

# Mental Health and Well Being of Mothers of Children with Intellectual & Developmental Disabilities

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## ABSTRACT

Physical and psychological distress related to parenting children, often reported to have effect on the wellbeing of Women who have children with disabilities. Intellectual disability is a generalized neurodevelopmental disorder characterized by significantly impaired intellectual and adaptive functioning. As a result of that the child with disability brings unexpected demands for which parents are not prepared. Mothers who are the primary care takers always experience challenges related to mental health as they dedicate themselves for the upbringing of the child. The purpose of this study was to find out the issues related to mental health experienced by mothers over a period of time and to gain better understanding of the effect of counselling on their psychological wellbeing. Data was collected from 60 mothers using a Pre-designed and validated questionnaire and face to face interviews. Subjective well-being is assessed with The World Health Organization's the day reconstruction method and a newly developed but experienced well-being measure, the HWB12, by Jacqui Smith and Arthur Stone (2011), a measure of 12 overall experiences of hedonic well-being referring to the previous day. The results of the study showed the mothers experienced at least two major issues related to Mental Health and neglected to seek counselling services for themselves. It is concluded that the psychological wellbeing of mothers having children with intellectual and developmental disability is issue of concern. There is need for developing supportive intervention programs such as counselling for improving their mental health.

*Key Words: Quality of Life, Children with Disabilities, Parents, Stress*

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## INTRODUCTION

Mothers provide primary care and helps in the journey of practical life to her children. There are known limitations in functioning of children with developmental disabilities which result in requirements for long term care far exceeding the usual needs of children as they develop, or the expectations of their families as a parent. Thus, while care giving is a normal part of being a parent, providing the high level of care required by a child with long term functional limitations can become burdensome and may impact both physical and psychological health of caregivers.

The burden and economic impact on caregivers having children with disabilities is poorly understood. Parents of children and adolescents with Intellectual Disability face unique parenting challenges. ID and Developmental Disabilities involve lifelong impairments in social communication and restricted interests or repetitive behaviours. In addition to these core symptoms, children and adolescents with ID have poor memory with accompanying deficits in everyday living skills.

The psychosocial impact starts when the family becomes aware of the existence of a developmental disorder in the child. In order to manage these symptoms and co-occurring behaviour problems, assist their son or daughter with everyday living skills, and cope with family-wide effects primary care givers often rely on formal and informal supports.

Families need to change schedules and routines, they need to make time to access support and therapeutic services and bear the financial costs of transporting the child to and from these services. These factors may affect the way parents deal with the child, creating the possibility of adverse effects on the relationship between family members and health of Mothers.

A study by C.S., A.R. and M.M. University of Zambia, 2015, Mothers experienced social isolation and marital problems, as well as negative attitudes from family, friends, community members and health care professionals.

Another study by Jieun Song,1 Marsha R., 2015, shows that Parenting children with disabilities over a prolonged period of time jeopardizes cognitive function (especially memory) among older mothers, possibly via the mechanism of heightened parenting stress due to higher levels of negative parenting experience.

Care giving and its related burden is considered to be an important aspect in determining the Quality of Life of caregivers. Quality of Life as a concept has been increasingly accepted as an important outcome measure in patients and caregivers of children with limitations in Intellectual Functions. A study in India by Shahzadi Malhotra, Waheeda Khan, M.S. Bhatia, 2012, revealed that Compared with parents of healthy children, parents in the MR and autism group reported impairment in all the four domains of Quality of Life.

For mothers raising children with significant disabilities, the most important instruments of work and livelihood are their physical bodies and minds, both of which are often compromised in their demanding care giving role. A study in Japan by Yui Yamaoka, Nanako Tamiya, 2016 reported that raising one or two children with disabilities was significantly related to maternal psychological distress compared to mothers of children without disability.

The primary caregivers experiencing a painful, sorrowful manner of being-in-the-world. Mothers find themselves unprepared to deal with the experience of having a disabled child, when seeking guidance from health professionals, the mothers failed to find the necessary support. According to a research study by Jenny Bourke, Bernadette Ricciardo, 2009, Mothers of children with Down syndrome appear to experience poorer mental health and may require greater support and services to improve behaviour management skills for their child and their own psychological well-being.

Long-term limitative conditions, especially for children, lead to stress for the individual and particularly for their family. Under difficult circumstances and beyond one's ability of adaptation, stress would be spread to every aspect of life and would lead the person to show an adaptive or non-adaptive response. These parents, other than bearing financial pressures, are always facing emotional pressures such as feeling ashamed or feeling guilty. Indian research by Amrita Sahay, Jai Prakash, 2013, helps to understand the implementation of Government Policies and services model in the community to provide financial support to family with intellectual disabilities.

Providing more support, such as home services, Counselling for mothers of children with ID or ASD, might make the way for the improved health of these mothers as stated by Jenny Fairthorne, Nick de Klerk, Helen Leonard, 2015. Importantly, mothers of children with ASD without ID were identified as a group needing special assistance.

This study aims to add knowledge and create awareness on everyday experiences and health issues faced by mothers living with children with ID and developmental Disabilities, and Health services received by them.

## **METHOD**

### **Participants:**

Participants included 60 Mothers having children with Intellectual Disability and Developmental Disability. Participants consent was taken in the study and in the case of mothers' unwillingness to cooperate for completing the questionnaires and giving full answers are excluded from the study. Total 75 mothers were considered and among them 60 mothers were chosen for the study.

### **Materials or Research Instrument:**

For this study data were gathered using Interviews. The greatest advantage of Qualitative interviewing is the depth of detail from the interviewee. Interviewing participants can paint a picture of an event or experience, tell us their perspective of such experience, as well as give other social cues. Social cues, such as voice, intonation, body language etc. of the interviewee can give the interviewer a lot of extra information that can be added to the verbal answer of the interviewee on a question. This level of detailed description, whether it be verbal or nonverbal, can show an otherwise hidden interrelatedness between emotions, people, objects unlike many quantitative methods of research.

To get the insight Researchers used Model Disability Survey (MDS) by World Health Organization 2017. Each instrument contains multiple modules addressing different aspects of disability and health in general populations. Among 10 different modules of MDS, 3(Three) are used to examine the objectives of this study. The MDS questionnaire consists of the following three main instruments.

- The Day Reconstruction Method and Well-Being Measure, HWB12
- 5000 Health Conditions
- 7000 Well-Being

WHO Model Disability Survey (MDS) was used as a data collection platform to collect comprehensive, comparable and relevant information from mothers having children with Intellectual and Developmental disabilities.

#### Procedure:

At an initial meeting, participants gave informed consent. Mothers were interviewed One on One in a room setting of 12 x 10 to avoid the distraction and influence of other participants. It maintained the privacy also. Participants were assigned by convenient method of sampling. Researchers interviewed the participants in between 10. 30 am to 3.30 in a day from those who are availing services from National Institute for the Empowerment of the Children with Intellectual Disability, Secunderabad. Inclusion criteria was having one child with one of the above mentioned disabilities.

#### Results or findings:

##### Statistical analysis:

Both Qualitative and Quantitative analysis were done. Quantitative data were expressed as Percentage and absolute value.

### RESULTS

In the present study out of the total population of 75 mothers, sample (n=60) 15 subjects were excluded as 10 were with average intelligence and 5 were excluded due to the incomplete information. Thirty parents of children with Intellectual disabilities and Developmental Disabilities were included in this study. Demographic information was collected from the participants for the better understanding of their experience and external factors that might influence their views. This information was collected to provide more detailed contextual information that can assist with data interpretation in qualitative research. The small sample size and nature of qualitative research precluded a statistical analysis of factors that predict parents view on various health services experienced by them. The key socio-demographic and clinical characteristics of the children and parents are detailed in Table-1.

**Table 1: Socio - demographic characteristics of the sample**

Demographic Variables	Criteria	Percent	N
<b>Age of Mother</b>	27 to 35 Yrs	30%	18/60
	36 to 45 Yrs	57%	34/60
	> 45 Yrs	13%	8/60
<b>Occupation</b>	Housewife	90%	54/60
	Service	10%	9/60
<b>Number of Child</b>	One	23%	14/60
	Two	63%	28/60
	>Two	13%	8/60
<b>School Going Child</b>	Regular School	27%	16/60
	Special School	73%	44/60
<b>Vocational Training</b>	Receiving	27%	16/60
	Not Receiving	73%	44/60
<b>Child's Age</b>	5-10 Yrs	27%	16/60
	10-20 Yrs	60%	36/60
	>20 Yrs	13%	8/60
<b>Number of Family Members</b>			

1 to 4 members	43%	26/60
> 4 members	57%	34/60
<b>Number of Mothers having Children with Disability</b>		
Learning Disability	50%	30/60
Intellectual & Developmental Disability	50%	30/60

**A look at Table 1 reveals the following points:**

The majority (60%) of children with intellectual disabilities were between 10 to 20 years of age. However, in four levels of intellectual disability, that is, mild, moderate, severe and profound, the majority of boys (35.5%) and girls (15.6%) were found to have a mild level of intellectual disability. Majority of the mothers (90%) were unemployed. Seventy three (73%) percent of children were studying in special schools as against 27% in regular schools. Most of the participants' age was in between 36 to 45 years. In case of mothers having children with learning disability, every student

**Table 2: Mental Health Condition among Mothers of Children with Intellectual Disability\* & Developmental Disability\*, among Mothers of Children with Learning Disability\***

Mental Health Parameters	Percent of Mothers having children with ID* & DD*	Percent of Mothers having children with LD*
Depression	67%	30%
Anxiety	73%	50%
Not feeling Happy	73%	73%
Not feeling content	77%	33%
Feeling Angry	80%	67%
Frustration	60%	37%
Sadness	60%	47%
Stress	53%	50%
Loneliness	63%	33%

Table 2 shows the Mental Health Condition of mothers having children with Intellectual and Developmental Disability. Percentage values of the collected data were worked out to determine the Mental Health Issues expressed by mothers. 67% of the mothers of children with disabilities reported Depression whereas 73% of mothers expressed anxiety. 77% and 73% of mothers respectively reported lower level of Happiness and lack of feeling content and simultaneously significant numbers of mothers (80%) reported the feeling of anger.

Whereas Mental Health Condition of mothers having children with Intellectual and Learning Disability, percentage values of the collected data were much less as compared to mothers having children with Intellectual and Developmental Disability. 50% of the mothers of children with disabilities reported Anxiety whereas 30% of mothers expressed depressed. 77% and 33% of mothers respectively reported lower level of Happiness and lack of feeling content and simultaneously significant numbers of mothers (67%) reported the feeling of anger.

**Table 3: Counselling services availed by mothers**

Counselling services availed by Mothers	Percent	N
Mothers who availed counselling	67%	40/60
Counselling availed from trained professionals	44%	18/60
Counselling availed from untrained professionals	57 %	22/60

From Table 3 we come know that 67% of mothers expressed the importance for discussing the problem and reaching its solutions. But Among them only 44% are availing the consultation from Trained Professionals and that is an

important issue of concern because consulting with untrained professionals is further leading them towards particular Mental and Physical Disorders which may lead to serious diseases in future.

**Table 4: Well-Being among Mothers of Children with Intellectual Disability\* & Developmental Disability\*, among Mothers of Children with Learning Disability\***

Well Being Parameters	Percent of Mothers having children with ID* & DD*	Percent of Mothers having children with LD*
Loneliness	93%	67%
Low daily energy level	90%	90%
Tiredness	87%	87%
Quality of Life	83%	67%
Lack of Health Satisfaction	83%	50%
Left out	83%	67%
Inability to perform daily activities	67%	77%
Poor personal relationships	60%	60%

Table 4 shows us the parameters of Quality of Life of mothers having children with Intellectual Disability and Developmental Disability. Majority of participants (93%) expressed loneliness and 83 % of mothers reported left out feeling.

Whereas the parameters of Quality of Life of mothers having children with Intellectual Disability and Learning Disability were better as compared to mothers having children with intellectual and other developmental disabilities. Participants (67%) expressed loneliness and (67%) of mothers reported left out feeling.

## DISCUSSION

This study was designed to examine Mental Health Issues Experienced by mothers and Utilisation of counselling Services by them under three domains such as Mental Health Condition, Availing counselling service and Well-Being. The result of this study indicated that most of the mothers expressed poor mental health condition and , the average percentage of parents expressed that though sometimes they take consultation for their mental health condition, very less percentage of mothers go to trained professionals. The results for mothers Physical metal Health our hypothesis, which postulated that individuals parenting a child with disabilities might be at an increased risk of Health Disorders or Diseases due to higher levels of exposure to stress. These mothers often face more chronically stressful situations due to their children's disabilities and due to unavailability of suggestions from trained professionals.

In the present study, it has been found thatmothers of children with Developmental Disability andIntellectual disability showed a significant impairment of Quality of Life, More specifically, mothers of children with Disabilities displayed poor mental Health, impairment in social relationships, in their psychological state and poorer perception of their social relationships. The presence of a child with developmental disability in the family calls for a lot of adjustmenton the Primary care givers, but in case of Mothers having children with learning disability psychological state and social relationship relatively better.

The domain of 'psychological well-being' is associated with negative feelings of mood, sadness, anxiety, and dissatisfaction with oneself. The psychological well-being of mothers of children in the study group was significantly associated with mother's feelings of isolation and with feelings of incompetence.

Further, the impairment in this domain may be because these developmental disabilities are often associated with anxiety about future of oneself and the child, leads to sadness about the condition ofthe child along with feelings of self-blame, guilt and social shame. Similar study done by J. M. Cramm and A. P. Nieboer , Netherlands, 2011, reflects the same conclusion.

In this study, mothers havingchildren with learning disability were more concerned with receiving guidance on how to access the various information about the child's condition or disabilities and its management, as well as they also need information about the supports and schemes provided by central and State Governments. Research findings are indicating that mothers are unable to get proper counselling assistance from Trained Medical Professionals. Unavailability of financial grant and insurance from Government impacts the Physical and psychological health condition of mothers. Study conducted by Karen M. Benzies, Barry Trute, Canada, 2010 draw to a close to similar results.



This study opens up another window where we can focus on the effect of types of disability on mothers' mental health's parameter. As Less numbers of Mothers who have children with learning disability experiencing depression, anxiety showing slightly better mental health condition. But this requires further research or cross sectional study.

The present findings have practical implications for assessing the mental health condition requirements of population (Primary Caregiver) for the planning of clinical care of individual primary care giver and for resourceAllocation.

## CONCLUSION

Mothers of children with ID and Developmental Disabilities seem to display a higher burden and a significant impairment in their Psychological Health and Quality of life. These finding must be taken into account in policy making to provide better and more specific supports and interventions for this group of People. More attention should be given to mothers' Mental Health Condition. Social support and different coping strategies should be developed to respond positively to individual changing needs and in buffering mothers from the stress of having a child with disability. New research should be conducted to measure the effectiveness of these strategies and on the effect of specific disabilities. In addition, effective and sustainable psycho-social programs are needed to provide necessary medical and psychological support for the special needs of the caregivers.

These specific challenges may cause mothers to experience high levels of emotional and personal tension, which in turn will impact on the Physiological and psychological well-being of Mothers. There is need for developing supportive intervention programs such as counselling for improving their mental health.

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