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Comparative Analysis Of Parental Needs: Raising Children With Mild And Moderate Intellectual Disability

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Abstract

The presence of a child with an intellectual disability necessitates considerable adjustment on the part of parents and other family members. While some families demonstrate greater resilience in adapting to this reality, others encounter significant challenges. This study investigates and compares the needs of parents—both mothers and fathers—raising children with mild and moderate intellectual disabilities. Conducted at the State Institute of Rehabilitation Training and Research (SIRTAR), Rohtak, Haryana, the research employs a purposive sampling method involving 24 parents of children aged 5 to 25 years, categorized by IQ levels (mild: 50–70; moderate: 35–50). Using the NIMH Family Needs Schedule and an interview-based approach, the study explores parental needs across cognitive, material, social, and emotional domains. Findings reveal that mothers consistently reported higher needs than fathers, particularly in areas related to child management and emotional support, while fathers expressed greater needs for vocational planning and access to government services. The study underscores the importance of early, individualized, and family-centered interventions that address both child-specific and broader familial needs. It concludes that assessing and responding to parental needs from the family's perspective is critical to improving developmental outcomes and enhancing parental capacity.

Keywords : Intellectual disability, parental needs, family support

The presence of a child with an intellectual disability necessitates considerable adjustment on the part of parents and other family members. While some families demonstrate greater resilience in adapting to this reality, others encounter significant challenges. Empirical evidence and experiential insights underscore that interventions aimed at addressing the needs of all family members rather than focusing exclusively on the child yield more effective outcomes in fostering familial coping mechanisms. One of the most efficacious strategies for enhancing parental competencies lies in identifying and supporting parents as they strive to meet the diverse needs of their household, including their own. Research further reveals a direct correlation between the number of unmet

familial needs and the incidence of emotional and physical health issues reported by parents. Consequently, understanding of how parental needs evolve over time particularly in families raising children with intellectual disabilities would enable service providers to tailor support services more appropriately to each family member. The present study seeks to fill this critical gap by analyzing the multifaceted needs of parents in such contexts. The presence of a child with intellectual disability invariably generates additional demands on parents. A "need" may be defined as a condition or resource that is desired, lacking, or essential for achieving a specific goal or outcome. Parents consistently articulate a pressing need for information regarding therapeutic, educational, and vocational programs. Notably, research indicates that when parental needs extend beyond child specific interventions, there is a heightened likelihood that parents lack the time, energy, or personal capacity to implement prescribed strategies for their child. Therefore, the initial step in any direct intervention must involve a thorough assessment of family needs as perceived by the family itself. Addressing these needs from the outset not only strengthens the family unit but also significantly enhances developmental outcomes for the child. Garshelis and McConnell (1993) conducted a comparative analysis of family needs assessments performed by interagency early intervention teams and individual professionals, juxtaposed with self-assessments provided by mothers of young children with disabilities. The findings revealed that individual professionals aligned with only 47% of the mothers' identified needs, whereas team-based assessments demonstrated a higher concordance, matching 57% of maternal responses.

An early investigation by Verma and Kishore (2009) examined the differential perceptions of needs among fathers and mothers raising a child with intellectual disability. The study also sought to understand the cumulative parental needs in relation to the child's age, sex, and severity of functional impairment. The researchers selected a sample of 30 couple, each with a child diagnosed with intellectual disability, and employed the NIMH Family Needs Schedule as the assessment tool. Findings revealed a significant divergence in the nature of needs expressed by fathers and mothers. These needs were further influenced by the age and sex of the child, whereas the severity of intellectual disability exerted comparatively less impact. Although certain parental needs may diminish as the child matures, they are typically supplanted by new concerns. Overall, the evolving nature of parental needs appears to be more closely associated with the child's sex than with the severity of the disability.

Noman and Yasir (2022) conducted a study to evaluate the needs of parents raising children with intellectual disabilities and to identify the socio-demographic variables associated with these needs. The sample comprised 123 parents of children diagnosed with intellectual disabilities. Findings revealed that 82.9% of parents reported a high degree of cognitive needs, 65% expressed high material needs, 75.6% indicated high social needs, and 52.8% demonstrated moderate emotional needs. The study also identified variations in emotional needs based on the age of the child, while cognitive, material, social, and emotional needs differed according to the severity of the intellectual disability. Among the various categories, material needs emerged as the most pressing concern for parents, followed by cognitive needs, social needs, and lastly, emotional needs.

OBJECTIVES

- To compare the needs of parents (Fathers and Mothers) having children with mild and moderate intellectual disability.
- To compare the needs of mothers having children with mild and moderate intellectual disability.
- To compare the needs of fathers having children with mild and moderate intellectual disability.

HYPOTHESIS

- There will be no significant difference between the needs of parents having children with mild and moderate intellectual disability.
- There will be no significant difference between the needs of mothers having children with mild and moderate intellectual disability.
- There will be no significant difference between the needs of fathers having children with mild and moderate intellectual disability.

SAMPLING METHOD AND SIZE

The sample selected based on purposive sampling method. Parents of 24 children with mild and moderate intellectual disability were included in the study, comprising of 12 mild (I.Q 50-70) and 12 moderate (I.Q 35-50) children with intellectual disability. The different variables related to the parents aged from 35 to 55 years, region (rural or urban area), the parents were literate or illiterate, in working or non-working condition. The age of individuals with mild and moderate intellectual disability were taken from 5 to 25 years. Consent of State institute of rehabilitation training and research (SIRTAR) Research was taken for collection of data.

Procedure:

After obtaining the consent from participants, clinical details and socio demographic details were taken. All the 24 mothers and 24 fathers of 12 mild and 12 moderate children were interviewed individually. Clinical details of the individual with intellectual disability were taken.

Statistical analysis:

Data analyzed using inferential statistics. In inferential statistics T-test was used. This method is used to compare the needs of parents having children with mild and moderate intellectual disability. Statistical techniques which are used in the study are: mean, standard deviation and T-TEST. SAS software is used to find the mean, standard deviation, and T-test values.

DATA COLLECTION

The primary data for this investigation. An assessment tool to gather information from parents having children with intellectual disability. Interview method is preferred over self-reporting method for gathering information using National Institute for the Mentally Handicapped Family needs Schedule NIMH-FAMNS (Parents). She applies this assessment tool on parents and collects information about the needs of parents having children with mild and moderate intellectual disability. After analyzing the obtained data, the researcher describes the needs of the parents and is there any difference between the needs of parents having children with mild and moderate intellectual disability.

Tool used:

A semi-structured interview schedule NIMH-FAMNS (Parents) was developed to elicit the needs of parents having children with intellectual disability. Each of the 48 parents were interviewed individually. Each interview lasted about 20-30 minutes depending upon how elaborate the respondent was. National Institute for the Mentally Handicapped NIMH- Family needs schedule (FAMNS) -Parents be used to know the difference between the needs of parents having children with mild and moderate Intellectual disability.

In this tool there are 15 areas/needs:

Information- condition, Child management, Facilitating interaction, Services, Vocational planning, Sexuality, Marriage, Hostel, Personal- emotional, Personal- social, Support- physical, Financial, Family relationships, Future planning, Government benefits and legislation.

Results and Discussion

- **Objective 1. To compare the needs of parents (Fathers and Mothers) having children with mild and moderate intellectual disability**

The mean scores, Standard deviation and t values have been shown in Table 1.

Variable	No. of Parents (Mother & father)	Mean	S.D.	t- test value
Father	24	43.33	10.18	0.80
Mother	24	45.84	9.97	

$P > 0.05 = 0.80$ at df 46

The mean score for Fathers and Mother having child with mild and moderate intellectual disability is 43.33 and 45.84 respectively. From the statistical analysis, it was found that there was no significant difference between the needs of parents having children with mild and moderate intellectual disability whereas in the hypothesis there was no significant difference between the needs of parents having children with mild and moderate intellectual disability is accepted.

- **Objective 2. To compare the needs of mothers having children with mild and moderate intellectual disability.**

The mean scores, Standard deviation and t values have been shown in Table 2

Variable	No. of Mother	Mean	S.D.	t- test value
Mother (Mild)	12	44.41	15.07	0.50
Mother (Moderate)	12	47.75	7.75	

$p > 0.05 = 0.50$ at df 22

The analysis of above table data:

The mean score for Mothers having child with mild intellectual disability and Mother having child with moderate intellectual disability is 44.41 and 47.75 respectively. T-test for both mother (mild) and mother (moderate) yield a value of 0.50 with 22 degree of freedom. The standard deviation of Mothers having child with mild intellectual disability 15.07 is higher than the standard deviation of mothers having child with moderate intellectual disability 7.75. Value of t- test for both yield a value of 0.5. From the statistical analysis, it was found that there was no significant difference between the needs of mothers having children with mild and moderate intellectual disability whereas in the hypothesis there was no significant difference between the needs of mothers having children with mild and moderate intellectual disability is accepted.

- **Objective 3. To compare the needs of fathers having children with mild and moderate intellectual disability.**

The mean scores, Standard deviation and t values have been shown in Table 3.

Variable	No. of Father	Mean	S.D.	t- test value
Father (Mild)	12	44.75	16.49	0.86
Father (Moderate)	12	45.66	7.49	

$p > 0.05 = 0.86$ at df 22

The analysis of above table data:

The mean score for fathers having child with mild intellectual disability and fathers having child with moderate intellectual disability is 44.75 and 45.66 respectively. T-test for both father (mild) and father (moderate) yield a value of 0.86 with 22 degree of freedom. The standard deviation of fathers having children with mild intellectual disability 16.49 is higher than the standard deviation of fathers having child with moderate intellectual disability 7.49. Value of t- test for both yield a value of 0.86. From the statistical analysis, it was found that there was no significant difference between the needs of fathers having children with mild and moderate intellectual disability whereas in the hypothesis there will be no difference between the needs of fathers having children with mild and moderate intellectual disability is accepted.

Discussion

TABLE 1: Revealed that fathers exhibited a greater need for support in areas such as government benefits and legislation, vocational planning, and access to related services. In contrast, mothers demonstrated heightened needs in domains pertaining to child management, marital dynamics, and informational resources regarding their child's condition. The presence of a child with intellectual disability imposes additional demands on parents, necessitating multifaceted support. Parents consistently express a strong need for comprehensive information concerning therapeutic interventions, educational opportunities, and vocational programs tailored to their child's developmental profile. Research has indicated that greater the number of needs unrelated to child-level interventions, greater was the probability that parents revealed that they didn't have the time, energy, or personal investment to carry out the intervention prescribed for their child (Dunst & Leet, 1987; Dunst, Vance & Cooper, 1986). Thus, assessing family needs as perceived by the family should be the first step in providing family directed interventions. Addressing family needs at the outset will lead to greater benefits for the child (Bailey, 1987). Modula (2022) investigated the support needs of families raising children with intellectual disabilities (ID) in South Africa. The study employed qualitative methodologies, including in-depth interviews and focus group discussions, with a sample of 26 families. Inductive thematic analysis was utilized to interpret the data. Participants articulated a range of support needs, notably the provision of information related to the care and management of children with ID, enhanced professional collaboration to ensure the safety of these children, and greater community engagement in their upbringing. Additionally, families emphasized the necessity of improving living conditions, particularly in light of the fact that most households were female-headed, economically disadvantaged, and in urgent need of financial assistance. In a recent study, Rooj (2023) examined the needs of parents raising children with intellectual and developmental disabilities (IDD). The findings revealed that the majority of parents expressed pronounced needs in several domains, including informational resources regarding their child's condition, child management strategies, access to available

services, government benefits and legislative support, financial assistance, vocational planning, and personal-emotional and social relationships. Conversely, parents reported relatively lower levels of need concerning topics such as sexuality, marriage, and hostel-related information.

Gender-based differences were also observed: mothers demonstrated greater needs in areas related to child management and informational support, whereas fathers predominantly emphasized financial assistance, vocational planning, and entitlements under government schemes. This study offers valuable insights into parental perspectives, highlighting both the strengths and deficiencies within existing support systems. A more nuanced understanding of these parental needs could enable communities to implement government policies and service delivery models with greater efficacy, particularly in extending financial support to families from socioeconomically disadvantaged backgrounds. The study concluded that there was no significant difference in needs of parents (Father and Mother) but areas of needs are different.

TABLE 2: Depicted that mothers of moderate intellectual disability children on average tend to have different needs compared to mothers of mild intellectual disability children. It was noticeable that mother education, occupation had a high impact on knowledge as well as on needs. The study revealed that the results were not found to be different between mild and moderate mothers especially in needs areas, such as Personal-Emotional, Personal- Social, Sexuality, Future planning and family relationships.

TABLE 3: Revealed that the results were not found to be different between mild and moderate fathers especially in areas major needs in knowing what the Government was doing for the intellectual disability individuals and for their families. Getting information on Government benefits/legislation was the first ranked area need expressed by fathers followed by Vocational planning, of their child, Future planning and information on Service for training the child.

The minimum endorsement of needs by father in a given area was in personal-emotional. The needs related to Financial Support, physical or Hostel though expressed by some of the fathers, do not however figure as front rank needs. They have expressed Personal-emotional as the lowest ranked need for themselves. Redressal of needs related to personal-emotional aspects is not fully recognized. Such concerns if and when identified are generally attended to, by the available family supports rather than through seeking professional help. Also, seeking professional help to promote mental health is largely considered as a sign of incompetence or a taboo.

CONCLUSION

The findings of the present study contribute to the body of knowledge concerning parental awareness, understanding, challenges, and needs associated with raising children with intellectual disabilities. To enhance the quality of life for these families, it is imperative to design and implement programs that offer professional support. On a practical level, assisting families in navigating the complexities of care giving is essential. The presence of a child with intellectual disabilities generates a range of specific parental needs. Assessing these needs from the parents' perspective is crucial for developing individualized family intervention programs. Addressing both parent and child-specific requirements fosters greater parental cooperation and engagement. Need-based interventions should commence as early as the diagnosis of developmental delays or intellectual disabilities. Early intervention enables professionals to positively influence parental attitudes, beliefs, and behaviors, thereby reducing the need to correct misconceptions later. However, before such

interventions can be effectively implemented, a professional audit is necessary to evaluate existing resources, attitudes, and competencies to ensure readiness for collaborative work with families.

Delimitations:

No research study is complete in itself, it has been rightly said, “endless invention, endless experiment brings knowledge of motion, not of stillness”. (T.S. Elliot)

- The present investigation was limited to Rohtak city only.
- The research work was limited to SIRTAR institute only.
- The present research work was based only on the tool NIMH - FAMNS (PARENTS) .

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