

## Anxiety among Parents of Individuals with Intellectual Disability

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### ABSTRACT

*Background:* Parents having child with intellectual disability experiences its impact on their psychology and may develop anxiety. *Objective:* To find out the anxiety among parents of Individuals with Intellectual Disability (IwID) with respect to their age, educational qualification and socio economic status and with respect to gender, and age of their wards. *Sample:* 100 parents of IwID falling in inclusion criteria, whose wards were studying at Government Rehabilitation Institute for Intellectual Disabilities (GRIID), Chandigarh, were selected, following simple random sampling technique. *Design:* Cross sectional survey research design was used to assess the anxiety among parents of IwID. *Tool:* Comprehensive Anxiety Test' (CA-Test) developed by Sharma, Bharadwaj and Bhargava, published by National Psychological Corporation- Agra, was used to assess the level of anxiety among parents. *Results:* Among selected 100 parents, only 82 responded to investigators positively. The results showed that 6.67% mothers had very high level of anxiety, 51.12% mothers had high, 26.67% had average, 11.12% had low and 4.45% had very low level of anxiety whereas in the case of fathers, 2.71% had very high, 5.41% had high, 40.55%, average, 43.25% low and 8.11%. very low level of anxiety. Mothers of IwID found to have more stress when compared with fathers. Aged parents of IwID have very remarkably higher level of stress when compared with younger parents. No significant difference in the level of anxiety was been found with reference to educational qualification. Parents who were earning less significantly have more anxiety than those who are earning more. Parents of females with intellectual disability significantly have more anxiety when compared with parents of males with intellectual disability. No significant difference among parents of IwID was found with reference to age of their wards. *Conclusion:* Study concluded that most of the parents of IwID tend to develop high level of anxiety due to insufficient support from the family and community, and the anxiety related to child's indeterminate future, which have not only an adverse effect on their own life but the lives of their kids and other family members too. It is suggested that there should be provision of stress management interventions program to enable parents to cope up with the adverse conditions and negative pattern of their thoughts.

**Keywords:** Anxiety, intellectual disability, parents

### INTRODUCTION

Disability is a multidimensional concept that has been defined and conceptualized in various ways, including from medical, socio-political, economic and administrative perspectives. The traditional perspective of disability is the medical model, which infers that a disability is a deficit or some sort of damage within a person's body that complicates the performance of activities.

Intellectual disability is a disability that occurs before age 18. People with this disability experience significant limitations in two main areas: intellectual functioning and adaptive behavior. These limitations are expressed in the person's conceptual, social and practical everyday living skills. Majority of persons with intellectual disability are mildly disabled. IwID who are provided appropriate individualized support and training over a sustained period generally have improved life outcomes

(AAIDD, 2011). In fact, many adults with intellectual disabilities can live independently in the community with support from family, friends, professionals and agencies working in this area.

Parents always plan for a perfect, healthy and normal child. They never expect or think about children with any kind of abnormality or disability. But if they meet with such situation in their lives, usually seen many emotional problems i.e., grief, loss, disbelief, guilt, rejection, helplessness, denial, shame, anxiety, anger and depression for a long period. Parents play a very significant and important role in one's life and they are real well wishers, care takers and custodians of the interest of their children. Parents understanding, love, care and affection are essential for the proper health, growth and development of the child. They can help in various ways for the welfare, care, as well as treatment of their children. Most of the parents appear to be anxious to learn about their children in the habilitation and rehabilitation process. Parents undoubtedly have the greatest emotional and intellectual investment in their own children development, problems and future.

All of us have many dreams and whenever a person loses his dream, it brings major changes in one's personality and in his/her physical and emotional environment. Parents have many dreams about their children and when a child with disability born, parents go through dramatic emotional changes; a state of grieving that puts an effect on parent's health, attitude, personality, priority, values and beliefs, and also their routine activities. It is commonly observed that if one child is disabled in family, parents usually suffer with different emotional and psychological problems. The reasons of parental depression, anxiety and stress were explained by Feather (1980) i.e., "society considers parenting as a positive thing, but it views the birth of a disabled child negatively. This attitude by society may produces stress and anxiety among family members. Marital relationship may also suffer excessively due to the stresses of guilt, shame, blame and anxiety. Further parental anxiety or stress negatively affects child development".

Everyone feels anxiety from time to time. Few people get through a week without some anxious symptoms with a feeling that something is not going well. Everyday anxiety is generally occasional, mild and brief, while the anxiety felt by the person with an anxiety disorder occurs frequently, is more intense, and lasts longer up to hours, or even days. Unfortunately, anxiety is commonly seen in people having children with intellectual disability. Occasional anxiety is a normal part of life. Anxiety disorders involve more than temporary worry or fear. For a person with an anxiety disorder, the anxiety does not go away and can get worse over time. The feelings can interfere with daily activities such as job performance, school work, and relationships. There are several different types of anxiety disorders. Examples include generalized anxiety disorder, panic disorder, and social anxiety disorder. Anxiety disorders are among the most common mental, emotional, and behavioral problems (Kessler et al., 2008).

"Anxiety is a subjective feeling of unease, discomfort, apprehension or fearful concern accompanied by a host of autonomic and somatic manifestations. Anxiety is a normal, emotional, reasonable and expected response to real or potential danger. However, if the symptoms of anxiety are prolonged, irrational, disproportionate and/or severe; occur in the absence of stressful events or stimuli; or interfere with everyday activities, then, these are called Anxiety Disorders" (DSM IV- 2000).

#### **NEED AND SIGNIFICANCE**

Parents are the very important persons in any individual's life and are concerned for their children more than anyone else. They get stressed and become anxious even due to the smallest problems of their children. Having a child with intellectual disability can be a more stressful condition for parents, which might cause the problem of anxiety and affect their daily life and life of their wards too. Studies show that parents who have children with disabilities are more stressed, depressed or anxious than the parents who don't have such children. These conditions create problems in leading a healthy daily life for both parents and children with intellectual disability themselves. In this study investigators tried to find out anxiety among parents of IwID.

## OBJECTIVES

- To find out the anxiety among parents (mothers and fathers) of individuals with intellectual disability.
- To find out the anxiety among parents of individuals with intellectual disability with respect to gender, age, educational qualification and socio economic status.
- To find out the anxiety among parents of individuals with intellectual disability with respect to gender, and age of their wards.

## METHOD

### Sample:

Investigators selected 100 parents of IwID who were falling in inclusion criteria on the basis of their willingness and whose wards were studying at GRIID, Chandigarh. Simple random sampling technique was used for selection of subjects. Among those selected parents, only 82 responded to the investigators positively.

### Inclusion Criteria:

- Parents of individuals having IQ below 70, diagnosed by trained and certified clinical psychologist.
- Parents of individuals with intellectual disability of any age group
- Parents whose wards with intellectual disability have various severity level (mild, moderate, severe and profound).
- Parents whose wards with intellectual disability were studying at GRIID, Chandigarh.
- Parents of age ranging 18-50 years.

### Exclusion Criteria:

- Parents whose wards with intellectual disability have any associated disability.
- Parents who have undergone (in past 2 years) or undergoing any kind of stress/anxiety management course(s).
- Parents who were single.
- Parents with mental illness.

### Design:

Cross sectional survey research design was used to assess the anxiety among parents of individuals with intellectual disability.

### Tool:

The investigators used 'Comprehensive Anxiety Test' (CA-Test) developed by Sharma, Bharadwaj and Bhargava, published by National Psychological Corporation Agra, to assess anxiety among parents of IwID. The test has 90 items relating to the symptoms of the anxiety, a reliable and valid instrument to assess manifest anxiety. It is meant for 18 to 50 years males and females. It takes about 15 minutes to complete the test.

### Procedure:

Subjects were selected with the prior permission of GRIID administration. Investigators obtained the list of parents, who fulfills the inclusion and exclusion criteria. Investigators met the parents and explained the purpose and objectives of the study. They have also been ensured about confidentiality of information and data and written consent was obtained. Tool was administered and the participants were thanked for their active participation.

## RESULTS

The values of skewness and kurtosis in the entire variables lies in  $\pm 2$ , shows that the distribution of scores was normal. The percentage of parents at various levels anxiety and t-test was used to find out anxiety among parents of IwID with respect to gender, age, educational qualification, socio economic status; gender and age of their wards.

Table 1 depicts comparative level of anxiety among mothers, fathers and overall parents of IwID in term of very high, high, Average, low and very low as per 'Comprehensive Anxiety Test' (CA-Test), where anxiety has been measured at these 5 levels.

Most of mothers i.e. 51.12% had high level of anxiety, whereas 6.67% mother had very high level of anxiety. Among 26.67% mothers, level of anxiety was average and 11.12% mother had low level of anxiety. Only 4.45% mothers had very low level of anxiety.

Table 1:  
Severity level of anxiety among mothers, fathers and overall (parents)

Score	Very high	High	Average	Low	Very low	Total
Mother	3(6.67%)	23(51.12%)	12(26.67%)	5(11.12%)	2(4.45%)	45(54.88%)
Father	1(2.71%)	2(5.41%)	15(40.55%)	16(43.25%)	3(8.11%)	37(45.13%)
Overall (Parents)	4(4.88%)	25(30.49%)	27(32.93%)	21(25.61%)	5(6.10%)	82

Whereas unlike mothers, most of the fathers i.e., 43.25% had low level of anxiety, 40.55% had average anxiety and 8.11% had very low level of anxiety. In case of fathers only 5.41% had high and 2.71% had very high level of anxiety.

In overall parents of them had average level of anxiety i.e., 32.93%, whereas 30.49% had high level of anxiety. 25.61% parents had low level of anxiety, 6.1% had very low level of anxiety and only 4.88% parents of IwID had very high level of anxiety.

Table no. 2 shows that the mean scores of anxiety of the mothers was 42.80 which was more than the mean score of anxiety of fathers which was 34.59. with the difference of 8.21. The t-test was applied to find out whether there is difference in anxiety among parents of IwID, with reference to gender, a significant difference of 8.21 ( $t=2.747, p<0.01$ ) was there for the difference in mean score of mother and father. It reveals that, mothers of IwID have very significantly higher level of anxiety when compared with fathers.

It can be seen that mean score for anxiety among parents of IwID was 30.52 for those having age below 35 and 41.68 for those with age above 35, with difference of 11.16 For anxiety among parents of IwID, with reference to their age, t-test was applied and a significant difference of 11.16 ( $t=3.217, p<0.01$ ) was there for the difference in mean score of age below and above 35. It clearly shows that, aged parents of IwID have very notably higher level of anxiety when compared with younger parents.

Table: No. 2 clearly depicts that mean score for anxiety

among parents having educational qualification up to 10th grade was 39.27, whereas for parents with educational qualification 12th grade and above mean score was 38.97 with a minimal difference of 0.24. Further t-test was applied to find out the level of anxiety among parents of IwID with reference of educational qualification. Result reveals that no significant difference in the level of anxiety was noted with reference of educational qualification of parents ( $t=3.217, p>0.05$ ). This explanation clearly shows that educational qualification does not play a significant role in determining the level of anxiety.

Mean score of anxiety among parents of IwID, whose monthly family income was less than Rs. 20,000 was 42.69 and for those whose monthly family income was more than Rs. 20,000, mean score was 35.32, with difference of 7.37. Further, t-test was applied to find anxiety among parents of IwID, with reference to socio economic status, and a significant difference of 7.37 ( $t=3.217, p<0.05$ ) was found. It evidently indicates that, parents who are earning less have more anxiety than those who are earning more.

The mean score of anxiety of parents of IwID was 36.02 for those whose wards with ID were male and it was 42.17 for those whose wards with ID were female, with a difference of 6.15. The t-test was calculated to find anxiety among parents of IwID, with reference to gender of their wards with ID, and clearly shows that a significant difference of 6.15 ( $t=3.217, p<0.05$ ). It markedly points that, parents of females with intellectual disability have more anxiety when compared with parents of males with intellectual disability.

Table No. 2:

Difference in anxiety among mothers and fathers of individuals with intellectual disability

Variables		N	Mean	SD	Difference in Mean	t-value	p-value
Gender of Parents	Mother	45	42.80	15.92	8.21	2.747	.007**
	Father	37	34.59	9.63			
Age of Parents	Below 35	19	30.52	8.10	11.16	3.217	.002**
	Above 35	63	41.68	14.40			
Educational Qualification	Upto 10	41	39.21	15.06	0.24	.078	.938 NS
	12th & Above	41	38.97	13.02			
Socio economic status	<20000	42	42.69	15.11	7.37	2.455	.016*
	>20000	40	35.32	11.75			
Gender of their wards	Male	41	36.02	11.44	6.15	2.026	.046*
	Female	41	42.17	15.69			
Age of their wards	<20	62	34.95	12.69	5.48	1.537	.128 NS
	>20	20	40.43	14.22			

\*Significant at 0.05 level, \*\*Significant at 0.01 level

In the table 2, it can be seen that mean scores of anxiety among parents whose wards with intellectual disability were more than 20 years was 40.43, whereas the mean score for those whose wards with ID have age below 20 years was 34.95 with mean difference of 5.48. The t-test was calculated to find out anxiety among parents of IwID, with reference to age of their wards with ID, and no significant difference was found for the anxiety among parents when compared with reference to age of their wards ( $t=3.217, p>0.05$ ).

## DISCUSSION

Result shows that 30.49% parents of IwID had high, 32.93% had average and 25.61% have low level of anxiety. 6.1% had very low and 4.88% parents of IwID had very high level of anxiety. Further, it has been found that 51.41% mother fallen in the category of high anxiety level and 11.12% have lower anxiety, whereas

43.25% fathers had low anxiety and 5.61% fathers were found to have high anxiety level, very clearly proves that mothers had more anxious when compared with father.

A significant difference was found on anxiety among parents of IwID, with reference to gender and age, at 0.01 level. Mothers of IwID shown very significantly higher level of anxiety when compared with fathers and aged parents of IwID have remarkably higher level of anxiety when compared with younger parents. No significant difference in the level of anxiety was found, with reference to educational qualification. Parents who were earning less have significantly more anxiety than those who are earning more, at 0.05 level. Parents of females with intellectual disability have significantly more anxiety when compared with parents of males with intellectual disability at 0.05 level. No significant

difference in anxiety among parents of IwID was found with reference to age of their wards.

The result of present study has been supported by couple of studies. The study conducted by Kaur & Pandit (2014) on 120 mothers and 120 fathers of 60 boys and 60 girls reported greater depression and anxiety among mothers as compared to the fathers. Kalgotra & Warwal (2016) indicated that the “mothers of children with severe intellectual disabilities experience more stress, when compared to fathers. Chouhan, Singh & Kumar (2016) found that parents of IwID experience more anxiety symptoms, especially mothers, than the parents of regular children and the levels of depressive symptoms also found to be significantly higher among parents of IwID, particularly, in mothers. Singh & Panday (2015) noted high level of anxiety among mothers than the fathers of children with intellectual disability. Azeem et al., (2013) revealed that, parents of children with intellectual disability were found to have diagnosis of anxiety, depression or both. The diagnosis of anxiety, depression or both among mothers was associated with the severity of disability in their children.

Another study conducted by Aldosari & Pufpaff (2014) indicates higher perceived stress levels in Saudi mothers compared to fathers regarding the overall parent-child relationship, the child's individual characteristics, and the parent's characteristics. Saudi mothers of children with ID also had significantly higher levels of stress compared to fathers in relation to the adaptability subscale of the Parent Stress Index (PSI).

Ramzan & Minhas (2014) highlights that mothers raising child with disability experience more anxiety and depression than mothers of non-disabled children. The prevalence of anxiety and depression among mothers having children with disabilities was found 78% and 76% respectively. Mother education, family income and age of the child were inversely related to mothers' anxiety and depression. Study also reports that mothers age positively related with anxiety and depression which supports the findings of present study.

Pocinho & Fernandes (2018) studied the depression,

stress and anxiety among parents of sons with disabilities. The findings the study suggest that Parents having children with disabilities showed higher levels of anxiety, depression and stress than the other parents. Further, added that levels of anxiety, depression and stress are associated with the age of their children (higher levels associated to older ages) and negatively with parent's education level (higher levels associated to lower education). The finding of present study goes in similar way, when mean scores compared for age of the wards and educational qualification of parent was compared, mean score for the stress of less educated parents and parents of wards with aged intellectual disability was high, but this difference was found no significant.

Uskun & Gundogar (2010) says that financial constraints are one of the major factors that affect the psychology of the parents of children with disabilities. Further, suggests that there should be a provision of social supports system which can help needy parents to pertaining to financial as well as home care needs. Akturk & Aylaz (2017) identified the difference between age, marital status, economic condition, education of the parents who have children with disability. Jaiswal, Subramanyam, Shah & Kamath, (2018) found depression is the most common psychopathology can be seen among parents of children with intellectual disability especially among mothers.

The study conducted by Rezendes & Scarpa (2011) on parents of children with autism spectrum disorders (ASDs) reveals that stress, depression, and anxiety are associated with child behavior problems. Another study was conducted by Solomon (2015) suggests that children with intellectual disability also need love, encouragement, and support. The children in their home feel depressed, anxious and stressed. Further, the result of the study conducted on 86 parents reveals that anxiety is found to be higher, which may be because the parents tend to be worried more about their children's future.

Kermanshahi et al (2008) emphasized on challenging the process of acceptance, painful emotional reactions, the interrelatedness of mother's health and child's well-

being, struggles to deal with oneself or the child, inadequate support from the family and the community, and the anxiety related to child's uncertain future. Ritzema & Sladeczek (2011) submits that there is a wide range of research advocates that there is an association between parent stress and child development in families of children with developmental disabilities.

## CONCLUSION

Parents of IwID may experience more daily parenting stress and depression than parents of regular children. More the stress, more is chances of depression. Lower the income of parent higher the stress and higher the age of parents, higher the stress. The stress and depression are found to be more among mothers than the fathers. Due to greater involvement in looking after daily needs of children with intellectual disability mothers experience greater stress as compared to fathers.

Result of the present study found high anxiety among parents of IwID; especially mothers. Aged and low earning parents have more anxiety. Parents of daughters with intellectual disability have more anxiety when compared with parents of sons. Disability is a condition which affects not just the individual who has it but a greater impact is seen in the lives of others related people. It is evident from the above study that the parents of IwID may suffer from anxiety lead depression and other psychological problems. This may hinder their health and affect the whole family. The current study supports the idea that there is mutual interaction between child characteristics and parent stress. Findings also suggests that there should be a provision of family-based interventions focusing on the challenging behaviours of children with developmental disabilities. There is a need to design intervention programs which can help such parents to cope up with their psychological states thus, promoting mental health and psychological well being of parents such parents having children with disabilities (Pocinho & Fernandes, 2018).

Therefore, there is a need to extend the researches for anxiety management of the parents of IwID. It will help the parents to accept their IwID in positive way and have a better life.

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