

Coping Strategies of Family Caregivers of Children with Intellectual Disability with Special Reference to Ashadeep- A Mental Health Society.

Manoj Kumar Sarmah¹, Dr. Gayatree Goswamee²

¹Research Scholar, Dept. of Education, Gauhati University

²Former Prof. & HOD, Dept. of Education, Gauhati University

Abstract

Intellectual disability originates during the developmental period and results in significantly sub average general intellectual function with concurrent deficits in functional life skills. Family caregivers of children with intellectual disability play a crucial role in the overall development and well-being of their children, often facing considerable psychological, social, and economic challenges. The present study aims to examine the coping strategies adopted by family caregivers of children with intellectual disability, with special reference to Ashadeep – A Mental Health Society, Guwahati, Assam. Using a descriptive survey method, the study was conducted on a purposively selected sample of family caregivers whose children are enrolled in Ashadeep. Data were collected through a standardized stress coping strategy scale. The coping strategies were analyzed under various dimensions such as avoidance, diet control, psycho-medicinal therapy, most liked activities, outer wall strategy and reducing physical stress. The data indicate that caregivers primarily employ adaptive coping techniques, including seeking social support, positive reframing, and problem-solving, while a modest degree of emotional stress and avoidance behavior was also noted.

Keywords: Intellectual Disability, Family Caregivers, Coping Strategies.

1. Introduction

Intellectual disability (ID) is often referred to as Mental retardation is a generalised neurodevelopmental condition marked by significantly decreased cognitive and adaptive functioning. It is characterised by deficiencies in two or more adaptive behaviours that impact daily living and an IQ of less than 70. In the past, the definition of ID was limited to a person's impairment of cognitive function. These days, it encompasses impairment in both cognitive and functional skills related to daily living (adaptive skills). Thus, a notable impairment in cognitive and adaptive behaviour is an indicator of intellectual disability. Intellectual disability is a disorder that has significant societal consequences; it impacts not just the individual with the disability but also the family and the community at large.

According to the tenth revision of the WHO (World Health Organization): Intellectual disability (ID) is a disorder defined by the presence of incomplete or arrested mental development, principally characterized by the deterioration of concrete functions at each stage of development and that contribute to the overall

level of intelligence, such as cognitive, language, motor and socialization functions; in this anomaly, adaptation to the environment is always affected. Children with disabilities experience social isolation, neglect, deprivation in society, and being apart from another child. Potentially, these negative attitudes of rejection and isolation can have an effect on the family caregivers' emotional and psychological health. By adopting different strategies for coping, parents and other family caregivers are able to manage the duties and stress associated with looking after their disabled child. Encouraging children with intellectual disabilities requires family caregivers to change to many aspects of their daily lives in addition to giving the child the attention they need. The particular behavioural and psychological techniques people employ to accept, lessen, or manage stressful situations are known as coping strategies. Caregivers of children with intellectual disabilities may face significant stress and challenges in raising them, which can affect their social lives.

Rationale of the Study: Families are essential in the upbringing, growth, and overall welfare of children with intellectual disabilities. Within the Indian socio-cultural framework, families, especially parents, function as the principal caregivers, offering ongoing emotional, physical, social, and financial assistance. Emotional distress, social isolation, financial hardship, and physical tiredness are just a few of the many difficulties that caregivers face when raising a child with an intellectual disability. These difficulties may eventually have a negative impact on the caregiver's quality of life, family ties, and mental health. Therefore, creating efficient support networks and interventions requires an understanding of how family caregivers manage these responsibilities. Family caregivers, who are often parents or close relatives, are the most crucial element in promoting the development and wellbeing of such children. However, this duty frequently leads to a lot of stress, emotional strain, financial difficulties, and social isolation. In the absence of good coping mechanisms, caregivers may experience burnout, anxiety, despair, or loneliness, all of which can affect the quality of care provided to the child. Therefore, it is crucial to comprehend the coping mechanisms used by family caregivers in order to recognize the advantages and disadvantages they encounter when providing care. Research on coping strategies used by families of children with intellectual disabilities in Assam is limited. Ashadeep – A Mental Health Society, Guwahati, has been playing a significant role in supporting family caregivers through training, awareness on coping skills. Conducting a study with special reference to Ashadeep will not only highlight the strategies employed by caregivers associated with this institution but will also generate insights relevant to similar communities across the region. Ultimately, this research will contribute to improving the quality of life of both caregivers and children with intellectual disability by fostering resilience, promoting adaptive coping, and informing policy and practice in the field of mental health and disability care.

Objectives of the Study:

- 1) To study the coping strategies used by family caregivers in raising a child with intellectual disability.
- 2) To explore the challenges faced by family caregivers in caring for children with intellectual disability.

Review of Related Literature:

Chaudhary et al. (2025) conducted a cross-sectional study involving 96 caregivers of children with intellectual disabilities aged 3–18 years attending the Psychiatry Department of Rajshree Medical Research Institute, Bareilly. Using a sociodemographic questionnaire and the Caregiver Strain Index (CSI), the study assessed caregiver burden and coping strategies. The findings revealed that parents experienced a high level of caregiver burden, which varied according to demographic characteristics. The study emphasized the need for accessible, integrated, and culturally sensitive support services to address the physical and psychological well-being of caregivers, particularly those from economically disadvantaged backgrounds.

Moyo and Maunganidze (2025) conducted a qualitative phenomenological study among eight parents of children with intellectual disabilities aged 5–18 years attending special schools in Harare, Zimbabwe. Data collected through in-depth interviews were analysed using thematic analysis to explore parental experiences, coping strategies, and support systems. The findings revealed that parents faced multiple challenges, including behavioural difficulties, financial constraints, cultural barriers, and interpersonal issues. The study further reported that prolonged caregiving responsibilities contributed to increased stress, trauma, and emotional distress among parents, highlighting the need for effective support services and interventions for families of children with intellectual disabilities.

Lakhani et al. (2024) conducted a study to examine the coping mechanisms and informal social support experiences of families raising a child with intellectual disability. The study aimed to identify the challenges faced by these families and explore their social support needs. The findings revealed that parents frequently experience social, psychological, and financial difficulties while caring for a child with intellectual disability. The review highlighted the crucial role of informal social support and emphasized the importance of adopting effective coping strategies at an early stage to manage caregiving challenges and enhance family well-being.

These studies have consistently emphasized the substantial caregiving burden faced by families of children with intellectual disability. These studies collectively demonstrate that parenting for children with intellectual disabilities presents multifaceted problems and highlight the need to enhance support systems and foster adaptive coping skills among family caregivers.

Research Method used in the Present Study: The present study adopted a descriptive survey research method to investigate the coping strategies of family caregivers of children with intellectual disability, with special reference to Ashadeep.

Identification of Population for the present Study: The target population of the study consists of- All parents who are primarily responsible for the daily care, supervision, and emotional support of children with intellectual disability enrolled in Ashadeep -A Mental Health Society, located in Guwahati, Assam. These caregivers represent diverse socio-economic and educational backgrounds and have been associated with Ashadeep for varying durations.

Sampling Technique: The present study adopted the purposive sampling technique, a form of non-probability sampling. In purposive sampling, the researcher intentionally chooses individuals who have particular features or experiences pertinent to the study's objectives. This research targets family caregivers

of children with intellectual disabilities; therefore, purposive sampling is the most suitable method, as it enables the researcher to select individuals possessing direct and substantial caregiving experience with children diagnosed with intellectual disabilities, specifically those affiliated with Ashadeep.

Sample for the Present Study: The sample for this study comprised family caregivers of children with intellectual disabilities enrolled at Ashadeep. A sample of 50 family caregivers was selected through purposive sampling, since they fulfilled the precise criteria of the study objectives. The sample comprised caregivers who were parents largely accountable for the daily care, supervision, training, and emotional support of children diagnosed with intellectual disabilities. Only caregivers of children who had received a clinical diagnosis and were registered at Ashadeep, and who consented to participate in the study, were included.

Tool Used in the Study: For this study, the data were collected from family caregivers by using self-structured interview schedule prepared by the investigator which comprise 24 statements including open ended and close ended questions related to coping skills and challenges faced by family caregivers while caring the children with intellectual disabilities. The tool was found to be reliable and valid as reported by the authors and was considered appropriate for the present study as it effectively measures stress coping strategies among family caregivers.

Statistical Techniques Used for Data Analysis: The collected data were examined employing descriptive statistical methods. Frequency and percentage were employed to examine the demographic features of the respondents and the coping mechanisms utilized by family caregivers of children with intellectual disabilities. The results were displayed in a tabular format and analyzed about the study's objectives.

Analysis and Interpretation of Data:

The data collected from 50 family caregivers of children with intellectual disability were analyzed using appropriate statistical techniques in accordance with the objectives of the study.

Table 1

Demographic Profile of Family Caregivers of Children with Intellectual Disability

(N = 50)

Variable	Category	Frequency	Percentage
Age Group	20–29 years	6	12.0
	30–39 years	18	36.0
	40–49 years	15	30.0
	50–59 years	8	16.0
	60 years and above	3	6.0

Gender	Male	25	50.0
	Female	25	50.0
	Other	00	00
Educational Qualification	Below HSLC	10	20.0
	HSLC	14	28.0
	Higher Secondary	11	22.0
	Degree	10	20.0
	Postgraduate	5	10.0
Religion	Hinduism	37	74.0
	Islam	9	18.0
	Christianity	2	4.0
	Others	2	4.0
Family type	Joint Family	14	28.0
	Nuclear Family	36	72
Monthly Family Income	Below ₹10,000	12	24.0
	₹10,000–₹20,000	23	46.0
	Above ₹20,000	15	30.0
Occupation	Cultivation	8	16.0
	Business	6	12.0
	Private Company Employee	5	10.0
	Housewife	12	24.0
	Service	10	20.0
	Daily Wage Labourer	9	18.0

Interpretation: The demographic analysis of the 50 family caregivers indicated that the predominant age group was 30–39 years, comprising 36.0%, followed by the 40–49 years group at 30.0%. The sample comprised an equal representation of male and female caregivers, each constituting 50.0%. Concerning educational qualifications, 28.0% had completed High School Leaving Certificate (HSLC), whereas 22.0% had attained Higher Secondary education. A majority of caregivers identified as Hindu (68.0%). A majority (58.0%) resided in nuclear families. Approximately 46.0% of the participants indicated a monthly

household income ranging from ₹10,000 to ₹20,000. Housewives were the predominant occupational category at 24.0%, followed by service holders at 20.0% and daily wage labourers at 18.0%. The data suggest that caregiving duties were primarily undertaken by middle-aged married individuals from nuclear families with average educational and economic status.

Objective 1

To study the coping strategies used by family caregivers in raising a child with intellectual disability.

Table 2

Coping Strategies Used by Family Caregivers of Children with Intellectual Disability

(N = 50)

SL. NO	COPING STRATEGY	YES FREQUENCY (%)	SOMETIMES FREQUENCY (%)	NO FREQUENCY (%)
1.	Received training on coping skills	18 (36.0)	-	32 (64.0)
2.	Seek support from relatives, friends and neighbours	30 (60.0)	15 (30.0)	5 (10.0)
3.	Seek information from families facing similar problems	28 (56.0)	12 (24.0)	10 (20.0)
4.	Take advice from professionals	35 (70.0)	10 (20.0)	5 (10.0)
5.	Participate in religious/spiritual programmes	32 (64.0)	10 (20.0)	8 (16.0)
6.	Seek advice from religious leaders	20 (40.0)	15 (30.0)	15 (30.0)
7.	Have faith in God/higher power	45 (90.0)	--	5 (10.0)
8.	Take help from counsellors	22 (44.0)	10 (20.0)	18 (36.0)
9.	Attend outreach programmes	24 (48.0)	15 (30.0)	11 (22.0)
10.	Accept stressful events as a fact of life	38 (76.0)	--	12 (24.0)
11.	Search internet for information	25 (50.0)	10 (20.0)	15 (30.0)
12.	Member of support groups	12 (24.0)	--	38 (76.0)
13.	Practice meditation/relaxation techniques	27 (54.0)	13 (26.0)	10 (20.0)

14.	Seek emotional support from others	29 (58.0)	12 (24.0)	9 (18.0)
15.	Engage in recreational activities	26 (52.0)	15 (30.0)	9 (18.0)
16.	Discuss problems with similar families	31 (62.0)	10 (20.0)	9 (18.0)
17.	Focus on positive aspects of life	34 (68.0)	10 (20.0)	6 (12.0)
18.	Spend quality time with child	42 (84.0)	6 (12.0)	2 (4.0)
19.	Express negative feelings with others	23 (46.0)	15 (30.0)	12 (24.0)
20.	Learnt to live with the situation	40 (80.0)	--	10 (20.0)

Interpretation

The results demonstrate that family caregivers utilize diverse coping mechanisms when caring for children with intellectual disabilities. A significant majority (90%) indicated belief in God or a higher power, implying that spiritual coping serves as a vital source of support. Likewise, 84% of caregivers reported engaging in quality time with their child, but 80% claimed that they had adapted to the situation, demonstrating acceptance-based coping. Professional assistance was also apparent, with 70% of caregivers consulting experts. Social support proved to be a significant coping strategy, with 60% seeking assistance from relatives, friends, and neighbours, while 62% engaged in discussions about their issues with families encountering analogous difficulties. Over 50% percent of caregivers indicated employing constructive coping mechanisms, including meditation and relaxation techniques (54%), participation in leisure activities (52%), emphasis on positive life aspects (68%), and pursuit of emotional support from others (58%). Nonetheless, merely 24% were affiliated with support organizations, signifying restricted access to structured support networks. Likewise, fewer than half (44%) indicated that they received assistance from professional counsellors.

The findings indicate that caregivers primarily depend on acceptance, spiritual beliefs, social support, and professional guidance to manage the problems of caring for children with intellectual disabilities.

Objective No. 2:

To explore the challenges faced by family caregivers in caring for children with intellectual disability.

The objective is analysed through open-ended Questions of the interview schedule. The responses of the 50 caregivers are categorized into major themes, and frequencies and percentages calculated for each theme as below:

Table 3

Challenges Faced by Family Caregivers in Caring for Children with Intellectual Disability (N = 50)

Serial No	Major Challenges Identified	Frequency (f)	Percentage (%)
1	Concern about the child's future and long-term care	24	48.0
2	Emotional stress, anxiety and psychological burden	20	40.0
3	Financial difficulties related to treatment, education and rehabilitation	18	36.0
4	Lack of specialized services and professional support	15	30.0
5	Behavioural problems of the child (aggression, hyperactivity, tantrums, etc.)	14	28.0
6	Social stigma, discrimination and negative attitudes of society	13	26.0
7	Lack of social and family support	11	22.0
8	Difficulty in balancing caregiving responsibilities with work and family life	10	20.0
9	Limited educational opportunities for the child	8	16.0
10	Physical exhaustion and health-related problems of caregivers	7	14.0

Interpretation: Table 3 illustrates the primary challenges encountered by family caregivers in the care of children with intellectual disabilities. The results indicate that apprehension about the child's future and long-term care was the most commonly stated problem, articulated by 48.0% of caregivers. Numerous caregivers expressed concern regarding who would assume responsibility for their child following their demise or in the event of their incapacitation. The second most prevalent difficulty was emotional stress, anxiety, and psychological burden (40.0%). Caregivers indicated enduring stress stemming from ongoing caregiving duties, uncertainty over the child's growth, and apprehensions about the future.

Financial troubles represented a significant challenge, as mentioned by 36.0% of respondents. Costs associated with medical treatment, special education, therapy, transportation, and rehabilitation programs imposed significant financial burdens on families. Approximately 30.0% of caregivers indicated a

deficiency in specialized services and professional support, highlighting challenges in obtaining access to qualified specialists, counselling services, therapy centres, and rehabilitation facilities. Likewise, 28.0% identified the child's behavioural issues, including aggression, hyperactivity, self-injurious behavior, and communication challenges, as a major source of stress. Moreover, 26.0% of caregivers encountered societal stigma and discrimination, frequently stemming from misconceptions and adverse perceptions regarding intellectual disability. Approximately 22.0% indicated insufficient social and familial assistance, hence exacerbating their caregiving burden. Additional hurdles were the equilibrium of caring obligations with professional and domestic responsibilities (20.0%), restricted educational prospects for children with intellectual disabilities (16.0%), and physical fatigue and health issues among caregivers (14.0%).

Discussion and Findings:

This study examined the demographic traits, coping mechanisms, and difficulties encountered by family caregivers of children with intellectual disabilities. The demographic analysis indicated that the majority of caregivers were aged between 30 and 49 years, signifying that caring duties were predominantly undertaken by middle-aged individuals. The study ensured equal representation of male and female caregivers. The majority of respondents had attained secondary or higher secondary education, were from Hindu families, resided in nuclear family structures, and indicated a monthly family income ranging from ₹10,000 to ₹20,000. The majority were married with two children, while housewives and service employees were the predominant occupational categories. The data indicate that caregiving is predominantly performed by parents who concurrently handle familial, professional, and social obligations.

The study indicated that caregivers employed diverse coping techniques to address the challenges of caring for a kid with an intellectual handicap. Faith in God or a higher power was identified as the predominant coping method, succeeded by engaging in quality time with the child, embracing stressful circumstances as inherent to life, and adapting to the child's condition. Positive coping strategies, including emphasizing life's favourable elements, seeking information, engaging in religious activities, and employing relaxation techniques, were also apparent. These data suggest that caregivers primarily utilize spiritual, emotional, social, and problem-focused coping techniques to manage caring duties. Despite the implementation of many coping strategies, caregivers indicated numerous difficulties. The foremost barrier identified was concern for the child's future, succeeded by mental stress, financial challenges, insufficient specialized resources, the child's behavioural issues, and social stigma. Caregivers expressed insufficient social support, challenges in reconciling caregiving with professional and familial obligations, and physical fatigue. These problems underscore the complex burden faced by family caregivers and illustrate the necessity for enhanced institutional, social, and professional support.

Overall, the findings suggest that while family caregivers employ diverse coping strategies to manage the demands of caregiving, they continue to face substantial emotional, social, and economic challenges. Therefore, strengthening caregiver support through counselling services, parent training programmes, community awareness initiatives, financial assistance, and accessible rehabilitation services is essential for improving the well-being of both caregivers and children with intellectual disability.

Suggestions

The study's findings indicate that government agencies, educational institutions, rehabilitation centres, and non-governmental groups should collaborate to offer comprehensive support services for family caregivers of children with intellectual disabilities. Systematic parent training programs, counselling services, caregiver support groups, and awareness initiatives should be implemented to improve caregivers' coping abilities and psychological health. Promotion of community-based support systems and inclusive social initiatives is essential to mitigate stigma and foster social acceptance of children with intellectual disabilities. Such measures can assist caregivers in navigating caring problems more efficiently and enhance the overall quality of life for both caregivers and their children.

References

1. Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation*, 107(6), 433–444.
2. Hastings, R. P., Beck, A., & Hill, C. (2005). Positive contributions made by children with an intellectual disability in the family: Mothers' and fathers' perceptions. *Journal of Intellectual Disabilities*, 9(2), 155–165.
3. Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Degli Espinosa, F., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9(4), 377–391.
4. Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, S. (2010). Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities* (pp. 241–278). Springer.
5. Beighton, C., & Wills, J. (2017). Are parents identifying positive aspects to parenting their child with an intellectual disability or are they just coping? A qualitative exploration. *Journal of Intellectual Disabilities*, 21(4), 325–345.
6. Beighton, C., & Wills, J. (2019). How parents describe the positive aspects of parenting their child who has intellectual disabilities: A systematic review and narrative synthesis. *Journal of Applied Research in Intellectual Disabilities*, 32(5), 1255–1279.
7. Sharma, M. K., & Sharma, S. (2019). *Stress coping strategies scale manual*. National Psychological Corporation.
8. Burke, M. M., Rios, K., Aleman-Tovar, J., Lee, C. E., Arnold, C. K., & Owen, A. (2020). Exploring the nature and correlates of caregiving among parents of adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 33(6), 1259–1267.
9. Lal, N. A., & Rajan, E. J. E. (2020). Extent and determinants of parenting stress in parents of children with intellectual disability, specific learning disability and slow learners. *International Journal of Indian Psychology*, 8(2), 708–720.
10. Kurowska, A., Kózka, M., & Majda, A. (2021). How to cope with stress? Determinants of coping strategies used by parents raising children with intellectual disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, 14(1), 23–49.

11. Staunton, E., Kehoe, C., & Sharkey, L. M. (2023). Families under pressure: Stress and quality of life in parents of children with intellectual disability. *Irish Journal of Psychological Medicine*, 40(2), 167–175.
12. World Health Organization. (2024). *Disability*. World Health Organization.
13. Gong, J., Chenand, M., & Li, Q. (2025). Understanding What Drives Nursing Undergraduates to Pursue Postgraduate Entrance: Insights from a Qualitative Study. *Journal of Integrative Nursing and Palliative Care*, 6(1), 24–33.
14. Lakhani, A., Ali, T. S., Ashraf, D., & Roy, D. K. (2025). Exploring informal social support experiences and coping strategies in families raising a child with an intellectual disability. *The Family Journal*, 33(1).