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## PROPOSAL OF A PROCEDURE FOR DEALING WITH A STUDENT WITH A RARE DISEASE IN A PRIMARY SCHOOL IN THE OPINION OF EARLY CHILDHOOD EDUCATION TEACHERS

**Annotation.** *A child with a rare disease can attend a public primary school with integration departments and a school with an educational center. Regardless of the type of institution he attends, a procedure should be prepared.*

*The conducted research aimed to describe a proposed procedure for dealing with students with a rare disease. The main research question was: How should the procedure for dealing with a student with a rare disease in primary school be structured in the opinion of early childhood education teachers?*

*The research was based on quantitative orientation, using the diagnostic survey method, the survey technique, and the author's questionnaire tool. In the research 38 early childhood education teachers participated. According to the respondents, the purpose of preparing the procedure for dealing with a student with a rare disease is to ensure their safety during their stay at school. It should primarily contain the characteristics of a given rare disease, along with a description of the student's functioning and characteristic symptoms of the disease affecting his/her learning.*

**Keywords:** *procedures; a student with a rare disease; a primary school.*

### Introduction

An increasing number of students diagnosed with a rare disease (RD) are attending mainstream elementary schools. So far, teachers have had experience primarily working with a child with a chronic disease. The educators know the specifics of his functioning and his resources and needs. They have also developed procedures for dealing with students on school grounds. The situation is different for a child with RD. A rare disease (RD) can be referred to when it affects no more than one in 2,000 people (Zubrzycka 2022, Doroszuk, Grybek 2022). It can affect both a child and an adult. It is chronic, and its consequences are often various developmental disorders and disabilities. Symptoms of a rare disease can manifest as early as infancy, preschool, or younger school age. Examples include Dravet syndrome or cystic fibrosis. Because of the severe consequences of RD on the child's motor, cognitive, and social development, it is possible to speak of the existence of individual communication and educational needs in the child, which translates directly into the choice of educational institution, as well as the proposed educational and therapeutic path. However, regardless of which elementary school the child will pursue compulsory education in, each school should have prepared procedures for dealing with a student with RD.



### Procedures for dealing with a student with a medical condition in an elementary school

Separate procedures for dealing with a student diagnosed with bronchial asthma, diabetes, and epilepsy can be found on the websites of educational institutions. Rare are procedures for dealing with a child with pollenosis, with anxiety disorders, or in the situation of a psychotic episode, and actions towards a student after hospital or psychiatric treatment. Few schools have a procedure developed for a child with cystic fibrosis or hemophilia. I assumed that a rare disease is also a chronic disease. Hence, I analyzed the procedures for dealing with a student diagnosed with a chronic disease. In addition, I also included procedures for dealing with a child with epilepsy since it often coexists in rare diseases. Based on the analysis of the ten procedures, several areas of work with the student can be identified. Each of the procedures consists of the following: a general description of the disease, symptoms, injunctions, prohibitions, restrictions, areas allowed and indicated for the student, and guidelines for dealing with increased symptoms of the disease. Some also include a school code of rights for a child with the disease (Table 1).

*Table 1 Procedures for dealing with a student with a chronic disease and/or epilepsy.*

Element of the procedure		Content
General description of the disease		Information on the inheritance of the disease, information on the course of the disease and treatment options (including the impact of pharmacotherapy on the child's behavior), an indication of the consequences for the development of the student, for example, a chronic disease is a pathological process that lasts more than 4 weeks.
Symptoms and features of the disease		Characteristic symptoms of the disease, the age of the child at which it may manifest itself, and its nature, such as chronic acute.
Psychological implications of the disease		Identification of psychological sequelae of the disease that may affect or limit the child's development, such as: -anxiety, sadness, feelings of insecurity, - focus on basic needs (drinking, eating, feeling safe); -focus on the current situation, on the "here and now," reluctance to plan and think about the future, - loss of life perspective and hope; -sense of lack of influence over events; - lowering of self-esteem and self-worth; a sense of shame and of being different; - reduction in external stimulation especially with prolonged immobilization, lying in bed; - reduction in motivation to act - passivity, boredom.
Levels of student support	Educational	Guidelines for working with students in class, such as adapting the educational process to individual capabilities and needs, that is, organizing learning following individual recommendations, limitations, and abilities, modifying the curriculum content following the physical and exercise capacity of the student, adapting the pace of work to the individual physical and mental capacity of the student, using methods and interventions of a therapeutic nature.
	Nurturing	Tips relating to the integration of the student with the disease with his peers, such as fostering the integration of the student with his peer group - participation in the life of the classroom, school
	Emotional	Indication of possible actions to support the student during



	support	the illness, both during its stabilization and resumption, when hospitalization is necessary, such as mainly supportive actions, accompanying in difficulties, listening, patience, paying attention, kindness, understanding, modification of a behavior towards the sick student according to his age and needs
Responsibilities of teaching staff	School headmaster	<p>-Define the school principal's responsibilities towards a sick student, e.g:</p> <p>-Organize training for teaching staff on how to deal with the student daily and in the situation of an exacerbation of symptoms or an attack of illness,</p> <p>-In consultation with the nurse or doctor, in conjunction with school staff, the principal should develop procedures for dealing with the student, both daily and in the event of an exacerbation of symptoms or attack of illness. These procedures may include, among other things, reminders to take medication, meals, etc. They should also specify the forms of ongoing cooperation with the child's parents the commitment of the institution's staff to apply them without fail.</p> <p>-If the child's symptoms of illness are exacerbated while at school, the principal immediately informs the parents or legal guardians of the situation,</p> <p>-Obtain from the student's parents detailed information about the illness and the resulting limitations in the child's functioning, as well as the effects of medication (may affect the child's behavior or ability to learn effectively),</p> <p>- To determine the forms of cooperation between the school and the child's parents,</p> <p>-Adaptation of the forms and conditions of the examinations (based on the child's health certificate issued by a doctor and by his recommendations),</p> <p>-Immediately inform the child's parents if the child's symptoms of illness worsen while at school,</p> <p>-In emergencies, when the child's condition suddenly deteriorates, and medical attention is required, taking pre-medical measures and calling an ambulance,</p> <p>-ensuring that the child's parents provide a set of documents confirming the child's illness and parental consent to take emergency action.</p>
	Class teacher	<p>Defining the responsibilities of the educator, e.g.</p> <p>-When the condition of a child suddenly deteriorates, and medical assistance is required, teachers are required to take pre-medical measures and call an ambulance. At the same time, they must notify parents and legal guardians of the situation,</p> <p>-Administration of medication to the child in case of such necessity - parents are obliged to inform what medication the child is taking (dosage, method of administration), submit a medical recommendation and written authorization for teachers,</p> <p>-Obtaining information from the student's parents about his illness and the resulting limitations in functioning,</p>



		<ul style="list-style-type: none"> <li>-With pedagogues and specialists employed by the school to adjust the form of didactic work, the selection of content and methods, and the organization of teaching to the psychophysical capabilities of the student, includes him in various forms of psychological and pedagogical assistance,</li> <li>-Keeping parents informed of their child's well-being or noticing changes in behavior while at school,</li> <li>- Noting in the school diary the symptoms that appeared suddenly during the student's stay in the classroom,</li> <li>-Keeping a student's illness diary, in which the educator will describe the student's behavior,</li> <li>-Taking into account the state of ill health and reduced intellectual performance caused, for example, by the occurrence of side effects of currently used pharmacotherapy,</li> <li>-Outside the period of deterioration and complications, the student should be treated equally with other children,</li> <li>-When organizing school trips, obliging parents to equip the child with everything needed, handing over a list on which the times of administration of medication meals are written,</li> <li>-Recognizing and meeting the developmental and educational needs of the student, the causes of difficulties in mastering skills and knowledge by the student,</li> <li>-Creating conditions for active and full participation of the student in the life of the school and the social environment</li> </ul>
	<p>Pedagogue and school psychologist</p>	<ul style="list-style-type: none"> <li>-With teachers and specialists, adjust the forms of didactic work, the selection of content and methods, and the organization of teaching to the psychophysical capabilities of this student, and include him in various forms of psychological and pedagogical assistance,</li> <li>-Organize training of teaching staff on how to deal with a sick child daily and in situations of exacerbation of symptoms or attack of the disease,</li> <li>-Recognizing the developmental and educational needs of the student and his psychophysical capabilities,</li> <li>-Recognizing environmental factors affecting the functioning of the student at school, the causes of difficulties in mastering skills and knowledge by the student,</li> <li>-Supporting teachers and parents in activities that equalize educational opportunities for the child, in solving educational problems,</li> <li>-Providing psychological and pedagogical assistance in forms appropriate to the identified needs of the student with the disease,</li> <li>-Minimizing the effects of developmental disorders, preventing behavioral disorders, initiating forms of assistance in the school and extracurricular environment, among others, for students with the disease,</li> <li>-Watching over the implementation of the student's</li> </ul>



	<p>compulsory education, -Cooperation with organizations and institutions interested in the problems of care, upbringing, and education of a student with the disease.</p>
Responsibilities of the parent	<p>Define the scope of the parents' responsibilities to the school and teaching staff , e.g. The School and the Staff. -In the case of a student starting school, the parent should, no later than September, provide the educator with information about the health status of the sick child, symptoms of illness, health risks, medications taken and their effect on the body, -If an illness is diagnosed while the child is attending school, the parent should immediately inform the educator, -The parent is particularly obliged to cooperate with the child's teacher at all times.</p>
The main ways to help the student on the school premises	<ul style="list-style-type: none"> <li>-Providing a sense of mental and physical safety, trust in the peer group and the teacher,</li> <li>-Assisting in overcoming difficulties, teaching independence and new skills,</li> <li>-Preparing class peers to meet a classmate with a disease,</li> <li>- Sensitizing healthy students to the needs and experiences of a student with an illness and a student with an illness to the needs and experiences of peers,</li> <li>-Motivating the student with illness to interact and interact with others (peers and adults),</li> <li>-Strengthening self-esteem,</li> <li>-Developing interests, talents, independence,</li> <li>-Creating situations that enable the child to act and succeed,</li> <li>-Motivating activity by providing the student with positive reinforcement and gratification, accepting successes and strengths, exposing the student's dispositions that can increase his attractiveness in the group,</li> <li>-Support when a student is behind in learning material due to hospitalization or drug treatment,</li> <li>-Adjusting the requirements to the student's current well-being and health,</li> <li>-Providing the child with psychological and pedagogical support and assistance, and, if necessary, social assistance,</li> <li>-Establishing constant and systematic cooperation with the child's parents in order to obtain information about current treatment, planned treatments, among other things,</li> <li>-Building friendly relations in the class team.</li> </ul>
Administration of medicines	<p>Determining the situations in which a child may take medication on school premises and the rules for administering it.</p>

Source own compilation based on: Szkoła Podstawowa im. dra Floriana Ceynowy w Przysiersku [https://cloud-8.edupage.org/cloud/Procedura\\_postepowania\\_w\\_przypadku\\_ucznia\\_przewlekle\\_chorego.pdf?z%3AaoqwrHi3OBDVIIWnpDjoRDIJIDIctHFZB1dNMV0YLUmVUPQuYRa%2FMGM5M81XGM%2Fi](https://cloud-8.edupage.org/cloud/Procedura_postepowania_w_przypadku_ucznia_przewlekle_chorego.pdf?z%3AaoqwrHi3OBDVIIWnpDjoRDIJIDIctHFZB1dNMV0YLUmVUPQuYRa%2FMGM5M81XGM%2Fi), Zespół Szkół nr 1 im. Stanisława Staszica w Nowogardzie, [https://www.zsp.nowogard.pl/images/2020/05\\_29\\_dokumenty/2020\\_05\\_29\\_procedury\\_postepowania\\_z\\_dziekiem.pdf](https://www.zsp.nowogard.pl/images/2020/05_29_dokumenty/2020_05_29_procedury_postepowania_z_dziekiem.pdf), Szkoła Podstawowa w Izdebniku <https://szisdebnik.szkolnastrona.pl/sp/download/Procedura-dziecko-chore.pdf>, Szkoła Podstawowa im. Stanisława Staszica w Kielcach, <http://sp1.kielce.eu/wp-content/uploads/2021/09/procedury-dziecko-przewlekle-chore.pdf>, Szkoła Podstawowa nr 11 im. Polskich Olimpijczyków w Głogowie, <http://sp11.glogow.pl/632-2/>, Zespół Szkół nr 1 im. Stefanii Sempołowskiej w Puławach, [http://www.zs1.pulawy.pl/dokumenty/20-21/Uczen\\_chory.pdf](http://www.zs1.pulawy.pl/dokumenty/20-21/Uczen_chory.pdf), Szkoła Podstawowa w Dębicy



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### *Methods of own research*

The research aimed to describe a proposed procedure for dealing with a student diagnosed with a rare disease. The research was embedded in a quantitative strategy, using a diagnostic survey method, a survey technique, and an author's survey questionnaire tool. The main question was: How should the procedure for dealing with a student with a rare disease in elementary school be structured in the opinion of early childhood education teachers?

The specific questions, on the other hand, are:

- What is the purpose of preparing a procedure for dealing with a student with RD?
- What elements should the procedure for dealing with a student with RD include?
- What should the description of the child's illness include, and what psychological consequences should it consider?
- What is to consist of, and at what level is to be implemented support of the student on the school premises? What are the main ways to help a child with RD possible on the school premises?
- What are the responsibilities of the school director, psychologist and pedagogue, educator, and parent towards a student with RD?

The research was conducted using an online tool. Principals and Headmasters of elementary schools in the Kujawsko-Pomorskie Voivodeship were sent a message with information about the research being conducted, requesting early childhood education teachers with a link to the survey questionnaire. In addition, school principals were contacted by telephone. The survey questionnaire consisted of two parts: 1) a metric of the people surveyed to obtain sociodemographic data, 2) a proposed procedure for dealing with a student with a rare disease in elementary school in the opinion of early childhood education teachers, which included questions about the various elements of the procedure.

### **Group of surveyed teachers**

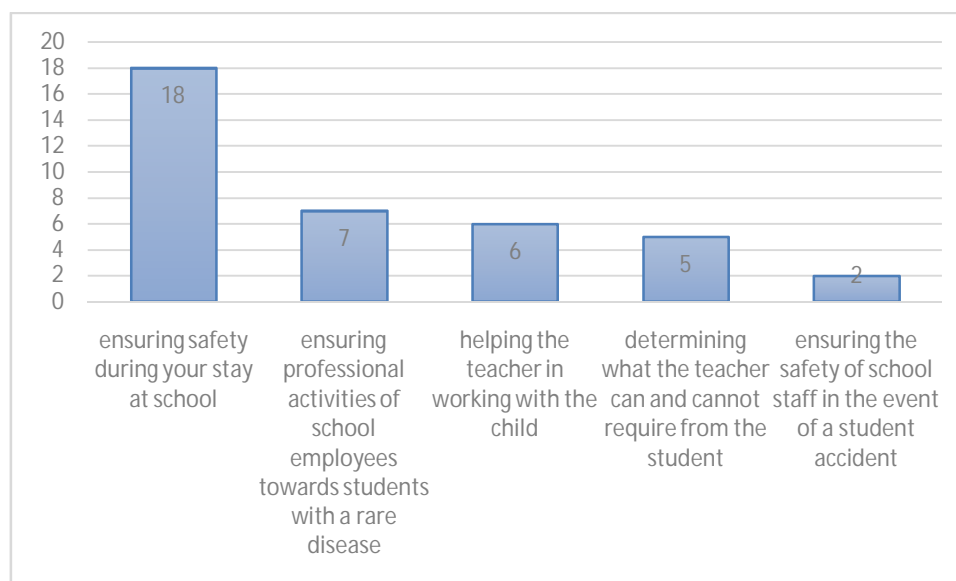
The study group consisted of early childhood education teachers. A total of 38 people participated in the study, with age ranges of 24-29 years (3), 35-39 years (15), 40-44 years (13), 45-49 years (5), and 55 years and older (2). Forty-five teachers completed the survey questionnaire, and seven questionnaires did not meet the criteria relating to teaching a student with a rare disease. The respondents worked with a child diagnosed with West syndrome, Rett syndrome, DiGeorge syndrome, and osteochondroma. The seniority of the respondents is 15-19 years (13), 5-9 years (10), 10-14 years (5), 20 - 24 years (6), 0-4 years (3), and over 25 years (1). Most teachers lived in a city with a population of 50,000 to 100,000 (15) and a city of more than 250,000 (13), the others in a rural area (5) or a city of up to 50 thousand residents (5). All respondents had a master's degree in early childhood education. They declared completion of special education (2) and psychology (1) as additional education.

### **Proposal of a procedure for dealing with a student diagnosed with a rare disease - results of our own research**

Most of the surveyed teachers believe that preparing a procedure for dealing with a student with a rare disease is to ensure his safety while at school (18). Others believe that it is to ensure

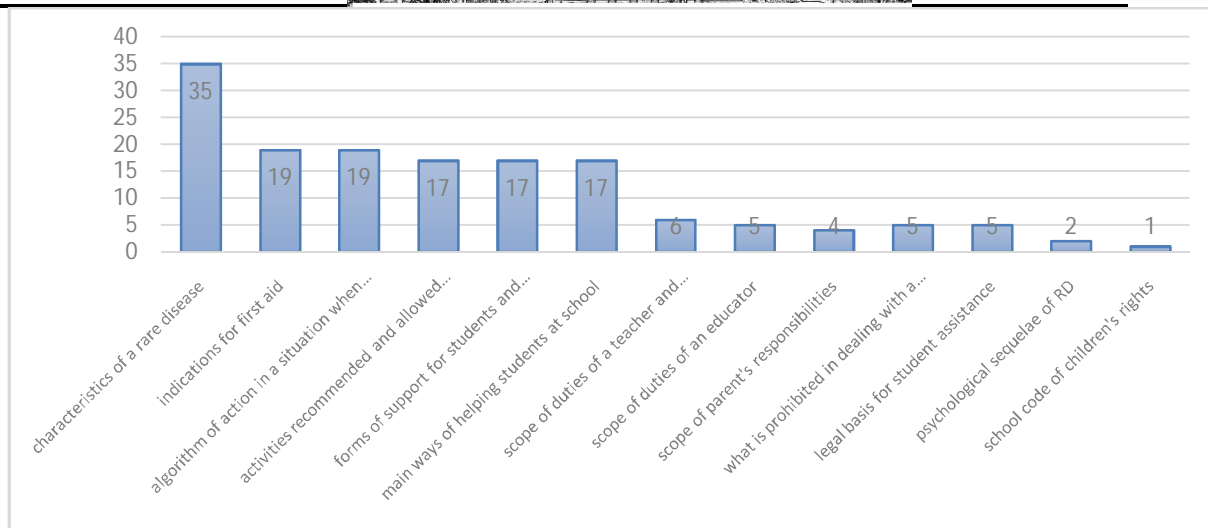


professional actions of school employees towards students with a rare disease (7) to help the teacher work with the child (6). It is also used to determine what a teacher can and cannot require of a student with a rare disease (5) and to ensure the safety of school personnel in the event of a student accident (2) (Figure 1).



*Figure 1. Purpose of preparing the procedure in the opinion of respondents.  
Source: own elaboration.*

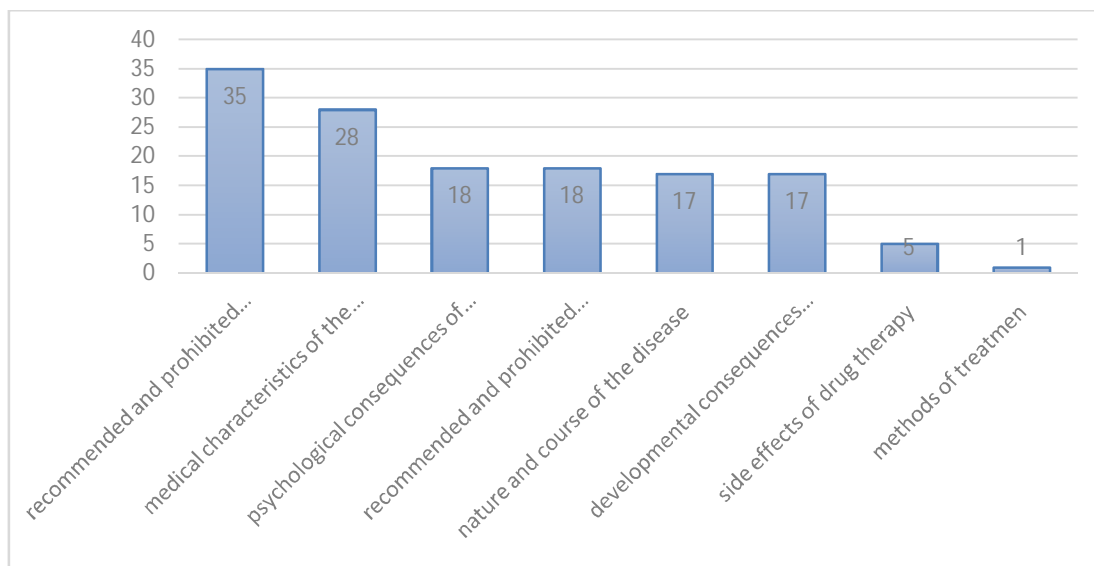
The next question referred to the elements the respondents believe the procedure for dealing with a student with RD should include. The question was multiple choice. Respondents believe that the characteristics of the RD in question are important, along with a description of the student's functioning and characteristic symptoms of the disease affecting his or her learning (35). The procedure should also include both indications for first aid when the symptoms of the disease worsen or in the event of a random accident (19), as well as an algorithm for dealing with the situation when the student's symptoms of the disease or adverse effects from the student's current drug treatment worsen (19). Half of the respondents indicated that one of the elements should be the actions indicated and allowed in students with a rare disease (17), the forms of support and parents (17), and the main ways to help the student on school grounds, including, among other things, the rules for administering medication, etc. (17). Few teachers believe that the procedure should describe the responsibilities of the school counselor and psychologist (6), the class teacher (5) and the parent (4) towards the student. They believe that guidance on what is forbidden in dealing with a student if he or she has an aggravation of the disease (5) and the legal basis for helping the student (5) are also not essential elements. The fewest responses referred to the psychological consequences of a rare disease (2) and the school's code of rights for a child with a rare disease (1) (Figure 2).



**Figure 2.** Elements of the procedure for dealing with a student with RD in the opinion of the respondents.

Source: own elaboration.

According to respondents, the description of a child's rare disease should primarily include recommended and prohibited forms of activity for the child (35), as well as the medical characteristics of the disease, including a description of the types of the disease, its stages, etc. (28). Further indications included: psychological consequences of the disease (18), recommended and forbidden therapies (18), the nature and course of the disease (e.g., chronic nature, mild course) and developmental consequences of the disease (17), side effects of drug therapy undertaken (5) and possible treatments and their course (1). Even though earlier in the question on what elements should be included in the procedure for working with a child with RD, a small number of respondents (2) indicated the psychological consequences of the disease, here it appeared as the third indication (Figure 3).



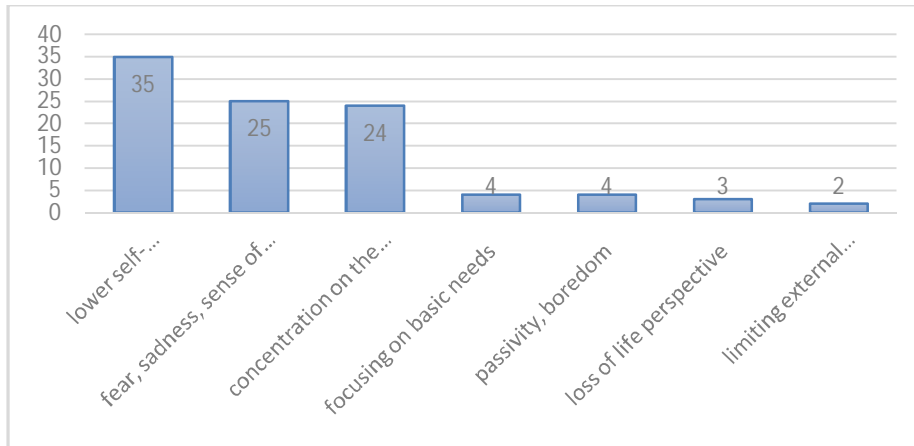
**Figure 3.** Elements of the RD description should be included in the procedure for dealing with students in the teachers' opinion.

Source: own elaboration.



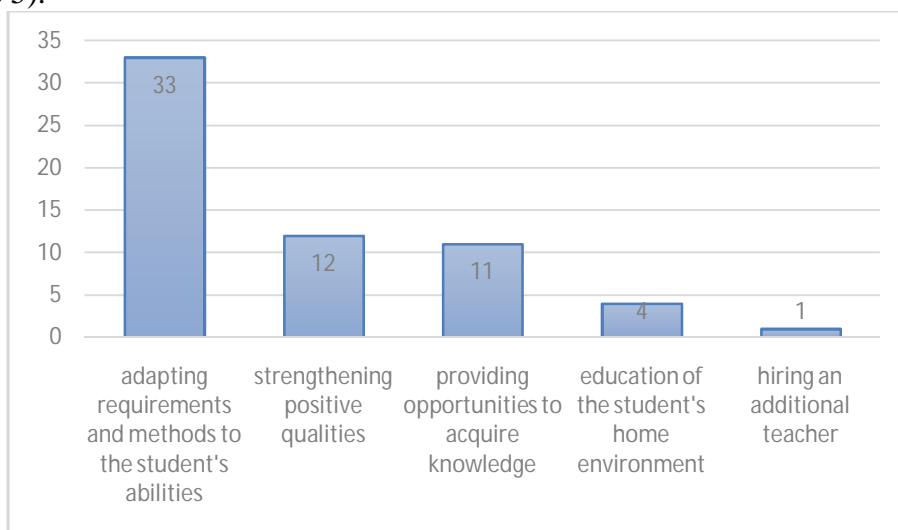


Among the psychological consequences of the student's illness, the teachers indicated, first of all, a lowering of self-esteem, self-esteem; shame and being different (35), anxiety, sadness, a sense of threat (25), and a focus on the current situation, "here and now," an unwillingness to plan and think about the future (24). Other respondents believe the consequences include focusing on basic needs (drinking, eating, feeling safe) and decreased motivation for action - passivity and boredom (4). They also pointed to a loss of perspective on life and hope, a feeling of not influencing events (3), and a reduction in external stimulation, especially with prolonged immobilization and bed rest (2) (Figure 4).



**Figure 4.** Psychological consequences of RD in the opinion of respondents.  
Source: own elaboration.

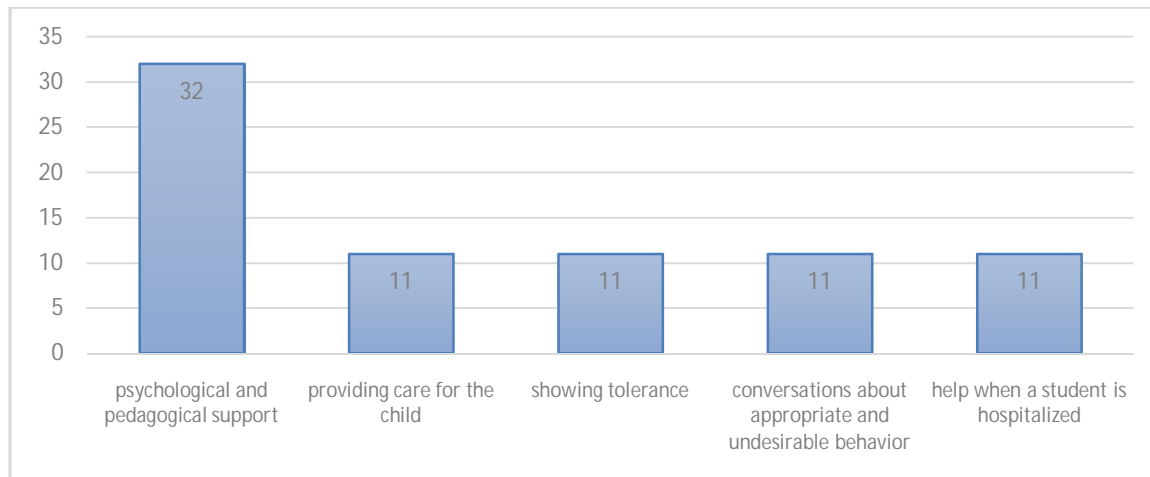
Supporting a student with a rare disease is possible on three levels: educational, educational, and emotional. Questions about them were open-ended. Each teacher had the opportunity to write an answer. According to educators, it is essential to adapt requirements and methods to the student's abilities (33). Respondents also believe that attention should be paid to reinforcing positive qualities and behaviors, realizing potential, discovering talents and skills (12), and providing opportunities to acquire knowledge (11). Few teachers believe that the educational level also includes educating the student's home environment (4) hiring an additional teacher, and teaching in inclusive classes (1) (Figure 5).



**Figure 5.** Support for a student with RD at the educational level in the opinion of respondents.  
Source: own elaboration.



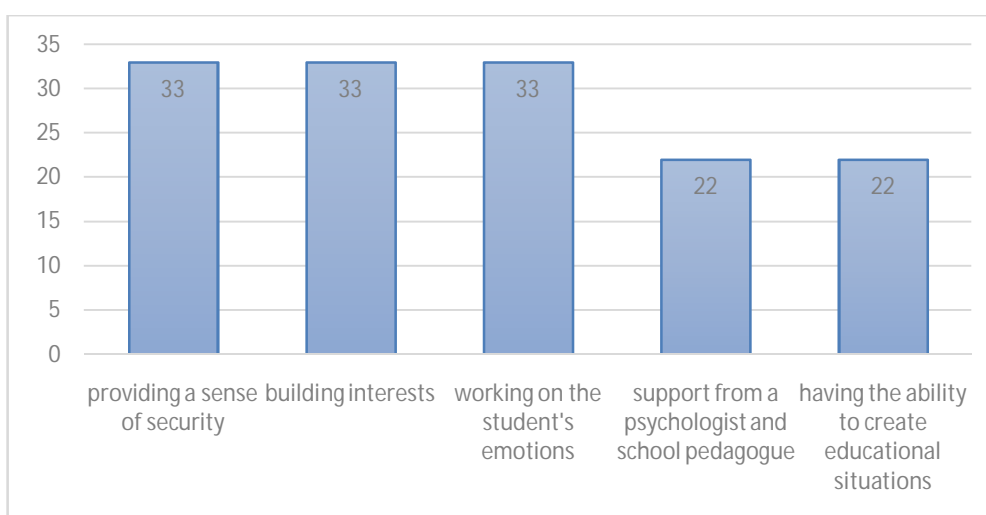
Most respondents identify student support at the educational level with psychological and pedagogical support (32). The rest of the respondents believe that it is based on surrounding the child with care (11), showing tolerance, acceptance, especially when his appearance is different from his peers (11), having conversations about appropriate and undesirable behaviors (11), and assistance when the student is hospitalized (11).



**Figure 6.** Support for a student with RD at the educational level in the opinion of respondents.

Source: own elaboration.

On the emotional level, on the other hand, teachers see support as providing a sense of security, acceptance, and self-esteem (33) and building interests, discovering passions, the joy of experiencing new sources of knowledge, and learning about the world (33). However, according to those surveyed, working on students' emotions when experiencing difficulties and successes is essential and teaching them how to cope with them (33). Teachers also equate this level of support with the support of a psychologist and school counselor (22) and having the student create educational situations (22) (Figure 7).



**Figure 7.** Support for a student with RD at the emotional level in the opinion of respondents.

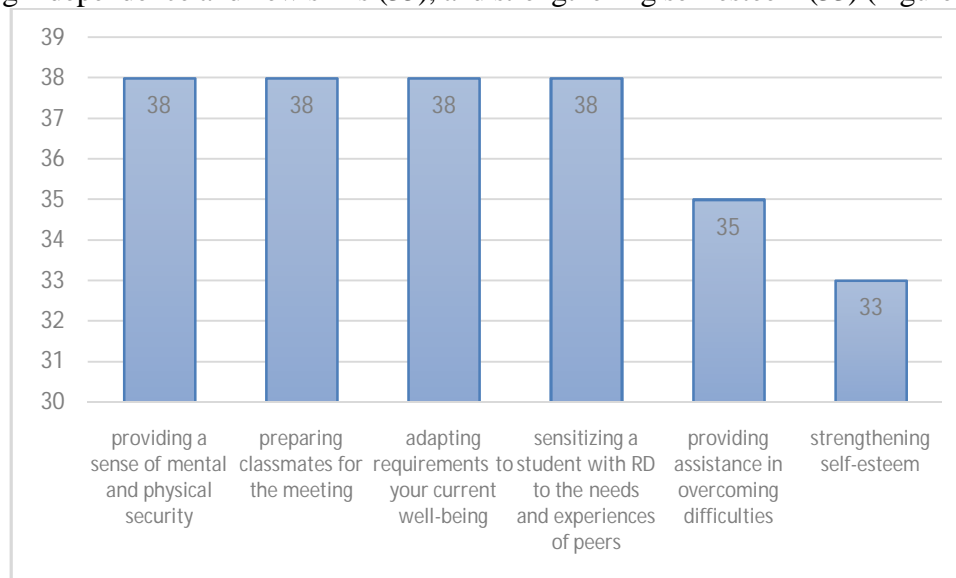
Source: own elaboration.



Among the main ways to help a child with a rare disease possible on school grounds, all respondents pointed to:

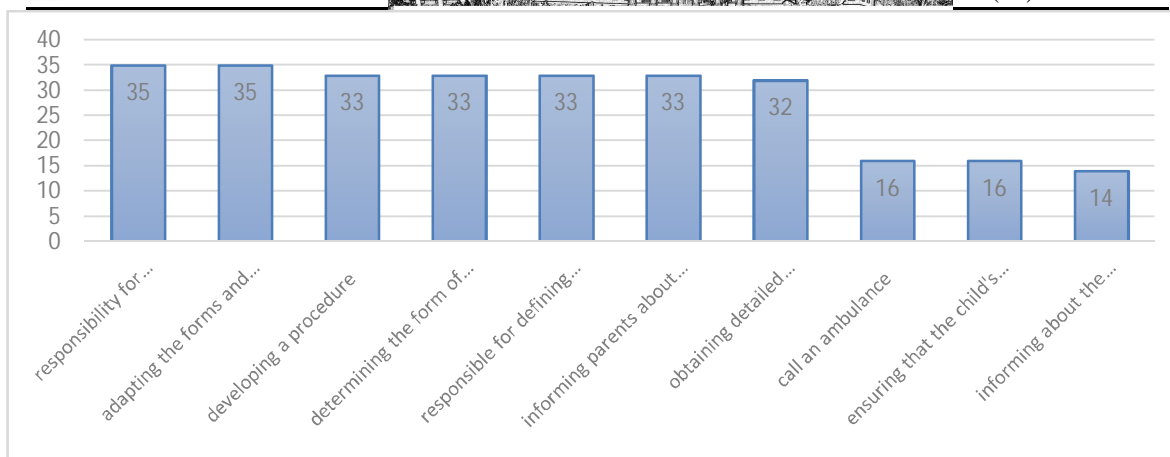
- providing a sense of mental and physical safety and trust in the peer group and teacher (38),
- preparing peers in the classroom to meet a fellow RD (38),
- adjusting requirements to the student's current well-being and condition (38),
- sensitizing a student with RD to the needs and experiences of peers (38).

Respondents also believed that the child could be helped by assisting in overcoming difficulties, teaching independence and new skills (35), and strengthening self-esteem (33) (Figure 8).



**Figure 8.** The Ways to help a student with RD at school in the opinion of teachers  
Source: own elaboration.

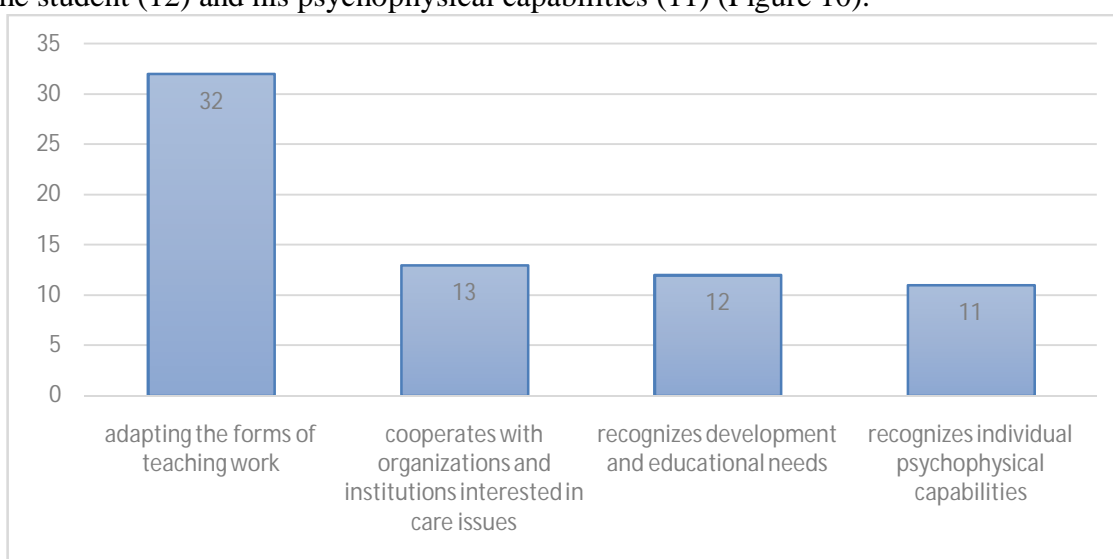
The majority of respondents indicated that the director of an educational institution attended by a student with RD should be responsible for arranging training for the teaching staff and other school employees on how to deal with the student both daily and in the event of an exacerbation of symptoms or attack of the disease (35) and adjusting the forms and conditions of examinations (based on the child's health certificate issued by the doctor and following his recommendations) (35). In consultation with the nurse or doctor, he should also, jointly with the staff, develop procedures for dealing with the student, both daily and in the event of an exacerbation of symptoms or attack of illness (33). These procedures may include, among other things, reminding or helping the student to take his or her medication, take regular meals, how to respond, etc. They should also specify the forms of ongoing cooperation with that child's parents (guardians) and the commitment of all facility employees to apply them without fail (33). The principal, according to the majority of respondents, is also responsible for determining the forms of cooperation between the school and the child's parents (33), and in the event of an increase in the child's symptoms while at school, immediately informs the parents of the situation (33). This relates to another indication by teachers, which refers to the school principal obtaining detailed information from the student's parents about the illness and the resulting limitations on the child's functioning and the effects of medication (32). Fewer than half of the respondents believe that the principal has a duty in emergencies when the child's condition suddenly deteriorates. Medical attention is required to take pre-medical measures and call an ambulance (16) and to ensure that the child's parents provide a set of documents confirming the child's illness and parental consent to take emergency measures (16). He should also be required to inform the child's parents immediately if the child's symptoms of illness worsen while at school (14) (Figure 9).



**Figure 9.** Obligations of the school principal towards a student with RD in the opinion of respondents.

Source: own elaboration.

On the other hand, the majority of respondents asked about the duties of an educator and school psychologist towards a student with a rare disease indicated that, together with teachers and specialists employed at the school, he should adjust the forms of didactic work, the choice of content and methods and the organization of teaching to the psychophysical capabilities of the child, as well as include him in various forms of psychological and pedagogical assistance (32). Less than half of the respondents believe that as part of their duties, the pedagogue and psychologist cooperate with organizations and institutions interested in the problems of care, upbringing, and education of a student with a rare disease (13), recognize the developmental and educational needs of the student (12) and his psychophysical capabilities (11) (Figure 10).



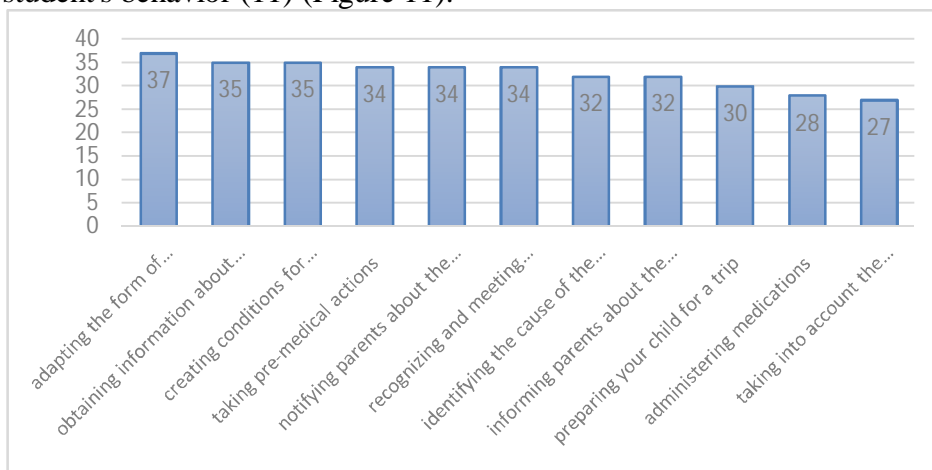
**Figure 10.** Obligations of a pedagogue and a school psychologist towards a student with RD in the opinion of respondents.

Source: own elaboration.

On the other hand, when organizing school trips, the educator should oblige the parents to equip the child with everything needed and provide a list on which the times of medication meals are written (the teacher's role is mainly to pay attention to whether the child does everything according to the list) (30). Due to illness, a student sometimes also has to take medication during the day while at school. According to more than half of the respondents, the educator is responsible for administering medication to the child when such a need arises (28). This is only possible if parents



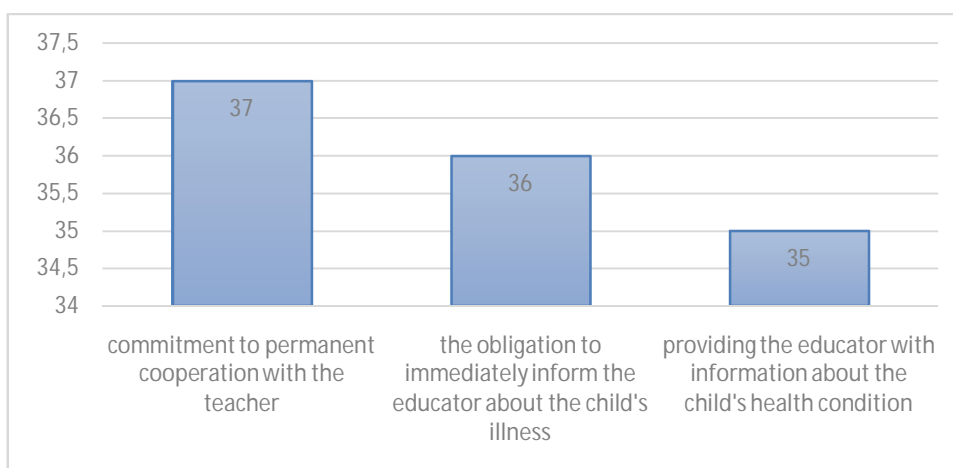
are required to inform what medication the child is taking (dosage, method of administration) and submit a doctor's recommendation and written authorization for teachers. Being sick is also related to the child's different state of well-being. In the respondents' opinion, the teacher should consider the state of poor well-being and reduced intellectual performance of the student caused, for example, by the side effects of the currently used pharmacotherapy (27). In addition to periods of deterioration and complications, the educator should remember to treat the student as an equal to other children (26). Less than half of the respondents believe that it is also the educator's responsibility to note in the school diary the symptoms that suddenly appeared while the student was in the classroom (12) and to keep a student's illness diary, in which the educator will describe the student's behavior (11) (Figure 11).



**Figure 11.** Responsibilities of an educator towards a student with RD in the opinion of respondents.

Source: own elaboration.

The last question referred to the responsibilities of the parent. According to almost all teachers, the caregiver of a child with a rare disease is particularly obliged to cooperate with the educator at all times (37). The parent should immediately inform the educator when the disease is diagnosed while the child attends school (36). When the child starts school, the parent should inform the educator about the child's condition, disease symptoms, health risks, medications taken, and their effects on the body (35) by September at the latest (Figure 12).



**Figure 12.** Children with RD parent duty in the opinion of respondents.

Source: own elaboration.

Summary and discussion



Educational institutions should be prepared to accept a student diagnosed with a rare disease, whether they have integrated departments or not. Hence, defining procedures for dealing with a child in mainstream schools is essential. According to the respondents, the purpose of preparing procedures for dealing with a student with a rare disease is to ensure his safety while at school. They believe that they should include the following elements:

- description of the student's functioning and characteristic symptoms of the disease affecting his learning process,
- indications for first aid in the situation when the symptoms of the disease worsen or in the event of a random accident,
- an algorithm for dealing with the situation when the symptoms of the disease or adverse effects resulting from the student's current drug treatment intensify,
- indicated and allowed actions in a student with RD,
- forms of support for the student and parents and the main ways to help the student on the school premises, including, among other things, the rules for administering medication, etc.

The description of a child's rare disease should include, first and foremost, recommended and prohibited forms of activity, as well as medical characteristics of the disease, including a description of the types of the disease and its stages. The fact that the respondents indicated that basic information about the disease should be included in the procedure corresponds with my earlier research on rare disabilities as an absent category in the training of preschool and early childhood education teachers (Kamyk-Wawryszuk, 2021). Their goal was to analyze the curricula of preschool and early childhood education majors in the context of the implemented content on disability issues, including rare disabilities. Content dealing with issues of functioning of children with disabilities is implemented in various modules, such as a child in school or a child or student with special developmental and educational needs in kindergarten and grades I-III of school. However, RD is not mentioned in them (Kamyk-Wawryszuk, 2021). Hence, an important clue is to include a basic description of RD and its psychological consequences in the procedure. According to the respondents, they primarily refer to a lowering of self-esteem, the child's sense of self-worth, shame, and being different. Anxiety, sadness, a sense of insecurity, a focus on the current situation, on the "here and now," and an unwillingness to plan and think about the future are also critical psychological consequences of RD.

Teachers, according to Renata Lukasik et al. – have a duty to give the student support, including by learning about the child's medical history, the medical procedures that will need to be followed at the facility, or the plan of action and life-saving procedures in case of an emergency (Lukasik et al., 2013). Support can take three levels: educational, educational, and emotional. The respondents believed that under the first, the teacher should primarily adapt requirements and methods to the capabilities of the sick student. This corresponds with the findings of a study conducted by Lukasik et al., which indicates that teachers believe that in the case of a student with a chronic disease, they are responsible for creating "the best possible educational conditions through the appropriate organization of the educational process and the use of methods and forms of teaching adapted to the psychophysical capabilities of the sick child" (Lukasik et al. 2013: 526). Respondents identified the second level with psychological and pedagogical support. Within the last level, respondents believe they should undertake activities that provide a sense of security, acceptance, and self-esteem. This support also includes activities that develop interests, passions, and enjoyment of experiencing new sources of knowledge of learning about the world. In addition, it is also essential to work on the student's emotions, which will be revealed in situations of experiencing difficulties and successes. Ways to help the student on the school premises are to provide a sense of mental and physical security and trust in the peer group and teacher, to prepare class peers to meet a classmate with a rare disease, to adapt the requirements to the student's current well-being and condition, and to sensitize the RD student to the needs and experiences of peers.



The headmaster should be responsible for organizing the training of teaching staff and other school employees in dealing with the student daily and in situations of exacerbation of symptoms or attack of illness, as well as adjusting the forms and conditions of examinations. On the other hand, the educator should adjust the forms of didactic work, the selection of content and methods, and the organization of teaching to the student's psychophysical capabilities and provide him with forms of psychological and pedagogical assistance. He is also tasked with obtaining from the student's parents detailed information about his illness and the resulting limitations in functioning. The educator also creates conditions for the student's active and full participation in the school's life and the social environment. Due to illness, a student sometimes has to take medication during the day while at school. According to Beata Antoszezwska, children diagnosed with chronic diseases usually do not receive support on school grounds to perform necessary medical procedures, such as taking medication or measuring blood sugar levels, for example (Antoszezwska, 2021). According to the early childhood education teachers surveyed, the educators are responsible for administering medication to a child if needed. They allow this possibility only if the parents inform them what medication the child is taking (dosage, method of administration) and submit medical recommendations and written authorizations to the teachers. This is also confirmed by a study done by Antoshevszkaya, which shows that teachers who have agreed to administer medication to a student will do so if they are prepared to do so. They believe that it is from parents and doctors that they will learn how to administer medication (Antoshevszkaya, 2021). According to the respondents, the parent should cooperate with the educator and inform the educator when the child's condition changes.

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**МЕКТЕПКЕ ДЕЙІНГІ БІЛІМ БЕРУ МҰҒАЛІМДЕРІНІҢ БАСТАУЫШ**  
**МЕКТЕПТЕ СИРЕК КЕЗДЕСЕТІН АУРУЫ БАР ОҚУШЫЛАРМЕН ЖҰМЫС ІСТЕУ**  
**ӘДІСТЕРІ**

**Аңдатпа.** *Сирек кездесетін ауруы бар балалар мемлекеттік жалпы орта білім беретін бастауыш мектептері мен білім беру орталықтарында да оқытылуы тиіс. Балалар баратын мектептерде оларға тиісті жұмыс процедуралары дайындалуы керек.*

*Зерттеудің мақсатты сирек кездесетін ауруы бар балалармен жұмыс жасасаудың ұсынылған процедурасын сипаттау болды. Негізгі мәселе мұғалімдердің пікірінше, бастауыш мектепте сирек кездесетін ауруы бар балаларды оқыту жұмысын жүргізетін процедуралары қалай құрылу керек?*

*Зерттеу диагностикалық сауалнама әдістерін және авторлық сауалнама құралдарын пайдалана отырып, сандық бағдарға негізделген. Зерттеуге 38 бастауыш сынып мұғалімі қатысты. Респонденттердің пікірінше, сирек кездесетін ауруға шалдыққан балалармен жұмыс істеу тәртібін дайындаудағы мақсат олардың мектептегі қауіпсіздігін қамтамасыз ету. Онда ең алдымен сирек кездесетін аурудың сипаттамалары, сонымен қатар балалардың оқуына әсер ететін ауруға тән қызмет ету және сипаттамалық белгілер болуы керек.*

**Кілт сөздер:** *процедуралар; сирек аурумен ауыратын оқушы; бастауыш мектеп.*

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**МЕТОДЫ РАБОТЫ С ОБУЧАЮЩИМИСЯ С РЕДКИМИ ЗАБОЛЕВАНИЯМИ В**  
**НАЧАЛЬНОЙ ШКОЛЕ ПО МНЕНИЮ УЧИТЕЛЕЙ НАЧАЛЬНОГО ОБРАЗОВАНИЯ**

**Аннотация.** *Ребенок с редким заболеванием может посещать как государственную начальную школу с инклюзивным образованием так и школу с образовательным центром. Независимо от типа организации, которую они посещают, должна быть подготовлена соответствующая процедура работы.*

*Целью проведенного исследования было описание предлагаемой процедуры работы с обучающимися с редким заболеванием. Основным вопросом исследования было: Как, по мнению педагогов, должна быть построена процедура работы с учащимся с редким заболеванием в начальной школе?*

*Исследование было основано на количественной ориентации, с использованием метода диагностического опроса, методик анкетирования и авторского инструментария анкетирования. В исследовании приняли участие 38 педагогов начального образования. По мнению респондентов, целью подготовки процедуры работы с учеником с редким заболеванием является обеспечение его безопасности во время пребывания в школе. В первую очередь он должен содержать характеристики данного редкого заболевания, а также описание функционирования учащегося и характерные симптомы заболевания, влияющие на его/ее обучение.*

**Ключевые слова:** *процедуры; учащийся с редким заболеванием; начальная школа.*