

EDUCATIONAL NEEDS OF PRESCHOOL CHILDREN WITH RECOGNIZED RARE DISEASE AND INTELLECTUAL DISABILITY – TEACHERS' PERSPECTIVE

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Abstract: *The studies concerned the creation of a picture of needs of children with a rare disease and intellectual disability in the post-positivist paradigm. The author used a quantitative strategy. She also used the preexperimental study, one-group pretest-posttest design - the experiment on the test group including the pretest and post-test, but without the control group - modified by the cascade strategy (double measurement), because it is more suited to the actual learning and consolidation of teachers' knowledge. The research involved teachers of randomly selected primary schools in Poland. On the basis of literature analysis, 27 educational needs were identified, which referred to three categories: rare disease, intellectual disability and common needs. Teachers creating a picture of educational needs of a child with a rare disease and intellectual disability perceive the most of their common features. With each stage of research, the awareness (ability to perceive) of educational needs related to diagnosing a rare disease in a child increased.*

Keywords: *educational needs; child with a rare disease; child with intellectual disability; teachers;*

Introduction

The way of thinking about the needs of children with developmental difficulties is constantly changing. It is a dynamic process, taking into account changes in the scope of early support of child development (a girl/boy with developmental difficulties is covered more earlier), professionalization of people involved in the issue, and changes in school image (inclusive education, integration classes, teacher-specialist, child assistant etc.) (Kamyk-Wawryszuk 2018). Hence, the discussion of educational needs of children with developmental difficulties is important. So far, only a few publications have appeared that address the issue of education of a child with rare disease and intellectual disability. This is due to the fact that many publications on the development and functioning of a child with rare disease are casuistic and they prevent any forecasting the overall development of a child, which determines the individual approach.

Educational needs of a children

There are a lot of definitions of educational special needs of children with developmental difficulties. Some of them underline medical aspects (somatics) of their functioning, and others refer to functional diagnosis. Taking into account the specifics of a child with rare disease, in theoretical assumptions it was assumed that:

„Children have special educational needs if they have a learning difficulty which calls for special educational provision to be made for them. Children have a learning difficulty if they: a) have a significantly greater difficulty in learning than the majority of children of the same age; or (b) have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools

within the area of the local education authority, (c) are under compulsory school age and fall within the definition at (a) or (b) above or would so do if special educational provision was not made for them” (The Education Act 1996).

At the same time, it was assumed that child's needs are superior to the category of special educational needs. This is due to the fact that parents associate the term "special educational needs" with a stigmatizing (special) way of thinking about their child who has health problems (Gernsbacher MA, AR Raimond, Balinghasay MT, Boston JS, 2016 , p. 1).

Based on a literature analysis (Griffin 2014, Bendová, Čecháčková and others 2014, Forrest, Bevans and others 2011), a total of 27 educational needs were specified, including 10 relating to intellectual disability, 10 to diagnosed rare disease and 7 common needs (Table 1). All needs included difficulties in physical, intellectual, social and emotional development.

Table 1. Educational needs of a child with rare disease and intellectual disability.

Educational needs		
Intellectual disability	Rare disease	Common needs
taking into account the slower than average rate of mental operations	strengthening relationships due to frequent absences or limiting the possibility of participating in all activities in classes	peer to view - making it possible to get to know multi-sensory
adjusting the level of difficulty (number of elements) of images, etc.	opportunity to participate in activities outside of the classroom (competitions, professions) adapted to the child's physical limitations	learning by solving problems
transmission of short and precise verbal messages	taking into account the slower pace of work resulting from specific physical limitations	strengthening the child's self-esteem in group and individual classes
adapting to the child's needs ways of presenting knowledge and developing skills and providing guidance	using breaks while working as needed	extending working time
using the work principle on particulars	using breaks during work in accordance with individual needs of a child, resulting from high physical fatigue or current treatment process	strengthening the child's interests
systematic repetition of new knowledge	frequent change of a seat position during work	combining the content of education with the closest environment of life and education, as well as individual experience
depending on child's needs, the recommendation to divide into smaller parts of material to	adjusting the level of physical activity necessary in the class to	functional teaching based on the child's activity, commitment, experience,

learn and to increase the number of repetitions of new knowledge	the current state of health/well-being of a child	discovery and cognition
controlling the pace of work	planned breaks during didactic classes resulting from the specifics of a child's treatment and medical-hygiene procedures	
the use of accessible instructions in didactic materials - picture, pictorial, and animated	very close cooperation with specialists during the creation of support programs	
reducing - to the necessary minimum – the number of subjects with a high degree of abstraction, far from the cognitive abilities and everyday life of a child	supporting active contacts with a child during periods of hospitalization	

Based on: Griffin 2014, Bendová, Čecháčková i in. 2014, Forrest, Bevans and others 2011.

At the same time, the author is aware that the above table may not take into account all the needs arising from the analyzed categories. It is due the fact that the development of a child with a rare disease and intellectual disability may occur individually, thus reveal other educational needs.

1.2. Child with a rare disease and intellectual disability

The portal for rare diseases and orphan drugs announces, that „Rare diseases are diseases which affect a small number of people compared to the general population and specific issues are raised in relation to their rarity. In Europe, a disease is considered to be rare when it affects 1 person per 2000. A disease can be rare in one region, but common in another” (Orphanet 2019). Thus, the number of patients can be up to several million (in Poland it is estimated that it is 3 million people). From this perspective, rare disease is not so rare, so it is likely that there may be several children in a rare disease in the region and even in a given school. Currently, over 8,000 rare diseases are diagnosed and described. Still, many of them have no name. Then we use a term SWAN, Syndrome without Name (brochure SWAN Australia 2019). Some rare diseases, such as Cri du Chat Syndrome, Corneli de Lange syndrome or Sanfilippo syndrome, coexist with moderate intellectual disability. This article adopts the definition of intellectual disability in accordance with the classification of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V):

„intellectual disabilities is a neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living. The DSM-5 diagnosis of ID requires the satisfaction of three criteria: (1) Deficits in intellectual functioning—“reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience”—confirmed by clinical evaluation and individualized standard IQ testing (2) Deficits in adaptive functioning that significantly hamper conforming to developmental and sociocultural standards for the individual's independence and ability to meet their social responsibility; and (3) The onset of these deficits during childhood” (T.F. Boat, J. T. Wu, 2015).

Diagnosis of a rare disease and intellectual disability may contribute to difficulties in physical and cognitive development that may translate into the emergence of individual educational needs.

The methodology of research

In the research in the post-positivist paradigm a quantitative strategy was used. The preexperimental study, one-group pretest-posttest design were applied - the experiment on a test group including pretest and posttest, but without the control group - modified by the cascade strategy (two-fold double measurement), because it is more suited to the actual learning and consolidation of knowledge. The second posttest was determined by an evaluation posttest. The third measurement was used to show the process of consolidation of knowledge ("knowledge composition") of surveyed teachers. Doing only one study could not indicate active involvement in learning and knowingly identifying/differentiating needs.

The following main research problem was formulated: How do teachers construct an image of educational needs of a child with a rare disease and intellectual disability? And detailed questions: What are educational needs of a child with rare disease, and what are educational needs of a child with intellectual disability in the opinion of teachers? What educational needs of a child with rare disease and a child with intellectual disability are common in the opinion of teachers?

The group of respondents consisted of 87 early school education teachers working in randomly selected primary schools in Poland (city has up to 50,000 residents - 33%, from 50,000 to 100,000 residents - 15%, over 250,000 residents - 21%). The group was different in terms of age (20-25 years - 3%, 26-30 years - 8%, 31-35 years - 18%, 36-40 years - 24%, 41-25 years - 15%, 46 years and more - 32%), and seniority (0-5 years - 23%, 6-10 years - 23%, 11-15 years - 19%, 16-20 years - 12%, 20 and more - 23%). Most of the surveyed teachers did not have contact in their work with a child who was diagnosed with a rare disease (81%), the others met with a child with Williams-Beuren syndrome (3%), Leigh syndrome (3%), DiGeorge Syndrome (2%) and Cornelia de Lange Syndrome (1%).

In the research, an original questionnaire was used, containing 27 definitions of educational needs of a child with intellectual disability and a rare disease specified on the basis of a literature analysis (Griffin 2014, Bendová, Čecháčková and others 2014, Forrest, Bevans and others 2011). The needs have been divided into three categories: (1) associated with intellectual disabilities, (2) with rare diseases, (3) common needs. Each category took into account the child's needs resulting from specific physical, cognitive, social and emotional development (Table 1). It is worth noting that, intentionally - forcing in-depth reflection - groups 1 and 2 are not fully disjoint (hence category 3).

The research protocol consisted of the following stages:

First meeting: (1) Pretest - included the assessment of teachers' knowledge about the educational needs of a child with rare disease and intellectual disability, (2) after the test, the first lecture on the educational functioning of a child with rare disease and intellectual disability (Cri du Chat syndrome, Cornelia de Lange Syndrome, Sanfilippo syndrome) and transfer of educational materials,

Second meeting (two weeks later): (1) Posttest - assessment of the variables under investigation after applying the intervention (lecture on the educational functioning of a child with rare disease and intellectual disability), (2) after the completion of the posttest, a second lecture,

Third meeting: (1) Posttest evaluation - consisted in evaluating the lecture two weeks after the last lecture on the functioning of a child with rare disease and intellectual disability (Figure 1).

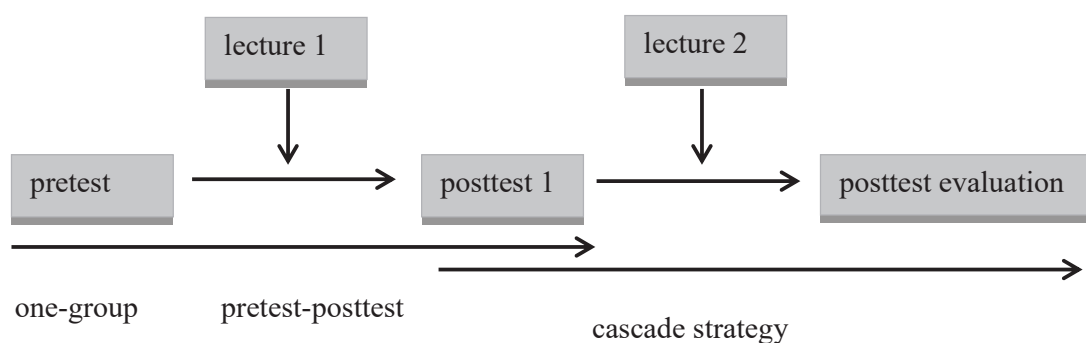


Figure 1. Research procedure.

The results and interpretation of the research

Based on the collected data, it can be concluded that, on average, teachers from I, II and III studies pointed to the common educational needs of a child with a rare disease and intellectual disability (study I $\Sigma = 44,96$; study II $\Sigma = 53,85$; study III $\Sigma = 41,96$) (table 2). The perception of educational needs varied and depended on the stage of research.

Table 2. The type of educational needs of a child with rare disease and intellectual disability in the opinion of the surveyed teachers.

Educational needs	Rare disease (N)			intellectual disability (N)			common needs (N)		
	I	II	III	I	II	III	I	II	III
application of the method of view - making it possible to get to know multi-sensory	7	7	8	41	30	26	39	50	53
learning by solving problems	8	10	10	52	40	36	27	37	41
strengthening the child's self-esteem during group and individual classes	8	8	6	20	19	20	59	60	61
strengthening peer relationships due to frequent absences or limiting the possibility of participating in all activities during classes	35	30	47	6	9	10	44	48	30
opportunity to participate in activities outside the classroom (competitions, professions) adapted to the child's physical limitations	22	23	50	20	18	7	45	46	30
taking into account the slower than average rate of mental operations	4	10	11	36	16	47	47	61	30
taking into account the slower pace of work resulting from specific physical limitations	31	31	47	16	10	10	40	46	30
extending working time	7	4	3	24	18	15	56	65	69
adjusting the level of difficulty (number of elements) of images and etc.	4	5	6	42	17	50	41	65	31
transmission of short and precise verbal messages	6	5	5	36	11	62	45	71	20
adapting to the child's needs ways of presenting	8	3	4	24	18	50	55	66	33

Educational needs	Rare disease (N)			intellectual disability (N)			common needs (N)		
	I	II	III	I	II	III	I	II	III
knowledge, developing skills, and providing guidance									
combining the content of education with the closest environment of life and education, as well as individual experience	11	5	7	28	21	20	48	61	60
using the work principle on particulars	8	5	5	35	21	50	44	61	32
depending on the child's needs, the recommendation to divide into smaller parts of the knowledge to learn and to increase the number of exercises and repetitions	4	5	5	42	23	43	41	59	39
controlling the pace of work	5	7	7	26	15	16	56	65	64
Using breaks while working as needed	8	8	7	13	9	8	66	70	72
the use of simple instructions in the didactic materials - pictorial, pictorial-verbal and animated	3	2	2	45	21	50	39	64	30
reducing to the necessary minimum subjects with a high degree of abstraction, far from the cognitive abilities and everyday life of a child	11	8	8	46	20	51	30	59	28
the need for functional teaching based on a child's activity, commitment, experience, discovery and cognition	12	14	13	24	13	14	51	60	60
breaks during work in accordance with individual needs of a child, resulting from high physical fatigue or current treatment process	21	29	40	8	4	8	58	54	39
frequent changes of a seat position during the task	39	35	39	14	9	11	34	43	37
adjusting the level of physical activity necessary during the class to the current state of health/well-being of a child	51	53	53	8	7	7	28	27	27
systematic repetition of new knowledge	5	6	5	33	24	23	49	57	59
strengthening the child's interests	20	16	16	18	21	21	49	50	50
planned breaks during the didactic classes resulting from the specifics of treatment and medical-hygienic procedures of a child	45	46	45	0	1	1	42	40	41
close cooperation with specialists during the creation of support program	29	35	36	2	5	4	56	47	47
maintaining active contact with a child during periods of hospitalization	60	62	65	2	3	2	25	22	20

N – numbers of answers, I- pretest, II- posttest, III – evaluation posttest

At the same time, while constructing the picture of child's educational needs during the first research, the attributes in the questionnaire were assigned to the following categories:

rare disease – 4 characteristics, intellectual disability - 6 characteristics, common - 17 characteristics (table 3). On the other hand, in the study of the second category of rare disease, the respondents assigned three traits, intellectual disability and one trait, and common 23 traits (table 4). In the last study (III), teachers pointed out 8 traits associated with a rare disease, 8 characteristics relating to intellectual disability and 12 common (table 5). In the first research the most points referred to the need of using breaks while working as needed, in second to the transmission of short and precise verbal messages and in third to the need of extending working time. All of those needs were attributed to the category of common needs.

Table 3. The type of educational needs of a child with rare disease and intellectual disability in the opinion of the surveyed teachers (first research).

Educational needs		
Rare disease	Intellectual disability	Common needs
frequent changes of a seat position during the task	application of the method of view - making it possible to get to know multi-sensory	strengthening the child's self-esteem during group and individual classes
adjusting the level of physical activity necessary during the class to the current state of health/well-being of a child,	learning by solving problems	strengthening peer relationships due to frequent absences or limiting the possibility of participating in all activities during classes
planned breaks during the didactic classes resulting from the specifics of treatment and medical-hygienic procedures of a child,	adjusting the level of difficulty (number of elements) of images and etc.	opportunity to participate in activities outside the classroom (competitions, professions) adapted to the child's physical limitations
maintaining active contact with a child during periods of hospitalization	depending on the child's needs, the recommendation to divide into smaller parts of the knowledge to learn and to increase the number of exercises and repetitions	taking into account the slower than average rate of mental operations
	the use of simple instructions in the didactic materials - pictorial, pictorial-verbal and animated	taking into account the slower pace of work resulting from specific physical limitation
	reducing to the necessary minimum subjects with a high degree of abstraction, far from the cognitive abilities and everyday life of a child	extending working time
		transmission of short and precise verbal messages
		adapting to the child's needs ways of presenting knowledge, developing skills, and providing guidance
		combining the content of education with the closest

	environment of life and education, as well as individual experience
	using the work principle on particulars
	controlling the pace of work
	using breaks while working as needed
	functional teaching based on the child's activity, commitment, experience, discovery and cognition
	breaks during work in accordance with individual needs of a child, resulting from high physical fatigue or current treatment process
	systematic repetition of new knowledge
	close cooperation with specialists during the creation of support program
	strengthening the child's interests

Table 4. The type of educational needs of a child with rare disease and intellectual disability in the opinion of the surveyed teachers (posttest 1).

Educational needs		
Rare disease	Intellectual disability	Common needs
adjusting the level of physical activity necessary during the class to the current state of health/well-being of a child	learning by solving problems	application of the method of view - making it possible to get to know multi-sensory
planned breaks during the didactic classes resulting from the specifics of treatment and medical-hygienic procedures of a child		strengthening the child's self-esteem during group and individual classes
planned breaks during the didactic classes resulting from the specifics of treatment and medical-hygienic procedures of a child		strengthening peer relationships due to frequent absences or limiting the possibility of participating in all activities during classes
		opportunity to participate in activities outside the classroom (competitions, professions) adapted to the child's physical limitations

	taking into account the slower than average rate of mental operations
	taking into account the slower pace of work resulting from specific physical limitations
	extending working time
	adjusting the level of difficulty (number of elements) of images and etc.
	transmission of short and precise verbal messages
	adapting to the child's needs ways of presenting knowledge, developing skills, and providing guidance
	combining the content of education with the closest environment of life and education, as well as individual experience
	using the work principle on particulars
	depending on the child's needs, the recommendation to divide into smaller parts of the knowledge to learn and to increase the number of exercises and repetitions
	controlling the pace of work
	breaks while working as needed
	the use of simple instructions in the didactic materials - pictorial, pictorial-verbal and animated
	reducing to the necessary minimum subjects with a high degree of abstraction, far from the cognitive abilities and everyday life of a child
	the need for functional teaching based on a child's activity, commitment, experience, discovery and cognition
	breaks during work in accordance with individual needs of a child, resulting from high physical fatigue or current treatment process
	frequent changes of a seat position during the task
	systematic repetition of new knowledge
	strengthening the child's interests
	close cooperation with specialists during the creation of support program

Table 5. The type of educational needs of a child with rare disease and intellectual disability in the opinion of the surveyed teachers (posttest evaluation).

Educational needs

Rare disease	Intellectual disability	Common needs
strengthening peer relationships due to frequent absences or limiting the possibility of participating in all activities during classes	taking into account the slower than average rate of mental operations	application of the method of view - making it possible to get to know multi-sensory
opportunity to participate in activities outside the classroom (competitions, professions) adapted to the child's physical limitations	adjusting the level of difficulty (number of elements) of images and etc.	learning by solving problems
taking into account the slower pace of work resulting from specific physical limitations	transmission of short and precise verbal messages	strengthening the child's self-esteem during group and individual classes
breaks during work in accordance with individual needs of a child, resulting from high physical fatigue or current treatment process	adapting to the child's needs ways of presenting knowledge, developing skills, and providing guidance	strengthening peer relationships due to frequent absences or limiting the possibility of participating in all activities during classes
frequent changes of a seat position during the task	using the work principle on particulars	extending working time
adjusting the level of physical activity necessary during the class to the current state of health/well-being of a child	depending on the child's needs, the recommendation to divide into smaller parts of the knowledge to learn and to increase the number of exercises and repetitions	combining the content of education with the closest environment of life and education, as well as individual experience
planned breaks during the didactic classes resulting from the specifics of treatment and medical-hygienic procedures of a child	the use of simple instructions in the didactic materials - pictorial, pictorial-verbal and animated	controlling the pace of work
maintaining active contact with a child during periods of hospitalization	reducing to the necessary minimum subjects with a high degree of abstraction, far from the cognitive abilities and everyday life of a child	breaks while working as needed
		the need for functional teaching based on a child's activity, commitment, experience, discovery and cognition
		systematic repetition of new

	knowledge
	strengthening the child's interests
	close cooperation with specialists during the creation of support program

As it can be seen from the above data, in each study the most indications referred to the category of common needs. At the same time, it can be noticed that along with subsequent lectures on a child's functioning with a rare disease and intellectual disability, the awareness of educational needs related to the diagnosed disease increased (I-4 traits, II-3 traits, III-8 features). This indicates the process of knowledge consolidation. All the features indicated as educational needs resulting from the diagnosis of a rare disease referred to the difficulties in somatic development and the resulting problems with fatigability (changing the position of the seat, the use of breaks, etc.) and reduced level of physical activity. In the case of educational needs related to the diagnosis of intellectual disability in a student, it can be noted that the most indications were in study III (8 needs) and least in study II (1 need), which may also indicate - as in the case of needs arising from rare diseases - about the consolidation of knowledge. This indicates the process of knowledge consolidation. For instance, the need <use of simple instructions in the didactic materials - pictorial, pictorial-verbal and animated> is connected to the diagnosed intellectual disability of child. In research I the most teachers pointed, that it belongs to that category. In research II to common needs, and in III again was pointed as intellectual disability.

All the features indicated as educational needs resulting from the diagnosis of a rare disease referred to the difficulties in somatic development and the problems with fatigability (changing the position of the seat, the use of breaks, etc.) and reduced level of physical activity. In the case of educational needs related to the diagnosis of intellectual disability in a child, it can be noted that the most indications were in study III (8 needs) and the least in study II (1 need), which may also indicate - as in the case of needs arising from rare diseases - about the consolidation of knowledge. All the indicated needs were related to difficulties of a child with intellectual disability in cognitive processes (perception, concentration of attention, cause and effect thinking, etc.). They did not take into account the often co-occurring health problems of a child (fatigue of the hand during writing, fatigue of eyes while working on the elements graphic etc.). In research III teachers created a picture of needs of children with a rare disease and intellectual disability closest to the image which based on literature analysis.

Conclusion

There are no publications dealing with the educational needs of a child with a rare disease and intellectual disability. The publications that have appeared so far present case studies and are of a casuistic nature, making it difficult to generalize. As the National Council for Special Education emphasizes, primary school teachers are responsible for the educational progress of all children, including those with special educational needs (National Council for Special Education 2014). Therefore, they should provide them with adequate support and assistance. In the case of a child with a rare disease and intellectual disability, pedagogues should have knowledge about the specific physical and cognitive functioning of these pupils and recognize the needs related to the current state of health (diagnosed disease) and the level of cognitive functions. At the same time, the author is aware that children with a rare disease are only part of a group of children with learning difficulties, hence the problem of choosing appropriate methods of work and preparing a personalized strategy to support such a child

may arise. This determines the lack of a specific path to support a child, hence it seems important to raise this issue during pedagogical councils or meetings of specialist teachers. The observation of educational needs resulting from a rare disease will allow to personalize therapeutic and pedagogical interactions and will enable the child - despite his/her uniqueness - to find himself/herself in a school group and follow his peers.

The following conclusions can be made on the basis of the research:

- teachers creating a picture of educational needs of a child with a rare disease and intellectual disability notice the most of their common features,
- the educational needs identified by the teachers related to a child with a rare disease were related only to the physical sphere (health problems) of the child, there were no indications of needs related to cognitive functioning,
- along with each stage of research, the awareness (ability to perceive) of educational needs related to diagnosing a rare disease in a child increased, which also indicates the need to consider this issue during training of the pedagogical board and in the teacher's study programs. This will enable to prepare future teachers to personalize teaching strategies and individualize therapeutic interactions,
- further research should be carried out on the perception of the needs of children with rare diseases.
- In the course of the research, other research areas have also been revealed, such as:
 - constructing personalized teaching strategies for a child with a rare disease,
 - combining therapeutic methods that will complement and support the child's development.

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