



An exploratory study on the type of information regarding needs of parents having children with Autism Spectrum Disorder (ASD)

KEYWORDS

Autism, needs

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ABSTRACT

Autism is neurological developmental disorder which is characterized impairments in communication and socialization associated with repetitive and ritualistic behavior and because of these significant difficulties children with ASD always require intensive intervention at home or in the school. Looking after a child with ASD unquestionably affects the normal pattern of family life. **Ahmadi et. al (2011)** studied 62 parents of children having ASD in Iran and found that many of the parents reported their needs related to services. The benefits of family centered interventions are being greatly recognized now more than ever before.

The present study is aimed to find out the information of needs of parents having ASD. The sample was selected from the parents who visited NIEPMD for the first time for assessment and intervention of their child. Random samples of 75 parents were undertaken for the study, these parents are those who were registered with NIEPMD during the year 2015-17. The no of sample consisted of both the parents i.e father and mother as one single sample. NIMH Family Needs Schedule (NIMH FAMNS) was used to collect the information as its reliability and validity is already established. The information collected was tabulated and calculated in simple percentile scores.

The results indicated that most of the parents of children with Autism Spectrum Disorder are having the needs of services.

INTRODUCTION

The word Autism comes from the Greek word *autos* meaning self. Autism is a complex neurobehavioral condition that includes impairments in social interaction and developmental language and communication skills combined with rigid, repetitive behaviors. Because of the range of symptoms, this condition is now called autism spectrum disorder (ASD) (*WebMed, 2017*). The significant difficulties children with ASD always require intensive intervention at home or in the school. Looking after a child with ASD unquestionably affects the normal pattern of family life. The lifelong nature of autism in a child has deep implications on parents as they are faced with a range of challenges and emotional consequences in raising the child (*Khim Lynn Ooi et.al.2016*). The specific cause of autism is still not very clear, there is an increase in the number of people being diagnosed with ASD (*Perepa, 2007*)

OBJECTIVES

- The objective of the study is to find out the needs of parents of children with Autism Spectrum Disorder
- To find out the which age group children of parents have more needs

HYPOTHESIS

There may not be any difference in the needs of parents having children with ASD

NEED FOR THE STUDY

Having a child with ASD affects every member of the family in many. Looking after a child with ASD unquestionably affects the normal pattern of family life. The Parents/caregivers must because of having a child with ASD place their primary focus on helping their child with ASD, which may put stress on their marriage, other children, work, finances, and personal relationships and responsibilities. The need of family centered intervention helps in the development of the child with ASD, reduces stress in the family and also family is better coped. Hence this study was undertaken to find out the type of needs the parents have (*Peshawaria. et. al, 1995*)

METHODOLOGY

The research methodology is exploratory and NIMH Family Needs Schedule (FAMNS) tool was used to collect the information. Randomly 75 parents (both father and mother) were pooled out from the list of registered parents of NIEPMD.

The sample was divided into the following:

S. No	Parents whose children are in the age group	No.
1	3 to 6 years	25
2	7 to 11 years	25
3	12 to 15 years	25
	TOTAL	75

The information was collected from the parents with the help of the NIMH Family Needs Schedule (FAMNS) tool. The data were pooled and tabulated in the mentioned table

TABLE 1

Parents whose children in the age group of (3-6Yrs)

S.N	Needs	No. of Parents (N=25)	%
1	Information-Condition	9	36%
2	Child Management	5	20%
3	Facilitating Interaction	0	0%
4	Services	11	44%
5	Vocational Planning	0	0%
6	Sexuality	0	0%
7	Marriage	0	0%
8	Hostel	0	0%
9	Personal Emotional	0	0%
10	Personal Social	0	0%
11	Support Physical	0	0%
12	Financial	0	0%
13	Family Relationships	0	0%
14	Future planning	0	0%
15	Govt. Benefits & Legislation	0	0%

GRAPH 1

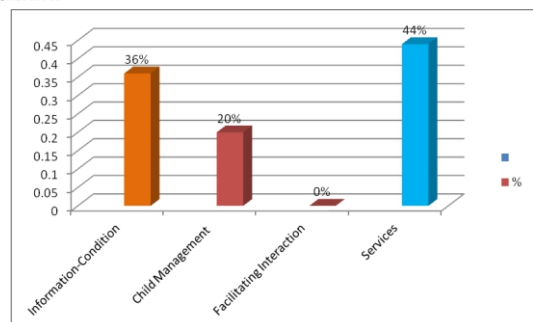


TABLE 2

Parents whose children in the age group of (7-11Yrs)

S.N	Needs	No. of Parents (N=25)	%
1	Information-Condition	5	20%
2	Child Management	9	36%
3	Facilitating Interaction	0	0%
4	Services	8	32%
5	Vocational Planning	0	0%
6	Sexuality	0	0%
7	Marriage	0	0%
8	Hostel	0	0%
9	Personal Emotional	0	0%
10	Personal Social	0	0%
11	Support Physical	0	0%
12	Financial	0	0%
13	Family Relationships	0	0%
14	Future planning	0	0%
15	Govt. Benefits & Legislation	3	12%

GRAPH 2

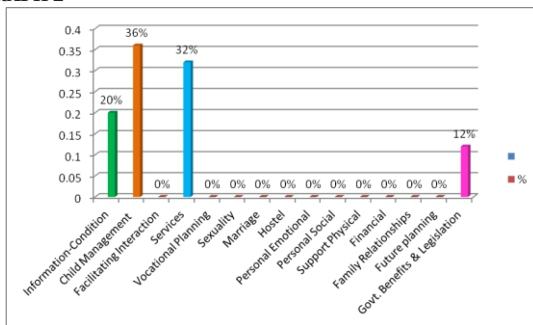
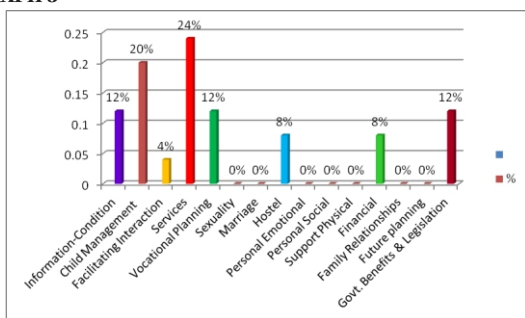


TABLE 3

Parents whose children in the age group of (12-15Yrs)

S.N	Needs	No. of Parents (N=25)	%
1	Information-Condition	3	12%
2	Child Management	5	20%
3	Facilitating Interaction	1	4%
4	Services	6	24%
5	Vocational Planning	3	12%
6	Sexuality	0	0%
7	Marriage	0	0%
8	Hostel	2	8%
9	Personal Emotional	0	0%
10	Personal Social	0	0%
11	Support Physical	0	0%
12	Financial	2	8%
13	Family Relationships	0	0%
14	Future planning	0	0%
15	Govt. Benefits & Legislation	3	12%

GRAPH 3



RESULTS

The result of the study states that 36% parents whose children are in the age group 3 to 6yrs are in need of Information about condition of the child, 44% of parents are in need of information about the

services available for their child.

In the age range of parents having children 7 to 11 yrs the need is primarily focused on Child Management and Services (36% and 32% respectively), 20% of the parents were concerned about the Information on condition.

In the age range of parents having children 12 to 15 yrs the need is primarily focused on Services i.e. 24%, 20% of the parents were concerned about the need on child management. 12% of the parents had their needs on Vocational Planning, 12% of the parents needs were for Govt. benefits & Legislation, 8% of parents needs were for Hostel.

CONCLUSIONS

This study not conclusive presents a picture about the various needs of the parents of children having Autism Spectrum Disorder (ASD). The parents of the children in various age groups have needs related to services as they are concerned about the type of services for their child. Generally when they come to National Institutes, they feel that all the services which are required for their child is available, which somehow they are unable to get under one roof outside. That is why there is a need of counseling for the parents as well as other family members to understand their child's condition. There is a need to develop services that are sensitive to family needs. Support groups for the whole family-parents, siblings, the individual and the extended family- need to be developed, where the emphasis need not always be on autism (Perepa, 2007)

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