

THE ROLE OF THE SPECIAL EDUCATOR AND REHABILITATOR WITH A CHILD WITH A RARE DISEASE

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Abstract

In the case of a child with a rare disease the role of the special educator and rehabilitator is important if in addition to the primary disease the child is affected by motor, sensory, mental or emotional deficiency. The special educator and rehabilitator participates in the discovery on their first visit to the health institution. For each child the special educator and rehabilitator prepares a file with all the relevant data, takes anamnestic data, or complements it, to get a complete picture of the problem, and inputs data from the observation. S/he collaborates with members of the professional team. S/he provides advice, assists and works with the parents. S/he assesses the psycho-motor abilities of the person and how the person functions in the environment.

The special educator and rehabilitator performs the following assessments: assessment of dominant lateralization; assessment of psycho-motor abilities of the upper extremities; assessment of psycho-motor abilities of the lower extremities; differentiation of the motor abilities of the fingers; assessment of the possibilities for maintaining the equilibrium of the body; assessment of coordination of the upper and lower extremities in rhythm. The special educator and rehabilitator assesses and examines the praxical organization, specifically melokinetic, ideomotory, ideatory and constructive praxis. This includes assessment of the graphomotoric as a practical activity through testing for quality of lineation, graphomotoric array through analysis of the maturity of the manuscript and the dysgraphia of the manuscript. Gnostic organization is examined through assessment of knowledge of body parts, assessment of knowledge of lateralization on themselves and others, assessment of experience and orientation in space and time. Practo-gnostic organization is examined with tests for imitation of movements. Evaluation of the organization of speech through the test of articulation on voices, semantic test and evaluation of lexical abilities and dyslexic reading. Assessment of the organization of cognitive functions where thought operation is expressed, and the special educator investigates the level of comprehension of: serialization, classification, correspondence and conservation. At the end, the child's behaviour is examined.

Based on the data obtained, a plan and a strategy for further treatment is developed. After a certain period of time the child is re-examined (evaluation) and we check whether there are any advances in education and rehabilitation. The special educator and rehabilitator is in constant contact with the parents for certain problems that the children have with social adaptation, and they build strategies for future activities.

Key words: special educator and rehabilitator, rare diseases, assessment, prevention, diagnosis, treatment.

Introduction

The rehabilitation of persons with difficulties in their development is a subject of

Special Education and Rehabilitation, applying the system of measures for: prevention of the appearance of any disability; removal in the

greatest possible measure or lessening of the consequences of the disability; discovery, recording and assessment of difficulties in development; correction, compensation and usage of the remaining abilities; returning the integrity of these persons to a level which enables such a person to have the status of an equal member of society.

The modern system of special education and rehabilitation is composed of the clinical, educational and socio-economic parts with their components: The clinical part consists of: prevention, detection, applying and recording, diagnostics and prognostics, treatment. The Educational part consists of: pre-school education, elementary education and qualification, secondary education, training and work qualification and also andragogy practice. The socio-economic part consists of: socialization, integration, identification, emancipation, culturization, employment, family life, social life, sport and recreation and social and institutional care of the mostly disabled persons.

The role of the special educator and rehabilitator in the work with a child who has a rare disease is significant if, besides the primary illness, the child is also affected by a motor, sensor, mental or emotional disability. The special educator and rehabilitator takes part in the discovery when they first arrive in the healthcare facility. For each child, the special educator and rehabilitator prepares a file composed of all the relevant data. He/She takes anamnestic data or completes them to get a full image of the problem and then enters the data from the observation. The observation sometimes begins in the preliminary part of the diagnostic procedure, in the hall before the entry. There, he/she notices the child's attitude towards his/her parents and vice versa, as well as the attitude of the child towards the special education and rehabilitation worker as an examiner. During the observation, the special educator and rehabilitator maintains his/her attention on the mimetic musculature, the smile, the body posture, walking and gesticulation. The observation, as a professionally performed diagnostic procedure, gives the transition of the subjective experience of the body by the special educator and rehabilitator towards the objectification of its qualities and its problems.

The special educator and rehabilitator, as a member of a polyvalent team, with his/her diagnostic procedures and professional qualification in the educational and rehabilitation process, makes an immense contribution to the discovery of a great number of hereditary, congenital or early gained causes, as well as to the prevention of consequences being left on the development of the personality itself.

The special education and rehabilitation branch, related to the medical, as a separate branch, also involves preventive activity. A well-timed detection and correct diagnostics can make it possible to remove, appease or bring to a tolerable level all the difficulties in development, so that the maximum possible level of development of abilities within a single person can be achieved.

The special educator and rehabilitator, using the application of the common special education and rehabilitation diagnostics, can complete the description of the child's personality from an aspect which is not available to medical or psychological diagnostics.

The findings of the special educator and rehabilitator are compared with the findings of the doctor and the psychologist. Also, through a multidisciplinary approach, these findings gain their full value. In the diagnostics, the special educator and rehabilitator deals with the functions of personality related to the existence of a personality in the social field, in space and time.

The special educator and rehabilitator cooperates with the members of the professional team. He/She advises them, helps them and works with the parents. He/She evaluates the psycho-motor abilities of the personality and how it functions in the environment itself.

The diagnostic approach in the special education and rehabilitation can generally be divided into common – applied by any special educator and rehabilitator, and specific – used specifically with regard to the nature of the handicap, which is a subject for the specialist – special educator and rehabilitator.

In the diagnostic procedure, starting from the rule that the personality needs to be completely processed, the special educator and rehabilitator tends to examine the function of the personality in different segments which the child uses to function in the social field.

By applying special education and rehabilitation tests during the diagnosis, the special educator and rehabilitator performs the following assessments:

- Assessment of the dominant lateralization on the level of being useful; this represents an examination of the body lateralization and the senses, as well as the level of domination of CNS functions.

- Assessment of the psychomotorics of the upper extremities; assessment of the psychomotorics of the lower extremities; differentiation of the motorics of the fingers; assessment of the abilities for maintaining body balance; assessment of coordination of the upper and lower extremities by rhythm.

- The special education and rehabilitation worker also makes an assessment and examines the praxical organization, more precisely, the melokinetic, ideomotor, ideator and constructive praxis. The assessment of graphomotorics as a practice activity through examination of the quality of lineation is also done here, the graphomotor line, analysis of maturity of the handwriting and dysgraphia of the handwriting.

- The gnostic organization is examined through an assessment of the knowledge of body parts, assessment of the knowledge of lateralization for themselves and for others, assessment of experience and orientation in space and time.

- The practognostic organization is examined with tests for imitation of movements.

- An assessment of organization of speech through the test for examination of voice articulation, the semantic test and a grade for lexical abilities and also dyslexic reading.

- An assessment of the organization of cognitive functions where thought operations are expressed and the special education and rehabilitation worker examines the level of adoption of: seriation, classification, correspondence and conservation.

- The attitude of the child is examined in the end.

The diagnosing requires qualifications, professionalism, responsibility and above all, multidisciplinary training. All the findings gained through the assessment of damage to the child should be synchronized, synthesized,

adjusted and mutually agreed in their final assessment. The further rehabilitation process will depend on the engagement of the experts in the diagnostic procedure, as well as their cooperation and quality in work.

The general special education and rehabilitation finding will make possible an insight in the other attributes of the personality, and serve for completion of the description of clinical manifestations of the examined person which have been noticed by the other members of the team – psychologist, neuro-psychiatrist, pediatrician, social worker, etc.

The description, which the professional team receives from the special educator and rehabilitator, reveals the possibility of the examined person in regard to his/her needs in the social field. While healthcare workers see the weaknesses by structure and function and psychologists speak about the quality of failure in relation to the structures and the functions, the special educators and rehabilitators speak about the functions not related to the structures, but related to the possibilities of the social field.

Based on the achieved data, a plan and strategy for further treatment are created. After a determined time period, the child is examined again (evaluation) and then it is noted if he/she is making progress in education and rehabilitation.

The special educator and rehabilitator is in constant communication with the parents regarding certain problems that the children may have with social adaptation, and together they create a strategy for further activities.

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Резиме

УЛОГАТА НА ДЕФЕКТОЛОГОТ ВО РАБОТАТА СО ДЕТЕ СО РЕТКА БОЛЕСТ

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Улогата на дефектологот во работата со дете со ретка болест е значајна доколку детето покрај примарната болест е погодено со моторен, сензорен, ментален или емоционален недостаток. Дефектологот учествува во откривањето при неговото прво доаѓање во здравствената установа. За секое дете дефектологот подготвува досие каде што се наоѓаат сите релевантни податоци. Тој зема анамнестички податоци или ги дополнува за да добие целосна слика за проблемот и ги внесува податоците од опсервацијата. Соработува со членовите од стручниот тим, ги советува, им помага и работи со родителите. Врши проценка на психомоторните способности на личноста и како таа функционира во самата средина.

Дефектологот ги извршува следниве проценени: проценка на доминантна латерализираност на употребно ниво; тоа претставува испитување на латерализација на телото и сетилата и нивото на доминација на функциите на ЦНС. Проценка на психомоторика на горните екстремитети; проценка на психомоторика на долните екстремитети; диференцираност на моториката на прстите; проценка на можностите за одржување рамнотежа на телото; проценка на координација на горните и на долните екстремитети по ритам. Дефектологот врши проценка и испитување на праксичката организираност, поточно на мелокинетичка, идеомоторна, идеаторна и конструктивна праксија. Тука спаѓа и проценка на графо-

моториката како праксичка активност преку испитување на квалитетот на линејацијата, графомоторниот низ, анализа на зрелоста на ракописот и дисграфичност на ракописот. Гностичката организираност се испитува преку проценка на познавање делови од телото, проценка на познавање на латерализираноста на себе и на друг, проценка на доживувањето и ориентација во простор и во време. Практичностичката организираност се испитува со тестови за имитација на движењата. Проценка на организираноста на говорот преку тестот за испитување на артикулација на гласовите, семантичкиот тест и проценка на лексичките способности и дислексичкото читање. Проценка на организираноста на сознјаните функции каде што доаѓа до израз оперативноста на мислењето и дефектологот го испитува нивото на усвоеност на: серијација, класификација, кореспонденција и конзервација. На крајот се испитува однесувањето на детето.

Врз основа на добиените податоци се прави план и стратегија за понатамошен третман. По определен временски период, повторно се испитува детето (евалуација) и се гледа дали напредува во едукацијата и рехабилитацијата.

Дефектологот постојано контактира со родителите за одредени проблеми што би ги имале децата со социјалната адаптација и заедно градат стратегија за натамошни активности.

Заклучок: Основните задачи на дефектологот во работа со дете со пречки во развојот е професионално согледување на детските развојни и посебни потреби, ублажување на тешкотиите и спречување развој на секундарни проблеми, со цел детето целосно да се интегрира во животот на пошироката општествена средина. Остварувањето на оваа цел е условено од соработката со родителите на детето, едукаторите и со стручните лица во градинките и надвор од градинките, едукација на сите учесници во образовниот процес и советодавната работа.

Клучни зборови: дефектолог, ретки болести, проценка, превенција, дијагноза, третман.