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The Professional Figure in the Relation to the Family of Special Need Children

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Abstract

Most of the professionals that work in the field of special needs help in development of the healthy relations with the families that have a child with special needs. Others continue to hide their profession behind the analyses conducted through medical diagnoses, and further more others judge the families, laws, conditions and what we normally have, a family of growing problems. The professionals should be active partners together with the families for the future of the children with special needs, by creating a relation based on respect and empathy. The attitudes of the professionals towards the families of the special need children make the relation to head to positivity or negativity. Normally these attitudes come from the perception that the professionals have for the feelings that parents experience, the impact of the child on the family, what they consider important to construct a collaboration and to assess when and how the parents need the professionals, or the characteristics that the relation present with these parents. The aim of the study is to point out the opinions that the professionals have in relation to the family; these opinions will help us to evaluate the attitudes of the professionals and their impact in the development of the collaboration with the families.

Keywords: professionals, parents, relations, special needs, opinions.

1. Instruments and the Sample

In order to achieve the objective of this study to get the opinion of the professionals of the area related to their service to this category of people, we conducted a survey in the field, exactly with these specialists such as doctors, teachers, physiotherapists, speech therapists etc., who take care directly for the special needs persons.

In this survey attended 80 participants, but the final database contains only 70 answers, as the other 10 did not have the necessary information to be included in the study. The participating professionals were randomly selected, different gender, profession and age groups making the sample more representative.

The methodology used in this study will function to achieve this goal. It combines primary data with secondary ones. Secondary data are the result of reviewing a wide and contemporary literature about the service provided by this category of specialists, the problems and expectations of patients (special need persons) who receive this service. This literature is provided by various electronic research, similar studies of neighboring countries and the region, etc., as well as from a variety of other sources serving to complement the theoretical part of the study. The use of the questionnaire as a method for data collection has its own advantages and disadvantages. The main concerns in

the use of questionnaires relate to assessing their validity and reliability (Saunders et al., 2009). According to the American Association of Psychology (1985, Quoted in Hinkin 1995) the measuring units of the questionnaire should indicate the validity of the content, the validity related to the criteria, the validity of the construction and the internal stability. The first three criteria relate to the assessment of the internal validity of the questionnaire, which indicates the ability of the questionnaire to measure what the applicant intends to measure (Saunders et al. 2009). The content validity refers to the extent to which the questionnaire provides proper coverage of investigating questions. One way to do this is by using the peer review to evaluate the questionnaire. The validity of the criteria is related to the ability of questions to make the appropriate prediction. This can be used for statistical analysis of correlation. Reliability (reliability testing) is whether the questionnaire will produce or not reliable results in different times and in different choices. One way to evaluate it is to measure internal consistency, for example by calculating Cronbach alpha correlation.

That's why during the development of the questionnaire we kept in mind two main elements which are the reliability which has to do with the fact that the questionnaire will give or not the consistent results in different times and different choices, and also the reliability of the questions.

In order to evaluate the reliability of the contents we used the methods of Peer Review, who participated in developing the questionnaire. The questions are developed in such a way so to be easier to understand from the participants, by choosing the answer with alternatives written in the questionnaire evaluated with the Likert Scale.

During the construction of the questionnaire an important attention was given not only to the structures of the questions, but also their proper formulation in order for them to be valuable and to serve the main objective.

As for the reliability testing, a method to assess it is to measure the internal consistency, for example calculating the Cronbach Alfa coefficient. Based on this we noticed that the calculations showed that the value was higher than 0.7 (allowed values) by showing a consistency of the questionnaire. Knowing that each of the questions represents a variable which may have more than one answer, we thought that the closed questions the alternatives should be as real as possible in order to get the necessary information.

We distributed the questionnaire in the cities of Vlore, Fier, Tirane, Berat and Lezhe.

The questionnaire consists of two sections. The first section provides general information on field professionals who participated in the survey, by providing information on work experience, gender, employment, type of field in which they are certified or graduated. The second section provides information about their work according to their respective fields, so we get their opinions about the importance of communicating with parents for the problem of their children, or by pointing out the impacts of these problems in their daily live such as work, education, social life, stress, etc.

The questions have mostly affirmative answers (Yes) or negative answers (No), but also measured with Likert scale. The questions are mostly closed.

The field survey lasted about 3 weeks, and interviews were conducted face-to-face with the participants (professionals) at their workplaces. They were randomly selected. Part of this process was the development of a database with the collected data as well as processing and analysis. Processing and analysis were carried out through software packages SPSS 17.0 and Excel.

Data analysis was performed through descriptive analysis, cross-tabulations, independence tests, correlations between variables, factorial analysis, construction and hypothesis examination, etc. Our analysis was not only descriptive, but also analytical. We performed a pilot testing on 10 randomly selected participants to see if there were any problems or ambiguities in filling it. The test result indicated that questions were formulated correctly and clearly understandable.

2. The Results of the Study

We included 70 professionals of the fields and different professions from whom 34.3%, were teachers, medical doctors 18.6%, therapists 617.1%, psychologists 15.7% and lastly physiotherapists and speech therapists respectively 8.6% and 5.7%, for the simple reason that the last ones are in low numbers in their professions, even though the numbers are getting higher in the

last years (Table 1). In order for us to have a more varied sample, we included such variety of professionals; this variety gave us a more view of the data collection. As for the professional formation, all the professionals had various levels of knowledge for the treatment of special needs children.

Table 1: The distribution of the participants according to their profession

Profession	Frequency	Percentage
Teacher	24	34.3
Medical doctor	13	18.6
Psychologist	11	15.7
Therapist	12	17.1
Physiotherapist	6	8.6
Speech therapist	4	5.7
Total	70	100.0

Graphic number one shows that 86% are female and 14% are males. This for the reason that the number of female teachers and psychologists is higher than males and all the questionnaire is conducted in the city, where the population or higher, mainly the specialists of physiotherapy and speech therapy work in the city.

Graphic 1. The gender of the professionals

The data on the experience of these professionals is presented in Table 2 and it ranges from 2 years to 13 years and the average is 7 years, which is a considerable value to receive valid feedback as this type of service for special needs children is fairly new. We are all aware that, not too long ago, parents or relatives kept people with special needs at home. This is probably for many reasons, whether it is non treatable, but also it was considered a shame for families to have a child with special needs. We cannot say that the family neglect or system of treatment of these people has disappeared today, as there are evidence that many families still keep children with special needs at home and, in some cases we can say that they also keep tied up, a fact that was also published on our television media a short time ago. However, the problems for the special needs people have received the attention of the professional field for the reason of their inclusion in the social life of the society, with a support and special promotion from their families.

Table 2. Descriptive statistics for the work experience

	Nr	Min	Max	Mean	Standard deviation	Variance
Experience	70	2	13	7.06	3.310	10.953

Related to the question – *what do you think it is important to the parent in the moment of communication?* The professionals of the field responded as followed:

The detailed information for 38.6% or according to the opinion of 27 professionals is very important, where the most part are the therapists, with 75% of the numbers of professionals, followed by the medical doctors and physiotherapists respectively with 53% and 50% followed by the psychologists and teachers with 45% and 12%, (Table 1 in ANEX). For 21.4 % of the participants the detailed information is very important, the same number stated that is is sufficient to

be known by parents. Meanwhile, the opinion of 13 professionals or 18.6% of them state that this information is somewhat important.

Related to – *data on the future of disability*, we notice that in 48.6% of the cases the professionals stated that it is sufficient important (mainly from the medicine professionals), where 100% are physiotherapist, psychologists in 82% of the cases, speech therapists in 75% followed by medical doctors and teachers (Table 2 in ANEX) with 31.4%, who state that the future of this disability is very important to be taken into consideration (mainly said from medical doctors, teachers and psychologists). For 2.9% this matter is very important or not at all important and only 14.3% or 10 professionals state that the future of special needs of children is not at all important to parents.

This maybe for the fact that the disability of their children continues for a long time and economic inability and not being able to get the specialized services in the country or abroad has made them very tired sooner than the parents previously thought.

Related to – *psychological help* – for 42.9% of the professionals (where the logopeadists are the first with 100% support, 63% of the psychologists, followed by 46.2% of medical doctors and 45.8% of teachers etc..) this help is stated to be very important for the fact that the psychological behavior of the parents remains an important element for follow up and treatment of their special needs children, also may serve as a powerful means of their improvement.

In 34.3% this help is sufficient (mainly for physiotherapists and therapists and less for medical doctors and psychologists) and for 5.1% it is considered extremely important from the parents side. Only in 2 cases is seen as not important at all.

Some professionals state “...often, the parents are tired and it is impossible to have them as partners in treating and working with the child...”, “...the anxiousness that often the parents suffer makes them to unrealistic in their requests...”, “...often it is needed that parents pass that feeling of suffering and denial in order to start the life project of their child ...”

Sometimes, the personal experience of the parents or their individual research are not sufficient for them to get all the information needed for treatment of special needs, this for the lack of information, time, tiredness, or poor results, or few results that they may have achieved, especially the non disbelief for a considerable part of them, around 57%.

Addressing to different parents' organizations, is considered as not important. For 22.9% as normal, and only for 12.9% sharing information and going to such organizations is very important, this being said and said over and over again mainly from the teachers in 33.3% of the professionals and 7.7% of medical doctors. This is explained by the fact that there is not enough information for the existence of such organizations, and their number is limited, as they operate in large urban areas. The most important fact is the lack of culture or civil education for sharing the information for their children special needs and especially the presentation as a family which has a child with special needs (Table 3).

The professionals state: “...if...the parents' organizations are often non confirmed and do not offer any direct service to parents ...”, “...parents' organizations wait to profit some projects to be active, in contrary they do not operate at all ...nothing...”

Table 3: The evaluation for the importance of the information for the disability

	Not important	%	Little important	%	Sufficient	%	Very important	%	Extremely important	%	Total	%
Detailed information	0	0.0	13	18.6	15	21.4	27	38.6	15	21.4	70	100.0
Data on future of disability	2	2.9	10	14.3	34	48.6	22	31.4	2	2.9	70	100.0
Psychological help	2	2.9	9	12.9	24	34.3	30	42.9	5	7.1	70	100.0
The address of the parents organizations	5	7.1	40	57.1	16	22.9	9	12.9	0	0.0	70	100.0

For the question – **In which moment have you asked for the help from a professional?** – Graphic 2 shows that in 45.7% of the cases this is required since the early moments of identifying the disability in the child, which often happens in the first years, in 38.6% during childhood and only in 15.7% during the teenage years, this for the reason that the disability may be psychological or physical from an accident that has happened during growth.

Graphic 2. The moment when the parents have asked for help

In the data presented in graphic 3 we notice that the parents with special needs children see the participation of a professional in the treatment of their child as little important in 54.3% of the cases, and in 37.1% as sufficient important, this for the reason of the culture and mentality of the parents not to make public of their child disability or sometimes the economical ability to treat the child to the specialists. For 2.9% this is considered as very important and in 5.7% as not important at all, exactly the most pessimistic part of the parents.

“.....sometimes it is paradoxal when the parent brings the child for therapy and does not want the child to participate, by stating that the child is fine and does not need therapy. In this moment, during my work I think Then why are you here??!! I am a special needs therapist ...”, “...a parent brings the child and wants me as a therapist to confirm that everything is fine with the child, but in fact this is not real. Then...? The parent goes and never returns. I think they do that to make peace with their conscience by justifying that the specialist is incompetent ...”

Graphic 3. The participation of the professionals

The professionals are asked the question: *how is the first aid offered to this category of children?* According to the data of graphic 4, the first aid is given mainly when it is asked for from the parents to the teachers, medical doctors, psychologists, etc and only 10% declare that this help is given without any request.

Graphic 4. How is the first aid offered?

The question- Which of these characteristics do you assess more important in parents in relation to developing the life projects of their children?

The professional participants responded: in 41.4% of the studies cases, the professionals declare that *the good quality in communication* is very important. Is there is to be achieved a good communication with parents, then the work to construct and function the life project would be easier to realize, as if there is communication between the parents and the professional will be partnership in responsibility for each partner.

Family relationship, for 20% of the participants this relation is important. For some of them the way the family functions affects the work with their child. However, most of the participants do not assess this element as very important.

Nearly in the same levels stays *the organizational skill*, where only 15.7% declare that *the good level of information and the feeling of no repetition* are of special importance.

The relation as a couple is assessed to be very important in 17% of the cases. So, mainly the family environment has a considerable importance in the continuous treatment of the children and relation with the field professionals.

There are professionals that state that the information has little importance, as there are others that state that the relation as a couple or organizational skills are of great importance. In relation to The perception that the professionals have for the parents who treat their special needs children in their practices the answers are: in 65.7% they are neutral so do not give any feedback, in 32.9% these perceptions are positive for the reasons of satisfactory collaboration between them, and only in 1.4% this perception remains negative, for the reasons of the relations that are created, expectations, the parents' culture etc.. The most part of the professionals state that they are neutral and this is not satisfactory, as it is not clear, and would be important to be treated in another study.

Graphic 5: Impression for the parents with special needs children

In relation to the hypotheses – the family relationship of the families that work with professionals has an impact in developing the construction of life projects for the child we have these results:

Relationships in family, for 20% of the professionals who participated in the study, think that this relationship is important. This for some of the professionals is justified because the way they work in the family affects their work. However, most of them do not value this element as very important.

Relationship in couple is estimated to be very important in 17% of cases. So, primarily, the family environment has significant importance in the ongoing treatment of children and the relationship with field professionals.

The professional participants in the study responded in this way: in 41.4% of cases, professionals report that *good quality in communication* is very important. If there is good communication with parents then the development of a life project will also be easier to achieve, as if there is communication between the parent and the professional there will be partnerships in the responsibility that each partner will receive.

Approximately at the same level is the *organizational skills*, 15.7% state that the good level of information and the feeling of non-repetition are of particular importance.

There are also some professionals who say that information is of little importance, as there are others that stated that relationship in the couple or organizational skills are of great importance.

According to a study from Chatelant (2009), conflicts in the relationship between parents and

professionals are faced in the beginning of receiving the communication about the child's disability. Earlier we mentioned negative factors of receiving this communication, where negative judgments between the parent and the professional emerge. One hypothesis is that relations between parents and professionals develop in times of crisis for the family but also because they are limited. However, this indicates that the situation within the couple or family significantly affects the relationship with the professional.

Studies with professionals point out parents' cooperation as the greatest source of stress in their work on developing life projects as they (parents) are experiencing a state of anxiety and it is undisputed that the relationship of a parent or family affects the relationship with the professional. (Turnbull and Turnbull, 1986)

It is important for parents to understand what causes the problem. It is important to overcome anxiety that many parents have, because they believe they are the cause of the problem. Collaboration and assistance must be mutually supportive.

According to Ndriu and Zeva (2011), this problem becomes even more apparent in our society because the family that has a child with special needs adds a great measure of experiencing everyday social and economic problems. Among other things, the level of information is low or confusing for the parents, which causes problems for a quality communication between parents and professionals.

Various professionals state:

...he had a child with autism problems and every time he came for therapy the father was drunk, starting to tell the family problems, it was impossible to discuss with him the child project, ...during my work I have encountered parents who often were dominant in the family by transmitting this not only to the child but also to the therapist, the wife offended the husband and told him he was careless, that she did everything, she knew everything....., and it was such a stressful situation.....I have worked with many families which had many economical, social and educational issues, but I want to mention one of them which was one of the most collaborative families that I have ever worked with. One day I wanted to tell the mother of the child that she should have been a colleague of mine ...

By referring the data of the study we reach into conclusion that the family relationships affect the relations with the professionals in developing the life project.

Table 4. The evaluation for the life programme

	Not important at all	%	Little importance	%	Sufficient	%	Very important	%	Extremely important	%	Total	%
Organizational skills	5	7.1	26	37.1	23	32.9	14	20.0	2	2.9	70	100.0
Good quality of discussion with the child	0	0.0	14	20.0	26	37.1	29	41.4	1	1.4	70	100.0
Good level of information	0	0.0	37	52.9	22	31.4	11	15.7	0	0.0	70	100.0
Feeling of nonadoption	4	5.7	25	35.7	30	42.9	11	15.7	0	0.0	70	100.0
Good couple relationship	1	1.4	20	28.6	34	48.6	12	17.1	3	4.3	70	100.0
Good relationship in family	1	1.4	7	10.0	48	68.6	14	20.0	0	0.0	70	100.0

3. Conclusions

On the other hand, there are professionals who, outside the profession, are people who, in daily work, have to face different emotions, problems and conflicts. As for professionals, they should have the capacity to build and use patterns in their intervention, adapting patterns according to context and situation. At the ethical level of realization of professional competences, the professional must respect the expectations and values of the parent, be able to transmit his knowledge and practical knowledge, favor exchanges between parents, practice adaptation and determination, and teach the parents how to share and take decisions. In the pedagogical aspect we have a Social Intervention Pedagogy (J.M.Bouchard, 2009), (J.C.Calubi 2009), where the professional learns from the parent and parent by the professional. The parent teaches the child

and child from the parent. It is created interdependence in personal, family and professional development. They all mutually learn to feel better together.

If we would talk for a more efficient intervention for the integration of the special needs children, we should assess initially this relationship, which means to firstly understand the parents of these children and the professionals too, and to determine the resources of help that connect these two actors of partnership. This was the goal of this study.

As for the hypotheses that the earlier in time the intervention from the professional, the higher the results for the life project, we took into consideration the elements of the life project by noticing which of these elements get more impact from the start. We concluded that:

The earlier the treatment of the child from the professional starts, the better *the personal wellbeing* of the child is. *The normal course* of the special needs child depends from the early treatment, as a considerable part of the various disabilities depend on the time of diagnoses. The earlier the diagnoses, the better and faster may they be prevented. The treatment of these issues since the early age gives better results; the same results are shown in the studies of J.M.Bouchard 1999, but contrary data are seen in rehabilitation centers or schools such as Emiglia Romagna 2011.

The study show that not always is true the fact of early treatment at the medical doctors, psychologist, therapist etc the faster the rehabilitation time.

In the relation to the other elements of life project, *the school performance does not depend on the time of intervention from the professionals*, the most appropriate time for school performance is the childhood, which is the moment when the child follows school and it is the phase where the effect belongs to the school performance. Another study of the author has similar results (A. Zhapaj 2009).

Regarding the other element of the life project, *the daily autonomy and the timing of child intervention by the professional* indicates that the autonomy of the child with disabilities is not necessarily dependent on the time of treatment from the professional, as there are cases requiring attention and continuous dedication, without interruption, although they can be frequently treated or always to the field specialist. For this issue, there are many cases and we know very well that the autonomy of a person with disabilities more than the time the professional devotes to, is what the person learns in daily life, so at home. Similar data result from other studies such as A. Zhapaj 2009, Lipsky 2008, where the most important and largest part of the child's autonomy is the family. However, this does not mean that a professional can not help and influence in terms of practical independence.

Fulfilling the emotive needs and the time of professional intervention of the child does not have an impact necessarily from the time of treatment. *Friends, and the relationship between them does not depend on the time of the professional treatment*, neither does sport.

As we have seen from the analysis of the time of treatment of a child by the professional and the project of life, we notice that not all the elements of the project depend on the time of the professional intervention. Part of the project elements are influenced by the family, making the relationship between family and professionals important as their partnership can give us a lifelong life project. The timing of intervention would be important for a good part of life project implementation, but the introduction of ecosystemic treatment is a strategic goal in order to continuously improve the quality of services to favor implementation in clinical processes, especially in Life Projects and implementation from the participants. Similar conclusions come from other studies that have addressed the plan of ecosystemic organization of C.R. Le Bouclier (2002).

According to Andolf (2000), in organizing the Life Project according to the systemic orientations, family is considered a complex ecosystem of the relations and relationships of interdependence with other social systems. He states that the family is a constant, active and open system, which means that the family is an adoptive system that adapts to the various needs in different development levels, it is self regulatory and is modified through the proofs-mistakes which allows the parents to experiment the relations of different natures till the definition of a stable relation such as the one with the professionals, as a system in relation to other systems such as schools, therapeutic institutions and other interest groups. This process comes as a result of keeping the balance between the partners, parent-professional. This means the the interfamily

relations are supported in the relations that they have with social relations.

Regarding the hypotheses that the experience of the professionals' formation is more self-taught, we reached in the conclusion that: professionals are more self-taught in issues of maltreatment and abuse, problem solving and prevention. The professionals believe on their practice and some of them have encountered these issues only at the beginning of their professional careers. The work in groups has considerable values, especially the ones that relate to the help, collaboration and problem solving.

As we mentioned before, we have some model professionals, who are experts, directors and partners.

The capacity of the professionals to use these three models in the intervention, by adopting the models with the context and situation, is the best way to make an expert professional. If we would refer to the study data where the professionals remain autodidactic, in the relation to the family will the professional be able to realize the professional competencies in the ethical and rights level? Would the professional be able to respect the expectations and the values of the parents, be able to develop the knowledge in theory and practice, favor the exchanges between the parents and practice the adaption and determination, and finally to teach the parents to share and make decisions? Would the professional be able to get the new scientific knowledge and know how to build partnerships? Would they be able to consider the family as a part of the ecosystem? The data of our study show that we cannot compare to other studies on other countries as this data is far from these studies, because the continuous development are the right of each professional and are included in the work code (are being implemented) (J.M.Bouchard, 2009), (J.C.Calubi 2009).

Regarding the hypotheses of the family relationship of the families that work with professionals affects in the development of life projects, we have concluded that: *the family relationship nad the couple relationship* is estimated to be very important in most of the cases. So, primarily, the family environment not only has a considerable importance in developing the life projects, but also in the continuous treatment of the children and relationship with the expert professionals. This for some professionals is justified that the methods of the family functions affect the daily work in realization of the child project. However, on the other side the professionals declare that the *good quality in communication* is very important. If a good communication is achieved with parents, then the work for developing and functioning the life project will be easier to be implemented, as it would be a partnership in sharing responsibilities between the parents and the professionals.

According to a study from Chatelant (2009), the conflicts between the parents and professionals are encountered in the beginning of receiving the news of child disability. Earlier we mentioned the negative factors that this kind of information has, the negative judgment between the parent and professional. A hypotheses is that the relationship between both of them is developed in a crises moment for the family, and they are limited too. But, this shows that the relationship within the couple affects the relation with the professional.

The studied conducted with professionals state that the collaboration with the parents is the highest source of stress in the professional's work in developing the life project, as the parents are experiencing a stressful and anxious situation and it is undisputable that the relation in the family affects the relation with the professional (Turnbull and Turnbull, 1986)

It is necessary that the parents understand the cause of the problems. It is important to take away the stress of the parents, as they mostly think it is their fault. Collaboration and help should be dual and continuous.

According to Ndriu and Zeva (2011), this problem is more obvious in our society as the family with a special need child has a huge burden of experiencing daily social and economical problems. Among others, the level of information is really lacking, which brings problems for a qualitative communication between the parents and professionals.

4. Recommendations

Strengthening the concept of family enables the improvement of life quality for the child and family. In this perspective the professionals, family and community organisations, the government should

facilitate the implementation of these families for recognition, capacities and resources that are necessary to use their responsibility and to be included in independent life. To favor the family in the social, educative and health services, for a partnership between the family and professionals and that the families get closer to community, here are some recommendations that can be given:

1. Institutions, especially health, education and rehabilitation ones, in cooperation with parents, should develop training programs to sensitize professionals about the expectations and reality and expectations of families with a disabled child, since partnerships of parents and family are the most important element for life programs and integration.
2. Adding services for parents by providing counseling and guidance on both the rights and the emotional state that parents go through.
3. Programs and curriculums dealing with integration and programs of people with disabilities and their families should be privileged. In this recommendation it would be worthwhile to study social pedagogy in the faculties of social sciences.
4. The government should establish by law joint contracts signed by parents and professionals for taking care and treating the child.
5. The participants, in cooperation with state and community organizations, should periodically receive information from the family regarding problems and resources, so they are treated equally.
6. Increasing the number of doctors/specialists of special areas such as speech therapists etc. who are in limited number and mostly concentrated in Tirana.

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