



A Study on Psychosocial Problems of Parents Having Children with Intellectual and Developmental Disability

Nandini Rooj

Assistant Professor in Education

Raiganj B. Ed. College (Govt. Sponsored)
Karnajora, Uttar Dinajpur

Abstract

Intellectual and Developmental Disability (IDD), earlier termed as Mental Retardation, is a disability condition that is characterised by having significant limitations in both intellectual functioning and in adaptive behaviour, that covers everyday social and practical skills of a person. In today's society the problem of Intellectual and Developmental Disability has become an alarming issue globally. It has drawn the attention of parents, teachers, professionals and psychologists in both the developed as well as the developing countries. In recent years a sharp increase in the number of studies, on working with parents of Intellectually and Developmentally Disabled children, have been brought out with valuable information. The parents as an agency of socialisation have great impact on the personality development of the child. Raising a child who had Intellectual and Developmental Disability, requires lots of emotional strength, flexibility, time and energy commitment. The parents of Intellectually and Developmentally Disable children have various psychological problems. The present study was aimed to identify various psychosocial problems faced by the parents who have children with Intellectual and Developmental Disability. Twenty (20) parents (mother/father) of Children with IDD were selected through purposive sampling from a child development centre located in Raiganj, Uttar Dinajpur district. Parents Problem Inventory (PPI), developed by Dr. Anju Singh, was used in order to collect the data for the current study. The collected data were analysed by Descriptive Statistics. Result showed that having a child with Intellectual and Developmental Disability (IDD) had huge effect on their parents. Most parents struggled with various psychosocial problems. Most prevalent problems faced by parents were psychological, physical, social, child management, school and vocational problems, profession advice and financial problems. The study also indicated that mothers faced more problems related to psychological, physical, social, child Management and psychosomatic problems, while fathers faced more financial problems, school and vocational problem, and profession advice problems. Conclusion of the study suggested that there was need for early diagnosis, prompt treatment and counselling for psychological problems in parents as well as proper profession advice, and proper information about Govt benefits and legislation's regarding child's welfare and financial help.

Keywords: *Intellectual and Developmental Disability, Psychosocial Problems, Parents of Children with Intellectual and Developmental Disability, Problem of Parents.*

Introduction

It's never been simple to be a parent. There is no compensation for working nonstop for 24 hours a day, 7 days a week. The profession of parenting has no preparation or training, has neither a sick leave nor a casual leave. Parents, who have children with special needs, especially who have children with Intellectual and Developmental Disabilities, must work without receiving a bonus or increment. According to AKKOK (1996), parents of children with Intellectual and Developmental Disabilities must put in more time, effort, and care than they would with children who are not Intellectually and Developmentally Disabled. Parents who are expected to raise the socially adapted child with special needs experience significant physical, social, and physiological repercussions as a result of childhood chronic illness. For the majority of parents, psychosocial problems involving parents and children who have Intellectual and Developmental Disabilities, can be extremely painful. A healthy child with special needs benefits from psychological elements as well as parental effects and familial influences.

When parents discover that their child has a disability, they start on a journey that takes them into a life that is frequently filled with intense emotion, tough decisions, contacts with many different professionals and specialists, and a continuing need for information and assistance. Parents might at first feel lonely and alone, unsure of how to look for knowledge, help, compassion, and support. A differently abled child has a significant influence on the family especially on parents.. Although having a differently abled child impacts the entire family, the parents bear the most of the burden. They experience a range of issues, including psychological, financial, emotional, and social ones.

Sen and Yurtsever (2007) carried a study on "difficulties experienced by families with disabled children. The primary objective of this study was to identify the challenges faced by families of differently abled children. The findings suggested that the families lacked sufficient information regarding their child's condition. Mothers expressed deep sadness and stated that having a disability child had a negative impact on their social life, job life, and relationships with their families. Families experienced money issues as well.

Intellectual and Developmental Disability (Previously Mental Retardation) is a condition that impairs both intellectual functioning and adaptive behaviour. As per American Association on Intellectual and Developmental Disabilities (AAIDD, 2010), Intellectual and Developmental Disability (IDD) is a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability condition originates before the age of eighteen (18).

S. K. Mangal (2009) asserted that Intellectual and Developmental Disabilities is a condition or state of mind. It is not a disease or illness of the mind. Instead, it has to do with the subnormal development of the brain or mind. In addition, he stated that Intellectual and Developmental Disabilities is also related to one's inadequate adjustment with the environment. The deficiency may be observed at birth or in early childhood. Intellectual and developmental disabilities may result from both the inherent and external factors.

The presence of a child with Intellectual and Developmental Disability in the family calls for a lot of adjustment on the part of the parents and the family members (Peshawaria & Menon, 1991). It takes so much of resilience and adaptability on the part of the parents to raise a child with Intellectual and Developmental Disabilities. Parents may get overburdened with different medical, caring, and educational duties because the

child has special requirements in addition to the regular needs of all children. The parents are inevitably impacted, regardless matter how complex or small the child's special needs are. Maintaining equilibrium in the home requires support from family, friends, the community, or paid caretakers.

Tsai and Wang (2009) investigated the association between caregiver's strains among mothers with school- aged Intellectually and Developmentally Disabled children in Taiwan. According to the findings, mothers with intellectually impaired children face significant stress and receive insufficient social assistance. Social support and strain had a substantial and unfavourable status, social support and amount of time spent as a caregiver or parent, as well as the dependent degree of daily living activity of Intellectually and Developmentally Disabled children, were strong predictors of caregiver's strain.

Parents with Intellectually and Developmentally Disabled children may experience physical weariness. The level of this exhaustion is typically correlated with the level of care required for their child. Physically, it is much simpler to feed, bathe, move, dress and diaper a newborn than it is to do the same for a person who weighs 70 pounds. The child may require strict medical supervision and may have more doctor's appointments and other healthcare appointments than the average child. In order to prevent accidental self-harm, such as tumbling down stairs or walking into traffic, he might also need to be taken care of. A parent may get physically exhausted as a result of these added duties. A child with Intellectual and Developmental Disability may cost more to raise than a non-disabled child. These costs may be related to transportation, schooling, tutoring, adaptive tools for learning, or medical supplies, equipment, and care. For that parents face financial problems in their life.

In this study, the term "psychosocial problem of parents" corresponds to family problems, psychological problems, physical problems, social problems, financial problems, problems related to profession advice, school and vocational aspect and psychosomatic problems faced by parents of children with IDD.

2. Objective

The primary objective of the current study is to identify various psychosocial problems faced by parents who have children with Intellectual and Developmental Disabilities (IDD).

3. Methodology

3.1. Research Design

A non experimental descriptive research design was adopted by the researcher to conduct the study.

3.2. Sample

The study was conducted on purposive sampling of twenty (20) parents (both mothers and fathers having children with Intellectual and Developmental Disabilities) taken from Shishumangal child development centre in Raiganj, Uttar Dinajpur district. The study included only those parents whose children were diagnosed with mild or moderate level of IDD.

3.3. Tool

Parents Problem Inventory (PPI) tool, developed by Dr. Anju Singh, were employed in the present investigation to collect the information about psychosocial problems of parents of IDD children. The PPI tool consists general information about family background information and 57 items were distributed over nine (9) problems areas. They were family problems, psychological problems, physical problems, social problems, school and vocational problems, profession advice problems, child management problems, financial problems and psychosomatic problems. In each area the number of items varied from 3-10. Family problem area consists of 10 items, psychological problem area consists of 6 items, physical problem area consists of 9 items, social problem area consists of 8 items, school and vocational problem area consists of 6 items, profession advice problem area consists of 4 items, child management problem area consists of 6 items, financial problem area consists of 5 items and psychosomatic problem area consists of 3 items.

3.4. Procedure for Data Collection

Written approval was taken from concerned authority to proceed for data collection. The researcher personally went to the location selected for the current study and briefed about the nature of her study to the parents of IDD children. Adequate rapport with the parents of IDD children was made at first. The Parent Problem Inventory (PPI) was individually administered on the parents of IDD Children. After getting back the filled questionnaires the investigator examined that respondents have given their answers to each and every question. If any question/item was found unresponsive then the questionnaire was referred back to the respondents again with the request to make their answer on the unanswered items.

4. Data Analysis

The collected data were analysed by Descriptive Statistics (Frequency Distribution and Percentage Count). Frequency Distribution of respondents on the basis of gender and age are presented in Table 1 and Table 2. Distribution of IDD Children according to the level of the disability is shown in Table 3. Data analysis of parents' problems are presented in Fig. 1.

5. Results and Discussion

Table 1: Distribution of Respondents (Parents) based on Gender (N=20)

Respondents	Frequency	Percentage (%)
Father	6	30
Mother	14	70

Table 2: Distribution of Respondents (Parents) based on Age (N=20)

Age Group	Frequency	Percentage (%)
20-30	5	25
31-40	13	65
41-50	2	10

Table 3: Distribution of IDD Children according to the Level of the Disability

IDD Children	Frequency	Percentage (%)
Mild	12	60
Moderate	8	40

Table 1 and Table 2 show the distribution of parents based on their gender and age. Table 3 shows the distribution of IDD children according to the level of the disability. Table 1 and Table 2 indicate that majority of respondents were mothers (70%) and most of the parents belonged to the age group of 31-40 (65%). From Table 3 it is clear that majority of the parents were having children of mild Intellectual and Developmental Disabilities (60%) followed by 40% of moderate Intellectual and Developmental Disabilities.

The study was designed with the aim to identify various psychosocial problems faced by parents who have children with Intellectual and Developmental Disabilities (IDD).

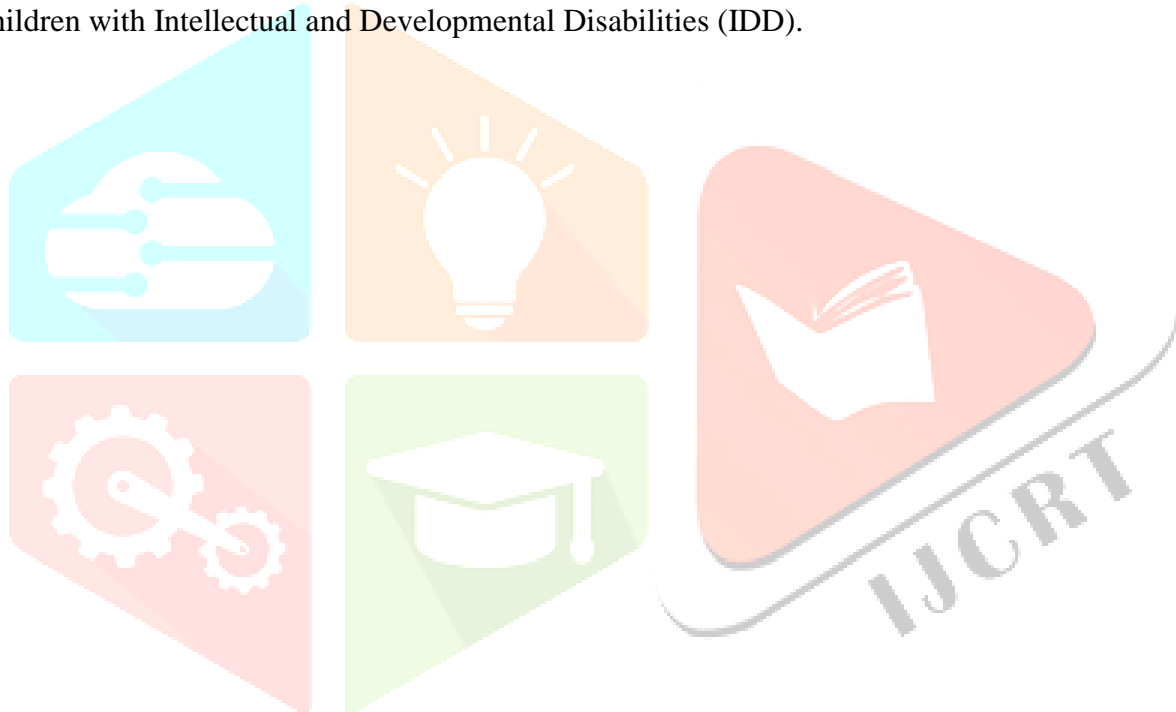
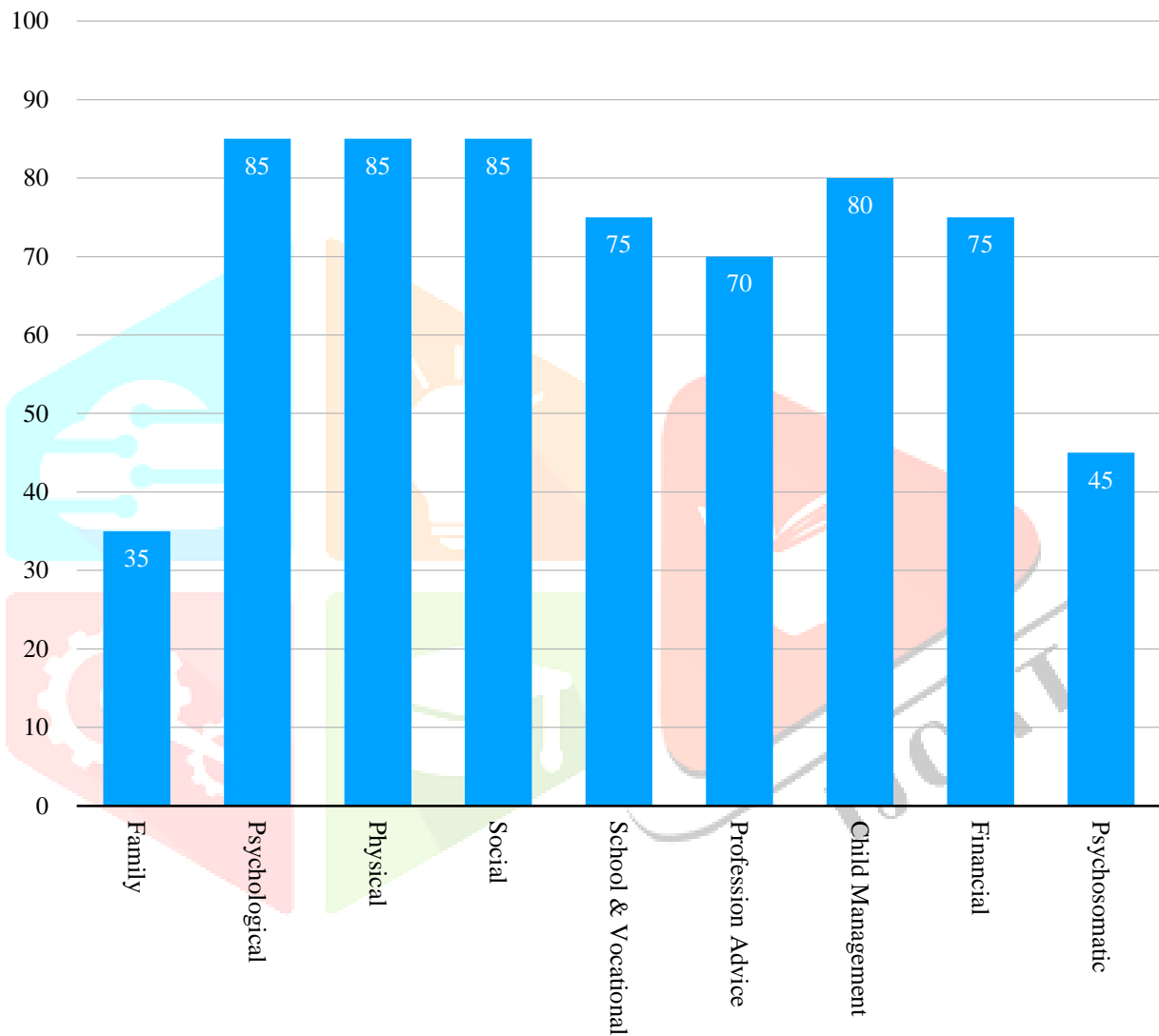


Fig. 1. shows percentage of responses of parents relating to each of the problem areas in the Parent Problem Inventory (PPI). The top percentage level was observed in the area of psychological, physical and social problems (85%). 80% parents expressed that they face various difficulties related to Child Management.

Fig.1. Percentage Endorsement of Problems of Parents with the help of PPI



The problems related to school and vocation and financial support were expressed by 75% parents. 70% parents expressed their problems regarding profession advice. 45% parents said that they suffer from psychosomatic problems and 35% parents expressed their family problems. Therefore by analysing parents' problems and experiences with the help of PPI tool, the findings of the study indicate that having a child with Intellectual and Developmental Disability (IDD) had huge effect on their parents. Most parents struggled with various psychosocial problems. Most prevalent problems faced by parents were psychological, physical, social, child management, school and vocational problems, profession advice and financial problems. The study also indicated that mothers faced more problems related to psychological, physical, social, child Management and psychosomatic problems, while fathers faced more financial problems, school and vocational problem, profession advice problems.

6. Conclusion

Conclusion of the study suggested that there was need for early diagnosis, prompt treatment and counselling for psychological problems in parents as well as proper profession advice, and proper information about Govt benefits and legislation's regarding child's welfare and financial help. The current study shed some light on the problems faced by parents of children with intellectual disability. Children with Intellectual and Developmental Disabilities are cared for by their parents who serve as their most constant and life-long caregivers. They play a vital and crucial role in shaping the development and life experiences of their children with Intellectual and Developmental Disabilities (IDD). Thus, parents of children with Intellectual and Developmental Disabilities have additional responsibilities and roles in caring for them (Gray, Grove & Sutherland, 2017). They experience various challenges in caring for their children. It is therefore fundamental for all stakeholders with an interest in parents of children with Intellectual and Developmental Disabilities to collaborate and have a better understanding of their challenges. Healthcare professionals, especially professional nurses, should take an active role in reducing the burden of care for parents of children with Intellectual and Developmental Disabilities.

References

- Abdul Hameed, P. V. & Kotian, S. (2022). A Systematic Review on Stress and Coping Strategies in Parents of Intellectually Disabled Children. *International Journal of Law Management and Humanities*, 5(3), 786 - 811 doi: <https://doi.org/10.1000/IJLMH.113124>
- Akkok F. (1994). An overview of parent training and counselling with the parents of children with mental disabilities and autism in Turkey. *International Journal for the Advancement of Counselling*, 17(2), 129-38.
- American Association on Intellectual and Developmental Disabilities (AAIDD). (2010). Defining Criteria for Intellectual Disability. Retrieved on October 7, 2022 from <https://www.aaidd.org/intellectual-disability/definition/>

- Egan, C., Mulcahy, H., & Naughton, C. (2022). Transitioning to long-term care for older adults with intellectual disabilities: A concept analysis. *Journal of Intellectual Disabilities*, 26(4), 1015–1032. <https://doi.org/10.1177/17446295211041839>
- Mangal, S.K. (2009). *Abnormal Psychology*. New Delhi: Sterling Publishers Private Limited.
- Peshawaria, R. (1995). *Understanding Indian families having persons with mental retardation*. National Institute for the Mentally Handicapped (Ministry of Welfare Govt. of India). Secunderabad.
- Peshawaria, R., & Menon, D.K. (1991). Needs of families of mentally handicapped children. *Indian Journal of Disability and Rehabilitation*, 1, 69-72.
- Sen, E., & Yurtsever, S. (2007). Difficulties experienced by families with disabled children. *Journal for Specialists in Pediatric Nursing*, 12(4). doi: [10.1111/j.1744-6155.2007.00119.x](https://doi.org/10.1111/j.1744-6155.2007.00119.x)
- Tsai, S.M., & Wang, H.H. (2009). Relationship between caregivers strain and social support among mothers with intellectually disabled children. *Journal of Clinical Nursing*, 18(4), 539-48

