



# REVIEW ON ANXIETY AMONG PARENTS OF INDIVIDUALS WITH INTELLECTUAL DISABILITY

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**ABSTRACT:** Anxiety is distinguished by a variety of somatic and autonomic symptoms, as well as a subjective sense of unease, discomfort, apprehension, or anxious concern. Anxiety is a common, emotional, reasonable, and expected response to risk, whether real or imagined. Parents have a lot of hopes for their children. When a family has a disabled kid, the parents often endure a variety of emotional and psychological challenges. This social mindset promotes conflict among family members, and marital relationships may deteriorate as a result of the strains of guilt, shame, blame, and blame-shifting. There is a need to think more carefully about the importance of establishing intervention programs that focus on the development of coping techniques to prevent or reduce parental anxiety, depression, and stress. This form of intervention is critical in preparing families to cope with these adversities, thereby improving the mental health and psychological well-being of parents and challenged children.

**Keyword :-** Anxiety, intellectual disability, parents

## I. INTRODUCTION

**1.1 Intellectual Disability:** Intellectual disability is a condition marked by severe impairments in cognitive functioning as well as adaptive behavior as shown by conceptual, social, and practical adaptive skills. (AAIDD, 2010)

Everybody experiences anxiety occasionally. Few people can get through a week without feeling a little apprehensive or as though things are not going to go according to plan. While anxiety experienced on a daily basis is often infrequent, mild, and short-lived, anxiety experienced by a person with an anxiety disorder is more frequent, more intense, and can persist for hours or even days.

Unfortunately anxiety is a condition that many people experience. It's common to have uneasiness every now and then. There is more to anxiety disorders than just passing apprehension or terror. Anxiety does not go away and can worsen over time for someone with an anxiety condition. The emotions can affect daily tasks like work performance, academic progress, and interpersonal relationships. Anxiety disorders come in a variety of forms. Generalized anxiety disorder, panic disorder, and social anxiety disorder are a few examples. According to Kessler et al. (2008), anxiety disorders are among the most prevalent mental, emotional, and behavioral issues.

Anxiety is characterized by a wide range of physical and autonomic signs as well as a subjective experience of unease, discomfort, apprehension, or worried concern. Anxiety is a typical, emotional, rational, and expected reaction to danger, whether it is actual or imagined. However, anxiety disorders are referred to as such if the symptoms are protracted, illogical, excessive, and/or severe; occur without the presence of stressful situations or stimuli; or impair daily activities (DSM IV-TR, 2000).

## 1.2 PARENTS OF INDIVIDUALS WITH INTELLECTUAL DISABILITY:-

We all have a variety of aspirations, and once someone loses one, their environment and personality undergo significant changes. When a crippled child is born, parents experience major changes; this condition of grief has an impact on the parents' health, attitude, personality, priorities, values, and beliefs, as well as their daily activities. Parents have many dreams for their children. It is a well-known fact that when a family has a disabled child, the parents typically experience a variety of emotional and psychological issues. (Feather, S. H., 1980) addressed the causes of parental sadness, anxiety, and stress by pointing out that while society values parenthood, it sees the birth of a crippled child adversely. This societal mindset causes tension among family members, and marital relationships may suffer as a result of the strains of guilt, shame, blame, and worry.

## II. REVIEW OF LITERATURE

**Kaur, J., et al., (2019)** conducted a study on 100 parents with intellectual disability falling in inclusion on anxiety from a special school Government Rehabilitation Institute for Intellectual Disabilities, Sector- 31 C, and Chandigarh. Among those selected parents, only 82 responded to investigator positively i.e., parents of individuals with intellectual disability with any severity level of age group below and above 18 years, random sampling technique. Standardized tools namely 'Comprehensive Anxiety Test' (CA-Test) were used to assess the level of anxiety among parents. The results showed that total level of father anxiety was found to be 45.13% which is very low as compared to mother. Overall total anxiety was found to be 82% among parent shows average level of anxiety. Mothers show high level of anxiety in children with intellectual disability.

**Azeem, M.W., et al., (2013)** conducted a cross-sectional study which is approved by the Institutional Research Committee conducted at a tertiary care hospital in Pakistan and assess the level of psychopathology i.e. anxiety, depression and both anxiety and depression together among parents i.e. 198 parents (99 fathers/99 mothers) of 100 children, aged 2-18 years with the diagnosis of children with intellectual disability (ID) by using DSM IV criteria. Significantly high proportion of mothers 89% (35%, 40% and 13%) had anxiety, depression, or both anxiety and depression together as compared to fathers 77% (42%, 31% and 3%). A significant association was also found between mother's anxiety, depression or both and degree of ID of their children.

**Bitsika, V., and Sharpley, C.F., (2004)** evaluate sample of 107 Gold Coast parents completed a questionnaire that assessed their demographic backgrounds, anxiety and depression scores on standardized inventories, and also tapped several aspects of those factors. Over 90% of parents reported that they were sometimes unable to deal effectively with their child's behaviour. Nearly half of the participants were severely anxious and nearly two thirds were clinically depressed. Factors that emerged as significant in differentiating between parents with high versus low levels of anxiety and depression included access to family support, parents' estimation of family caregivers' expertise in dealing with the behavioural difficulties of a child with ASD, and parental health.

**Tabassum, R., and Mohsin, N., (2015)** studied the relationship between depression and anxiety among parents of children with disabilities by Pearson Product moment correlation method and compare the parent's depression and anxiety with the type of disability among children by using sample t-test. Purposive sampling technique to select the sample that comprised of 80 parents among which 58.12% were mothers and 41.875% were fathers having one or more disabled children with the age range of 4-18 years. In that Depression, Anxiety and Stress Scale, DASS (Lovibond & Lovibond, 1995) with 42 items was used. The results of this study showed that a highly significant positive correlation was found between depression and anxiety. A significant difference was found on depression subscale of DASS among parents with disabled boys than disabled girls.

**Sharpley, C.F., et al., (2009)** carried out a survey of 219 parents of children with autism was administered on a confidential and anonymous basis. As well as tapping information about the nature of the child's disorder, parental well-being (anxiety, depression), parents daily level of stress arising from parenting, their confidence in handling their child's major difficulty, Data indicated that, although social support has previously been

posited as an alleviating factor for parental stress, this may be a result of the perceived expertise of the family member who provides respite care for the parents.

**Kalgotra, R., and Warwal, J.S., (2016)** evaluated sample of the intellectually disabled children from the special schools of Jammu district of J&K state. Total of 60 children were selected and were categorized as groups as X, Y and Z. each group have 40 parents (20 mothers and 20 fathers) with severe, mild or borderline and healthy intellectual disabled children The results indicated that the mothers (as compared to fathers) of group X experiences more stress than group Y and Z. There exists the positive correlation between levels of anxiety and perceived stress. (HARS and FISC scores) among mothers and fathers in the groups X, Y and Z.

**Majumdar, M., et al., (2005):-** conducted a study in the Child Guidance Clinic of a tertiary care psychiatry hospital to comparing the stress perceived by parents of mentally retarded and normal children are limited. The study sample, comprising 180 subjects in group A (60 parents of profound to moderately mentally retarded children), group B (60 parents of mild to borderline mentally retarded children) and group C (60 parents of children with normal intelligence), which served as the control group. Each parent was evaluated using the Family Interview for Stress and Coping (FISC) in Mental Retardation, and the Hamilton Anxiety Rating Scale (HARS). Parents in group A had a significantly higher frequency of stressors and level of anxiety as compared to those in groups B and C. A positive correlation was found between the level of anxiety and stressors.

**Karande, S., et al., (2009)** conducted a study on one hundred mothers of children (70 boys, 30 girls) with specific learning disability were interviewed using the Hamilton to measure the levels of anxiety and find out the cause of anxiety in mothers of children with specific learning disability. Levels of anxiety were absent in 24%, mild in 75%, and moderate in 1% of mothers. Their mean total anxiety score was 5.65, mean psychic anxiety score was 3.92 and mean somatic anxiety score was 1.76. Most mothers of children with specific learning disability have already developed mild anxiety levels by the time this hidden disability is diagnosed. These anxieties should be addressed by counseling to ensure optimum rehabilitation of these children.

**Ramzan, N., and Minhas, K., (2014)** conducted a comparative study to find differences in the level of anxiety and depression in both groups of mothers i.e. among mothers of disabled and non-disabled children in district Sheikhpura. A convenient sampling technique was used to select 340 mothers belonging to both groups (n = 170 in each group). Anxiety and Depression Scale (HADS) was used to assess anxiety and depression in mothers. Data was analyzed using ANCOVA (SPSS version 17) which revealed statistically significant differences in the level of anxiety and depression in both groups of mothers. As the disabled child advances in age, mother better understands the demands of raising a disabled child and thus can cope with these demands affectively and with lesser anxiety.

**Daniel, M., (2015)** reported that all children need love, encouragement, and support and especially the differently able children when the parent have a differentially able children in their home they fell depressed, anxious and stress. This study like bring out the highlights in these areas. The standard scale was used to assess the depression, anxiety and stress (DASS 42) Lovibond and lovibond (1995) and researcher intended to study the level of depression, anxiety and stress which is experienced by 86 parents of children with differently able children and the findings reveals that among Depression, Anxiety and stress, the number of parents experiencing anxiety is found to be high, which may be because the parents tend to be worried more about their children's future.

**Kaur, J., and Pandit, N., (2014)** conducted a study on 120 mothers and 120 fathers of 60 boys and 60 girls in the age group of 5-14 years, randomly selected from the special schools of Chandigarh. Standardized tools namely Beck depression inventory (1996) and Sinha's Comprehensive Anxiety test (1995) were used. The results showed that mothers reported greater Depression i.e. minimal (40%), moderate (33%) and mild depression (20%). Only 7% respondents reported severe depression and Anxiety i.e. high (29%), low (17.5%) and extremely high anxiety (11.5%). Extremely low anxiety was reported by only 7% parents as compared to the fathers. Depression was greater among parents of children with physical impairment but Anxiety was greater in parents of children with visual impairment.

**Bumin, G., et al., (2008)** performed a study in three rehabilitation centers in Ankara with One hundred and seven disabled children's mothers. Beck Depression Inventory (BDI), State Trait Anxiety Inventory (STAI) and Nottingham Health Profile's Part -1 (NHP) were used to assess depression, anxiety and quality of life of mothers. The assessments were performed during children's treatment in rehabilitation centers and study indicated that mothers with disabled children have anxiety and depression. Increased depression and anxiety level affected with badly in mother's quality of life.

**Dave, D., et al., (2014)** conducted a study at the Outpatient Department (OPD) Of Psychiatry, Govt. Hospital, Jamnagar, and Gujarat. Parents fulfilling inclusion and exclusion criteria consenting for the study were selected and Zung's self-rating anxiety and depression scale was used. Prevalence of anxiety was 57% and depression was 63%. Earning status and Type of family has been significantly associated with high anxiety score and other socio-demographic variables i.e. Gender, Religion, Education and marital status were not associated with high anxiety score among caregivers. Out of all socio-demographic variables only age of caregiver was significantly associated with high depression score.

**Chouhan, S. C., et al., (2016)** carried out a study at outpatient department (OPD) of Psychiatric Centre, S.M.S. Medical College Jaipur with the specific aims to assess and compare daily parenting stress and anxiety among parents of children with intellectual disability. According to Intelligence Quotient (IQ) of children, three groups were created: Group A (30 parents of moderate to profound MR children), group B (30 parents of mild to borderline MR children) and control group C (30 parents of children normal intelligence). IQ of the children was assessed by trained clinical psychologist and diagnosis was made as per ICD-10 criteria. data was analyzed that Parents in group A had significantly higher level of daily parenting stress and anxiety than groups B and C, group B parents had higher level of anxiety and daily parenting stress than group C. Mothers experienced greater anxiety and daily parenting stress compared to fathers.

**Merkaj, V., et al., (2013)** conducted a quantitative research, the questionnaire used in this study is DASS 42 (Depression, Anxiety, Stress, Scale 42, Lovibond 1995), the sample was taken to compare the symptoms of stress, depression and anxiety between parent's i.e. 70 of autistic children and parents i.e. 70 of typically developing children. Parents of autistic children report more symptom of stress, depression and anxiety that parents of clinically healthy children. Mothers of children with autism show a significant difference in symptoms of stress depression, and anxiety compared with fathers of children with autism.

**Altindag, O., et al., (2007)** evaluate the depression and anxiety levels in mothers of children with Cerebral Palsy and relation with the functional limitations in their children. Patient group consisted of mothers of 52 children with cerebral palsy. Control group consisted of 67 mothers having healthy children. Sociodemographic characteristics were gathered using a sociodemographic form. Our results indicated that there is a relation between functional disability levels in children and psychological distress in their mothers.

**Almansour, M.A., et al., (2013)** evaluate the presence of depression and anxiety in parents/caregivers of autistic spectral disorder (ASD) children, and to identify associated factors that evaluation was conducted in Child Clinic at King Abdulaziz Medical City, Riyadh between July and December 2011. The study included 100 parents/caregivers, 50 cases and 50 controls. More than 50% of the control group was in the age group 26-30 years (56%), while 42% of cases were in the age group 31-35 years. Both the mean depression score and the mean anxiety score was significantly higher among cases when compared with controls. Autism is associated with burden and stress for parents/caregivers of the affected child.

**Azeem, M. W., et al., (2013)** conducted a cross-sectional study on anxiety and depression among parents of children with intellectual disability in Pakistan on sample of 198 parents (99 fathers/99 mothers) of 100 children, aged 2–18 years with the diagnosis of children with intellectual disability (ID) by using DSM IV criteria. Significantly high proportion of mothers 89% (35%, 40% and 13%) had anxiety, depression, or both anxiety and depression together as compared to fathers 77% (42%, 31% and 3%). A significant association was also found between mother's anxiety, depression or both and degree of intellectual disability of their children.

**Al-Farsi, O.A., et al., (2016)** indicated that psychological disorders of the CASD (caregivers of children with autism spectrum disorder) are marked with high levels of stress, anxiety, and depression. This finding has been attributed to the reaction of having to care for a child with neurodevelopment disorders. All indices of stress, depression, and anxiety were higher in CASD compared to other caregivers in the control group. This

study corroborates with other studies carried out in other populations that caring for children impacts the mental health status of caregivers

**Verama, R., and Sharma, S., (2011)** assess the mental health status and attend to the needs of care givers. The study was carried out in the Neurology in-patient setting in a tertiary care hospital in New Delhi. Thirty consecutive patients receiving in-patient care were included in the study. The anxiety and depression levels of these individuals were assessed using the Hospital Anxiety and Depression Scale (HADS). The female care givers had significantly higher scores on HADS-Total, HADS-Anxiety and HADS-Depression sub scales. Additionally there was a significant correlation between the number of family members with chronic illness and HADS-Anxiety sub scale scores.

**Rudolph, M., et al., (2003)** assess the prevalence of anxiety and depression in mothers of speech impaired children in hundred mothers (age  $33.4 \pm 5.3$  years, range: 22–47 years) of 100 preschool children (32 girls, 68 boys; age  $4.2 \pm 1.5$  years, range 1;3–7;7 years) with a speech impairment were investigated. Children with cochlear hearing loss, syndromes or other developmental disorders were excluded from the study. Assessed by the Hospital Anxiety and Depression Scale (HADS) 11% of the mothers of speech impaired children met criteria for depression compared to 2.5% in the control group. The prevalence in the study group was significantly higher.

**Abasiubong, F., et al., (2006)** determine the general Health Questionnaire (GHQ) score of mothers of children with learning disability. To identify sociodemographic variables and to assess anxiety and depression in them. Using structured questionnaires between March and May 2002, 106 mothers of children with learning disability in a Mentally Handicapped Home for children in Lagos, Nigeria were assessed and compared with mothers of normal healthy children in Lagos. The mean age of the subjects was  $40.0 \pm 6.6$  years. More of the subjects (26.4%) compared with mothers of normal healthy children (9.9%) had a high GHQ score and high levels of anxiety (25.5%) and depression (10.4%).

**Rezendes, D.L., and Scarpa, A., (2011)** studied that parents of children with autism spectrum disorders (ASDs) have been shown to experience increases in stress, depression, and anxiety, which are also associated with child behavior problems related to ASDs. Using a sample of 134 mothers, these potential mediators were tested. Hypotheses were supported, indicating that parenting stress mediated the relationship between child behavior problems and decreased parenting self-efficacy, and decreased parenting self-efficacy in turn partially mediated the relationship between parenting stress and increased depression/anxiety.

**Kono, K., and Mearns, J., (2013)** investigated the psychological factors that might help these parents maintain well-being; in particular Negative Mood Regulation Expectancies (NMRE). Research has shown NMRE to buffer the effects of stress: stronger NMRE are associated with less symptoms of distress, including depression and anxiety. We examined the associations of NMRE, coping, and severity of the child's ID with parental distress (somatization, depression, and anxiety) among 106 Japanese parents (mean age = 56.7 years) caring for at least one child with an ID. The age of the parent was negatively associated with parental distress, particularly anxiety. NMRE were also negatively related to distress, independent of the age of the parents.

**Pocinho, M., and Fernandes, L., (2018)** conducted a cross-sectional observational study on Depression, Stress and Anxiety among Parents of Sons or daughters with Disabilities. Data were collected at schools and at special education institutions through self-administered questionnaires. Participants were recruited according to a random stratified (by sons/daughters' age and gender) random sampling. The Depression Anxiety Stress Scale (DASS-21) was administered to both groups of parents, with the collaboration of special education teachers and school psychologists. Data were analyzed using SPSS version 21.0. Descriptive and parametric inferential statistic (t-tests and ANOVA) were performed. Effect sizes based on differences between means were also calculated. Most of the children had intellectual disabilities ( $n = 206$ ), followed by autism ( $n = 143$ ) and multi-deficiency ( $n = 52$ ). Parents with children/youth with disabilities showed higher levels of anxiety, depression and stress than the other parents. Levels of anxiety, depression and stress are associated with disabled sons/daughters' age (higher levels associated to older ages) and negatively with parent's education level (higher levels associated to lower education).

**Scherer, N., et al., (2019)** the percentages of parents at risk of moderate depression or anxiety were calculated using recognized clinical cut-off scores for each screening tool. Meta-analyses, in which pooled effect sizes of elevated depression and anxiety symptoms were calculated, were conducted across two IDD conditions, autism and cerebral palsy. Of the 5,839 unique records screened, 19 studies fulfilled the inclusion criteria. The majority of studies were conducted in high-income (n = 8, 42%) or upper-middle income countries (n = 10, 53%). Of the 19 studies, 69% focused on parents of children with cerebral palsy (n = 7, 37%) or autism (n = 6, 32%). Nearly all studies found a positive association between parenting a child with IDD and depression (n = 18, 95%) and anxiety (n = 9, 90%) symptoms. Factors associated with higher levels of depression symptoms amongst parents of children with IDD included disability severity (n = 8, 78%) and lower household income (n = 4, 80%). Approximately one third (31%) of parents of children with IDD reach the clinical cut-off score for moderate depression, compared with 7% of parents of children without IDD. 31% of parents of children with IDD reach the cut-off score for moderate anxiety, compared with 14% of parents of children without IDD. The meta-analyses demonstrated moderate effect sizes for elevated depression amongst parents of children with autism and cerebral palsy. Results show that the elevated levels of depressive symptoms amongst parents of children with IDD. Quality concerns amongst the existing literature support the need for further research, especially in low- and middle-income countries.

**Salceanu, C., and Sandu, M., (2020)** conducted a study on anxiety and depression in parents of disabled children. A comparative study was conducted on 30 adults (15 parents with disabled children and 15 parents with normal children) has been assessed with Beck Depression Inventory and with Cattell's Anxiety Questionnaire. The main objectives of the study aim to identify if there were significant differences between the two categories of parents regarding anxiety and depression, and if there were a significant statistical correlation between the two personality traits. Results indicated that higher anxiety and depression levels for parents of disabled children, and a significant correlation between the two traits.

**Aldehami, S., (2023)** investigated an online survey study on Anxiety of Parents of Children with Intellectual Disabilities in Saudi Arabian on 98 parents. The levels of anxiety about school services for their children with intellectual disabilities according to two anxiety subscales: environment and communication, as per demographic variables. The findings demonstrated that there were no statistically considerable distinctions in parental anxiousness about the school setting or information exchange based on gender, and there are also no statistically meaningful distinctions in parental anxiousness about the school setting based on parental degree of education. The results indicated that the parents who had children in higher grade levels were less anxious about their children's school environment and communication.

**Merla, S., and Naveen Kumar, S., (2021)** conducted a study on the levels of depression, stress and anxiety of parents having children with intellectual disability. A Comparative Study was conducted on 80 parents including 40 fathers and 40 mothers were randomly selected From Hyderabad, India. A DASS21 scale was administered on these samples. The result shows that there were no significant difference in Depression, Stress and Anxiety levels that mothers and fathers are subjected, Depression, Stress and Anxiety persistently existent in both female and male gender. Depression, Stress and Anxiety have an association, if one exists other two also exists in parents.

### III. CONCLUSION

Many studies have been conducted to find out the level of anxiety among parents of children with intellectual disability. In most of the literature, parents of children with intellectual disability (ID) of 2-18 years of age were assessed for level of anxiety. Results indicate that there is a need to more deeply reflect about the necessity of designing intervention programs targeting the development of coping strategies to prevent or minimize parent's anxiety, depression and stress. This type of intervention is of key importance to capacitate families to cope with these adverse conditions, thus promoting the mental health and psychological wellbeing of parents and disabled children. On the basis of literature review, we found that mothers shows high level of anxiety or depression in children with intellectual disability but there is a lack of research done on anxiety among parents of adults with intellectual disability.

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