions that are not related to the health sector:

- municipal institution of the Lviv Regional Council "Lviv Regional Center for social rehabilitation of disabled children" - 80 people/year;

- municipal institution of the Lviv regional council "Lviv City Rehabilitation Center" 500 people/year;
- municipal institution of the Lviv regional council "Educational and rehabilitation center "Lewenia" 240 people/year;
- municipal institution of the Lviv Regional Council Educational and Rehabilitation Center "Mriya" 250 people/year;
- municipal institution of Lviv Regional Council Educational and Rehabilitation Center "Svitanok" 250 people/year [2].

Given that there are more than 11,000 children with disabilities in the region alone, this figure does not fully reflect the need for children's medical rehabilitation services, as there are also children with disabilities who do not have a disability but need the rehabilitation assistance, the specified state resource is too little - it covers only about 10% of the need.

However, even the total capacity of all private rehabilitation institutions is not able to meet the 100% need for children in the region for medical rehabilitation services. According to some of these institutions (LLC "Kozyavkin International Rehabilitation Clinic", Children's training and rehabilitation center "Dzherelo", LLC "Elita Rehabilitation Center") there is currently a long queue for rehabilitation courses [4].

In general, all institutions of the Lviv region that provide medical rehabilitation services to children provide rehabilitation assistance to about 4 thousand people (35%) per year. Accordingly, annually only more than 7 thousand (65%) children with disabilities in the region do not receive their appropriate medical rehabilitation services. The shortage of rehabilitation services especially affects children with congenital malformations, visual and hearing impairments, acquired musculoskeletal injuries, etc.

In line with national policy priorities and decentralization reform, both the state and local governments have to ensure the development of all types of health care for the country's population, including children with disabilities.

The system of medical rehabilitation of children in Ukraine still works as it was introduced in the Soviet Union. However, several modern rehabilitation facilities have been established, but they are new individual models and do not represent the health care system as a whole. This leads to a significant shortage of rehabilitation services (Assessment of the rehabilitation system in Ukraine. Evaluation Mission-September, 2017), so the development of a wide range of rehabilitation services for children is an urgent need [5].

This is especially true of providing rehabilitation assistance to young children, who with proper and rapid rehabilitation achieve high functional results, which are a prerequisite for their successful socialization in the future.

At the same time, the main goal of the DI reform is to change the children's institutional care and upbringing system to a system that provides care and upbringing of a child in a family or close to the family environment. Given that orphanages perform the function of constant medical care of young children, provide medical and diagnostic and rehabilitation care for children with physical and mental

disabilities, as well as have professional staff and the necessary material and technical base, they have the best potential to become rehabilitation institutions for such children at the stages of deinstitutionalization reform.

Steps in this direction began in 2010, when the Ministry of Health of Ukraine in the context of the main objectives of the State Target Program for reforming the system of institutions for orphans and children deprived of parental care by order of February 2, 2010, № 70 "On measures to development of orphanages" approved the Concept of development of orphanages for the period up to 2017, the main purpose of which was to develop and implement modern methods of children's rehabilitation, taking into account the possibility of orphanages functioning as institutions for children's rehabilitation open type.

A similar vision of the continued existence of orphanages is declared in the National Strategy for reforming the children's institutional care and upbringing system for 2017-2026. In this regard, the Cabinet of Ministers of Ukraine adopted a resolution dated July 10, 2019, № 675 "On approval of the Regulations on the center of medical rehabilitation and palliative care for children", which is the legal basis for the transformation of orphanages into new types of institutions - medical rehabilitation centers and/or palliative care for children. The main tasks of the centers will be to provide children with medical rehabilitation and/or palliative care services, comprehensive rehabilitation services, social and educational or other services, regardless of their social status and age [4].

In pursuance of the National Strategy for reforming the children's institutional care and upbringing system in the Lviv region, a Regional strategic action plan for reforming the children's institutional care and upbringing system for 2019-2026 was developed, which provides for the transformation of regional orphanages into centers for medical rehabilitation and/or palliative care for children [6].

The Ministry of Health of Ukraine, in coordination with local state and executive authorities, selected a municipal institution of the Lviv Regional Council "Orphanage №2 for children with central nervous system and mental disorders" as a pilot institution for transformation into the Lviv regional center for children's medical rehabilitation.

In accordance with the order of the Lviv Regional State Administration dated 05.07.2019 No. 749/0/5-19 in order to prepare a plan for the transformation of this institution, a comprehensive assessment of the institution was conducted. The comprehensive assessment of the orphanage was based on a multi-component process of studying the needs of the child and his family, human, financial and other resources of the institution [6].

According to the results of the assessment, it was concluded that almost 60% of the orphans have various health disorders. These are mainly motor dysfunction (32% of children), mental and intellectual development disorders (34% of children) and speech development disorders (39% of children), which developed as a result of hypoxic-ischemic or organic lesions of the central nervous system. Also in the institution are almost 40% of children who, according to the anamnesis, were born

prematurely and have a combination of several disorders, including visual and hearing impairments.

At the same time, all children with health disorders in the institution are provided with appropriate preventive, curative and rehabilitation medical care, which is based on modern domestic and international clinically proven methods. All children with disabilities have individual rehabilitation plan (IRP), according to which they are provided with a set of rehabilitation measures. The institution is equipped with treatment and prevention, physiotherapy and correctional equipment.

Also, all children are under the constant supervision and accompaniment of full-time pediatricians, neurologists, psychologists and other specialists. The medical staff of the institution consists of 92 people: 5 people - doctors, 50 people - nurses, 37 people - auxiliary medical staff. Employees of the institution are characterized by a sufficient level of professionalism. All medical staff undergoes timely refresher courses, as well as additional training. In work with children such methods of rehabilitation as medical treatment, massage, medical physical training, balneological therapy, stone therapy, art therapy, physiotherapy, sensory therapy, fairy tale therapy are used.

The obtained results of the comprehensive assessment of the orphanage showed the resource capacity and sufficient experience of practical activities of the institution in providing not only medical but also comprehensive rehabilitation care for children, which indicates the possibility of further development and expansion of rehabilitation services on the basis of the pilot orphanage. At the same time, the orphanage provided rehabilitation services during the year to an average of 65 children, and the estimated capacity of the new institution will be about 600 children with dysfunction and/or disability.

Thus, given the results of a comprehensive assessment of the pilot orphanage, the presence in the Lviv region of a significant shortage of medical rehabilitation services for children, an underdeveloped network of children's rehabilitation institutions, as well as negative trends in increasing the number of children with disabilities, it can be considered expedient to create an institution on the basis of a pilot orphanage, which will specialize in providing medical rehabilitation services, primarily for children with neurological disorders and musculoskeletal disorders, which will reduce the shortage of medical rehabilitation care for children; to improve the indicators of physical and mental development of children in the Lviv region; create a new type of institution that will provide quality and modern rehabilitation services for children and their families, regardless of their social status, and will be able to set an example for the transformation of orphanages in other regions of the country.

Discussion. Thus, we have determined that in recent years in the Lviv region there has been a negative trend in the rate of child disability, along with an annual decline in the birth rate, which, predictably, in five years will lead to a twofold increase in the percentage of children with disabilities in the total number of children in the region. According to official statistics, the leading positions among the main causes of disability of children in the Lviv region are congenital malformations,

central nervous system diseases, mental and behavioral disorders, musculoskeletal system diseases, diseases of the visual and auditory organs. Each of these groups of diseases involves the use of its own, clinically proven list of medical rehabilitation services, which aims to most effectively eliminate the clinical manifestations of the disease and restore the functional state of the patient. The total capacity of medical rehabilitation services as of the end of 2020 of all children's rehabilitation institutions in the Lviv region is about 35% (4 thousand people) per year. Accordingly, more than 7,000 children with disabilities (65%) in the region annually do not receive their proper medical rehabilitation services.

Thus, the current system of medical rehabilitation in the Lviv region does not meet the urgent needs and is not able to provide children with disabilities with services as close as possible to the place of residence. In addition, children with disabilities who have not been diagnosed with a disability are excluded from this system. The pilot orphanage provides a comprehensive and systematic approach to addressing all aspects of rehabilitation of sick children with congenital malformations, mental retardation, statokinetic development, neurological diseases, movement disorders, etc. The institution has a clear system of medical rehabilitation of children, which is based on modern domestic and international clinically proven methods.

It should be noted that the obtained data of the analytical study, as well as the purpose of deinstitutionalization reform and the planned change of further activities of orphanages in accordance with the principles of medical reform, testified to the possibility and expediency of establishing the institution on the base of a pilot orphanage, specializing in medical rehabilitation services, aimed at eliminating functional disorders in children who already have a disability and prevention of disability in children with restriction of vital functions.

Conclusions. When implementing a new set of medical rehabilitation services in the new institution, it is necessary to take into account the need for material and technical equipment of the institution and its provision with the necessary qualified personnel who will have appropriate training (including expanding the range of professions involved in providing services to children and to their parents - a doctor of physical and rehabilitation medicine, physical therapist (occupational therapist), assistant physical therapist (assistant occupational therapist), doctor of functional diagnostics, social work specialist, social educator, an assistant educator for children with disabilities, etc.) It is also important to coordinate the cooperation of the institution with the territorial communities of the Lviv region regarding the algorithm of providing children from communities in need of rehabilitation, a range of services, including medical rehabilitation, psychological and pedagogical correction, social services for parents or their substitutes, who care for children with disabilities, and the financial mechanism for providing those services that are not paid for from the state budget.

However, without a doubt, the creation of a new rehabilitation institution in the Lviv region will reduce the shortage of medical rehabilitation care for children in the region; will improve the indicators of physical and mental development and

socialization of children in the Lviv region; will ensure the region's need for quality and modern rehabilitation services for children and their families, regardless of social status, and will become an example for the transformation of orphanages in other regions of the country.

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