

## Economic burden and psychological wellbeing among parents of children with autism and learning disability

Dr. Pushpalatha. R<sup>1\*</sup>

### ABSTRACT

The word disability is stigmatized be it physical or mental disability. The disabled population along with the caregivers face unfriendly attitude in the society. The types of disability include loco-motor, hearing, speech, visual and mental disability. Many parents and families with a child diagnosed with autism farewell. However, a high level of parents experience stress, anxiety and depression. Autism is based on presence of persistent and pervasive deficits of social communication and interaction, and restricted and repetitive behaviors that interferes with functioning in everyday activities (American Psychiatric Association 2013). Additional stressors not related to child –specific factors, such as financial strain, changes in employment related to having a child with autism and caregiving responsibilities to other family members, can also influence maternal psychological wellbeing (Dardas & Ahmad 2014; Hodgetts et al. 2014). The birth of a child with a learning disability often has a profound effect on the family, requiring one or more family members (usually the parent(s)) to adopt the role of ‘carer’. Traditionally, research on caregiving for children and young people with disabilities has highlighted the stresses or burden’ imposed on parents by the many, and often complex, demands of caregiving (Brannan et al.1997; Egan & Walsh 2001; Hassall et al. 2005; McGilloway et al. 1995; Saloviita et al. 2003; Shearn & Todd 2000). The difficulties of managing the care recipient contribute to objective caregiver strain whilst subjective strain is more strongly related to caregiver characteristics and comprises internalized (e.g. worry, sadness) and externalized subjective strain (e.g. anger or resentment towards the child or the behavior). The aim was to study economic burden and psychological well being among parents with autistic and learning disability children. Parents of children aged between 8 to 12 years were considered for the study. The sample consisted of 30 parents of learning disability and 30 parents of autism. Financial impact scale and psychological well being questionnaire were administered to the parents. A purposive sampling technique was opted for the study. The mean, SD, and “t” will be computed using appropriate statistical measures. The data will be further analyzed based on the obtained results.

**Keywords:** *Autism, Economic Burden, Learning Disability, Parents and Psychological well being*

<sup>1</sup>Assistant professor, Maharani Women’s Arts Commerce and Management College, Karnataka State, India  
*\*Responding Author*

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## **Economic burden and psychological wellbeing among parents of children with autism and learning disability**

**A**utism is a lifelong developmental disability that includes deficits in social interaction, communication and restricted, repetitive patterns of behavior, interests, or activities. Autistic child may show unusual interests and behaviors and may have problems with sleeping and eating. Caring for children with ASD is challenging as caregivers have to face difficulties in dealing with the unusual behaviors of their child, teaching them to interact, teaching them basic life skills, protecting them from danger and preparing for their transition into adulthood. Due to this multidimensional requirement of caregiving, caregivers experience tremendous stress, misconceptions, feeling of guilt and self-blame regarding child's disorder. As parent's well-being could positively influence caregiving and thus decrease the burden of care, research concerning caregiving is necessary.

Burden on caregivers concerning people with chronic diseases is described as a disorder resulting from dealing with physical dependence and mental incapacity of the person, in need of attention and care (Braithwaite V., 1992). Autism as childhood developmental disorder can cause intense stress on caregivers, as a consequence of which the caregivers may develop depression which negatively affect both the parents and the child (Sanini C., 2010). By taking on the role of guardian or caregiver, they become responsible for the welfare and care of a family member who is dependent on them due to which the caregivers are subjected to a lot of stressors, as well as feeling satisfaction and wellness for helping the person (Lawton M, 1989). Due to the presence of a disabled child at home there may have several implications for the family dynamics, arising from changes in the activities of the daily living, high level of stress and low level of quality of life of the family members to the possibility of developing adaptability and resilience. Moreover, many parents face financial problems, given high out-of-pocket health care expenses, under employment or employment loss.

Learning disorders are diagnosed when the individual's achievement on individually administered standardized tests in reading, mathematics or written expression is substantially below that expected for age, schooling and level of intelligence (Nakra, 1996). The learning difficulties significantly interfere with the child's academic achievement or activities of daily living that need reading, writing skills and mathematical aptitude. The child with learning disability shows an inconsistency between achievement and intelligence. The role of the family of the disabled child is vital. The level of acceptance of the disabled may vary from one family to the next. The diagnosis of disability in a child is a traumatic event. Parental reactions to their child's disability are highly individualistic. The type and intensity of their response depends on how parents handle crisis situations in general, stability of the marital relationships and parental aspirations. Some of the common reactions include guilt, disappointment, shame, grief, anger and disbelief.

The positive aspects of caregiving, e.g. positive behavioral and cognitive responses (Beach et al., 2000), often requires additional physical, emotional, social, and financial resources (Murphy et al., 2006). Parents must also manage the child's many aspects related to medical, educational, and developmental interventions while balancing challenging family needs (Silver et al., 1998). Such needs can cause parental stress and lower caregivers' psychological well-being (Dunn et al., 2001; Hastings et al., 2005; Murphy et al., 2006; Raina et al., 2004; Yirmiya and Shaked, 2005) which may result in anxiety and depression (Chadman et al., 1991; Kronenberger and Thompson, 1992). Parental stress is a strong predictor of caregivers' psychological well-being and usually results in decisions to place

## **Economic burden and psychological wellbeing among parents of children with autism and learning disability**

the children out of the home (Blacher and Hanneman, 1993; Bromley and Blacher, 1991; Llewellyn et al., 1999; Rimmerman and Duvdevani, 1996). Poor and worsened caregiver's psychological well-being is also a predictor of lower quality of life among children with intellectual disabilities (Cramm and Nieboer, 2011).

### **METHODOLOGY**

#### ***Aim***

- To study the economic burden and psychological well being among parents of children with autism and learning disability.

#### ***Objective***

- To find out if there is any difference in economic burden and psychological well being among parents of children with autism and learning disability.

#### ***Hypothesis***

1. There will be no significant difference in the economic burden among parents of children with autism and learning disability.
2. There will be no significant difference in psychological well being among parents of children with autism and learning disability.

**Independent variable:** Parents of autism and learning disability children

**Dependent variable:** Economic burden and Psychological wellbeing

#### ***Sample***

A sample of 60 parents of which 30 were parents of children with autism and 30 were parents with learning disability children. Purposive sampling technique was used to select the sample.

#### ***Inclusion criteria***

1. Autistic children whose age ranged from 08-12 years.
2. Learning disability children whose age ranged from 08-12 years.
3. Parent's age ranged between 30-40 years
4. Parents accompanying their children to the school were considered for the study

#### ***Exclusion Criteria***

1. Parents' of normal children and other differently enabled children
2. Parents who were not accompanying their wards to the school.
3. Parents with major psychiatric/psychological problem

#### ***Research Design***

A between groups research design with purposive sampling was considered for the study

#### ***Tools***

Todtman, K., & Gustafson, & Gustafson, A. W. (1991). Financial Impact Scale: The scale is a 20-item Likert-type scale designed to assess the financial impact on an individual and his or her family of caring for the long-term needs of a disabled individual. The scale has a reliability of Cronbach's Alpha of .93 and a good validity correlation  $r$  of .6682,  $p < .001$

## Economic burden and psychological wellbeing among parents of children with autism and learning disability

Bhogle S, Jaiprakash I.(1995). Psychological Well Being Scale: The scale has 28 items. It is answered in yes or no format. The scores range from 0-28, higher scores indicating better psychological well being. Test-retest reliability is 0.71, split half co-efficient is 0.91, and alpha co-efficient is 0.84 (internal consistency). Each response was score as per the author’s norms.

### **Plan**

The financial impact and psychological well being scales were administered to the parents of children with autism and learning disability. The scales were scored appropriately. Mean, SD and t-values were derived to find out the significant difference between the parents of children with autism and learning disability.

### **Procedure**

The aim was to study the economic burden and psychological well being among parents with autism and learning disability. 60 parents of which 30 were parents of autistic children and 30 parents having children with learning disability and those fulfilling the inclusion criteria were considered for the study. Those parents who volunteered for the study were administered financial impact and psychological well being scales. The scales were scored appropriately as per the author’s norms. Mean, SD and t-value were derived to find the significance difference between the parents of children with autism and learning disability.

### **ANALYSIS OF DATA**

The data was scored appropriately as per the author’s norms. The mean, SD and t-test were used to analyze if there was significant difference between the parents of autistic and learning disability children.

**Table 1 shows the demographic details of parents of autism and learning disability children**

Sample Group	N	Age	Education qualification	Relationship with ward
Parents of autism children	30	30-40 years	Degree	Parents
Parents of Learning Disability children				

Table 1 shows the demographic details of parents with autism and learning disability children. The sample consisted of 60 parents of which 30 were parents with autistic children and 30 had children with learning disability, the age of the parents ranged from 30-40 years and the minimum education qualification required was degree. Only parents who were accompanying their wards to the school were considered for the study.

**Table 2 shows the Mean, SD and “t” values for parents of autism and learning disability children in each area.**

Sl. No.	Areas	Group	N	Mean	SD	‘t’
1.	Economic Burden	Autism	30	18.10	1.37	5.82**
		Learning Disability		16.30	0.98	
2.	Psychological well being	Autism	30	17.60	0.89	6.89**
		Learning Disability		20.36	2.00	

P> 0.01\*\* significant at 0.01 level.

## **Economic burden and psychological wellbeing among parents of children with autism and learning disability**

Table 2 shows the Mean, SD and 't' value obtained in economic burden and psychological well being among parents with autism and learning disability children. The mean score obtained for economic burden for parents of autism and learning disability children are 18.10 and 16.30. The SD being 1.37 for parents with autistic children and 0.98 for parents with learning disability children. The obtained 't' value is 5.82 which is significant at 0.01 level indicating that there is significant difference in economic burden of parents with autistic children and parents with learning disability children. The obtained results are not in accordance with the hypothesis which states that there will be no significant difference in the economic burden among parents of children with autism and learning disability. The results of the present study has been supported by the study carried out by *Kamaralzaman, S., et.al (2018)*. *The researchers have revealed that the parents face huge economic burden while caring for the child with autism. According to the study conducted by Jian-Jun Ou, et.al (2015) has reported that families having children diagnosed with autism specter disorder faced severe employment and financial burdens.*

Similarly, the mean score obtained for psychological well being for parents with autistic and learning disability children are 17.60 and 20.36. The SD being 0.89 for parents with autistic children and 2.00 for parents with leaning disability children. The obtained 't' value 6.89 which is significant at 0.01 level which indicates that there is there is significant difference in psychological well being of parents with autistic children and parents with learning disability children. The obtained results are not in accordance with the hypothesis which states that there will be no significant difference in the psychological well being among parents of children with autism and learning disability. The findings of the present study have been supported by the study carried out of researchers Nikmat, A.W. et.al (2008). The study revealed that parents with autistic children have high prevalence of stress and psychological disturbances. Velsamy,P (2016) in his study on "the psychological well being among the parents of children with autism" has revealed that the mothers of children with autism had poor psychological well being.

### **CONCLUSIONS**

Parents with autistic children have immense economic burden compared to the parents with learning disability. Parents with autistic children have poor psychological well being when compared with parents with learning disability children.

#### **Limitations**

1. The study was conducted on a small sample size
2. Only those parents who were accompanying their wards to the school were considered for the study
3. Parents residing in urban area were considered for the study hence limiting the scope for generalization.

#### **Implications**

1. The results of the present study indicate that parents with autistic children have poor psychological well being than the parents with learning disability children. Hence intervention is suggested to the parents to help them to adjust better and improve their well being while handling their wards.
2. The obtained results of present study indicate that the parents of autistic children have more economic burden than the parents of learning disability children. Advice is needed to help the parents to manage their finances and prioritize their needs and

## **Economic burden and psychological wellbeing among parents of children with autism and learning disability**

cut on some unnecessary expenses so that they would be able to better manage their finances.

3. The parents of disabled children need social support and timely help from the professionals. Now a day's awareness regarding mental disabilities is created among the public through electronic media. However it has not reached to all section of the societies. People even today feel that having a disabled child at home affects their family and social life. The stigma of disability still persists in our society. It may take more time for people to accept the disabled individuals and treat them with respect. The efforts to bring awareness among people should continue by the educated people until the disabled individual and their family is treated with respect.

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## **Economic burden and psychological wellbeing among parents of children with autism and learning disability**

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## **Economic burden and psychological wellbeing among parents of children with autism and learning disability**

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**Economic burden and psychological wellbeing among parents of children with autism and learning disability**

***Conflict of Interest***

The author declared no conflict of interest.

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