

## Impact of children's intellectual disability on parents

Sukant Chhotaray<sup>1\*</sup>

### ABSTRACT

The family members of children with intellectual disability experience considerable distress due to care giving and other special needs of these children and the interference caused in their day to day life and the occupational responsibilities. The present paper examines the differential effects of children's intellectual disability on their mothers and fathers. Both mother and father of 30 children diagnosed as having intellectual disability due to significantly sub-average intellectual functioning and impaired adaptive functioning enrolled in a special school were taken for the study. NIMH Disability Impact Scale developed by Peshawaria et al. (2000) was individually administered on each parent. Mean S.D. were computed and compared with student's t-test. Results suggested that both mother and fathers were affected by the disability however mothers were affected significantly more than the fathers. These results suggest the role of maternal caring and cultural influences in the care-giving role of mothers which might contribute to higher disability impact and stress in mothers of the children with disabilities.

**Keywords:** *Intellectual Disability, Family Of Persons With Disability, Caregivers' Stress In Disabilities*

The very first knowing about the diagnosis of intellectual disability evokes a series of emotional reactions in their parents. They get shocked, denies, feel guilty, express grief, anger and make readjustment. A comprehensive model of these emotional reactions is provided by Hedderly, Bairdward, McConachie (2003). There are plenty of researches that indicate family stress in families of children with intellectual disability which affects their health. Singh, Indla, Indla (2008) observed difficulties in meeting extra demands for physical care of the child and health-related issues, career problems and decreased support of spouse in one fourth sample of parents of children with mental retardation. Apart from impaired adaptive behaviours, the children with mental retardation also show problem behaviours of various kinds such as stereotype behavior, aggressive behavior which also causes stress in the caregivers. Neely-Barnes and Dia (2008) reported stress due to maladaptive behavior.

Parenting stress has implications for clinical and social functioning; and can lead to marital conflict, and the neglect of child (Mash et al, 1983; Belsky et al, 1985). Gupta (2007) observed that greater parenting stress was associated with developmental disability when

<sup>1</sup>Principal, Training Centre for Teacher's of Mr. Nilachal Seva Pratisthan, Odisha, India

\*Responding Author

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compared to disability due to medical conditions. It is suggested that parenting stress depends upon the nature and severity of disability, the number of invasive procedures such as surgeries, other diseases, associated handicap and the type of disability (Breslau et al, 1982)

The extant literature suggested that mothers of such children experienced greater amount of stress (e.g. Farber, 1960; Heller, Hsieh & Rowitz 1997; Peshawaria et al., 1998; Seshadri, Verma & Prashad 2000; Hedov, Anneren & Wikblad, 2000). Mother experienced depression (Olsson and Hwang, 2001), burden of care (Heller et al,1997) and more stress (Herring et al, 2006).

Over the decades lots of development has taken place with respect to the service availability, medical facilities, early intervention services and mobility to the place of services, awareness regarding disabilities, educational levels and the type of families. It would be of interest to study whether the reported findings of more stress in mothers still continue in this changing scenario.

### *Aim*

The aim of the present study was to compare the impact of having a child with intellectual disability on mothers and fathers.

## **METHODOLOGY**

### *Sample*

A sample of 30 children with intellectual disability enrolled in special school and having both the parents living together were taken for the study. This included 30 fathers and 30 mothers of these children. The parents having known history of psychiatric illness, low intellectual functioning, disability and major medical conditions were not included.

### *Tools:*

***NIMH Disability Impact Scale (DIS)***: DIS was developed by Peshawaria et al. (2000). The scale consists of 11 areas physical care, health problems, career adjustment, loss of support, financial problems, social restrictions, embarrassment, negative effects on relationships, negative effects on siblings, specific negative thoughts and positive impact. Only first 10 areas were considered for analysis in the present study.

### *Procedure*

The parents of children with intellectual disability enrolled in a special school in were approached. They were briefed about the nature of the study. The criteria for inclusion were determined. The parents who consented to the study were individually administered NIMH Disability Impact Scale.

### *Analysis of data*

Mean, S.D. and t-test were calculated to analyze the data.

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**Table No. 1 Sample Characteristics**

Characteristics		Mean/ Percentage	SD
Age in Years	Fathers	37.26	5.44
	Mothers	31.83	5.98
	Children	9.24	2.14
Years of Education	Fathers	12.36	2.88
	Mothers	10.06	3.16
Domicile	Rural	56.7%	-
	Urban	43.3%	-
Religion	Hindu	86.7%	-
	Others	13.3%	-
Socio-economic Status	Low	36.7%	-
	Lower Middle & Middle	63.3%	-
Family Type	Nuclear	70%	-
	Joint	30%	-
Occupation	Unemployed	40.7%	-
	Employed	59.3%	-

The mean age of fathers was 37.26 with an S.D. 5.44 years which is more than the mean age of mothers 31.83 and S.D of 5.98 years. The mean of the children with intellectual disability was 9.24 years with an S.D. of 2.14 years. The education level of fathers was higher than the mothers. The proportion of rural and urban sample was more or less equal. The parents from Hindu religion were very high than the other religions. The sample consisted of more parents from lower middle and middle socio-economic status. More parents belonged to nuclear family and 59.3% were employed in gainful occupation.

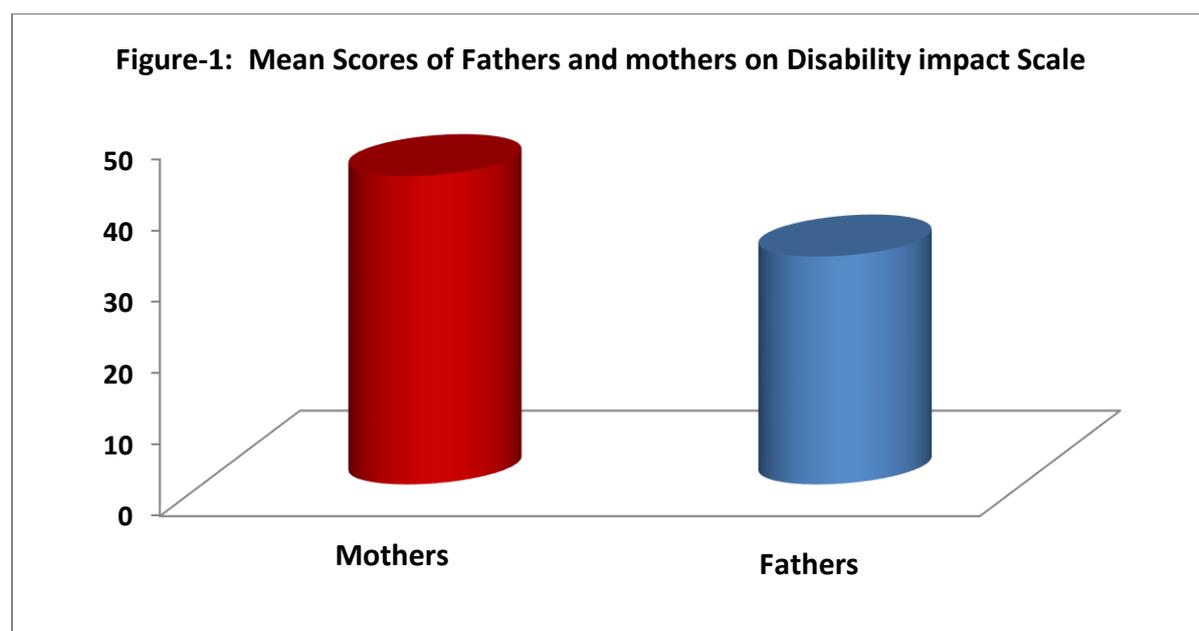


Figure-1 depicts mean scores of fathers and mothers on NIMH Disability Impact Scale. It is clearly evident that the mean scores of mothers was greater than the mean scores of father. To determine significance of mean difference, t-test was calculated, the results are given in table-2.

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**Table No. 2 Mean, S.D. and t-value for Scores on Disability Impact Scale**

DIS: Domains	Grouping	N	Mean	Std. Deviation	t-value
Physical Care	Mothers	30	9.20	4.83	1.39
	Fathers	30	7.50	4.60	
Health	Mothers	30	3.50	2.76	1.21
	Fathers	30	2.76	1.81	
Career	Mothers	30	1.63	1.42	1.73
	Fathers	30	1.03	1.24	
Support	Mothers	30	2.90	1.58	-.55
	Fathers	30	3.10	1.15	
Financial	Mothers	30	5.23	1.94	1.86
	Fathers	30	4.40	1.49	
Social	Mothers	30	3.30	1.68	<b>2.19*</b>
	Fathers	30	2.46	1.22	
Embarrassment/ Ridicule	Mothers	30	2.00	1.14	<b>3.68**</b>
	Fathers	30	1.06	.78	
Relationships	Mothers	30	3.10	1.49	<b>6.32**</b>
	Fathers	30	1.13	.81	
Sibling Effect	Mothers	30	5.66	1.29	<b>5.47**</b>
	Fathers	30	3.03	2.29	
Specific thoughts	Mothers	30	1.90	.84	<b>2.18*</b>
	Fathers	30	1.46	.68	
Positive effects	Mothers	30	4.76	1.52	<b>2.05*</b>
	Fathers	30	3.96	1.49	
DIS: Total	Mothers	30	43.20	10.95	<b>4.29**</b>
	Fathers	30	31.93	9.27	
DIS: Domains 1-10	Mothers	30	38.43	11.11	<b>3.98**</b>
	Fathers	30	27.96	9.13	

*\*Significant at .05 level; \*\*Significant at .01 level*

Table-2 indicates that there were significant differences in the disability impact across mothers and fathers on following domains: Social, Embarrassment/ Ridicule, Relationships, Sibling Effect, Specific thoughts and Positive effects. Overall mothers were more affected than the fathers. Also, mothers had better positive impact of having a child with intellectual disability. The comparison of mean by excluding the positive impact domain, suggested that the adverse impact was also significantly more on mothers than fathers (DIS: Domains 1-10).

The present study was designed to study the impact of child's disability on parents of intellectual disability and to compare the impact across fathers and mothers. The results of NIMH Disability Impact Scale suggested that mothers were affected more than the fathers which are in agreement with the findings of the previous studies having similar results (Farber, 1960; Heller, Hsieh & Rowitz 1997; Peshawaria et al., 1998; Seshadri, Verma & Prashad 2000; Hedov, Anneren & Wikblad, 2000). The differential impact on mothers continue to exist over as it had been observed in the past despite so many advancements in the service facilities for persons with intellectual disabilities. The mothers still experience social issues, feel embarrassment and negative thoughts towards self. The reasons can be obvious that in patriarchal family systems, mother is required to perform the role of primary caregiver of the children including the children with intellectual disabilities. There is also a positive aspect that mothers had relatively more positive impact than fathers. They become more sensitive, tolerant and empathic towards the situation. This might be serving as a protective factor for their own wellbeing.

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The children with intellectual disabilities need long term care and support from family members even for meeting their basic needs. Of course, parents do adapt to the continued stress still there are points of difficulties and concern which continue to trouble them throughout. For example, the associated handicaps and problem behavior add to their continued distress and may limit their participation in social activities to the fullest. Also, with increasing age, they become concerned for the survival and caring of their child with disability. They often ask what would happen to this child after them. Who would look after? These issues remain largely unresolved causing worries.

Ha et al. (2008) reported that continued dealing of a problem for longer duration lead to more stress. According to cumulative stress model, weariness and exhaustion remain higher in the person who are involved in taking care of chronic and long-lasting problems than the persons caring for a short lived condition. In the light of this model, it can be expected that parents would continue to feel stressed due to the lifelong and stable disability of their child. The only thing which can be achieved is the mitigation of their stress by family psychoeducation, enrollment of children in special school, availability of professional support and the support of self-help groups. Lazarus and Folkman (1984) suggested that longer is the duration of stress, the persons affected by it tend to develop new skills and coping mechanisms to deal with the continued stress. This is reflected in the domain of positive impact of Disability Impact Scale in the present study. Both parents experienced positive impact and mothers had both greater negative as well as positive impact.

### CONCLUSION

The present study aimed at estimating the impact of having a child with intellectual disability on parents and compare the impact across mothers and fathers. The results revealed that mothers were affected more for both negative and positive impact. They experienced greater distress as well as positive impact due to the child with intellectual disability. Despite so many developments in special educational and rehabilitation facilities, the parents still experience the stress of caring their children and need continued social and professional support to deal with the situation.

### REFERENCES

- Belsky J, Lang M E, Rovine M (1985). Stability and Change in Marriage across the Transition to Parenthood: A Second Study, *Journal of Marriage and the Family*; 47:855–865
- Breslau N, Staruch KS, Mortimer EA (1982). Psychological distress in mothers of disabled children. *American Journal of Diseases of Childhood*; 136: 682-686.
- Farber (1960) Family organization and crisis: Maintenance of integration in families with several mentally retarded child. Monograph of society Research and child development, 25(1). DOI: 10.2307/1165524
- Gupta VB (2007). Comparison of parenting stress in different developmental disabilities. *Journal of Developmental & Physical Disabilities*; 19: 417-425.
- Ha, J. Hong, J. Seltzer, MM and Greenberg, JS (2008) Age and Gender Differences in the Well-Being of Midlife and Aging Parents with Children with Mental Health or Developmental Problems: Report of a National Study. *J Health Soc Behav*. 2008 September; 49(3): 301–316
- Hedderly, T. Baird, G. McConachie, H. (2003) Parental reaction to disability. *Current Paediatrics*. 13,30-35.
- Hedov G, Anneren G, and Wikblad K. (2000) Self perceived health in Swedish parents of children with Down's syndrome. *Quality of life research*. 9(4): 415-422

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- Heller T, Hsieh K, and Rowitz L. (1997) Maternal and Paternal caregiving of persons with mental retardation across the life span. *Family relations*; 46 (4): 407-115.
- Heller T, Hsieh K, Rowitz L (1997). Maternal and paternal caregiving of persons with mental retardation across the lifespan. *Family Relations*; 46(4): 407-415
- Herring S, Gray K, Taffe J, Tonge B, Sweeney D, Einfeld S (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*; 50(12): 874-882.
- Lazarus, R.; Folkman, S. (1984) *Stress, Appraisal, and Coping*. Free Press; New York.
- Mash, E J, Johnston C, Kovitz KA (1983). Comparison of the mother-child interaction of physically abused and non-abused children during play and task situation. *Journal of Clinical Child Psychology*; 12: 337-346
- Neely-Barnes S L, Dia D A (2008). Families of children with disabilities: A review of literature and recommendations for interventions. *Journal of Early and Intensive Behaviour Intervention*; 5(3): 93-107
- Olsson M B, Hwang C P (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*; 45(6): 535-543
- Peshawaria R, Menon D K, Ganguly R, Roy S, Rajan Pillay P R S, & Gupta S. (1998) A study of Facilitators and Inhibitors that effect coping in parents of children with mental retardation in India. *Asia Pacific Disability Rehabilitation Journal*; 9(1).
- Peshawaria R, Menon DK, Bailey D, Skinner D. (2000) *NIMH Disability Impact Scale (NIMH-DIS)*. Secunderabad, Andhra Pradesh, India: National Institute for the Mentally Handicapped (Under the Ministry of Social Justice and Empowerment, Government of India)
- Seshadri M K, Verma S K, and Prashad, D. (2000) Impact of mental retardation of child on the family in India. *Journal of Clinical Psychology*; 473-498.
- Singh T K, Indla V, Indla R R (2008). Impact of disability of mentally retarded persons on their parents. *Indian Journal of Psychological Medicine*; 30(2): 98-104

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### ***Conflict of Interest***

The author declared no conflict of interest.

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