

# Awareness and Problems of Parents of Children with Autism Spectrum Disorders

Dr. Aadil Bashir<sup>1</sup>, Shabana khurshid<sup>2</sup>, Dr. Foziya Qadri<sup>3</sup>.

<sup>1</sup>Assistant Professor, Department of Social Work, University of Kashmir, India.

<sup>2</sup>Research Scholar, Department of Social Work, University of Kashmir, India.

<sup>3</sup>Research Associate, Department of Social Work, University of Kashmir, India.

---

**Abstract:** Autism has been described as a condition with a greater number of stress than any other disability. Research that has been accomplished is explored and used as a basis to study new directions required to meet the needs of parents coping with the demands. Raising a child with autism is one of the hardest things a parent will ever have to do. The present study aimed to assess the awareness and problems faced by parents of children with autism and the objectives of the study were to assess the awareness of parents regarding autism and what different problems they faced while dealing with day to day challenges of child. The self-devised interview schedule was applied on parents in order to collect requisite information from them. Results of the present study indicated that majority parents suffered due to over expenditure on treatment of child due to which other expenses did not meet-up and affect overall family. Parents has been affected in different ways but majority of them stated that mental stress invites many problems in family as their whole mind and time revolves around the disable child. The life of the parents has entirely changed and usually experience social isolation which shattered their mental and physical wellbeing. It is seen from the results that family support and faith on God bring positive attitude among parents and act as a motivation and coping mechanism while dealing with day to day challenges of disable child. Majority of parents were not aware about the autism disorder however only few percent were exposed about the ASD during consultation of child specialist.

**Keywords:** Awareness, Problems, Autism, Parents and children.

---

## I. INTRODUCTION

It's widely agreed that parenting is the hardest job of all -- and this is especially true for parents of children with autism, who face a different set of challenges. Autism is a developmental disorder that appears in early childhood, usually before age 3. While cases range from mild to severe, all autism spectrum disorders affect a child's ability to communicate and interact with others. Even though the struggles facing parents of children with autism can seem insurmountable, the good news is that for every challenge, experts say there are solutions to ease the stress and worry that can accompany this very difficult role (Daley, 2002). Various research reports stated that parents of disabled children are particularly vulnerable to stress as high levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children. In addition, both the general psychological literature and specific studies of disabled children show that parental distress and family functioning impacts children in numerous ways, affecting their cognitive, behavioral and social development. Although there are many other developmental disorders, autism is unique in several ways.

First, this disorder has no clear biological marker, unlike many other developmental disabilities such as mental retardation, deafness, and blindness. Without a definitive test, the diagnosis of and prognosis for autism is fraught with uncertainty. This ambiguity makes it extremely difficult for parents to accept the child's condition and second, because it is characterized by

problems of social interaction, such as forming attachments and showing affection, parents of children with autism are often denied some of the fundamental rewards of parenthood. As a result, autism has been considered as one of the most complex and intractable developmental disorders with which families may have to cope. In fact, research has shown that autism can create greater parental anxiety and tension than parents of non-disabled children than parents of children with other physical or learning disabilities or parents with children with other developmental disabilities (Budzienski, 2014). Characteristics that are common among children with autism and contribute to parenting stress include scattered intellectual abilities or isolated skills and pervasive problem behavior such as self-stimulatory behaviors. The deficit in emotional expressiveness of autistic children may lower empathy between mother and child, and thus induce greater parental stress. Existing studies of families of children with autism suggest that behavioral, social, and cognitive dimensions of the disorder are associated with stress in parents. It is true, that the more severe the child's symptoms, the greater will be the degree of parental stress. Furthermore, the more the negative characteristics a child has, the more socially isolated the family will be and more the feelings of stigmatization that they will experience (Pathappili, 2011). Gray conducted a study in 2003 found that almost all parents with children with autism have felt stigmatized in public situations for example at the supermarket or a shopping mall), and that parents of younger and/or more severely disabled children felt more stigmatized.

Other important factors associated with parental stress in families of children with autism, include, feelings loss of personal control, absence of spousal support, informal and professional support. Research further suggests that parents of autistic children are likely to encounter increased risks of experiencing persistent feelings of distress and sorrow. the uncertainty generated by the unpredictability of their child's future quality of life, and stress related to the child's lack of ability to communicate or to his incomprehensible and bizarre behavior, may hinder the development of adequate parenting practices (Ebata et al). Parents also feel overwhelmed by the challenges of achieving the social inclusion of their child both at school and in the community.

Gray 1993 found in a study that many parents have reported positive experiences about rearing a child with autism. They find greater meaning in their own lives, and being delighted with their child's accomplishments , Despite these positive reports substantial research evidences indicates that the parents of children with autism , especially mothers , experience greater amounts of stress and depression than do the parents of children who are developing in typical ways or who have other types of developmental disorder. The first challenge parents of children with ASD face is the diagnosis itself, which can bring heartbreak, anxiety, anger and a feeling that life has been unfair. Another hurdle for parents is the strain having a child with such extensive needs places on the family unit.

According to Autism Society they highlighted that siblings feel overshadowed by the needs of the child with autism, and while some are able to form a close relationship, others may grieve the loss of a typical playmate. But there is certainly hope in this realm. It is important to remember that while having a sibling with autism or any other disability is a challenge to a child, it is not an insurmountable obstacle. Most children handle the challenge effectively, and many of them respond with love, grace, and humor far beyond their years." Many parents of autistic children also report feeling a lack of support. A study published in the journal Qualitative Health Research in 2008 by Sauna, found that a common feeling which is found in majority of families are extreme social isolation and a lack of understanding about the disorder. Sometimes the difficulties of autism can lead to behaviors that are quite challenging for us to understand and address. Autism Speaks recommends that parents consult with their child's team -- usually consisting of special education teachers, the occupational therapist, the speech-language pathologist, the behavioral therapist and other professionals who may provide direct services -- to help them create a consistent plan for dealing with challenging behaviors in and out of school. Parents also faced heavy financial demands of having a child with autism.

Keeping in view the above statements and studies it's imperative that families of autistic children need proper guidance and support from the society in order to overcome their problem while dealing with such children. Government and policy makers should formulate and introduce new practices in special schools which are meant for these children only so that it could help them to bring improvement in their day to day life.

## II. The objectives of the present study are as follows

- 1) To assess the awareness of parents regarding Autism Spectrum Disorder.
- 2) To study various challenges faced by parents of children with Autism Spectrum Disorder.

## III. Research Methodology

**Sample and Sampling Technique:** The sample of the present study comprised parents of five autistic children who were screened through standardized tool namely ISAA from urban areas of district Srinagar. Systematic random sampling technique was used to select the respondents.

**Research Instrument:** Self devised interview schedule were applied on parents in order to collect requisite information from them. The schedule was divided into seven broad headings.

**Locale of the Study:** District Srinagar.

## IV. Results

The results of the present study are as follows:

**Table 1: Problems faced by Parents of Children with Autism**

Variables	Number of parents (5)	Percentage
Social stigma	1	20%
Financial	3	60%
Lack of Awareness	1	20%
Any other	00	0%

From the above table it is inferred that majority of families i.e. 60% had suffered financial problem due to the over expenditure on medication. 20% of the respondents said that they faced social stigma because of the disability of child and rest of the respondents shared that because of the lack of awareness they were not able to get expose of various remedial measures which could helps them to bring improvement in the condition of child.

**Table no 2 .Things that affect the family most**

Variables	Number n=5	Percentage
Extra-expenses	1	20%
Social Stigma	1	20%
Mental stress	2	40%
Burden of over-caring	1	20%
Any other	00	0%

The table reveals that majority of the respondents (40%) stated that their mental wellbeing has been affected them as they were constantly worried about the child's future.20% of the respondents said that unexpected pressures from society affects

their day to day life as their child are always become the center of criticism. Some parents highlighted that extra expenses on treatment and medication of their children create problems in family to meet up other expenses. And rest of the parents shared that they had put more attention on him or her especially mother due to which they felt overburdened. The above findings are corroborated with results of the study conducted by Boyd in 2002 that majority mothers are struggle with an increase of responsibilities, inequity of the division of household and above all societal pressures which affect their overall being.

**Table no. 3 Parental Concern towards Child**

Variables	Number n=5	Percentage
Yes	2	40%
No	3	60%

It's evident from the above table that majority parents (60%) were constantly worried about their child. They said that medication and efforts did not bring any kind of improvement into his/her day to day behavior and such condition will not allow them to lead independent life. Parents shared that getting older become one the reason to worry about the disable child. Whereas 40% of the respondents said they didn't worried as they have left the fate of their child to Almighty because it's a gifted child. The findings are corroborated with the results of study carried out by Sigman 2002 that families are seen in stress and are worried about the condition of child due to non availability of provisions from outside and within home. Majority parents chose to have another child after an existing child had been diagnosed with autism, explicitly for the purpose of having a caretaker for the autistic child after the parent's death.

**Table no. 4 Perception of parents regarding attribution of child's disability**

Variables	Number n=5	Percentage
God's will	3	60%
Past sins done by parents	0	0%
Lack of medical facilities	1	20%
Lack of awareness.	1	20%

The above table reveals that 60% of the parents have attributed their child's disability to Almighty will. They said that it has been gifted to them and they don't have any regret to have such child in family. 20% of the respondents attributed their child's disability to lack of medical facilities at hospitals which affects the condition of child. While rest of them highlighted that due to lack of awareness among community especially whose children suffered from any type of disability become one of the reason for them to overlook the condition of child.

**Table no 5: Coping Strategies adopted by Parents**

Variables	Number n=5	Percentage
Family Support	2	40%
Faith on God	2	40%
Financial Security	1	20%
Any other	00	0%

The information from the above table reveals that 40% respondents shared that their family support helps them to move on in life, whereas same number of percent said that their faith on God bring positive attitude in them to manage their day to day life. While rest 20% respondents felt that their financial security reinforces them to meet up with the day to day expenses spent on disable child and motivate them to manage life smoothly.

**Table 6: Perception of parents regarding the impact of disable child on their life**

Variables	Number n=5	Percentage
Yes	3	60%
No	2	40%

From above table it is inferred that majority respondents perceived that disability of child affect their day to day life as their illness badly shattered their mental and physical wellbeing that inhibit them to live their fully. During interviewing the parents; one of the parent stated that “their life has completely finished due to their child’s disability. While rest of them shared that disability of child did not affect them and their day to day routine. These findings are supported with the results of the study conducted by Boyd 2002 that families faced continuous struggle to have a child with autism as they experience social isolation and remained cutoff from the *outside* world.

**Table no 7. Awareness of parents about Autism Spectrum Disorder**

Nnnnn	Number n=5	Percentage
Yes	1	20%
No	4	80%

It’s found from the above table that only few percent of parents were aware about the autism whereas majority of them did not heard about it. Parents said that they came to know about the autism when they consulted pediatrician regarding the delayed milestones of child.

**Table no 8. Awareness of Parents about Intervention therapies for children with autism**

Response	Number n=5	Percentage
Yes	2	40%
No	3	60%

It’s evident from the table that majority 60% respondents were not aware about intervention therapies meant for autistic children, while 40% of the respondents were aware about few of the therapies.

## V. Conclusion

Autism is a disorder that affects children throughout the entire world. It is a neural developmental disorder characterized by impaired and deviant social interaction and communication, in addition to stereotypical behavior and restrictive interest. Children with autism often have a restrictive range of expression (Cashin, 2005). A study by Hackett 1999 found that families did not initially report concern about the children with autism because they accepted their behavior as a part of their age and did not consider it to be symptomatic of any particular disorder and its attributed to their lack of awareness in society. The

major findings of the present study concluded that majority of parents suffered due to over expenditure on treatment of child due to which other expenses did not meet and affect overall family. Parents have been affected in different ways but majority of them stated that mental stress invites many problems in family as their whole mind and time revolves around the disable child. The life of the parents has entirely changed and usually experience social isolation which shattered their mental and physical wellbeing. Investigator also observed mothers was usually seen most affected by the stress-induced factors that result from raising a child with disability. Some percent of parents expressed that unexpected pressures from society affect their day to day life as their child always become the reason of criticism. Results also indicate that majority of parents were worried about the child as the medication and other treatments did not bring any improvement in his /her condition. It is seen from the results that family support and faith on God bring positive attitude among parents and act as a motivation and coping mechanism while dealing with day to day challenges of disable child. Result also bring out that majority of parents were not aware about the autism disorder however only few percent were exposed about the ASD. Keeping in view the above findings there is a dire need to spread awareness among local masses especially parents to get sensitized about the alarming disorder so to come forward and have exposure of different remedial measures which helps to bring holistic changes in children with ASD.

## **VI. Suggestions**

On the basis of findings few suggestions are forwarded to the parents to develop competence in order to deal children with ASD in proper manner.

- Parents need to consider counseling to help manage their own feelings about their child's diagnosis.
- Parents need to search for best approach for their child and family as there are different approaches to the management of autism.
- Parents can start by doctor or pediatrician.
- Parents should make social groups especially families of children with ASD to share information and experiences while dealing with such children.
- Parents should also access internet and have exposure of different literature available to get deeper insight about the disorder.
- Parents should focus on positive and praise the child instead of punishment.
- Parents should give encouragement to child to get involve in different activities to gain confidence and competence.
- Parents should provide stimulating environment to children in order to grow in a holistic manner.
- Parent should never allow the children to go out alone but try to accompany them. The communication between parents and professionals needs to be improved so they will be able to work together more easily.
- It is imperative to develop a training program for workers in the educational system to learn skills on how to work with children with Autism. This will help to ensure that the children with Autism are taught the right behaviors and will receive the most benefit from their education.

## **Acknowledgement**

We sincerely acknowledge the support provided by Parents of children with Autism Spectrum Disorders of District Srinagar, whose name could not be disclosed as per their desire. Without their support the study could not have been even thought about.

### References

- [1] Daley T.C. (2002). The need for cross-cultural research on the pervasive developmental disorders. *Transcultural Psychiatry*, 39, 531-550.
- [2] . Budzienski, J. (2014). The Challenges of being a Parent of a Child with Autism. *Journal of Autism and Developmental Disorders*, 24, 501-515.
- [3]. Pathapilli, J.S. J. (2011). *A Qualitative Study on Indian Mothers and their Perception of Autism* Unpublished M.Sc Dissertation, Department of Psychology.
- [4]. Gray D.E (2003). *Gender and coping: The parents of children with high functioning autism. Social Science and Medicine*, 56, 631-642.
- [5]. Meadan, H., Halle, J.W., Ebata, A.T. (2010). Families with children who have autism spectrum disorders: Stress and support. *Council for Exceptional Children*, 77 (1), 7-36.
- [6]. Gray, D.E. (1993). Perceptions of autism: The parents of autistic children. *Sociology of Health and Illness*, 15 (1), 102-120.
- [7]. Sanua V.D. (2008). *Is infantile autism a universal phenomenon? An open question. International Journal of Social Psychiatry*, 30, 163-177.
- [8]. Boyd, B.A (2002). Examining the Relationship between Stress and Lacking of Support in Mothers of Children with Autism. *Focus on Autism and other Developmental Disabilities*, 17 (4), 28-215.
- [9]. Sigman M.D. (2002) *Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. Journal of Autism and Developmental Disorders*, 32, 13 -23.
- [10]. Cashin, A. (2005). Autism: Understanding Conceptual Processing Deficits. *Journal Of Psychosocial Nursing and Mental Health Services*, 43, (4), 22-30.
- [11]. Hackett R, Hackett, L. (1999). *Child psychiatry across cultures. International Review of Psychiatry* ; 11, 225-235.