

## The Role of the Parents in Assisting Children with Autism

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**Abstract:** *The study aims to identify the role of the parents in assisting children with autism (3-6 years old). The qualitative method was used in the study. Semi-structured interview with open-ended questions was the instrument for data collection. Data collections were made possible by interviewing of 11 parents of children with ASD, who were outpatients and inpatients at National Centre for Growth, Development and Rehabilitation in Tirana, Albania. Through data analyses it came out that the assistance of parents towards children with autism consisted of the following: (i) every day services of personal care such as eating, washing, dressing, personal security, etc; (ii) socializing of the child in out of home environment as well as encouragement to participate in games and other activities with his/her peers; (iii) accompaniment of children in receiving services provided for them and implementation at home of specific tasks asked by the professionals; (iv) mothers are the ones bearing more responsibilities due to the fact that fathers are the main bread winners at home. In conclusion, it can be said that parents of the children with autism with their assistance have a very important role in facilitating and provision of important development and educational possibilities for these children.*

**Keywords:** *children with autism; role of parents;*

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### 1. Introduction

The role of the parents in assistance and treatment of children with autism is very important especially when bearing in mind the difficulties that these children have in behaviour and communication and when socially interacting. The assistance and continuous intervention of parents at home coordinated with other activities in development centers, kindergardens and schools, facilitate and provide important development and educational possibilities for these children. Parents are natural component of a child's development and therefore every change of this role would not be correct. Their main aim is to assist in an optimal development of the child in a safe environment. Here, something is clear that in order for a child to move forward the role of the parents is irreplaceable. The role and assistance of the parents towards their children is affected by a number of factors. It is of importance to understand that the role of the parents differs from one culture to the other (Gopfert, Webster, & Seeman, 2004).

Understanding this role of parents as a social role should be seen from various perspectives. The traditional models of parenting are focused in the basic care toward the child leaving aside many other indicators such as warmth, behaviour, etc. Outside the basic needs the children have other needs and therefore it is very important that the parents fulfil them. Studies show that children have needs related to health, education, emotional and behavioural development, capacities of selfcare, family and social relations, etc (Largo, 2000).

Presently, the role of the parents is considered very important for various areas of the development of the child such as stimulation, directions, etc. The parents need to understand their child and in order to get to this they should adapt themselves with the circumstances and demands of the child (Smith & Cowie, 1993). Children with autism should not be separated and locked up, but assisted and stimulated and this should be felt as part of them. The aim should be to teach the children to perform as many activities in their life. This asks for patience, devotion and knowledge from their parents (Powers, 2000).

The parents hold different views regarding whether the child's development depends on hereditary factors or their social impact (Largo, 2000). If they think that all future characteristics and capabilities of the child are inherited, they become fatalists, but even if the parents are of the opinion that the social environment in which children grow is the only deciding factor in his/her development then they take upon themselves a great responsibility. Inheritance and social environment are not opposites, they complement each other.

The development of a child is characterized by uniformity and variability. Each child is unique in his way (Largo, 2000). Parents rightly understand and with intuition the behaviour of their child. Personal experiences as a child play a crucial role besides intuition. The manner in which the parents have lived through their childhood and the relation they had with their parents affects their attitude. A child needs the help of the parents in order to have good development. A child grows better when parents suit to their needs (Jordan & Powell, 1995). Impacts or consequences of unfavorable living conditions and psychosocial neglect on children have been proven through numerous studies.

The role and support of parents towards the child can be affected by many factors such as marital conflict, stress, health problems, substance abuse, etc. These factors may lead to reduction of parental help to children (Gopfert, Webster, & Seeman, 2004). Given that parents of children with autism also lose their jobs and face economic difficulties, social problems, children with autism are seen as a stress for the family system. The capacity of the family to cope with this situation depends on family resources like money, the ability of parents to work with the child, their ability to solve problems, their attitude towards life and their religious faith. At the same time when other support networks such as friends, relatives, social service agencies exist, families have an easier time coping with this situation and therefore experience less stress.

Parents are forced to play many roles and perform many tasks and what is troubling is that an overload of a role or function may affect the fulfillment of other roles and therefore cause stress for parents (Boyece, Behl, Mortensen, & Akers, 1991).

Studies have shown that parents of children with disabilities experience high levels of stress and other problems of mental health due to intensive care that they show to their child, (Atkin & Ahmad, 2000; Hastings & Beck, 2004). Accordingly, another study by Eikler (1981) shows that single mothers are more stressed, are less likely to be employed and have greater need for financial, personal and social support.

Although, the majority of literature in this area focuses on the needs of children with autism, it should be noted that the needs of parents who care for these children are very important. The separation of services for children and adults makes the process of identifying their needs difficult, especially when parents attend their children's services (Small, 2004). Capacity building of parents is a very important element because the assistance they would offer to their children would be the best possible. Of course, assessing the needs of parents depends on many factors such as resources, philosophy, culture, development of services, etc. Every time that the parents interact with their children, they learn something from them, but the capacity for positive change in children is limited. Today, many parents of children with autism have taken individual initiatives to expand their knowledge, learn more in order to better help their children. Whereas other parents who are too busy with work, are becoming more aware that they should provide more opportunities for their children by being involved in the process themselves (Trevarthen, Aitken, Papoudi, & Robarts, 1996).

Identify the needs of parents with children with autism is a very important process because according to them, professionals and policymakers will be able to develop effective intervention strategies and policies to meet the needs and minimize the problems and difficulties with which they encounter while providing daily care (Reder & Lucey, 1995). Identifying the needs of parents with children with autism requires cooperation with professionals. Only cooperation will enable their needs to be clear and work with children with autism have the desired result.

In conclusion, we can say that parents have an irreplaceable role and impact on the overall development of children with autism. Today, despite numerous problems, a new phase has begun for children with autism, an phase in which parents and professionals work together with the aim of providing the most specialized assistance and creating greater opportunities for development for these children.

## **2. Research Methodology**

The aim of the study was to identify the role of the parents in assisting children with autism (3-6 years old).

### *2.1 Method*

The qualitative method was used in the study. Selection of method and instrument for data collection was carried out in compliance with the aim of the study.

### *2.2 Instrument*

The instrument used in this study for data collection was the semi-structured interview with open-ended questions. The questions of the interview were developed based on the literature of the field as well as to the purpose of the study. In

order to group the information of the study the interview was made up of three sections, which included variables for which I was interested. The use of descriptive questions was a very important element encouraging the collection of qualitative data. Also, in order to create broader space to the participants in their responses the questions were of reflective and building character.

### 2.3 Participants

Data collections were made possible by interviewing of 11 parents of children (3-6 years old) with ASD, who were outpatients and inpatients at National Centre for Growth, Development and Rehabilitation of Children, Tirana, Albania. Their selection and participation in this interview was conducted on the basis of certain criteria such as representation, capacity to describe the phenomenon under study, area of residence and age of the child.

The interview process was conducted face to face, each of which lasted about an hour. Participants in the interview were encouraged to speak freely and openly. Interviews were recorded to be analyzed later. Interviews of participants were conducted in a suitable and comfortable environment at the National Centre for Growth, Development and Rehabilitation of Children in Tirana. Consideration of ethical issues and the preservation of the identity of participants and their children has been a priority of the study.

The study sample consisted of 10 mothers and 1 father. Data showed that the age of the sample participating in the study ranged from 23-41 years. Marital status of all participants in the study was married. 8 of them were resident in the urban areas, while the remaining 3 in the rural areas. 4 parents of children were outpatients whereas 7 others were inpatients. With regards to their education status; 2 parents had university degrees, 7 parents were with secondary education and 2 others with elementary education.

Parents involved in the study had in common the age of the child with autism (3-6 years). Of course, they had their particular characteristics regarding age, residence, education, etc.

The process of collecting and processing data of the study was conducted in the period 01/10/2011-31/10/2011.

### 3. Findings and Discussion

The analyses of the interview process provided a clear picture about the role of parents in helping children with autism. Criteria for the validity of these results were a very important element of the study. The validity of the findings consisted of a cooperative relationship between the data and interpretive method.

Although, individual experiences of parents and their children involved in the study were unique, there was much in common between them. Descriptions of parents are an important tool in order to analyze the tematics, similarities and differences between them. Transcripts of the interviews are provided in order to support the interpretation of data and examples.

Through data analyses which were made possible by interviewing 11 parents of children (3-6 years old) with autism, who were outpatients and inpatients at National Centre for Growth, Development and Rehabilitation in Tirana, we found that:

(i) The role of parents of children with autism consisted of daily assistance in terms of major personal services. Parents stated that their help had to do with bathing, feeding, clothing, safety, etc. According to parents, children have difficulty in achieving personal care services, so it is necessary to assist in carrying them out as well as in learning and performing as many individual activities with the aim of being independent. Also these children can not concentrate, are in continuous motion and indicate obliviousness to different situations or circumstances. These children need ongoing monitoring and care of parents in terms of personal safety aspect, because, according to parent these children may be at risk at any moment. Although, parents constantly insist on the implementation of guidelines, in most cases children with autism have difficulty in understanding and therefore implementing these guidelines. Parents would spent a major proportion of their time doing these activities with the child. To illustrate the qualitative data are some descriptions of parents.

This is what the mother of a 5 year old child says;

*"My role as a mother has to do with the daily main activities how to feed, dress, wash, and be especially careful because the unexpected may come from him. My child needs taken care of for everything".*

Another mother says;

*"As it is a child with problems, care for him is thorough and continuous, for everything. I can call it, total care".*

(ii) Data collected showed that in their daily activity parents of children with autism were focused in socialization activities for children. Parents attempted and tried to involve their children in activities with other children. According to them, children with autism do not like to be involved and participate in relations with children and other people. They show no interest in verbal communications. Also, they do not prefer to approach and play with their peers, and when they do, they do it for a very short moment. Another feature of them is the isolation or the desire to stay alone at home, and this they do often, and therefore parents encourage them to get out and stay with other children. Another aspect of the activity of the parents was the socialization and teaching of children with feelings of fear, because according to them in most cases the children do not know it. The parents wanted the child to be taught to operate both within the family environment, as well as out of it in an open environment.

This is what the father of 5.5 year old child says;

*"I, myself dedicate a lot of time to my son. When I can, because I'm at work, I go out with him, I walk with him. My wife tries to engage him with other children although it is very difficult".*

Another mother says;

*"Although my child can not stay focused and finds it difficult to stay with other children, I try to teach him in an open environment. He prefers more to stay alone".*

(iii) Another activity carried out by the parents was participation of services offered to children with autism. According to them, this activity is very important not only for children because specialized treatment creates greater opportunities for development but also for them because it offers opportunities for more knowledge in this area hence a more suitable assistance for children at home. Parents would follow these services correctly, showing the maximum attention to the advice of specialists and would try to implement them. As this activity was taking considerable time and require great commitment, it would often leave other activities unfinished. Also, implementation at home of specific tasks given to them by the experts was a very important activity for them, but also very tedious, because it requires great concentration and extensive knowledge. Given the problems of these children, parents emphasized the lack of specialized services in areas where they lived, and the need for more services for children as well as for themselves.

Here's how a mother responds;

*"I have accompanied my child at the specialists. I listen carefully to everything you say. Then I try to implement them at home. Truth be told the other duties are often overlooked. However we are tired because this is every day".*

While another one stresses;

*"I bring my child on regular basis to therapy. I try not to miss any days because the child needs it. Every day that passes does not come back".*

(iv) Data proves that mothers are those who spend more time with the child with autism. Mothers are occupied almost all the time with them, taking care of everything from basic care to the specialized one. Given the fact that mothers in most cases are unemployed as a result of the comprehensive care necessary for the child, it is the fathers who most of the time are occupied at work or other activities so as to ensure economic and financial income for the family. However, mothers stressed that fathers too when they return home and when they have the opportunity they deal constantly with the child.

This is what the mother of 4.5 year old boy says;

*"I am the one dealing with the child almost singlehandedly. My husband is 90% of the day at work from morning till night because we have to eat. It is only on Sundays, his day off that my husband deals with him by going out".*

While another mother says;

*"I deal with the child all day, because I'm at home whereas the husband works. He deals only in the evening when he comes home, but is more relaxed than I am".*

The discussion on the results of the study takes into account many factors. It is important to understand that every parent has his/her own individuality and that each child is different. Of course, the differences between them are not only due to each individuality but also because of the environment, culture, resources, etc. The interaction among these factors brings about a better understanding of issues related to the role of parents in helping children with autism.

The above results reveal what studies in this field have stressed (Smith, & Cowie, 1993; Largo, 2000; Gopfert, Webster, & Seeman, 2004) that parents have a very important and irreplaceable role in assisting and development of children. The role consisted not only in daily personal care activities such as bathing, feeding, clothing, safety, etc, but also in other activities related with socialization, guidance, support, treatment, etc.

With regards to socialization activities, the results showed that more and more parents are involved in these activities so as to provide more opportunities for the children (Trevarthen, Aitken, Papoudi, & Robarts, 1996; Harris & Glasberg, 2003). Parents would stimulate the children in games and activities with other children. Suitability of the child with the external environment was very important for them.

The commitment and correctness of parents in the following of specialized services for child was accompanied by a desire to learn more in this area with the aim of extending appropriate assistance to the child at home. Despite positive developments in the treatment of children with autism, the lack of specialized services in many areas is still notable. The need for more services is not only for children but also for their parents.

The study showed that mothers are more involved than fathers in activities and time spent with the child. Mothers would spend almost all the time taking care of them, from basic care to specialized one. The role of the father is seen as the traditional role, that of providers of economic and financial income of the family. However, when possible even fathers would engage in activities with the child.

This discussion emphasizes once again, but in the context of the albanian reality what scientific studies in this field stress that parents have a very important and irreplaceable role in supporting and development of children with autism.

#### 4. Concluding Remarks

In conclusion we can say that the parents of the children with autism with their assistance have a very important role in facilitating and provision of important development and educational possibilities for these children. Their role consisted in: (i) every day services of personal care such as eating, washing, dressing, personal security, etc; (ii) socializing of the child in out of home environment as well as encouragement to participate in games and other activities with his/her peers; (iii) accompaniment of children in receiving services provided for them and implementation at home of specific tasks asked by the professionals; (iv) mothers are the ones bearing more responsibilities due to the fact that fathers are the main bread winners at home.

I think that some proposals may be necessary to increase efficiency and further develop the role of parents in helping children with autism in the future, so for example; greater support and assistance to parents by experts, training of parents with individual and specific programs for their children, greater participation and involvement of the parents in this process, establishment of support programs for parents, establishment closer collaborative relations among parents and professionals, greater participation of fathers in activities with children, establishment of new services not only for children but also for parents, and provision of extension services in as many cities, etc.

This study is a first attempt to answer the issues raised concerning the role of parents in helping children with autism, and it needs to be followed by other studies. In order to achieve this it is necessary the work and dedication and greater cooperation of professionals who operate in this field.

#### References

- Aarons, M., & Gittens, T. (1999). *The Handbook of Autism*. (2nd ed.). London: Routledge.
- Batten, A. (2006). *Autism and education: The reality for families today*. London: The National Autistic Society.
- Cleaver, H., Unell, I., & Aldgate, J. (1999). *Children's Needs-Parenting Capacity*. London: The Stationery Office.
- Eikler, L. (1981). *Chronic stresses of family, of mentally retarded children*. *Family Relation*. 30-63.
- Fawcett, M. (1996). *Learning Through Child Observation*. London: Jessica Kingsley Publishers.
- Gopfert, M., Webster, J., & Seeman, M., (2004). *Parental Psychiatric Disorder. Distressed Parents and their Families*. Cambridge University Press, 62-87.



- Harris, S., & Glasberg, A. (2003). *Children with autism: A guide for families*. Bethesda: Woodbine House, 11-61.
- Jordan, R., & Powell, S. (1995). *Understanding and Teaching Children with Autism*. Chichester: John Wiley & Sons Ltd, 1-121.
- Largo, R. (2000). *Vitet e foshnjerise*. Tiranë: Uegen, 13-25, 395-404.
- Mc Clannahan, L. & Krautz, P. (1999). *Activity Schedules for Children with Autism*. Woodbine House.
- Notbohm, E. (2005). *Ten Things Every Child with Autism Wishes you Knew*. Arlington: Future Horizons.
- Powers, D. M. (2000). *Children with Autism: A Parents guide*. (2nd ed.). Bethesda: Woodbine House, 19-119.
- Reder, P. & Lucey, C. (1995). *Assessment of parenting*. London: Routledge.
- Siegel, B. (2003). *Helping Children with Autism Learn*. Oxford University Press, 13-64.
- Small, A.M. (2004). *Developmental Perspective on Children with Autism*. London.
- Smith, P. K., Cowie, H. & Blades, M. (2003). *Understanding Children's Development*. (4th ed.). Oxford: Blackwell, 92-129.
- Trevarthen, C., Aitken, K., Papoudi, D., & Robarts, J. (1996). *Children with Autism*. London: Jessica Kingsley Publisher, 116-134