

## Anxiety and Stress among Parents of Children with Intellectual Disability

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### ABSTRACT

**Background:** Compared to parents of children who are growing normally, parents of children with intellectual disabilities (ID) are more likely to experience distress. **Aim:** The purpose of the study is to determine anxiety and stress level among parents of children with intellectual disability and also to find significant difference in anxiety and stress levels based on demographic variables (gender, age, education, family type, occupation and economic status). **Sample and tools:** The Parent Stress Scale (Berry and Jones, 1995) – an 18 item self-report scale to measure the levels of stress experienced by parents, GAD-7 (generalized anxiety-7) – a 7 item self-report scale by Robert et al., 2006, were administered to a purposive sample of 52 parents of clients (CWID) in Hyderabad, India. The collected data was analysed using standard statistical tools such as descriptive statistics, t- test, one way ANOVA and Pearson’s correlation test. **Result:** The result indicated a significant difference in anxiety and stress levels among parents with respect to gender. Also, there is a significant positive correlation between anxiety and stress levels of parents of children with intellectual disability.

**Keywords:** Parent Stress, Generalized Anxiety, Intellectual Disability

The birth of a child is a miracle to the family, especially the parents. When a child is born disabled, the situation worsens. The parents experience a range of emotions, including rejection, remorse, rage, and isolation. Parental roles become more difficult in parenting a disabled child than normal behaviour. They have gone through numerous stages in their journey to accept and acknowledge their child's impairment. They see everything as being upside down because of societal and environmental factors. Parenting a disabled child can be extremely stressful for parents. Beckman (1992) reported higher levels of stress across all domains in parents of children with developmental disabilities. Several studies have shown that parents of disabled children experience significantly more parental stress than parents of children without impairments. Parents of children with long-term disabilities—both mental and physical—face additional challenges that lead to stress (Tew & Laurence, 1975; Breslau et al, 1982; Stein, 1988; Miller et al, 1992). This suggests that parents of disabled children view parenting as a more stressful role than parents of children without disabilities.

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### ***Intellectual disability***

Intellectual disability, also known as intellectual developmental disorder or mental retardation (in older terminology), refers to a condition characterized by limitations in intellectual functioning and adaptive behaviour. These limitations manifest during the developmental period, causing difficulties in areas such as communication, learning, self-care, and social skills. Intellectual disability varies in severity, ranging from mild to profound, and it can affect individuals differently. It is typically diagnosed through standardized assessments of intellectual and adaptive functioning. People with intellectual disabilities may require varying levels of support to lead fulfilling lives and participate in their communities.

### ***Characteristics of children with intellectual disability are as follows:***

- Developmental delay or deviance
- Gradual Response
- Lack of Orientation
- Unable to pick things up quickly
- Unable to comprehend things fast
- Lack of coordination
- Unable to make a decision
- Absence of focus
- Inability to recall
- Impairment in multiple domains
- Language and communication skills
- Evident across lifespan
- Impact on daily functioning

### **Anxiety**

Anxiety is a complex psychological condition characterized by feelings of worry, nervousness, or fear that are disproportionate to the actual threat or situation. It is a normal human emotion that everyone experiences from time to time, but for some people, it can become chronic and interfere with daily life. Anxiety disorders are a group of psychological disorders in which anxiety is excessive. Some anxiety disorders are agoraphobia, generalized anxiety disorder [GAD], social anxiety, specific phobia, PTSD [post-traumatic stress disorder] etc.

### **Generalized Anxiety Disorder (GAD)**

It is a common mental health condition characterized by persistent and excessive worry or anxiety about a wide range of everyday events or activities. This worry might have physical effects and is difficult to control.

GAD rarely occurs without a comorbid psychiatric disorder, with the patient experiencing constant worry over multiple areas of his or her life for at least 6 months (Schweizer, 1995). Managing anxiety involves a combination of strategies aimed at reducing symptoms and improving overall well-being. A few effective ways to manage generalized anxiety include relaxation techniques such as deep breathing, progressive muscle relaxation, mindfulness meditation, balanced diet, adequate sleep, challenging negative thoughts, and practising self-care.

### **Risk factors of GAD**

There are numerous risk factors such as genetic factors or biological basis (e.g., alterations in brain chemicals), traumatic and stressful experiences, learned behaviour, substance abuse, negative cognition, work related stress and neuroticism.

### **Stress**

Stress is a normal physiological reaction that happens when one experiences a perceived threat, difficulty, or demand—real or imagined. One's body is preparing to deal with a challenging scenario by going into "fight or flight" mode, depending on whether to choose to run from it or fight it off. Periodic or severe stress can have detrimental consequences on physical and mental health, even while it can occasionally be good a person—it might inspire to work harder or handle problems. There are two types of stress; 1) Acute stress, and 2) Chronic stress. Stress can be triggered by a wide range of factors, including family, work, financial problems, major life changes, relationship issues, health concerns, and traumatic events.

Healthy coping strategies for managing stress include regular exercise, relaxation techniques (such as deep breathing, meditation, or yoga), maintaining a balanced diet, getting enough sleep, setting realistic goals, time management, seeking social support, and engaging in enjoyable activities.

### ***Parent stress and anxiety in raising children with intellectual disability***

While interviewing the parents, it was reported that families of children with special needs face challenges such as lack of access to healthcare and education, financial strain, social rejection, marital disagreement, emotional breakdown and social isolation. The respondents showed physiological and psychological symptoms of distress such as high blood pressure, teary, hopeless, panic, indigestion, sleep disturbance, loneliness, loss of appetite, frequent headache, muscle tension, worry due to child's convulsions & seizures, restlessness, irritability, Further, according to studies conducted by Mash et al., (1983), and Belsky et al., (1985), parenting stress can cause marital discord and abuse and neglect of children. Further, many issues can arise in the lives of families with children with disabilities. For instance, a great deal of financial strain or stress may result from having to pay for the necessary medical expenses, special equipment for their easy access, special schools, special transportation, caretakers during parent absences, challenges in entertaining friends and family at home, sibling marriages, etc. may cause mild to severe stress and emotional disturbance in the parents of the disabled children.

In addition to external resources including support from friends, neighbours, family, professionals, the community, and government policies and programs, coping resources also include "faith in God, energy, self-determination, and perception of the situation" (Peshawaria et al, 1998). Dunst and Trivette (1990) described two types of social support systems in relation to community support. Professional services from organizations like school programs, parent education specialists, therapists, and respite-care agencies are examples of formal social supports. Informal social supports include the bonds that exist between friends, neighbours, family, and community organizations. This leads to that such studies should also focus on coping stress of parents, interventions on dealing with anxiety, emotions and anger.

## REVIEW OF LITERATURE

A cross-sectional study conducted by **Sharma et al., (2023)** on 99 parents of children and adolescents with intellectual disability. The researcher assessed anxiety and depressive symptoms in parents using Hospital Anxiety and Depression Scale (HADS). The findings include that the mothers were found to be the primary care givers and they experienced symptoms anxiety and depressive more compared to fathers.

"The impact of perceived social support on psychological distress among parents of children with developmental delay" was the study conducted by **Kumaraswamy (2023)**. The National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD), located in Chennai, Tamil Nadu, provided the study's sample of fifty parents of children (age 1 – 6 years) with developmental delays made. The instruments utilized were the Kessler Psychological Distress Scale (K10), a self-report screening tool that measures psychological distress, and the Multidimensional Scale of Perceived Social Support (MSPSS), a 13-item scale that measures perceived social support. The researcher found the psychological suffering of parents of children with developmental delays varied significantly according to the caregiver's gender. Psychological distress scores were much higher for mothers. Also, there is a relationship between perceived social support and psychological distress.

**Amruta and Lata (2023)** investigated on stress factors in children with autism spectrum disorder (ASD). Parents of children with ASD who attended special schools and therapy centers in Hubballi, Dharwad, and Bengaluru provided the data. A self-structured questionnaire and the Parenting Stress Scale by Abidin were employed. The majority of parents reported clinically significant levels of stress, according to the research's findings. Parenting stress was significantly correlated with occupation and marital status. Parenting stress was high among parents who had graduated.

**Abdi and Subodh (2022)** assessed parental support group effects on perceived stress, self-esteem of parents of children with special needs using Perceived stress scale (Cohen et al., 1983) and Rosenberg self-esteem scale (SES; Rosenberg, 1989) on 100 parents. The researchers concluded that the parents who had membership with parental support groups had better self-esteem and high perceived stress than parents without support groups.

In the Indian state of Telangana, families with children diagnosed with autism and mental retardation were surveyed once by **Clement and Sekhar (2021)** in Hyderabad Metropolitan City. The researcher looked at the mothers who had children with mental retardation and autism spectrum disorder and their stress levels. According to the study's findings, mothers are sacrificing more of their lives to meet their children's needs and fulfil their demands. They reported how having children with special needs prevented them from enjoying life, and they felt alone and friendless.

In 2020, **Ramachandran et al.** evaluated stress levels in caregivers of children with mental disabilities including attention deficit hyperactivity disorder, intellectual disability, and autism spectrum disorder. By use of the Kingston Caregiver Stress Scale, 101 people in total were evaluated. The National Institute for Empowerment of Persons with Multiple Disabilities in Chennai, Tamil Nadu, served as the site of data collecting. Majority of the caregivers had severe level of stress. The study found a statistically significant association between the caregivers' level of stress and their gender, economic situation, family type.

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**Joseph and Chacko, (2018)** conducted a study in selected special schools of Kolkata to assess parenting stress and identify related factors affecting among parents of differently abled children. Parent stress scale (PSS) by berry berry and a self- structured questionnaire to identify related factors was administered to a sample of 150 patients. The study's conclusions showed that parents, regardless of gender, dealt with both mild and severe parental stress. The study also revealed that more caregiving responsibilities, changes in social interactions, anxiety, and disruptive child behaviour were the main causes of parental stress.

**Gopiraj and Esther (2017)** determined the level of stress in parents with intellectual disabled children in Malappuram district, Kerala. 100 parents were assessed through Kindler's Personal Stress Assessment Inventory and the social demographic questionnaire. Parents showed a high level of stress. The level of stress and socio-demographic variables correlated significantly.

### **METHODOLOGY**

Aim, objectives, inclusion and exclusion criteria, hypotheses, research design, sampling method, sample size, standardized tools, and statistical analysis in the present research study are discussed here.

#### *Aim*

The present study aimed at assessing the stress and anxiety levels among parents of children with intellectual disability.

#### *Objectives of the study*

- To find out the anxiety among parents of children with intellectual disability with respect to their gender, age, education, family type, occupation and economic status in Hyderabad, India.
- To find out the stress among parents of children with children with intellectual disability with respect to their gender, age, education, family type, occupation and economic status in Hyderabad, India.
- To find out the relationship between stress and anxiety among parents of children with intellectual disability in Hyderabad, India.

#### *Hypotheses*

- **H<sub>01</sub>**: There will be no significant difference in anxiety levels among parents of children with intellectual disability based on their gender, age, education, family type, occupation, and economic status.
- **H<sub>02</sub>**: There will be no significant difference in stress level among parents of children with intellectual disability based on their gender, age, education, family type, occupation, and economic status.
- **H<sub>03</sub>**: There will be no a significant relationship between anxiety and stress among Parents of children with intellectual disability.

#### **Inclusion criteria**

- Parent of a child diagnosed by intellectual disability and associated conditions such as communication issues, ASD, attention deficit and hyperactivity disorder, learning issues.
- Either the mother or the father should be the child's primary caregiver.

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- Parents who are aged between 25 to 50 years and above.

### Exclusion criteria

- Parents with mental illness or related conditions.
- Family members other than parents (grandparents, siblings, relatives).

### Design

- Descriptive (survey) study design was used.
- Sample and sampling technique of the study
- The study population comprised of 52 parents of children with intellectual disability in Hyderabad, India. The method of sampling was purposive sampling.
- Standardized tools used
- A demographic schedule, two standardized tools were used PSS (Parent Stress Scale) and GAD-7 (Generalized Anxiety Scale).

### Demographic details

A profile prepared by the researcher to collect the demographic information of the participants was used. It includes age, gender, education, family types, occupation, and economic status.

1. **Parent Stress Scale (PSS):** In 1995, Berry and Jones developed the Parent Stress Scale (PSS) to assess parents' stress levels, an alternative to 101-item Parenting Stress Index. The 18 items on the PSS self-report scale reflect both the good (such as emotional rewards and personal growth) and bad (such as resource needs and limits) aspects of parenthood. About the average relationship that respondents have with their child or children, they either agree or disagree. Responses on a 5-point Likert scale: strongly disagree, disagree, uncertain, agree, and strongly agree. High stress levels are indicated by high scores. The reliability of the scale is 0.96.
2. **Generalized Anxiety Disorder scale (GAD):** The Generalized Anxiety Disorder Scale (GAD-7) is a widely utilized diagnostic self-report tool for anxiety disorder screening, diagnosis, and severity evaluation. Dr. Robert and colleagues created it in 2006. The seven items on the GAD-7 scale, which are categorized as "not at all," "several days," "more than half the days," and "nearly every day," respectively, measure the frequency and severity of anxiety symptoms over the previous two weeks. These items are related to nervousness, worry, and restlessness. Anxiety levels are classified as low, mild, moderate, and severe on the GAD-7, with a total score ranging from 0 to 21 for the seven items. GAD's validity and dependability are both >0.82.

### Statistical tools used

As a quantitative study, data was analysed by employing independent sample t-test, Pearson correlation, and one-way ANOVA (Analysis of variance) with the help of SPSS.

## RESULTS AND DISCUSSION

The obtained data was analysed using standard statistical tools such as t-test, one way ANOVA, and Pearson's correlation test to find out the stress and anxiety among parents of intellectual disability based on their gender, age, education, family type, occupation, and economic status.

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*Table-1 shows the percentage of participants in the study with respect to gender, age, education, family type, occupation, and economic status*

Variable		N	Percent (%)
Gender	Male	19	36.5
	Female	33	63.5
Age	Below 35 years	15	28.8
	36 to 45 years	26	50.0
	Above 46 years	10	19.2
Education	Uneducated	8	15.4
	School level	25	48.1
	Higher education	19	36.5
Family type	Nuclear	38	73.1
	Joint	14	26.9
Occupation	Homemaker	21	40.4
	Non-Professionals	19	36.5
	Professionals	12	23.1
Economic status	Low	1	1.9
	Middle	45	86.5
	High	6	11.5

Source: Primary data

From table-1, it is interpreted that majority of the caretakers (parents) were mother of the children (N=33; 63.5%), 50% (N=26) participants were between 36 to 45 years, educated till SSC and below (N=25, 48.1%) whereas respondents 36.5% (N=19) completed their higher education (graduates). Majority of participants (N=38; 73.1%) were living in a joint family with their children whereas; 26.9% (N=14) caregivers were from nuclear family. More than half respondents (N=45; 86.5%) were from Middle class (economic status) and 11.5% (N=6) were from high economic status. In occupation, homemakers (mothers; N=21) formed 40.4% majority of subjects, 36.5% (N=19) were non-professionals including skilled labours, helper, driver, cook, wielder, tailor, farmer whereas 23.1% (N=12) respondents were professionals such as engineer, reporter, HR.

*Table-2 shows the mean, SD, F-value, and p-value of anxiety of participants in the study based on gender, age, education, family type, occupation, and economic status*

Variable		N	Mean	SD	F value	p value
Gender	Male	19	5.31	4.41	5.392	.024S
	Female	33	8.57	5.11		
Age	Below 35 years	15	8.00	4.69	1.366	.264 NS
	36 to 45 years	26	7.65	5.53		
	Above 46 years	10	5.10	3.92		
Education	Uneducated	8	9.87	5.05	1.148	.326 NS
	School level	25	7.00	5.46		
	Higher education	19	6.84	4.47		
Family type	Nuclear	38	8.13	5.33	3.182	.081 NS
	Joint	14	5.35	3.75		
Occupation	Homemaker	21	8.85	5.13	2.136	.129 NS
	Non-Professionals	19	7.15	5.30		
	Professionals	12	5.16	4.01		

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Variable		N	Mean	SD	F value	p value
Economic status	Low	1	3.00	2.87	.981	.382 NS
	Middle	45	7.75	5.090		
	High	6	5.33	5.00		

Source: Primary data, S-Significant, NS-Not significant

From table-2, it is inferred that the anxiety score of mothers of children with intellectual disability differ significantly from fathers ( $F=5.392$ ;  $p<0.005$ ) whereas on the basis of age ( $F=1.366$ ;  $p>.005$ ), education ( $F=1.148$ ;  $p>.005$ ), family type ( $F=3.182$ ;  $p>.005$ ); economic status ( $F=.981$ ;  $p>.005$ ), and occupation ( $F=2.136$ ;  $p>.005$ ) did not differ significantly in anxiety scores. Hence, the results show that among parents of children with intellectual disability, there is a significant difference in level of anxiety on the basis of gender which means the null hypothesis 1 ( $H_{01}$ ) is rejected.

*Table-3 shows the mean, SD, F-value, and p-value of stress of participants in the study with respect to gender, age, education, family type, occupation, and economic status*

Variable		N	Mean	SD	F value	p value
Gender	Male	19	38.31	9.29	8.590	.005 S
	Female	33	45.90	8.82		
Age	Below 35 years	15	46.13	10.26	.913	.442 NS
	36 to 45 years	26	42.65	10.08		
	Above 46 years	10	40.60	7.22		
Education	Uneducated	8	44.00	9.36	.435	.650 NS
	School level	25	44.12	8.82		
	Higher education	19	41.47	10.99		
Family type	Nuclear	38	42.76	10.09	.206	.652 NS
	Joint	14	44.14	8.54		
Occupation	Homemaker	21	44.85	9.44	1.520	.229 NS
	Non-Professionals	19	43.84	10.02		
	Professionals	12	39.00	8.89		
Economic status	Low	1	34.00	5.64	.552	.580 NS
	Middle	45	43.08	9.89		
	High	6	45.00	8.09		

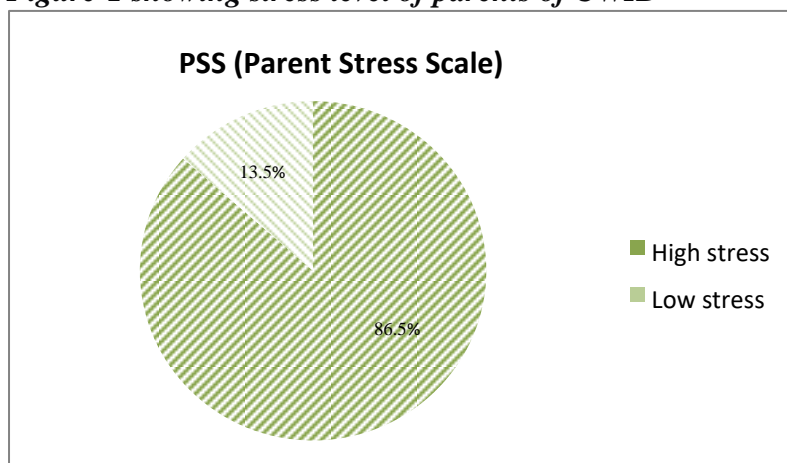
Source: Primary data, S-Significant, NS-Not significant

In the above table 3, the mean parenting distress scores of parents of children with intellectual disability differ significantly based on gender ( $F= 8.590$ ;  $p<0.005$ ). Participants did not differ in their stress level based on age ( $F=.913$ ;  $p>.005$ ), education ( $F=.435$ ;  $p>.005$ ), family type ( $F=.206$ ;  $p>.005$ ), economic status ( $F=.552$ ;  $p>.005$ ), and occupation ( $F=1.520$ ;  $p>.005$ ). Therefore, the results show that, there is a significant difference in levels of stress among parents of CWID with respect to gender which means the hypothesis 2 ( $H_{02}$ ) is rejected.



## Anxiety and Stress among Parents of Children with Intellectual Disability

**Figure-1 showing stress level of parents of CWID**



The results from the above figure-1 show that 86.5% parents (N=45) experienced high stress level where as 13.5% of participants has low level of stress which means caretakers (parents) experience significant stress level in parenting a child with intellectual disability (CWID).

**Figure-2 showing anxiety level of parents of CWID**

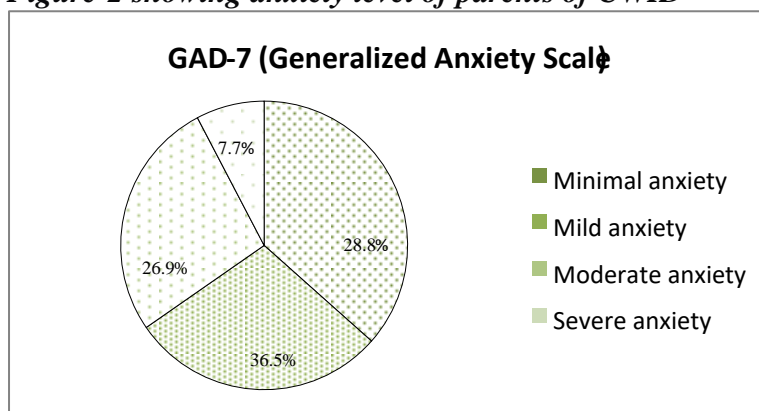


Figure-2 depicts the scores of parents categorized into levels as specified by GAD-7 as minimal anxiety, mild anxiety, moderate anxiety and severe anxiety. 36.5% caretakers forming majority has minimal anxiety, 28.8% (N=15) have mild anxiety. However, 26.9% (N=14) caretakers have moderate anxiety.

**Table-4 shows Correlation coefficient and its statistical significance of the respondents**

N=52	Generalized anxiety
Parent Stress	.435**

\*\* . Correlation is significant at the 0.01 level (2-tailed)

Table-4 depicts the correlation between parent stress and generalized anxiety. Obtained results show that there is a significant positive relationship between anxiety and stress among parents (caretakers) of children with intellectual disability at 0.01 levels. Thus, the null hypothesis 3 ( $H_{03}$ ) is rejected.

### SUMMARY, CONCLUSION AND IMPLICATIONS

The focus of the present study is to measure the stress and anxiety levels among parents of children with intellectual disability in Hyderabad, India. For this purpose, 52 parents of

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CWID participated. The caretakers were assessed using standardized tools such as PSS (Parent Stress Scale) by Berry and Jones (1995)- an 18 item self-report scale and GAD-7 (Generalized Anxiety Disorder) - a 7 item anxiety scale developed by Robert et al., (2006) . The data gathered and results were analysed via descriptive statistics, Pearson correlation and One Way- ANOVA (analysis of variance). Parents (mothers) showed high anxiety and stress level compared to fathers. The above finding is in accordance with the results of research conducted by Radhey. S., Kavita (2014) that the mothers of children with mental disability scored significantly higher level of parenting stress and majority mothers of children and adolescents with ID to have either anxiety or depressive symptoms, or both (Rachit. S., et al., 2023) Mothers were more anxious than fathers because they were often the ones who had to provide the majority of the child's care (Joseph and Chacko, 2018). The study also found that anxiety and stress correlated in parents of CWID (children with intellectual disability). Therefore, it is important to identify factors that distress the parents of children with intellectual disability to minimize the impact on primary caretaker and unexplained psychological burden.

As in most studies on parent stress, primary caretakers (mothers) experience high stress (Bhushan et al., 2012). Parents of children with intellectual disability such as IwID (Individuals with Intellectual disability) have tendency to develop high level of anxiety due to lack of family and community support (Jaspreet et al., 2019). Disability is a condition that impacts family members in addition to the child. There is a need of extended help and support for caretakers, especially mothers in taking care of children with intellectual disability. The current study determines that higher level of stress and anxiety can link to other psychological issues. Consequently, intervention programs that assist parents of children with disabilities in managing their emotional highs and lows. Thus, supporting parents of disabled children's mental health and psychological well-being (Pocinho, Fernandes, 2018).

Moreover, social support services could be delivered through camps, radio, newspaper, podcasts, and television in various regional languages to host awareness campaigns on a range of topics and tips that promote the coping, resilience and emotional management of parents with intellectual disability. It is also suggested that short training sessions for parents could be organized to teach their children everyday skills, which would lessen the caregiver's workload. Additionally, studies on mindfulness-based counselling for parents of children with special needs are becoming more prevalent. In order to plan for intervention, more effective research on the requirements of parents can be carried out.

### ***Major Findings***

Mothers of CWID (children with intellectual disability) experience anxiety and stress more frequently than fathers.

Anxiety and stress correlate among parents of CWID.

### ***Suggestions For Further Research***

- The current research has its own objectives, scope, focus, and constraints. The following are some recommendations for potential future study projects:
- It is possible to investigate the influence of other comorbid conditions and psychosocial factors, such as parenting styles, personality types of parents, involvement of siblings, and single parenting, in psychological distress and related conditions.

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- The research can focus on determining the factors that influence parenting stress, anxiety and related conditions.
- Understanding and creating well-structured treatment programs for children with autism, intellectual disabilities, learning disabilities, or other developmental problems can also be a focus of work.

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

The author(s) declared no conflict of interest.

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