

# Magnitude of problem of persons having intellectual disability its impact on parents and their unmet needs in Indian subcontinent

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## ABSTRACT

**Background :** Intellectual disability is the clearest example of the mixture of medical and social system models. People with intellectual disability do not represent homogenous groups. Their unmet needs and impact on parents as caregivers also vary especially with changing social milieu, socio economic status and ethnicity. **Objectives :** To assess the disability of intellectually disabled and the nature and degree of impact on their parents. **Methods :** The clinico-demographic profile of 102 intellectually disabled and intellectually average children and their caregivers were compared. The impact of disability was measured in NIMH-DIS scale. **Results :** Mothers experienced more difficulties than fathers in physical care ( $p<0.03$ ), health ( $p<0.02$ ), career ( $p<0.03$ ), sibling effect ( $p<0.04$ ) and specific thoughts domain ( $p<0.04$ ). Fathers experienced more trouble in support ( $p<0.02$ ), financial ( $p<0.05$ ), social ( $p<0.01$ ), embarrassment/ridicule domains ( $p<0.02$ ). There was no difference in Relationship domain ( $p=0.56$ ) between the parents. Higher patience ( $p<0.02$ ) and empathy ( $p<0.04$ ) were found among mothers and higher tolerance ( $p<0.03$ ) and sensitivity ( $p<0.04$ ) were found among mothers. The impact on mothers increased in physical care, health and specific thoughts domains whereas the impact on fathers increased in financial and embarrassment/ridicule domains. **Conclusions :** Rehabilitation needs increase with severity of disability and impact on parents as caregivers. Appropriate assessment and finding out unmet needs can guide to formulate individualized treatment plan for them as well as for their parents.

**Key Words :** Intellectual disability, parents burden, NIMH DIS scale, rehabilitation needs.

## INTRODUCTION

The term “intellectual disability” is gradually replacing the term “mental retardation” nationwide. In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the APA replaced “mental retardation” with “intellectual disability (intellectual developmental disorder).

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Intellectual disability is the clearest example of the mixture of medical and social system models. Child with disability means a child who deviates from a normal child in mental or physical characteristics to such an extent that he requires special education and related services. People with intellectual disability do not represent homogenous groups.<sup>1</sup> Their unmet needs and impact on parents as caregivers also vary especially with changing social milieu, socio economic status and ethnicity. Studies have shown that beyond public and self-stigma, stigma can also

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impact family members especially the internalised aspects of stigma, known as affiliate stigma, among family caregivers of individuals with disabilities.<sup>2</sup>

As a result of gains in health care, people with intellectual disability are outliving their parents, creating an unprecedented need to support this population.<sup>3</sup> Siblings represent the longest lasting family relationships and often become caregivers for their brothers and sisters with intellectual disability when parents pass away.<sup>4</sup> Findings suggest that siblings who have greater access to services and supports experience greater well-being and ability to support their brothers and sisters with intellectual disability.<sup>5</sup>

## METHODS

The clinico-demographic profile of 102 intellectually disabled and their caregivers were compared. The impact of disability was measured in NIMH-DIS scale. FISP-PMR (1998-2003) i) Nature & degree of impact of parents, ii) Nature & degree of impacts on family members, iii) Nature & degree of impact on caregivers other than family members, iv) To identify

thrust areas of FISP, v) To objectively evaluate the functioning of FISP.<sup>6,7</sup>

The pilot study on NIMH-DIS scale was conducted on 20 patients by researchers and the inter-rater reliability among two individuals was found to be good ( $r=0.849$ ;  $p<0.00$ ). The eleven domains of the scale with maximum scores are as follows: physical care (22), health (16), career (14), support (18), financial (16), social (12), embarrassment/ridicule (14), relationship (18), sibling effect (20), specific thoughts (14), positive impact (18).<sup>8,9</sup>

## RESULTS

The age of 102 parents (51 fathers & 51 mothers) were as follows : age of father (38.40; 10.28) and age of mother (34.22; 8.54) which was not statistically significant. Age of marriage ( $p < 0.002$ ) and age of childbirth ( $p < 0.003$ ) was found to be statistically significant. Difference in income emerged as one of the demographic variables which was statistically significant ( $p < 0.048$ ). However there was no statistical difference birth order (Table 1).

**Table 1 : Demographic Comparisons**

Demographic Variable	Group	N=102	Mean	SD	F	Significance P value
Age	Father					
	Mother	51	38.40	10.28	1.75	0.172
Age of Marriage	Father	51	34.22	8.54		
	Mother	51	28.54	7.28	11.54	0.002 **
Age of Childbirth	Father	51	31.54	5.47	18.72	0.003**
	Mother	51	23.36	3.28		
Birth Order	—	—	2.11	1.82	3.02	0.41
Income	Father	51	3.12	1.02	3.12	0.048*
	Mother	51	1.21	0.86		

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Majority of sample belonged to age group 3-6 years (n=47; 46.8%) followed by 6-18 years (n=31; 30.4%) and more than 18 years age group (n=16; 15.7%). Most were having mild intellectual disability and peak incidence was in the age group 3-6 years (n=25; 55.5%) (Table 2). There was no statistical difference in the family adjustment and economic adjustment domains in the rural-urban comparisons. However the difference was statistically significant in the Health adjustment (p=0.04), Social adjustment (p=0.02) and Parental adjustment (p=0.004) domains (Table 3).

Mothers experienced more difficulties than fathers in physical care (23.4% vs 21.7%;  $p < 0.03$ ), health (27.9% vs 19.7%;  $p < 0.02$ ), career (28.1% vs 34.3%;  $p < 0.03$ ), sibling effect (24.0% vs 21.5%;  $p < 0.04$ ) and specific thoughts domain (33.4% vs 30.5%;  $p < 0.04$ ). Fathers experienced more trouble in support (26.1% vs 18.6%;  $p < 0.02$ ), financial (30.0% vs 22.8%;  $p < 0.03$ ), social (35.3% vs 25.1%;  $p < 0.01$ ), embarrassment/ridicule domains (63.5% vs 34.3%;  $p < 0.02$ ). There was no difference in Relationship domain (29.5% vs 30.1%;  $p = 0.56$ ) in between the parents.

**Table 2 : Age distribution of intellectually disabled children.**

Age	Mild ID	Moderate ID	Severe ID	Total
0-3 yrs	3 (6.6%)	4 (9.8%)	1 (6.7%)	8 (7.1%)
3-6 yrs	25 (55.5%)	17 (41.5%)	5 (31.1%)	47 (46.8%)
6-18 yrs	12 (26.7%)	14 (34.1%)	5 (31.1%)	31 (30.4%)
>18 yrs	5 (11.2%)	6 (14.6%)	5 (31.1%)	16 (15.7%)

**Table 3 : Rural-Urban comparison of parents with intellectually disabled children (Modified adjustment inventory)**

Variables	Groups	N=102	Mean	SD	Students t test	p
Family adjustment	Rural	68	58.44	10.52	-1.014	0.64
	Urban	34	31.65	7.12		
Emotional adjustment	Rural	68	59.21	9.59	1.006	0.38
	Urban	34	29.81	6.24		
Health adjustment	Rural	68	57.12	12.42	-1.842	0.04*
	Urban	34	28.24	9.78	2.141	0.02*
Social adjustment	Rural	68	54.82	14.74		
	Urban	34	24.72	12.71		
Parental adjustment	Rural	68	84.72	21.56	-3.798	0.004**
	Urban	34	52.78	18.76		

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Higher patience ( $p<0.02$ ) and empathy ( $p<0.04$ ) among mothers and higher tolerance ( $p<0.03$ ) and sensitivity ( $p<0.04$ ) was found among fathers. The impact on mother increased in physical care, health

and specific thoughts domains whereas the impact on father increased in financial and embarrassment/ridicule domains in successive assessments (Table 4).

**Table 4 : Domain wise scoring of NIMH-DIS scale in parents of intellectually disabled children**

Areas	Maximum	Obtained Score	Percentage (%)			
	score	Father Mother	Father		Mother	P value
Physical care	1430	310	334	21.7%	23.4%	0.03
Health	1040	205	291	19.7%	27.9%	0.02
Career	910	256	312	28.1%	34.3%	0.03
Support	1170	305	218	26.1%	18.6%	0.02
Financial	1040	312	237	30.0%	22.8%	0.03
Social	780	275	196	35.3%	25.1 %	0.01
Embarrassment/Ridicule	910	312	198	34.3%	63.5%	0.02
Relationship	1170	345	352	29.5%	30.1%	0.56
Sibling effect	1300	279	312	21.5%	24.0%	0.04
Specific thoughts	910	278	304	30.5%	33.4%	0.04
Total negative thoughts	10660	2877	2754	26.9%	25.8%	0.65
Positive impact	1170	534	532	45.6%	45.5%	0.57

## DISCUSSIONS

The parents of intellectually disabled children experienced more positive impact than negative impact due to changes in life style, standard of living, changes & means of recreation & leisure activities and perception of family members towards disabled child.<sup>10</sup>

Positive impact inversely correlated to behavioural problems.<sup>11</sup> Latino mothers score better than Anglo mothers in respect to positive impact on children having ID. Indian mothers score more in positive impact (55.38%) than negative impact (26.26%). Mothers spent more time, offered more types of support & perceived more caregivers burden.<sup>12, 13</sup> Parents usually take pride in their

children's achievements but are easily hurt by their children's failures.

The challenges faced by aging parents of adults with mental disability are plenty. External service agencies that aim to cater to the needs of persons with mental disability only, don't serve the purpose. Services that pay equal attention to the needs of the parents are essential. Social Workers and other professionals, while considering the well-being of the disabled, need to consider the well-being of the parents of disabled too.

Two changes have made enormous impact in caregiving for intellectual disabled. They are increased longevity and paradigm shift from

institutional caregiving to home caregiving.<sup>14, 15</sup> The core themes of positive impact are source & joy of happiness, increased sense of purpose, expanded social & personal networks, community involvement, increased spirituality, source of family unity & closeness, increased tolerance & understanding, personal growth & strength and positive impact on others/community.<sup>16, 17, 18</sup>

## SUMMARY & CONCLUSIONS

The rehabilitation needs increase with severity of disability and impact on parents as caregivers. Appropriate assessment and finding out unmet needs can guide to formulate individualized treatment plan for them as well as to their parents. The implications of present study is that by assessment of burden with available social support, appropriate strategy and intervention can be formulated which will help in counselling the parents and thus will reduce the burden of caregivers of intellectually disabled children. 19 This will help the parents to accept children as they are. They may not unnecessarily reject, punish, and show hostility towards their children. Majority of studies on parenting stress and family burden associated with raising a disabled child have focused on mothers.

Mothers face more stress as compared to fathers because mothers bear disproportionate share of responsibilities in raising their disabled child. Parenting with intellectually disabled children is not an easy job. Parents or other caregivers can be affected by many ways by having children with intellectual disability.<sup>20</sup>

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The skills training to the caregivers can help them to deal effectively with the person with ID. It will also

help to improve the quality of life, and take positive steps to handle the children more constructively. The limitations of present study are first only modest sample size (n=102). Majority of sample are from the urban background. A longitudinal study with more subjects is required to corroborate the findings of the present study.

Despite these shortcomings present study explores new dimensions in parental burden with caregiving for children having intellectual disability. A community based study is required with liaison between interdisciplinary team (Psychiatrists, Paediatrician etc) with other mental health care professionals (Clinical psychologist, Special educator, Speech & language therapists etc) which could be a cost-effective measure.

**Conflicts of interest : none**

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