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**THE ROLE OF FAMILY IN THERAPY OF CHILDREN WITH ASD**

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***Abstract***

Family-centered therapy is described as a rather controversial approach and sometimes difficult to implement because of its philosophy of recognizing and respecting the family as an equal partner in the entire therapeutic process with specialists, but there are situations when this approach is not viable either due to the absence of parents from the lives of children, or due the lack of interest from them. Through this study, carried out over a period of 4 years, we decided to investigate the effectiveness of two models of therapy approach, respectively specialist-centered therapy vs. family-centered therapy, from the point of view of the development of the children with nonverbal ASD, on these five areas: social, cognitive, language, personal autonomy, and motor. The results revealed the fact that family-centered therapy is more effective, with significant differences in the acquisition of the social, cognitive, motor spheres and also in the children's mental age evolution, and less effective and with insignificant differences, in the areas of language development and personal autonomy, where the results were more relevant in the case of specialist-centered therapy. Also, regardless of the therapeutic approach model, all 6 children included in the study presented a disharmonious profile during the intervention, the most significant deficiencies being observed in the sphere of communication and language skills.

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**Keywords:** family-centered therapy/practice, expert-centered practice/therapy, autism spectrum disorders, non-verbal, development profile.



## 1. Introduction

Family-centered therapy is described as a rather controversial approach and sometimes difficult to implement because of its philosophy, of recognizing and respecting the family as an equal partner with the specialists, in the whole therapeutic process. This involves investing family members with active roles in the process of evaluating and implementing the intervention, where both parents and professionals are seen as equal partners (Brewer, McPherson, Magrab, & Hutchin, 1989). Based on these considerations, family-centered practice does not only mean establishing a trusting relationship between the specialist and the parent, but also the existence of a balance of power in decision-making, mutual respect and honesty (Keen, 2007).

References to family-centered practice begin to emerge around the 1950s, but interest in this approach manifests around the 1970s-1980s. In the conclusions of his study, Bronfenbrenner (1975) emphasized the impact of family involvement on children's development and implicitly their performance. The interest in this approach is gradually increasing, because by the end of the 1980s, ACCH (Association for Child Health Care) mentioned the basic elements of this approach in the intervention of children with special needs (Shelton, Jeppson, & Johnson, 1987).

During this period, experts in the field have developed several models in approaching family-centered practice, models that are part of a continuum regarding assuming the roles of expertise and decision-making power at the intervention level (Dunst, Johanson, Trivette, & Hamby, 1991). In this framework, we talk about Professionally-centered model, Family-allied model, Family-focused model, Family-centered model (Dunst, Johanson, Trivette, & Hamby, 1991; Spe-Scherwindt, 2008). If in the Professionally-centered model, the decision-making power in the selection and implementation of the intervention activity is in the hands of the specialists, the role of the parents being minimal, both in terms of involvement and in establishing the deployment framework and the resources needed to perform the therapy, in the Family-centered model, parents and specialists become equal partners, the intervention being individualized to the needs of the child and the family, flexible, parents having a decisive role in the final decisions. Thus, by recognizing that the family is a constant in the child's life, the family-centered practice focuses on the interpersonal relationship between parents and the professional, who, together, identifies the most appropriate means to meet the child's needs starting from his / her acquisitions and strengths (O'Neil, Palisano, & Westcott, 2001).

The family-centered practice is based on three basic elements: (1) the emphasis placed on the strengths, interests and acquisitions of the child and not on his deficits; (2) equipping the family with decision-making power and control over the intervention activity; and (3) developing a close collaborative relationship between parents and professionals. To specialists, this paradigm shift was and is a real challenge, simply because they have to replace the role of decision-maker, coordinator, organizer, counselor, partner, facilitator and consultant in carrying out the intervention (Mikus, Benn, & Weatherston, 1994). According to Dunst, Trivette, and Hamby (2007), family-centered practice is a systematic way of creating a partnership with families, a partnership that involves (a) treating with dignity and respect, (b) respecting values and choices, and (c) giving support to strengthen and improve the functioning of the family environment.

Starting from these aspects it is surprising that the family-centered therapy has two major components: (1) the relational component based on a series of abilities such as active listening, empathy, trust in the other's potential, unconditional acceptance, respect, all necessary for professionals to build efficient, constructive and functional relationships with family members (Dempsey & Dunst, 2004; Dunst, Boyd, Trivette, & Hamby, 2002); and (2) participatory supportive practices, which are action / intervention oriented, including control and the distribution of roles. The specialists share information with the parents, analyze and discuss them on their side, encourage them to make informed and realistic decisions alone, use their knowledge, skills and competences to carry out the intervention, and the professionals help them acquire the new skills for the new therapy, and implicitly the progress of the child and the consolidation of a well-being at the family level (Dempsey & Dunst, 2004; Dunst et al., 2002; Martin, Garske, & Davis, 2000).

The philosophy of family-centered practice has been adopted in a wide variety of areas of health, therapy, early intervention, special education (Murray & Mandell, 2006), and education (Stormshak, Dishion, Light, & Yasui, 2005).

The specialized literature places an increasing emphasis on the involvement of the family in the process of evaluation and early intervention, recognizing that the family is a constant in the life of the child, that it is part of a family unit, which in turn is part of a family, wider community (Crais & Calculator, 1998; Dunst, Johanson, Trivette, & Hamby, 1991; Iacono & Caithness, 2009). Beukelman and Mirenda (2005) underline the need for family involvement in the evaluation and intervention process for young children or with serious disabilities, to identify the problems with the team of specialists, to rank them, and to set intervention goals and strategies.

## **2. Problem Statement**

There is ample evidence in the literature that (a) family-centered practice offers many proven benefits and positive outcomes for both children and their families (Dunst & Trivette, 2005; King, King, Rosenbaum, & Goffin, 1999; Trivette, Dunst, Boyd, & Hamby, 1995; Trivette, Dunst, & Hamby, 1996; Wilson, 2005), and (b) families are more satisfied and more involved in intervention than other existing models (Dempsey & Keen, 2008; Dunst et al., 2002; Espe-Scherwindt, 2008; King, King, Rosenbaum, & Goffin, 1999). However, the reality shows that there is a perception gap between professionals and family, the professionals being less focused on the family as a resource than they think, regardless of the category of persons with whom the intervention is carried out, and this is determined by the paradigm shift (Dunst, 2002). Thus, the paradigm shift is faced with a "slow adoption rate" being less used by professionals (Crais, Roy, & Free, 2006), even though comparative studies have surprised that specialist-focused programs rely less on relational practices (Dunst et al., 2002) and implicitly the results have less impact on the family and child (Dunst et al., 2002; Trute & Hiebert-Murphy, 2007) compared to family-focused practices.

Campbell and Halbert (2002) investigated this issue and overlooked the main reasons why family-centered practice was not very large. A first reason is the gap between the scientific world and practitioners, respectively they fail to keep up with all trends (Bruder, 2000; McWilliam, 1999). Another reason why specialists avoid this approach is the lack of proper and accurate training (Bailey, Aytch, Odom, Symons, & Wolery, 1999; Bruder, 2000; Gallagher, Malone, Cleghorne, & Helms, 1997) as well as the need to

produce many time-consuming documents, much needed for intervention and collaboration with the family (O'Neil et al., 2001). Last but not least, the lack of support from the team of professionals (Murray & Mandell, 2006) regarding the partnership with the family, as well as the difficulty of perceiving the family as experts and equal members in the evaluation and intervention team (Affleck et al., 1989; Trivette, Dunst, Boyd, & Hamby, 1995) are barriers to the implementation of family-centered practice.

The efficiency of family-centered practice has been demonstrated in several program categories and with a wide variety of participants: from interventions in the medical field, early education, rehabilitation, education (Dunst, Trivette, & Hamby, 2007; Reich, Bickman, & Heflinger, 2004) to programs involving parents with intellectual disabilities (Wade, Mildon, & Matthews, 2007), parents with children of various ages (Dempsey and Dunst, 2004), parents with different socio-economic status (Law et al., 2003; Trivette et al., 1995; Trivette, Dunst, & Hamby, 1996) or from different cultures (Dempsey & Dunst, 2004).

In a meta-analysis by Dunst, Trivette, and Hamby (2006), which focused on 18 studies, it was surprising that family-centered practice has a strong impact on parents' beliefs about self-efficacy, positive perceptions of the program performance and outcomes, the behavior of the child and its evolution, as well as a greater confidence in his own parental abilities.

Dempsey and Keen (2008) found that this new paradigm correlates with a variety of child and family outcomes, consistent with the hypotheses of family-centered practice (Dunst, Trivette, & Hamby, 2007) as follows: (1) family centered practice reduces stress and increases well-being perceived by parents (King et al., 2003; Keen et al., 2010; O'Neil et al., 2001; van Schie et al., 2004); (2) parents develop parental skills (Dunst, Trivette, & Deal, 1988; Heller, Miller, & Hsieh, 1999); (3) the progress / evolution of the child (Mahoney & Bella, 1998; O'Neil et al., 2001) and especially when talking about early intervention (Dunst, 1999); (4) developing desirable behaviors in the children (Judge 1997); and (5) self-control (Dunst, Trivette, & LaPointe, 1994; Trivette, Dunst, Hamby, & LaPointe, 1996).

### **3. Research Questions**

Q1. Will there be significant differences between the results obtained through the two approaches (specialist-centered practice vs. family-centered practice), regarding the performance of the child with ASD, in terms of acquisitions at the level of the developmental profile (social, cognitive, personal autonomy, motor skills)?

### **4. Purpose of the Study**

In the present study we intend to comparatively analyze the efficiency of the practice focused on the specialist vs. family-centered practice in the therapeutic intervention of the children with ASD, setting the following objectives: (1) sampling the study participants on the 2 therapeutic approaches; (2) conducting the initial evaluation of the study participants (on the development profile components) according to the type of approach; (3) establishing and implementing the intervention program according to the approach; (4) reassessment of the performance of the study participants; (5) establishing the differences existing in the evolutionary process of the participants according to the type of approach and comparing the results.

## 5. Research Methods

### 5.1. Participants

The research was conducted with six children divided into two experimental samples, respectively sample 1, who benefited from family-centered therapy (Ef) and sample 2, who benefited from expert-centered therapy (Ee). The detailed presentation of the participants' samples can be found in table 1. The criteria that were the basis for the sample of the participants in the study were the following: (1) Preschool children aged 3-4 years; (2) Children diagnosed with one of the disorders included under the autism spectrum dome; (3) Non-verbal or children who have not acquired functional communication skills.

**Table 01.** Description of the participants' samples

Sample	N	Age	Sex	Diagnostic
Sample (Ef) - family-centered therapy	N1	3 years and 10 months old	M	DPP-NOS Expressive language developmental delay
	N2	3 years and 6 months old	M	DPP-NOS Expressive language developmental delay
	N3	3 years and 7 months old	M	Autism Severe delay in language development
Sample (Ee) - family-centered therapy	N4	3 years and 3 months old	F	Pervasive developmental disorder Severe delay in language development
	N5	3 years and 8 months old	M	Autism infantil Delay in language development
	N6	3 years and 7 months old	F	Autism infantil Delay in language development

### 5.2. Measurement instruments

The Portage Development Scale was used to evaluate the performances/acquisitions of the study participants. This evaluation tool allows to identify the level of development of children aged 0-6 years, both at the general level and on the 5 areas of development (motor, language, cognitive, personal autonomy, social). With the help of the inventory of behaviors and abilities, we obtained a rigorous assessment of the performances of the children, quantified in the development level on each of the 5 areas of the profile, as well as a general development level. Items are structured on age levels, describing specific behaviors that naturally occur in the harmonious development of a child for a certain age stage.

The results regarding the reliability of internal consistency of the scale indicated the following: socialization .80, language .81, autonomy .73, cognitive .70, motor skills .75, and for the whole scale, the coefficient of internal consistency indicated a result of .80 (Arvio, Hautamaki, & Tilikka, 1993), The results obtained by evaluating with the Portage development scale were compared with the level of development offered by other research tools. Both methods have shown almost identical cross-sectional results in the

case of individuals with cognitive impairment, which argues for the use of this tool as a reasonable evaluation method in clinical research (Arvio et al., 1993).

### **5.3. Procedure**

Family-centered therapy was used in the intervention aimed at the first sample of participants (N1-N3). Within it, parents, especially the mother of the child, participated actively in the evaluation phase of the child, where she generated a series of essential information about the child, used subsequently as starting points in the intervention, and during the implementation period of the program and/or its revision at regular intervals of 6 months. Thus, the family members provided information about the child (interests, strengths, abilities, difficulties, ways to convey to others the needs), so that later, together with the team of specialists, they set the objectives of the intervention program, the techniques used, the resources and the necessary means. Also, the activities initiated and/ or learned by the child together with the specialists were continued by the parents at home so that the behaviors acquired by the child are generalized in the most varied contexts. Also, in situations where parents encountered difficulties or identified new ways to obtain favorable results, they were discussed with the specialist and included, respectively rejected, as elements of the therapeutic intervention. The family's role in the therapeutic program was one of the partners, having the possibility to make decisions regarding the intervention and control during the program. Expert-centered therapy was used in the second sample of participants (N4-N6). Within them, the family was not involved in the evaluation, the setting of the objectives, the means and the resources used in the therapeutic program addressed to the 3 participants. In their case, the parents either did not show interest in getting involved in the child's therapy or were absent from his / her life (institutionalized child). In these conditions, the activities carried out with children were learned and strengthened together with the specialists, and the family and caregivers were advised to continue the activities at home.

### **5.4. Research design**

The present study was based on the ABA experimental design on a single subject, conducted through 6 longitudinal case studies over a 4-year period (Table 2). According to the methodology imposed by the current research approach, the study design has the following structure:

-The first phase consists of evaluating the 6 participants in the study using the Portage Development Scale on all five areas (language, cognitive, social, personal autonomy and motor), in order to collect information and data to establish the basic level.

-The second phase of the study, consisting of conducting the experiment. Within this stage of the study, two intervention practices were used, respectively for sample 1 (Ef), which included N1-N3 participants, the intervention focused on family-centered therapy, and in the case of sample of participants 2 (Ee), included N4-N4 participants, the intervention focused on expert-centered therapy.

-The third phase of the study consists of the final evaluation aimed at determining both the differences existing between five development areas from the initial and final stage of the experiment, as well as the efficiency of the two therapeutic approaches analyzed from the perspective of the results obtained by the study participants, in the 4 years of intervention.

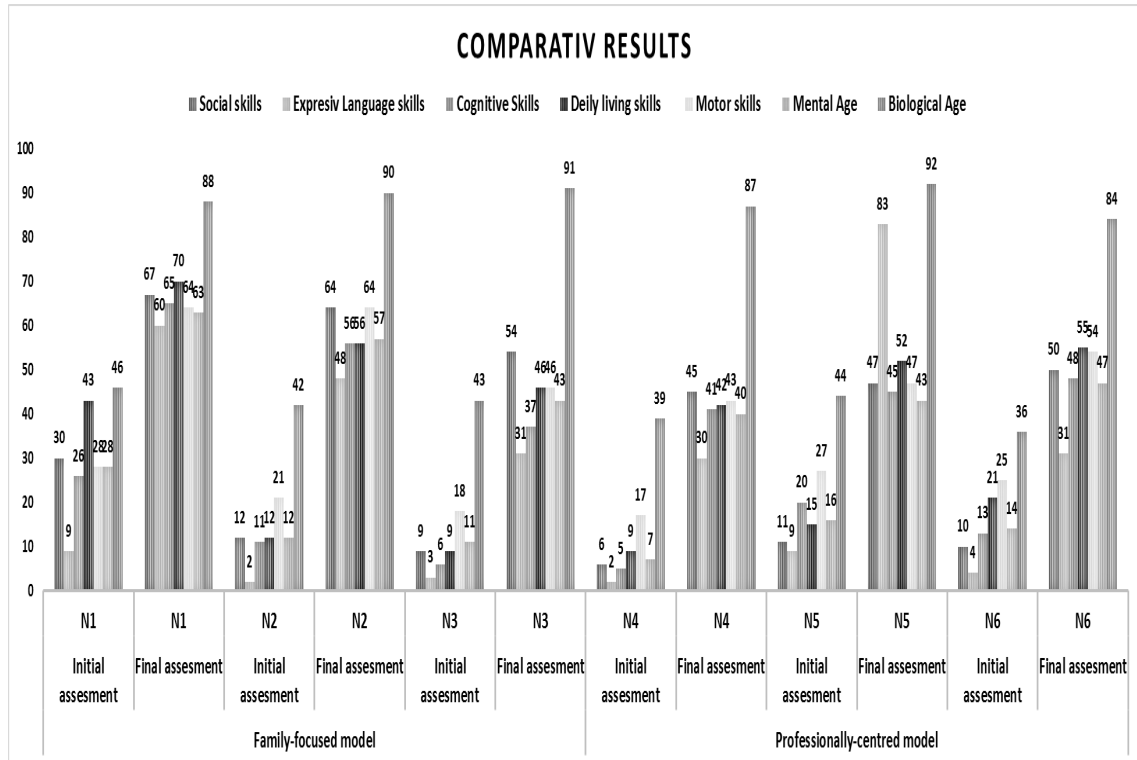
**Table 02.** Research design

	<b>Sample 1 (Ef) N1-N3</b>	<b>Sample 2 (Ee) N4-N6</b>
Pre-experimental stage	Evaluation Portage Development Scale	Evaluation Portage Development Scale
Experimental stage	Family-focused therapy	Expert-focused therapy
Post-experimental stage	Evaluation Portage Development Scale	Evaluation Portage Development Scale

## 6. Findings

**Table 03.** Comparative results initial evaluation-final evaluation, family-centered model vs professional-centered model

Model	Participants	Assessment	Social skills	Expressive Language skills	Cognitive Skills	Daily living skills	Motor skills	Mental Age	Biological Age
Family-focused model	N1	Initial assesment	30	9	26	43	28	28	46
		Final assesment	67	60	65	70	64	63	88
	N2	Initial assesment	12	2	11	12	21	12	42
		Final assesment	64	48	56	56	64	57	90
	N3	Initial assesment	9	3	6	9	18	11	43
		Final assesment	54	31	37	46	46	43	91
Professionally-centred model	N4	Initial assesment	6	2	5	9	17	7	39
		Final assesment	45	30	41	42	43	40	87
	N5	Initial assesment	11	9	20	15	27	16	44
		Final assesment	47	83	45	52	47	43	92
	N6	Initial assesment	10	4	13	21	25	14	36
		Final assesment	50	31	48	55	54	47	84

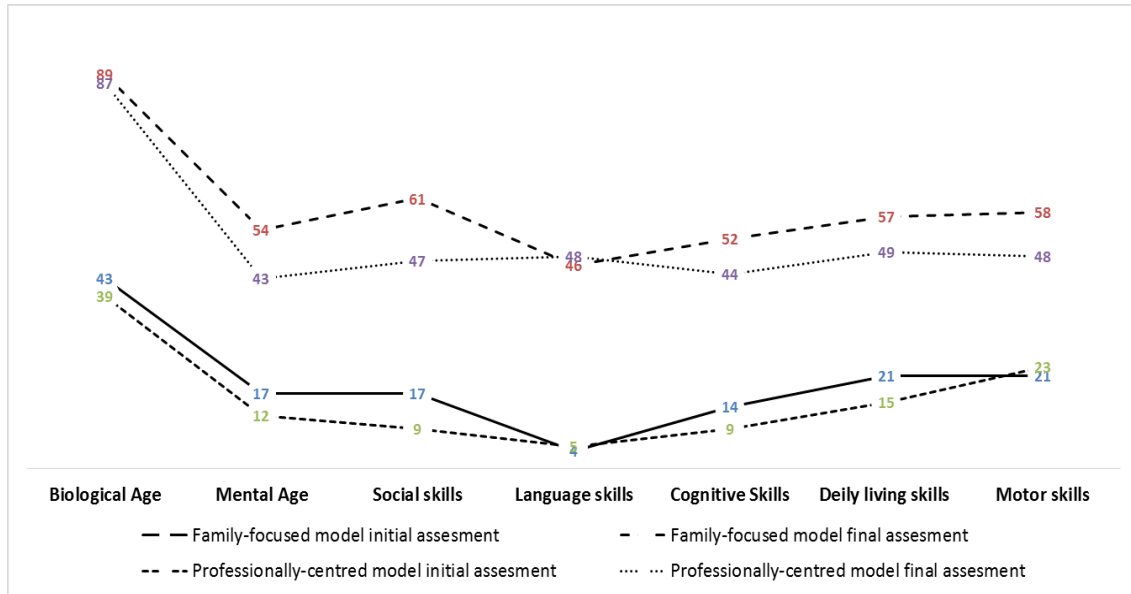


**Figure 01.** Comparative results: initial evaluation-final evaluation, family-centered model vs. professional-centered model

**Table 04.** Comparative results regarding the difference between the biological age (months) of the participants and the level of development by areas

Model	Assessment	Biological Age-mental Age gap	Biological Age-social Abilities gap	Biological Age-language Acquisition Gap	Biological Age-Cognitive Skills gap	Biological Age-Autonomy Skills gap	Biological Age-motor Skills gap
Professionally Centered model	Initial	24	30	35	30	34	16
	Final	44	40	<b>39*</b>	43	<b>38*</b>	39
Family focused model	Initial	26	26	38	29	22	22
	Final	<b>35**</b>	<b>28**</b>	41	<b>37*</b>	40	<b>31*</b>





**Figure 02.** Comparison between performance averages in development areas: the family-centered model vs. the specialist-centered model

## 7. Conclusion

### 7.1. Final conclusions

Through this study, conducted over a period of 4 years, we decided to investigate the effectiveness of two models of approach to therapy, respectively specialist-centered therapy vs. family-centered therapy, in the case of children with nonverbal ASD, in terms of their development on the five areas of development (social, cognitive, language, personal autonomy, motor).

The results obtained in the research are in agreement with the results obtained in the specialized literature, respectively, the children with low-functional autism have significant deficits in all areas of development. Regardless of the type of approach (specialist-centered therapy or family-centered therapy), the data indicate a contoured developmental profile that is different from case to case (Fig. 3). What is similar for all 6 children investigated is the fact that communication deficits are the most severe, despite the acquisition of functional communication skills through AAFCs.

It was also found that the acquisition of functional communication skills stimulated the development of social skills, children interacting, within limits significantly below the average, with other people.

According to the data obtained and presented in table 3 and table 4, a comparative analysis finds changes in the acquisition of behaviors on all 5 development areas of the 6 study participants regardless of the model approached, in both situations the profile of participants' disclosure being developed disharmonically.

The comparative analysis of the data on the two samples surprised that the average results for the 3 participants in the sample who benefited from family-centered therapy are better in terms of evolution as follows (Fig 2). The most significant differences are found in the area of social skills acquisition, where the gap between the biological age and the performances of the children specific to this area of development is 28 months, with a difference of 12 months, compared to the sample that benefited from specialist-focused therapy.

Another significant difference in favor of family-centered therapy is the evolution of mental age. If in the case of children who have benefited from specialist-centered therapy the gap is 44 months, in the case of children who have benefited from family-centered therapy the gap is 9 months less than 44, 35 months respectively.

Less significant differences are also observed in the case of cognitive development and motor acquisition. Thus, the children who benefited from family-centered therapy recorded a gap between the biological age and the acquisitions in the sphere of cognitive abilities of 37 months, with 6 months less than in the case of the children who benefited from specialist-centered therapy, the difference being in this case of 43 months. Also, motor skills are more developed for children who have benefited from family-centered therapy, 8 months difference (the existing gap is 31 months), compared to children who have benefited from specialist-focused therapy (the gap being 39 months).

If the gap between the biological age and the mental age, social skills, cognitive abilities and motor skills are smaller in the case of children who have benefited from family-centered therapy, the data obtained have surprised smaller, but not significant differences in the areas of language and personal autonomy, in the case of children who have benefited from specialist-focused therapy. It was found that in the case of children who have benefited from specialist-centered therapy, the gap between the biological age and the level of language acquisition is 39 months, 3 months less than in the case of children who have benefited from family-centered therapy, where the gap is 41 months.

Significant differences between the two experimental samples can be found in the case of the specific acquisitions of the personal autonomy skills, where the children who have benefited from specialist-centered therapy have a gap of 38 months, 2 months less than the children who have benefited from focused therapy on the family, where the gap is 40 months.

By analyzing the data obtained as a whole, we can say that family-centered therapy for children with nonverbal ASD is more effective than specialist-centered therapy, the significant differences being noticeable in the following areas of development: social skills, cognitive abilities, motor skills and level of mental development, and insignificant, in favor of therapy focused on specialists, in the sphere of language and personal autonomy (Fig. 1., Fig.2).

## **7.2. The limits of the research and new directions of action**

Beyond the results obtained and their value, this research has a number of inherent limitations. So, opting for case studies as a research method, entails a first limitation of this investigation. Therefore, the results obtained have no statistical value and cannot be generalized. In this respect, it is recommended to extend the present research, by selecting a statistically significant sample. Also, comparing the results obtained with those of a control sample, would provide a much more valuable connotation to the study, but we consider this approach to be unethical, respectively depriving some children with autism the chance to benefit from any intervention, just to be able to complete a control lot.

Another inherent limitation of this research is the ripening effect. During the course of the experiment, the participants were involved in their own evolutionary process, normal and natural. In these conditions there is the possibility that the differences that have arisen between the repeated measurements are due to some extent to their maturation and not just the manipulation of the experimental variable. In

order to obtain the most valid data in this regard, it is recommended to carry out studies on comparative samples (experimental lot - control lot), but as mentioned above, this is unethical.

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