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**STUDY ON PARENTS' INVOLVEMENT IN THE AUTISTIC
CHILDREN THERAPY SUPPORT**

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Abstract

The present study aims at obtaining relevant data on the impact of the Autism Spectrum Disorders (ASD), on the quality of family and other environment integration of the children and young people attending the Community Services Center for Children with Disabilities in Focșani, within the framework of Vrancea General Directorate for Social Assistance and Child Protection (D.G.A.S.P.C. Vrancea). The research was carried out on a group of 22 parents who answered the questionnaire which was applied between February and March 2018, in the Community Services Center for Children with Disabilities in Focșani. The purpose of the research is to evaluate the correlation between the level of knowledge of the parents with ASD children on this diagnosis and the degree of the internal resource mobilization (motivational and family) and external (institutional: medical services, specific rehabilitation therapy services, educational institutions) in the integration of children with ASD into the family, social and school environment. The hypotheses of the study, according to which *early diagnosis (between 1-3 years) of children leads to earlier access to the therapeutic intervention services and according to which parents of the children with autism are fully involved in their understanding and treatment, have been confirmed*. The information obtained through the survey method, its analysis, revealed good information on the diagnosis of the child, the parents' involvement in the provision of medical and therapeutic services, the organization of the child's life programme, the child's adaptation to different forms of education. There were also answers that were punctually different.

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1. Introduction

Recent research shows that autism spectrum disorders can affect any family, regardless of race, ethnicity, or social environment (Peeters, 2009). From the perspective of the ASD incidence, the sex ratio is 4 to 1 for boys, and from the perspective of the degree of illness it seems that females are more severely affected than males. Even though ASD can be diagnosed from the age of 2, most children are diagnosed only later, for various reasons. Diagnosing and establishing the disability degree can facilitate an early intervention that “could maximize children’s ability to function and participate effectively in the community they belong to.” (Christensen et al., 2016). At the national level, there is no specific statistical data on the number of children and people with ASD in Romania. A pilot study performed by the Help Autism Association between April 2016 and March 2017 on 613 children aged between 1 and 3, from nurseries and kindergartens in Sector 3, Bucharest, in order to offer specialized services for 30 children identified with delays in development as well as in order to develop a good practice guide to assist parents on recovery, revealed that out of the 613 children included in the project, 12 were diagnosed with ASD, which is an incidence of 1 out of 51 children. The diagnosis occurred more frequently among boys (1 in 40) than among girls (1 out of 84), but overall it is above the world average of 1 in 68 children (1 din 51 de copii este diagnosticat cu Autism (n.d.).

The issue of children and people with ASD in Romania is insufficiently approached. We refer to the study conducted for the Romanian Angel Appeal (Toth, Mita, & Bojinca, 2013), which mentions a series of problems faced by the children with ASD in Romania, highlighting aspects related to diagnosis and family, school and social integration of these children. These issues have a heterogeneous manifestation due to the significantly affected area of development (language, socialization, self-service, motor or cognitive), the chronological age and the age at which the child was diagnosed, the social context (including family), access to specific therapeutic services, etc.

Psychiatrist Leo Kanner, since 1943, notes the fact that mainly in autism there is an inability of children to relate to life and situations from the beginning of their lives. He claims that "this is not, as in the case of schizophrenic children or adults, a deviation from an initially present relationship; it is not a withdrawal from the existing participation. From the beginning, there is an *autistic loneliness which*, whenever possible, ignores, stops everything that comes from the outside of a child".

2. Problem Statement

The research aimed at assessing the impact of specific therapy services on the beneficiaries of the Community Services Center for Children with Disabilities from Vrancea General Directorate for Social Assistance and Child Protection (D.G.A.S.P.C. Vrancea), by applying a questionnaire regarding the degree of information of parents / children’s tutors regarding the diagnosis of their children, the relationship with the doctor and other professionals, the medication the child benefits, the quality of school integration, the opportunity of information and counselling offered in the center, etc. Considering that such information has not been identified and presented in a socio-family, medical, etc. analysis so far, we believe that it may be the basis for future wider research on this topic.

3. Research Questions

- Early diagnosis of children (1-3 years) leads to earlier access to intervention services.
- Parents of children with autism are fully involved in their understanding and treatment.

4. Purpose of the Study

The aim of the research is to evaluate the correlation between the level of information of the parents of children with ASD on this diagnosis and their degree of rallying their internal resources, motivational, but also family resources, as well as their external resources, institutional-medical services, of specific recovery therapy, educational institutions, maximizing the chances of family, social and school integration of children with ASD.

5. Research Methods

The methods which helped us in conducting the research were the following:

- the bibliographic study regarding the updates about the medical, psychosocial information, etc. on autism, ASD, other neurodevelopment disorders, information on the service network at the level of Vrancea County and not limited, the types of intervention approached in the rehabilitation practice of a child with ASD and other developmental disorders in connection with the school network at the level of Vrancea County, respectively, pre-school education, mass school and special education, pre-school and school level;
- the survey method by applying a questionnaire to the sample of subjects;
- the statistical and mathematical processing in order to process the collected data and their interpretation;
- the graphical method for performing the graphical representation of the monitored parameters variations and of the measured indices based on them;
- the data analysis and interpretation.

6. Findings

The questionnaire was applied to a number of 22 parents whose children, diagnosed with ASD and disabled, receive specific recovery therapies within the Community Services Center for Children with Disabilities in Focșani of D.G.A.S.P.C. Vrancea.

For the question: *What is Autism?*, the parents' answers provide a picture of the varied diagnosis of their child (Table 1), proving the existence of previous information on this subject. The answers presented in Table 1 highlight the parents' approaches, ranging from "autism is a pathological state manifested by breaking the contact with the outer reality and by excessive living of the inner state" - mother (C.C.), - "untreatable disease" (N.C.), "an irreversibile disease" - mother (T.N.) "it is a disease that decreases the ability to communicate, to interact with others" - mother (M.M.), "the most complex developmental disorder, neurological disorder" - mother (R.T.), to "a disorder, a social delay" (B.M.'s mother) or "a delay in collaboration" - father (S.N.), etc.

Table 01. Summarizing table containing the answers to the question: *What is Autism?*

No. subjects	Sp	CSw	Dd	Dn	Dsd	DIn	STp	Dpc	DIi	NA	Total
	1	1	7	1	2	1	1	3	2	3	22
Percentages	4.54	4.54	31.81	4.54	9.09	4.54	4.54	13.63	9.09	13.63	100%

Legend Sp = Pathological state, Weak communication skill = CSw; Developmental Disorder = Dd; Neurologic Disorder = Dn; Socializing Delay Disorder = Dsd; Neuropsychiatric Disease = DIn; Psychic State = STp; Psychocomportamental Disorder = Dpc; Irreversible disease = DIi; no answer = NA

For the question: *At what age was your child diagnosed ?*, according to the answers provided, we found that, to a large extent, the medical diagnosis was made until the age of 5 years (Table 2).

Table 02. Summarizing table containing the answers to the question *At what age was your child diagnosed?*

No. subjects	1 year	2 years	3 years	4 years	5 years	Total
	3	13	3	1	1	22
Percentages	13.63	59.09	13.63	4.54	4.54	100%

To the question: *What was the reason to go to the doctor's? which were the first symptoms?*, the answers provided show that the first symptoms are among the most varied of the less specific ones such as digestive problems (GI's father), to the most obvious – “she was a child who reached the age of 3, NON-VERBALLY, sleep disorder, selective food, hyperactive, lack of responses whenever she was called” (E.-RL's Mother). Parents reported about symptoms that are part of the clinical picture of Autism Spectrum Disorder: lack of inter-human and social communication – “the first symptoms were stereotypical, apathy and disinterest towards the parent, the visual contact was absent” (TM's mother) , “he would not communicate with us, he was sleeping all the time, he was inattentive, he would not respond when we called him” (TG's mother), “he would not answer when he was called, he would swing his hands frequently, having a certain way to rub himself”, behaviour problems, going up to self-aggression and sensory hypo-hyperactivity problems – “showing agitation and rubbing his head against the wall until his skin was peeled off” (TN's mother); “Stimulated, he would lie on the floor, hitting his head with his hand” (P.I.'s father), behaviours and activities of self-stimulation and stereotypes – “blocking himself on certain objects, colours; he would not socialize with strangers and lost of language”, as well as other socially disadaptive behaviours, including lack of integration in the school environment (kindergarten, school).

To the item: *Is your child currently being monitored by a specialist?* - 21 parents of the 22 surveyed responded affirmatively (table 3);

Regarding the administration of the medication - 19 parents of the 22 questioned answered affirmatively, specifying also what exactly: - neurotrophic medicine: 10 children; psychotropic medication: 4 children; neurotrophic medication + psychotropy: 5 children; without medication: 3 children;

Table 03. Summarizing table containing the answers to the question: *Is your child currently being monitored by a specialist? Does he receive medication?; What medication?*

No. subjects	Msd		Rm		Mnt	Mp	Mm	NA	Total
	Yes	No	Yes	No					
	21	1	19	3	10	4	5	3	22
Percentages	95.45	4.54	86.36	13.63	45.45	18.18	22.72	13.63	100%

Legend: Monitored by a specialized doctor = Msd, Receives medication = Rm; Neuro-trophic medication = Mnt; Psychotropic medication = Mp; Mixt medication = Mm; No medication = NA.

After analyzing the answers to the question: *Does your child have therapy sessions?*, we found that all the children of the 22 parents surveyed benefited from specific therapy sessions.

According to the answers to the question: *What type of therapy does he make?*, we could find out that all of these children have therapies like: TEACCH therapy, ABA therapy, physical therapy, psychological counseling, logopaedics, massage.

By analyzing the answers given to the question: *How long have they received therapy?*, we found that these children started specific therapies at varying time intervals from 4 months - 1 child, up to 11 years - 1 child.

These data (Table 4) indicate that a child diagnosed with ASD needs specific therapies for a long period of time, requiring specialized lifelong support.

Table 04. Summarizing table containing the answers to the question: *How long have they received therapy?*

No. subjects	4 months	1 year	2 years	3 years	4 years	5 years	6 years	9 years	11 years	Total
	1	5	4	3	2	2	3	1	1	22
Percentages	4.54	22.72	18.18	13.63	9.09	9.09	13.63	4.54	4.54	100%

According to the answers to the question: *What is the weekly frequency of the therapy sessions?*, we found that the weekly frequency was from one day a week to seven days a week. It is to be noted that when a parent comes with the child at the center once a week, he benefits from several therapies that day.

Considering the answers to the question: *Do you benefit from counselling and advice on improving the abilities, behaviour of the child in the family environment?*, we noticed that most parents receive advice and recommendations. The answers presented in Table 5 show that 19 parents responded affirmatively and 3 parents answered negatively.

Table 05. Summarizing table containing the answers to the question: *Do you benefit from counselling and advice on improving the abilities, behaviour of the child in the family environment?*

	Yes	No	Total
No. subjects	19	3	22
Percentages	86.36	13.63	100%

By analyzing the answers given to the questions: *Do you think the counselling useful, do you follow it?*, we noticed that most parents consider these recommendations to be helpful. The answers presented in Table 6 show that 21 parents responded affirmatively and a parent answered negatively.

Table 06. Summarizing table containing the answers to the questions: *Do you think the counselling useful, do you follow it?*

No. subjects	Yes	No	Total
	21	1	22
Percentages	95.45	4.54	100%

From the evaluation of the answers to the question: *Which family member spends the most time with the child during the day?*, we found that most children spend most time with their mother (Table 7).

Table 07. Summarizing table containing the answers to the question: *Which family member spends the most time with the child during the day?*

No. subjects	Stm	Stf	Stmg	Stmf	Sta	Stbp	Total
	13	4	2	1	1	1	22
Percentages	59.09	18.18	9.09	4.54	4.54	4.54	100%

Legend: Spending time with mother = Stm, Spending time with father = Stf; Spending time with mother and grandparents = Stmg; Spending time with mother and brothers = Stmb; Spending time with aunt = Sta; Spending time with both parents = Stbp;

Regarding the answers to the question: *How does the child relate to the other family members?*, we noticed that in the parents' opinion, most children have an adequate relationship with the family members (Table 8).

Table 08. Summarizing table containing the answers to the question: *How does the child relate to the other family members?*

No. subjects	Rfbmf	Rbmf	Rfbtbm	Rfbmdt	Rbmtdf	Rpm	NA	Total
	4	9	3	1	4	1	1	22
Percentages	18.18	40.90	13.63	4.54	18.18	4.54	4.54	100%

Legend: Relates very well with the family members = Rvwfm; Relates well with the family members = Rwf; Relates very well with the father and well with the mother = Rvwfw; Relates very well with the mother and at all with the father = Rvwmdf; Relates well with the mother and father, but distant with the brothers = Rwmfdb; Relates a little with the mother = Rlm; No answer = NA

The answers to the item: *Is the child currently studying at school?* show us that most children have a form of schooling. The answers presented in Table 9 highlight the fact that 20 parents responded affirmatively and two parents answered negatively.

Table 09. Summarizing table containing the answers to the question: *Is the child currently studying at school?*

	Yes	No	Total
No. subjects	20	2	22
Percentages	90.90	9.09	100%

By analyzing the answers to the question: *What kind of schooling does the child attend?* we noticed that most children follow a form of schooling, two children being unskilled (Table 10).

Table 10. Summarizing table containing the answers to the question: *What kind of schooling does the child attend?*

No. subjects	Sm	Km	Ss	NA	Total
	3	11	6	2	22
Percentages	13.63	50	27.27	9.09	100%

Legend: Mass school = Sm; Mass kindergarten = Km; Special school = Ss; No schooling = NA;

The evaluation of the answers provided to the question: *How is the child's diagnosis reflected on you and on the way the family works?*, we noticed that the diagnosis of children has completely changed the lives of the majority of those questioned. "Our life has changed to 360 °, everything spins around it for

recovery” - Mrs. E.-R.L. The same answer we receive from Mrs. C.C. and A.F. “Finding the diagnosis has completely changed our way of life.” Acceptance proves to be one of the toughest options; sadness and discouragement are constantly present. “We were angry, but now it’s better,” said Mrs. P.D., and Mrs. T.G. says “we have hardly accepted the situation and we are still working on adaptation.”

Such a diagnosis is a traumatic event for the parents, family – “I felt a shock when I found out, and afterwards, in time I accepted” (Mrs. T.N.). It is a diagnosis that spurs a family and challenges its members, giving a feeling of insecurity, “all life has been disturbed, the uncertainty of the future, the awareness that we are dying and we do not know whether he will be an independent person, etc.” (Mrs R.T.). For some, finding out the diagnosis has triggered revolt, feelings of guilt and disappointment. For Mr. G.I., it is simply “overwhelming”, and he does not have the power to elaborate his answer; the same for Mrs. B.I. who describes the experiences as “something unusual, something bad”. Mrs. G.M. she feels “a disappointment, a great burden”, and for Mrs. B.M. the acceptance came as a relief: “we were upset at first, revolted, but we are reconciled with the idea now.”

According to the parents’ responses, we can notice that once the situation is accepted, a process of finding answers and positive solutions begins, exceeding an important threshold on recovery – “it is not a joy to have children with health problems, we accepted the situation, and we are working it out”. Overcoming the critical moment and adapting to the new situation are found in the parents’ statements: “the diagnosis of my child reflects well on the family because I have accepted him as a normal child” (Mrs. TM), “we are trying to find a way to solve it” (Mr. MA) and to see our child as a child without problems.” (Mrs. NC).

To the question: *From your point of view, what is the degree of adaptation of the child to the family/ social / school environment?*, 19 parents consider their children to be adaptable, and three consider that they are poorly adapted, and as far as the social / school environment is concerned, 12 parents consider their children to be adaptable, seven are poorly adapted, one is inadequate, two do not attend any form of schooling (Table 11).

Table 11. The table summarizing the answers to the question: *From your point of view, what is the degree of adaptation of the child to the family/ social / school environment?*

No. Subjects	Family environment			School environment			NA	Total
	A	Pa	N	A	Pa	N		
	19	3	0	12	7	1		
Percentages	86.36	13.63	0	54.54	31.81	4.54	9.09	100%

Legend: Adapted = A; Less adapted = La; Unadapted = U; No schooling = NA;

7. Conclusion

The analysis of the answers to the questionnaire highlighted the fact that part of the parents used theoretical explanations to define autism, proving their need to be adequately informed, and others resorted to design their own psychological state, labelling autism in terms of their relationship with their child’s diagnosis – “a difficult disease”, etc.

Regarding the age of diagnosis of the children in the target group, it became apparent that most of them were diagnosed around the age of two and three of them even at the age of one, which confirms that

early diagnosis autism has become a practice, parents being much more informed and more attentive to the evolution of their own children, and asking for help from the doctor much earlier than in the last years. This also correlates with the realistic identification of the first inappropriate symptoms and behaviours in the child, the doctor confirming by diagnosis that these children have ASD. The importance they give to the communication with a specialist is also due to the fact that almost all children in the target group are regularly monitored by the INP doctor and have been undergoing medical treatment, largely based on neurotrophic medication, some with psychotropic medication, in order to control the psychotic symptoms, depression, anxiety, etc. There are also non-medicated children in the target group, with only recovery therapies. Regarding the access to the recovery therapies, children in our group began various forms of therapy, either in the day center with state subsidies or in private clinics.

The number of sessions varied from one child to another from one age to another. In terms of the home recommendations and communication with the specialists working with their child, most parents consider this information to be useful, having in our group also a different-opinion parent. As far as reporting the child to the family is concerned, most of the children spend their time with their mother mostly, having a better relationship with her. These children establish a good relationship as well with the other family members from their parents' point of view. Regarding the representation of how the child's disability is reflected in the functioning of the family, we have found a great variability of opinions, most parents still being at the stage of non-acceptance and refusal, of psychic blocking, associated with sadness and insensitivity to the situation created by the diagnosis of their child and others being already in the acceptance phase and finding a way of the situation of their child, expressing ideas and experiences of generosity, calmness, reconciliation and hope.

As for schooling, most children in our group attend a form of education, only two of them not being educated. From the parents' point of view, a significant number of them consider that their children's family and school adaptation is good, having cases which face difficulties in adapting both in the family and social environment.

The hypothesis according to which *an early diagnosis (1-3 years) leads to access to intervention services* was confirmed with the help of the applied questionnaire. Its analysis showed that most children were diagnosed at the age of 2 (13 out of 22), and the initiation of the specialized therapy was performed immediately after diagnosis.

The hypothesis *according to which the parents of the children with autism are involved in their understanding and treatment* has been confirmed, the information provided by the questionnaire answers highlighting the need to inform them about this issue. In addition, the parents' involvement in the recovery of their children is underlined by the steps taken to access specific therapy services, support provided, accompanying children during daily activities, collaboration with the specialist doctor, psychologist and other special intervention therapists, as well as with the school, the teachers, but also with the state institutions in the initiatives to obtain the support of the relevant legislation, etc..

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