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STUDY OF THE FEATURES OF HABILITATION OF A CHILD WITH DOWN SYNDROME IN THE FAMILY

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Аннотация: В статье раскрывается важность медико-психолого-педагогической абилитации детей с синдромом Дауна. Также в статье приведено исследование, основанное на наблюдении детей с синдромом Дауна в семейных условия. Освещены особенности работы с семьёй такого контингента детей.

Abstract: The article reveals the importance of medical, psychological and pedagogical habilitation of children with Down syndrome. The article also presents a study based on the observation of children with Down syndrome in family conditions. The features of working with the family of such a contingent of children are highlighted.

Ключевые слова: синдром Дауна, семья, абилитация, медико-педагогическая абилитация, комплекс, индивидуальная программа

Keywords: Down syndrome, family, habilitation, medical and pedagogical habilitation, complex, individual program.

According to the Law of the Republic of Uzbekistan "On Education", every child has the right to education. The extension of inclusion to children with disabilities involves the creation of special educational conditions for them to receive a full-fledged education, for further participation in society and socialization. There are many children with Down syndrome among children with special needs. Down syndrome is the most common genetic anomaly, which is determined by the presence of an additional 47th chromosome in human cells. Every 700th child on the planet is born with Down syndrome. This ratio is the same in different countries, climatic zones, and social strata. It does not depend on the lifestyle of parents, their health, bad habits, skin color, nationality.

Children with Down syndrome and their parents represent a permanent group of patients in need of interdisciplinary support. Along with the growing number of appeals from parents to polyclinics and rehabilitation centers raising children with Down syndrome in the family, the majority of children with this diagnosis are still transferred to orphanages. In conditions of deprivation, in the absence of a close social environment, children with Down syndrome cannot fully realize their potential. The established diagnosis dictates the need to start the habilitation process, because with proper treatment, education and upbringing, such children can become full-fledged family members.[32] Moreover, the results of habilitation are the better, the earlier work with the child is started.

Habilitation of a child with Down syndrome is a task for a team of specialists of different profiles. It is implemented in sanatoriums, rehabilitation centers, centers of medical, psychological and pedagogical support. According to most experts, success is ensured by the habilitation environment in which the child resides constantly.

For full-fledged habilitation, a short-term stay of a child in an habilitation environment is not enough, for example, only for the duration of correction in the conditions of a medical, psychological and pedagogical center or for the duration of receiving a course of treatment in a children's sanatorium. It is necessary to create a habilitation environment in the place of permanent residence of the child. If the child is in such an environment from infancy, its impact on the further development of the child will be more effective.

The aim of the study is to analyze the effectiveness of early habilitation of children with Down syndrome at home.

To achieve this goal, 10 children from the age of four months to three years with Down syndrome were observed, whose parents applied to the Republican Center for Social Adaptation of Children in Tashkent. Parents were trained to conduct classes with children according to an individual program developed for each family, taking into account the

[32]Yevtushenko OS, Yevtushenko SK, LisovskyYeV, PoroshinaYeV, AleshnikovaLYa, Yevdushchenko TG. Cerebrocurin in complex rehabilitation of children with Down's disease in specialized rehabilitation center. Child's health. 2008; (3): 63-66. Russian (ЕвтушенкоО.С., ЕвтушенкоС.К., ЛисовскийЕ.В., ПорошинаЕ.В., АлешниковаЛ.Я., ЕвдущенкоТ.Г. ЦереброкуринвкомплекснойреабилитациидетейсболезньюДаунавусловияхспециализированногоцентрареабилитации //Здоровьеребенка. 2008. № 3. С. 63-66)

child's condition and living conditions. The program provided for the formulation of tasks in the direction of motor, speech, and psychomotor development. During the work of specialists with children, parents also received special training, which allowed them to create a habilitation environment at home. Parents were given forms for keeping a diary in order to regularly record the dynamics of the child's development. Special importance was attached to the psychological support of the mother, the family as a whole. The criteria for inclusion in the study were the presence of Down syndrome in a child and parental consent to participate in the study. Exclusion criteria: comorbid pathology, which serves as a contraindication to conducting classes with a child, parents' refusal to participate in the study.

When building individual programs of work with children, we proceeded from the fact that only a comprehensive medical, psychological and pedagogical approach is able to ensure the success of the habilitation process. Children aged four months were taken under observation. The child's development was monitored at the beginning of the study and during the corresponding epicrisic periods: six, nine months and at the age of one year. The work of specialists, whose group included a neurologist, a psychologist, a specialist in physical therapy and a defectologist, included classes with children, training parents, issuing recommendations for independent work at home both during the course of classes with specialists and during the inter-course period.

Down syndrome is characterized by cerebellar hypoplasia, which results in general muscular hypotension, difficulties in the formation of coordination of movements, from performing simple locomotor and manual functions to articulation and phonation. The hippocampus suffers selectively, as a result of which the connections of various brain structures with each other are disrupted. As a result, memory, attention, and learning ability suffer[33]. Thinking is slow, children find it difficult to switch from one type of activity to

[33]Grigoryev KI, Vykhristyuk OF, Donin IM, Zavadenko AN. Down's syndrome: comorbidity and program objectives in the work of pediatrician with such children. Difficultpatient. 2017; 15(1-2): 64-70. Russian (Григорьев К.И., Выхристюк О.Ф., Донин И.М., Заваденко А.Н. Синдром Дауна: коморбидность и программные цели в работе врача-педиатра с такими детьми //Трудный пациент. 2017. Т. 15, № 1-2. С. 64-70)

another; however, they are prone to imitation, easily susceptible to suggestion. Emotional disturbance, as a rule, is less profound than intellectual.

Based on these features, the parents relied on reflex activity in their work, which they evoked in light, then in normal, and finally in complicated conditions; mechanical memory; imitation and positive emotions. Forming locomotor and postural activity, the symmetry of the formation of poses and movements was monitored. The duration of home lessons ranged from 5 to 20 minutes, depending on the well-being and mood of the child, 4-8 times a day during any communication: games, changing clothes, preparing for feeding, going for a walk, during the walk itself.

Motor development included the formation of postural, locomotor activity, manual functions in the order determined by the ontogenesis of a healthy infant. To form the control of the head position, the following reflexes were used: indicative, vestibulotonic and oral automatism.

When communicating with the child, the orientation reflex was stimulated, alternately placing bright, sounding, favorite toys on different sides of the head. Before eating, the reflexes of oral automatism were stimulated several times, causing turns and tilts of the head. Passing by a child lying on his stomach, the Galant reflex was stimulated by pinpoint pressure and a stroke[34].

Parents used a fitball to practice with their child. Placing the child with his back on the ball, they rolled the fitball, thereby provoking the child to carry out flips on his side, on his stomach, transferring through the side to a sitting position. Continuing to roll the fitball with the child in the belly position on the ball, they provoked flips to the side, holding in this position, moving to all fours, formed support on the hands, locomotor reflex from the hands, withdrawal of the arm and leg.

[34]Zagorodnikova OA, Konovalova NG. Method of Galant's reflex formation in infants with spinal disorders. RF patent for invention No. 2581272 dated 23.03.2016; claimed 28.04.2015; publ. 20.04.2016. Bulletin № 11. Russian (ЗагородниковаО.А., КоноваловаН.Г. СпособформированиярефлексаГалантаумладенцевсоспинальныминарушениями: патентРФнаизобретение № 2581272 от 23.03.2016; заявл. 28.04.2015; опубл. 20.04.2016. Бюл. № 11)

Psychomotor development included stimulation of tactile, visual, auditory perception, the formation of various types of grip, ranging from planar, ending with forceps, visual-motor and auditory-motor interaction. Pre-speech development included stimulation of auditory perception and preparation of the speech apparatus. The first was achieved by using sounding toys, pronouncing all actions when communicating with the child, clear articulation when pronouncing each sound, provocation achieved the repetition of individual syllables by the child. Adults repeated the sounds uttered by the child, articulating the same way as he did, and thereby stimulated him to pronounce them again.

Muscle training plays an important role in pre-speech development. The emotional development of children was facilitated by the fact that adults communicated with them regularly, accompanied all their actions with pronouncing and affectionate touches, talking kindly to the child face to face, gave the face a joyful expression with wide-open eyes, a smile, to which the child also began to respond with a conscious smile.

We analyzed the initial psychomotor development of children who entered the observation group at the age of four months. The development of the three infants corresponded to the lower limit of the age corridor, they controlled the position of the head, rolled over from back to side, held objects in their hands, smiled consciously. At the same time, they maintained low muscle tone, open mouth, drooling, tongue protruded from the oral cavity, but these children did not have problems with feeding.

By the age of six months, all children could hold their heads on their stomach for a short time on their own and when the body was verticalized, reacted to loud sounds and bright objects in their field of vision, confidently sucked the mixture from the bottle.

By the age of nine months of life, children mastered flips from the back to the stomach and from the stomach to the back. All the children consciously took and held the toys that interested them in two hands, both simultaneously and alternately. Children preferred to play with bright sounding toys, reacted differently to sounds made by different objects, musical instruments (drum, tambourine, metallophone ...). Children were taught to eat with a spoon and drink from a cup with the help of their parents. Absolutely all children were offered baby cookies to train their chewing muscles, which they ate with pleasure. No one

had a vocabulary corresponding to a one-year-old child, but the individual syllables "ma-ma-ma", "ba-ba-ba", "give" could be pronounced by six of the observed group. All the children, without exception, periodically kept their mouths slightly open, occasionally sticking out their tongue. Salivation was not observed in anyone.

Thus, by the end of the first year of life, a delay in psychomotor development in six children was noted for two epicrisic periods, and in four – for one.

The results of our work cannot be called unexpected, they confirm the fact that the creation of a habilitation environment in the family ensures the motor, emotional and communicative development of a child with Down syndrome. To create such an environment, it is necessary to actively participate all family members (grandparents, older brothers and sisters) and, first of all, the child's parents in classes with specialists, as well as regular independent classes at home several times a day.

All families, without exception, noted the important role of the team of specialists who accompanied the child and the family in the habilitation process and helped, including parents, to survive severe negative feelings and gradually adapt to the specific needs of their "special" children, as well as to a new parental role.

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