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Аннотация

Background:

According to the Federal Law «On Education in the Russian Federation», children with disabilities are guaranteed the creation of special conditions in an educational organization in order to obtain a quality education and socialization. At the same time, there are no recommendations in the regulatory documents on the organization of the teaching process for disabled children with rare disorders in an educational institution, which makes it impossible to take into account their individual educational needs.

Objectives:

To evaluate the social functioning of children with glycogen storage disease in an educational institution in order to formulate educational optimization proposals.

Methodology:

37 disabled children (average age of 13.5 years) with glycogen storage disease (16.2% - at the stage of metabolic compensation, 59.5% - subcompensation, 24.3% - decompensation), studying on basic general education programs. Of these, 56.7% are on internal mode of study and 43.3% - on external mode of study.

Methods and Techniques:

Medical documents; analysis, conferences with parents and PedsQL 4.0 Generic Core Scales Questionnaire.

Results:

According to the level of psychosocial functioning, children with glycogen storage disease were divided into three groups:

I – a group with a relatively high level of psychosocial functioning (the scale value is 76%) with internal mode of study in an educational institution combined children with the VI and IX types of glycogen storage disease with metabolic compensation (21 children). At the same time, a questionnaire survey of teachers and parents showed that neither the teaching load nor the mode fully corresponded to children's psychophysical capabilities, leading to

depletion and affecting both children's academic performance and the implementation of medical appointments, including the use of clinical nutrition.

II – a group with an average level of psychosocial functioning (the scale value is 67%) with external mode of study in an educational institution included children of the III, VI and IX types with metabolic compensation/subcompensation (7 children). The results of the PedsQL 4.0 Generic Core Scales Questionnaire and conversations with parents and teachers reveal that the children are willing to attend internal classes at school with an individually selected mode. A flexible combination of internal and external modes of study will ensure the implementation of medical procedures and allow children to gain the necessary social experience and become more independent;

III – a group with a low level of psychosocial functioning (the scale value is 40%) in the external mode of study in an educational institution combined children with I and III types of glycogen storage disease with metabolic subcompensation/decompensation (9 children). It has been established that external study form does not allow children to realize their personal and cognitive potential without special adaptation of programs and teaching methods to their educational needs and psychophysical capabilities.

Conclusions:

Children's physical well-being and learning conditions influence their psychosocial functioning. Therefore, it is necessary to take these two factors into account in order to provide adequate selffulfilment for children with glycogen storage disease. Creating a variable learning environment for disabled children with rare disorders is an essential prerequisite for their effective treatment and socialization.

Ключевые слова: children with disabilities, psychosocial functioning of schoolchildren with rare disorders, glycogen storage disease, learning environment for disabled children.