Tuijin Jishu/Journal of Propulsion Technology
ISSN: 1001-4055
Vol. 46 No. 2 (2025)

"Psycho-Social Challenges Of Parents Raising Children With Intellectual Disabilities: A Study In Wayanad District, Kerala."

[1]Sulfina Jasmin P.P,[2] Anju. R, [3]P. Swathi, [4]Floyid Vargheese, [5]Sreeja P.S ,

[1]*MSW, Nehru Arts and Science College Coimbatore.*

[2]*MSW, Nehru Arts and Science College Coimbatore.*

[3]*MSW, Nehru Arts and Science College Coimbatore*

[4]*.MSW, Nehru Arts and Science College Coimbatore.*

[5]*Assistant Professor, Department of Social Work, Nehru Arts and Science College*

Abstract:-

Raising a child with Intellectual Disability (ID) poses significant psychosocial challenges for parents, particularly in rural areas like Wayanad, Kerala, where access to specialized services is limited. This quantitative study explores parental stress, financial burden, social stigma, and coping strategies through structured surveys with randomly selected parents of children with ID. Findings reveal high levels of stress, anxiety, and economic hardship, influenced by limited healthcare access, job instability, and social exclusion. The study emphasizes the need for family-centered interventions, improved healthcare services, and targeted support programs to enhance parental resilience and promote social inclusion.

***Keywords**: Intellectual Disability, Parental Stress, Psychosocial Challenges, Coping Mechanisms, Financial Burden, Social Inclusion, Wayanad, Kerala.*

1. Introduction

Intellectual Disability (ID), formerly known as Mental Retardation (MR), is a developmental disorder characterized by below-average intellectual functioning and significant limitations in adaptive behaviors such as communication, self-care, and social skills. It typically manifests before the age of 18 and affects around 2.5–3% of the global population. In Kerala, the prevalence of ID is rising, underscoring the urgent need for effective interventions and support systems. Children with ID often experience delays in reaching developmental milestones like walking and talking, which places a significant burden on their families, particularly parents. These challenges are amplified in rural regions such as Wayanad, where healthcare access and support services are limited. The emotional, social, and financial strains experienced by parents can lead to stigma, isolation, and even marital conflict. Despite various government and non-governmental initiatives, there is a lack of focused research on the psychosocial issues faced by parents in such settings. This study seeks to bridge that gap by exploring the lived experiences of parents raising children with intellectual disabilities in Wayanad district, aiming to inform future policy and intervention strategiesIn addition to the developmental delays and adaptive challenges faced by children with intellectual disabilities, the caregiving role assumed by parents becomes a lifelong responsibility that demands immense emotional resilience and social adjustment. The diagnosis of ID often comes as a shock to families, leading to a reorganization of roles, routines, and priorities within the household. Parents, particularly mothers, may be forced to leave jobs, compromise on personal goals, or experience a decline in their mental health due to constant stress and worry about their child's future. Financial strain is another significant factor, especially in rural areas like Wayanad, where access to specialized education, therapy, and healthcare facilities is scarce or unaffordable. Families often rely heavily on extended relatives or informal community networks for support, which may not always be reliable or effective.

Moreover, societal attitudes toward disability in rural India often contribute to feelings of shame, embarrassment, and social exclusion. Cultural misconceptions and stigma surrounding intellectual disabilities may lead to the isolation of both the child and their caregivers. Public awareness about ID remains low, and many families struggle alone without the knowledge or means to seek professional help. This study is crucial in shedding light on these multifaceted psychosocial challenges and identifying the gaps in support systems. By understanding the real-life experiences of these parents, the research aims to advocate for inclusive policies, improved mental health services, and culturally sensitive interventions that promote the overall well-being of families affected by intellectual disabilities in under-resourced regions like Wayanad.

2. Objectives

The primary objective of this study is to investigate the multifaceted psychosocial challenges encountered by parents raising children with intellectual disabilities (ID) in the Wayanad district of Kerala, a predominantly rural and underserved region. This research seeks to systematically examine the sociodemographic background of these parents and analyze how variables such as income, education, employment status, and family structure influence their caregiving experiences. A core focus of the study is to identify and understand the psychological burden experienced by these parents, including stress, anxiety, depression, and emotional exhaustion, which often result from continuous caregiving and social stigma. Furthermore, the study aims to explore the extent of social problems such as exclusion, marginalization, and the breakdown of social networks due to the perceived societal shame attached to intellectual disabilities. Financial strain is another critical area of inquiry, particularly in the context of limited access to specialized services and increased costs associated with long-term care, therapy, and education. The study also aims to examine the support systems available to these parents, both formal (e.g., healthcare, educational institutions, government programs) and informal (e.g., extended family, community, religious institutions), and assess their adequacy and impact. In doing so, the study aspires to generate evidence that can inform policy development, encourage family-centered service delivery, and promote inclusive practices in education and healthcare. Additionally, by identifying gaps in existing support mechanisms and highlighting the resilience and coping strategies of affected families, the research aims to contribute meaningfully to the discourse on disability, caregiving, and rural mental health in the Indian context.

3. Methods

The study, titled “Psycho-Social Challenges of Parents Raising Children with Intellectual Disabilities: A Study in Wayanad District, Kerala”, was undertaken with the aim of exploring the multifaceted psychological and social difficulties faced by parents of children with intellectual disabilities, particularly in rural settings where awareness, accessibility to services, and support mechanisms are often limited. Despite the existence of national and state-level programs and interventions targeting the welfare of children with disabilities, there remains a significant gap in research concerning the lived experiences and daily realities of caregivers in regions like Wayanad. This study attempts to bridge that gap by offering a comprehensive understanding of their challenges and highlighting the urgent need for inclusive policies, family-centered care, and accessible support services tailored to their unique context.

In order to maintain conceptual clarity and consistency throughout the research, key terms were operationally defined. Mental Retardation (MR) refers to individuals with an Intelligence Quotient (IQ) below 70 along with significant limitations in adaptive behavior, originating before the age of 18. Parental Stress is defined as the emotional and psychological strain resulting from the continuous caregiving demands, uncertainties about the child’s future, and social stigma. Social Isolation refers to the experience of being withdrawn from the community or social networks due to stigma, time constraints, or caregiving responsibilities. Coping Mechanisms are behavioral, cognitive, or emotional strategies employed by parents to manage stress and adapt to caregiving roles. Support Services encompass medical, psychological, educational, and community-based resources available to assist families of children with intellectual disabilities.

A descriptive research design was chosen for the study, as it facilitates the exploration and documentation of the existing conditions, experiences, and perspectives of the respondents without manipulating variables or establishing causal relationships. The study population consisted of parents or primary caregivers—either mothers, fathers, or guardians—of children aged between 5 and 18 years, diagnosed with varying levels (mild to profound) of intellectual disability. These participants were selected from different parts of Wayanad district, Kerala. The inclusion criteria required that the participants be the primary caregivers of children within the specified age range who have been clinically diagnosed with intellectual disability. Parents or caregivers who were experiencing current mental health problems or physical illnesses, as well as those caring for children below the age of 5, were excluded from the study to maintain the reliability of responses and reduce confounding factors.

A total sample of 80 parents was selected through the convenience sampling method due to the geographical and time constraints of the study. The primary data collection tool was a structured, self-developed questionnaire that covered demographic details, perceived psychological stress, social experiences, coping strategies, and access to support services. To enhance the tool's clarity and appropriateness, a pilot study was conducted on April 7–8, 2024, with a small group of participants. Feedback obtained from the pilot study was used to revise ambiguous items and improve overall content validity. Furthermore, a pre-test was carried out on April 26, 2024, with four participants to assess the reliability and consistency of the questionnaire items.

Data were collected from May 1 to May 6, 2024, using a combination of offline methods (direct interactions, interviews, and physical forms) and online surveys via Google Forms to ensure wider reach and flexibility for participants. The responses were coded and entered into SPSS (Statistical Package for the Social Sciences) for analysis. Descriptive statistical tools such as frequency distribution, percentages, and graphical representations were used to interpret and present the findings.

Ethical considerations were meticulously addressed throughout the research process. Prior to data collection, the study proposal received ethical clearance from the Departmental Ethics Committee. All participants were provided with a detailed participant information sheet outlining the purpose of the study, the voluntary nature of participation, and their rights to withdraw at any time without any consequences. Written informed consent was obtained from each participant. Anonymity and confidentiality were strictly maintained, and all collected data were used solely for academic and research purposes.

4. Results

The study revealed significant insights into the psycho-social challenges faced by parents raising children with intellectual disabilities in Wayanad district. One of the key findings pertained to the effect on family dynamics. A considerable proportion of respondents—56.8%—reported that the presence of a child with mental retardation had a noticeable impact on the overall family environment, including increased stress levels, changes in sibling relationships, and altered marital interactions. Conversely, 43.2% of the participants stated that their family dynamics remained unaffected, indicating variability in how families perceive and adapt to the caregiving experience.

Financial strain emerged as a critical issue among the participants. A striking 97.5% of the parents reported facing financial difficulties related to the care of their child. These challenges included increased medical expenses, the need for special educational resources, transportation costs, and in some cases, the loss of income due to a parent reducing or giving up employment to provide full-time care. Only 2.5% of the respondents indicated that they did not experience financial difficulties, highlighting the pervasive nature of economic stress in these households.

Interestingly, despite the psychological and financial burden, none of the respondents—100%—reported experiencing social exclusion. This finding suggests a relatively supportive community or cultural context in Wayanad, where families with children with intellectual disabilities may not be as marginalized as in other settings. It may also reflect strong familial bonds or localized support systems that reduce the feeling of exclusion, although this aspect warrants deeper qualitative exploration.

The study revealed that a significant proportion of the children (84%) had severe mental retardation (MR), followed by 9.8% with moderate MR and 6.2% with mild MR. Among the parents, the most commonly reported issue was mental health problems, indicating a high level of psychological distress associated with caregiving. More than half of the respondents (56.8%) reported experiencing considerable lifestyle changes following the birth of their child with intellectual disabilities. A strong familial support system was evident, as 97.5% of parents stated that they received caregiving support from other family members. Additionally, 88.9% had access to financial or service-related support, although 11.1% reported lacking such assistance. Social isolation emerged as a major concern, with 87.7% of parents feeling isolated due to their caregiving responsibilities, and 90% reporting an inability to attend social events, further reflecting the burden on their social life. Half of the respondents (50%) experienced psychosocial challenges in their daily life, with psychological issues being more prevalent than social ones. Notably, parents of children with severe MR experienced higher levels of psychological distress compared to those with children diagnosed with mild or moderate MR, emphasizing the need for targeted mental health interventions for caregivers in such circumstances.

5.Discussion

The study reveals that the majority of parents of children with MR, particularly severe MR, encounter intense psychological strain, including anxiety, isolation, and financial hardship. Despite receiving caregiving help from family members, many parents still struggle with emotional and social burdens. Contrary to expectations, none of the respondents reported experiencing direct social exclusion, though 87.7% felt isolated due to caregiving demands. This could indicate a nuanced form of internalized exclusion rather than overt discrimination. Parents emphasized the importance of mental health services and social support. The study supports findings from previous literature highlighting the need for structured coping mechanisms, accessible support services, and stigma reduction.

Refrences

[1] ScienceDirect. (n.d.). Retrieved from https://www.sciencedirect.com/

[2] EBSCOhost. (n.d.). Retrieved from https://search.ebscohost.com/

[3] Roos, P. (1977). Parents of mentally retarded people. International Journal of Mental Health, 6(1), 96-119. https://doi.org/10.1080/00207411.1977.11448758

[4] Parenting | Britannica. (2024, January 10). Retrieved from https://www.britannica.com/topic/parenting

[5] Meng, W., et al. (2022). A lightweight CNN and Transformer hybrid model for mental retardation screening. Computers in Biology and Medicine, 151, 106281. https://doi.org/10.1016/j.compbiomed.2022.106281

[6] Murray, M. A. (2002). Needs of parents of mentally retarded children. In J. Blacher & B. Baker (Eds.), 49–56. Retrieved from https://books.google.com/