CARE GIVING PRACTICES AND EXPERIENCES OF CAREGIVERS OF ADULTS WITH INTELLECTUAL DISABILITY.

A Dissertation submitted to the University of Kerala in Partial Fulfilment of Requirements for the Master of Social Work Degree Examination.

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CERTIFICATE OF APPROVAL

This is to certify that this dissertation entitled **"Care giving Practices and Experiences of Caregivers of Adults with Intellectual Disability."** is a record of genuine work done by Ms. ASHILY P.H, fourth semester Master of Social Work student of this college under my supervision and guidance and that it is hereby approved for submission. Date: 10-07-2026 Thiruvananthapuram Research.

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DECLARATION

I, ASHILY P.H do hereby declare that the dissertation titled "**Care giving Practices and Experiences of Caregivers of Adults with Intellectual Disability.**" is the result of my original research conducted during the academic years 2024-2026. This work is submitted to the University of Kerala as part of the requirements for the **Master of Social Work** Degree Examination. I confirm that it has not been previously submitted for any other degree, diploma, fellowship, or similar academic recognition.

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ABSTRACT

This study focuses the caregiving practices and experiences of caregivers of adults with Intellectual Disability in Thiruvananthapuram district, Kerala. Caring for adults with Intellectual Disability is a lifelong responsibility that extends beyond meeting physical needs and includes providing emotional support, supervision, behaviour management, and assistance with daily living activities. Although considerable attention has been given to childhood interventions, relatively little research has focused on the lived experiences of caregivers during the adulthood of individuals with Intellectual Disability. The present study seeks to understand the everyday caregiving practices, challenges, emotional experiences, and support systems of family caregivers.The study adopted a qualitative research approach using a multiple case study design. A purposive sampling technique was employed to select caregivers of adults with Intellectual Disability residing in Thiruvananthapuram district. Data were collected through semi-structured, in-depth interviews, allowing participants to share their experiences freely. The collected data were transcribed, coded, and analysed using thematic analysis, resulting in four major themes: caregiving practices in daily life, emotional and social behaviour of adults with Intellectual Disability, skill development and daily functioning, and caregiver experiences, challenges, and support systems.

The findings reveal that caregiving is a continuous and demanding responsibility requiring constant supervision, patience, and emotional involvement. Caregivers experienced emotional stress, financial burden, concerns regarding the future care of the individual, and limitations in their personal and social lives. Despite these challenges, they demonstrated resilience and commitment while relying primarily on family support, with limited access to formal support services.The study highlights the need for strengthening family-centred support services, caregiver counselling, community awareness programmes, respite care services, and policies that recognise and address the needs of caregivers of adults with Intellectual Disability. The findings contribute to the field of social work by providing a deeper understanding of long-term family caregiving.

Keywords: Intellectual Disability, caregivers, caregiving practices, caregiving experiences, family caregiving, thematic analysis, social work.

CHAPTER I

INTRODUCTION

CHAPTER I: INTRODUCTION

1.1 Introduction

Intellectual Disability is a lifelong condition that affects an individual's intellectual functioning and adaptive behaviour, including communication, social interaction, and daily living skills. Although the condition begins before the age of 18, its impact continues throughout adulthood. Many adults with Intellectual Disability require continuous support in their daily lives, especially in areas such as self-care, emotional regulation, and social participation.

Although significant advances have been made in the fields of healthcare, education, and rehabilitation, adulthood continues to be one of the least explored stages in the lives of persons with Intellectual Disability. During childhood and adolescence, individuals often receive structured educational programmes, therapeutic interventions, and family-centred support aimed at promoting their development. However, once they reach adulthood, opportunities for structured learning, vocational engagement, community participation, and rehabilitation frequently become limited. Consequently, many adults with Intellectual Disability continue to depend on their families for assistance in managing everyday activities, making family caregiving a lifelong responsibility rather than a temporary role.

The transition from adolescence to adulthood also brings changes in the nature of caregiving. As adults with Intellectual Disability grow older, their social, emotional, and practical needs evolve, requiring caregivers to adapt their approaches accordingly. Responsibilities that were once associated with parenting a child gradually transform into long-term support involving supervision, decision-making, emotional guidance, healthcare management, and assistance with participation in community life. This transition often places additional demands on caregivers, who must balance caregiving responsibilities with their own personal, occupational, and family commitments.

In most cases, this responsibility is taken up by caregivers, who are usually family members such as parents, siblings, or close relatives. Caregiving is not limited to physical assistance, but also includes emotional support, behaviour management,

supervision, and decision-making. Over time, caregiving becomes a central part of the caregiver's life, influencing their routine, relationships, and overall well-being.

The caregiving role also changes as adults with Intellectual Disability progress through different stages of adulthood. Unlike caregiving during childhood, adult caregiving often extends over several decades and requires continuous adaptation to changing physical, emotional, and social needs. As caregivers themselves grow older, they frequently experience increasing concerns regarding their own health, financial security, and ability to continue providing care. These changing circumstances make caregiving a dynamic and lifelong process that requires resilience, flexibility, and sustained commitment.

Caregiving is therefore not merely a series of routine activities but a continuous process of responding to changing needs across different life situations. Caregivers often modify their caregiving approaches based on the individual's level of independence, behavioural responses, health status, and social environment. Such flexibility enables caregivers to support both daily functioning and long-term development while maintaining stability within the family.

Family caregivers occupy a unique position in the lives of adults with Intellectual Disability because they are involved in almost every aspect of everyday living. Their responsibilities extend beyond meeting physical needs and include encouraging independence, promoting social participation, managing behavioural concerns, providing emotional reassurance, and advocating for the rights and well-being of the individual. Through continuous interaction, caregivers develop a detailed understanding of the individual's abilities, preferences, behavioural patterns, and support needs. Such knowledge enables them to respond to changing situations in ways that formal service providers may not always be able to achieve.

Caregiving practices play an important role in shaping the behaviour and emotional development of adults with Intellectual Disability. According to Social Learning Theory (Bandura) (1977), individuals learn behaviours through observation and interaction with significant others. In this context, caregivers act as primary models, and their actions, communication style, behavioural responses, and reinforcement

strategies influence the development of adaptive behaviours, emotional regulation, and social functioning among adults with Intellectual Disability."

At the same time, caregiving is a complex and demanding experience. Studies have shown that caregivers often experience emotional stress, financial burden, and social challenges.Some studies highlighted that caregiving in India involves continuous supervision, physical effort, and emotional involvement, often with limited institutional support. Similarly, other studies found that caregivers experience high levels of psychological stress and reduced quality of life, mainly due to financial strain and lack of formal support systems.

Providing long-term care to an adult with Intellectual Disability involves multiple responsibilities that extend beyond physical assistance. Caregivers frequently coordinate healthcare, supervise daily activities, manage behavioural concerns, facilitate communication, encourage participation in family and community life, and support decision-making. These responsibilities often influence caregivers' emotional well-being, physical health, family relationships, employment opportunities, and financial stability. The extent of these experiences may vary depending on the level of disability, availability of support systems, and the family's socio-economic circumstances.Caregiving experiences are also shaped by social and cultural factors. In many Indian families, caregiving responsibilities are shared within the family, but the primary burden often falls on one individual. Social stigma, lack of awareness, and limited access to services further increase the challenges faced by caregivers.

The emotional dimension of caregiving is equally important. Qualitative studies, such as Sopingi (2024), have shown that caregivers experience a range of emotions including stress, responsibility, and personal growth. Caregiving is often described as a continuous learning process, where individuals develop resilience and coping strategies over time. This aligns with Caregiver Stress Theory, which explains how long-term caregiving can lead to emotional and physical strain, especially when adequate support is not available.

In the Kerala context, caregiving experiences are influenced by local cultural values, family structures, and availability of services. Studies conducted in Kerala, such as IJIP

(2023), have shown that caregivers face emotional stress while managing behavioural and social challenges, along with a strong sense of responsibility. However, there is limited research focusing specifically on caregivers of adults with Intellectual Disability, especially in understanding their daily practices and lived experiences.

Therefore, this study focuses on exploring the caregiving practices and experiences of caregivers of adults with Intellectual Disability in Thiruvananthapuram. The study aims to understand how caregivers manage daily responsibilities, how they experience caregiving, the challenges they face, and the support systems available to them. Despite the growing recognition of disability rights and the expansion of welfare programmes, the everyday realities of caregivers of adults with Intellectual Disability remain insufficiently documented, particularly within qualitative research conducted in Kerala. Much of the available literature has concentrated on childhood interventions, parental stress, or developmental outcomes, while comparatively little attention has been given to understanding how caregivers experience long-term caregiving during adulthood. Exploring these experiences is important because caregiving responsibilities often continue throughout the lifespan and influence not only the well-being of the individual with Intellectual Disability but also the quality of life of the caregiver and the family as a whole.

Understanding caregiving from the perspective of caregivers themselves provides valuable insights into the practical realities, emotional experiences, coping strategies, and support needs associated with long-term family care. Such understanding is essential for developing responsive social work interventions, strengthening community-based support services, and informing policies that promote the well-being of both caregivers and adults with Intellectual Disability.

1.2 Statement of the Problem

Caregivers of adults with Intellectual Disability play a central role in supporting their daily functioning and well-being. Despite their important role, they often face multiple challenges including emotional stress, financial burden, and lack of formal support systems.

Existing studies have mainly focused on parenting stress, emotional development, and caregiving during childhood or adolescence. There is limited research that explores caregiving practices and lived experiences in adulthood, especially in the Indian and Kerala context.In Thiruvananthapuram district, there is a lack of qualitative studies focusing on how caregivers manage daily caregiving, how they experience this responsibility, and what challenges they face over time.

The increasing life expectancy of persons with Intellectual Disability has resulted in a growing number of families providing care well into adulthood. Unlike childhood, adulthood is characterised by changing developmental needs, greater expectations for community participation, vocational engagement, and independent living. However, many adults with Intellectual Disability continue to require substantial assistance in areas such as personal care, communication, decision-making, social relationships, and everyday functioning. Consequently, family caregivers often continue to provide long-term support for many years, making caregiving an enduring responsibility rather than a temporary role.

Although the demand for long-term caregiving has increased, comparatively little attention has been given to understanding the experiences of caregivers during adulthood. Much of the existing literature focuses on childhood intervention, educational outcomes, or parental stress during the early years. As a result, there is limited qualitative evidence regarding how caregivers adapt to changing responsibilities, manage daily caregiving practices, and cope with the long-term emotional, social, and practical demands associated with adulthood.

According to the World Health Organization (WHO), approximately 1% of the global population lives with Intellectual Disability, making it one of the most common developmental disabilities worldwide. In India, a significant number of persons with Intellectual Disability continue to live with their families throughout adulthood and depend on family caregivers for support in daily functioning, social interaction, healthcare management, and decision-making. Census data and disability reports indicate that a considerable proportion of persons with intellectual and developmental disabilities require varying levels of lifelong assistance, placing long-term caregiving

responsibilities on family members. As life expectancy has increased among persons with disabilities, the duration of caregiving has also extended, often continuing for several decades. This prolonged responsibility may affect caregivers physically, emotionally, socially, and economically. Many caregivers experience restrictions in employment opportunities, reduced social participation, increased financial expenditure, and constant concern regarding the future care and security of their family member. Despite the growing number of adults with Intellectual Disability requiring long-term support, limited attention has been given to understanding the everyday caregiving practices and personal experiences of caregivers in the local context. Therefore, an in-depth exploration of these experiences is essential for understanding their realities and for developing appropriate support mechanisms and social welfare interventions.

The caregiving role becomes particularly complex during adulthood because the developmental and social needs of adults with Intellectual Disability differ from those of children. While educational and rehabilitation services are often available during childhood and adolescence, support services tend to decrease once the individual reaches adulthood. As a result, families frequently become the primary and sometimes the only source of care and support. Caregivers are expected to assist in areas such as personal hygiene, medication management, mobility, social interaction, emotional well-being, and participation in community life. In many cases, the level of dependence remains unchanged over the years, requiring caregivers to provide support on a daily basis without significant periods of relief. Such long-term responsibilities can influence family relationships, employment opportunities, leisure activities, and overall quality of life. Understanding how caregivers manage these responsibilities in their everyday lives is therefore essential for gaining a comprehensive understanding of caregiving in adulthood.

Research findings from different parts of the world have consistently highlighted the multidimensional impact of caregiving on family members of persons with Intellectual Disability. Several studies have reported elevated levels of stress, anxiety, emotional exhaustion, and social isolation among caregivers. Financial challenges are also frequently reported due to healthcare expenses, transportation costs, specialised

services, and reduced opportunities for regular employment. In developing countries, where disability services may be limited and family-based care remains the dominant model of support, caregivers often shoulder these responsibilities with minimal professional assistance. The burden becomes more pronounced when caregivers themselves are ageing, experiencing health problems, or managing multiple family responsibilities simultaneously. Despite these realities, many caregivers continue to demonstrate resilience, commitment, and adaptability in meeting the needs of their family members. Exploring these experiences can provide valuable insights into both the challenges and strengths associated with long-term caregiving.

Caregiving experiences are not uniform across families but are influenced by several contextual factors, including the severity of disability, family composition, socioeconomic circumstances, availability of support networks, and accessibility of rehabilitation services. These factors shape the ways in which caregivers organise daily routines, respond to behavioural needs, and manage the demands associated with long-term caregiving. Understanding these differences is important for developing interventions that reflect the diverse realities of caregivers rather than assuming that all caregiving experiences are similar.

While caregiving is frequently associated with stress and burden, it also involves resilience, adaptation, and the development of practical knowledge over time. Many caregivers gradually acquire effective strategies for communication, behaviour management, and emotional support through continuous interaction with the individual. Examining both the challenges and strengths experienced by caregivers provides a more balanced understanding of caregiving and contributes to the development of family-centred and strengths-based social work interventions.

In Kerala, considerable progress has been made in the fields of education, healthcare, and social welfare. However, the availability of specialised services for adults with Intellectual Disability remains limited when compared to the growing needs of this population. Families often rely on informal support networks, including relatives, neighbours, and community members, to cope with caregiving responsibilities. Access to respite care, vocational opportunities, independent living programmes, and long-term

residential facilities continues to be inadequate for many families. Consequently, caregivers may experience uncertainty regarding future planning, social security, and sustainable support arrangements for their family members. These concerns are particularly significant in the case of ageing caregivers who worry about the continued care and protection of adults with Intellectual Disability after their own lifetime. Examining caregiving practices and experiences within the local context of Thiruvananthapuram can therefore contribute to a better understanding of existing needs and gaps in support services.

The present study seeks to address these concerns by examining the caregiving practices and experiences of caregivers of adults with Intellectual Disability in Thiruvananthapuram district. By focusing on their daily caregiving responsibilities, emotional experiences, challenges, coping strategies, and available support systems, the study attempts to provide a deeper understanding of the realities of long-term caregiving. The findings may contribute to the development of more responsive social work interventions, community support programmes, caregiver assistance services, and policy measures aimed at enhancing the well-being of both caregivers and adults with Intellectual Disability.

1.3 Scope of the Study

This study focuses on caregivers of adults (18 years and above) with Intellectual Disability in Thiruvananthapuram district. It mainly explores caregiving practices, lived experiences, challenges, and support systems within the family and community context.The scope of the study is limited to informal caregivers, especially family members such as parents, siblings, and relatives, who take primary responsibility for caregiving. The study does not focus on institutional caregivers or professionals, but rather on those who provide care in a home setting.

The study also focuses on understanding caregiving in the context of adulthood, which is often less explored compared to childhood and adolescence. Previous studies have mainly concentrated on parenting practices and developmental outcomes in children with Intellectual Disability (Sopingi et al., 2024; Scripps et al., 2025). However,

caregiving responsibilities continue even after the individual reaches adulthood, often with increased dependency and long-term support needs.

The study also attempts to understand caregiving as a dynamic and evolving process rather than a set of routine activities. Caregiving responsibilities often change according to the age, health condition, behavioural patterns, and support needs of the adult with Intellectual Disability. Therefore, the study provides an opportunity to examine how caregivers adapt their practices over time and how they respond to emerging challenges in everyday life. By focusing on the experiences of caregivers from different family backgrounds, the study seeks to capture variations in caregiving practices and the factors that influence them.

Another important aspect within the scope of the study is the exploration of caregiver perceptions regarding the emotional and social development of adults with Intellectual Disability. Caregivers spend a significant amount of time with the individual and possess valuable knowledge regarding behavioural patterns, emotional expressions, interpersonal relationships, and daily functioning. Their observations can provide meaningful insights into the ways adults with Intellectual Disability interact with family members, participate in social situations, and cope with daily life experiences. Such understanding contributes to a broader perspective on caregiving beyond physical assistance alone.

The study further includes an examination of the challenges encountered by caregivers in different domains of life. These challenges may include emotional stress, physical fatigue, financial difficulties, social restrictions, and concerns regarding future care arrangements. Understanding these challenges within the local context can help identify areas where caregivers require additional support. The study therefore extends beyond the experiences of adults with Intellectual Disability and considers the well-being of caregivers as an equally important area of enquiry.The study explores the availability and utilisation of support systems that assist caregivers in performing their roles. These support systems may include family support, community resources, government welfare programmes, healthcare services, rehabilitation facilities, and social networks. By examining the accessibility and effectiveness of such resources, the study aims to

provide a more comprehensive understanding of the caregiving environment within Thiruvananthapuram district.

The study adopts a qualitative approach to understand the depth of caregiving experiences, including emotional, social, and practical aspects, which are often not captured through quantitative methods. The scope of the present study also extends to understanding caregiving as a lived experience rather than merely a caregiving responsibility. By documenting caregivers' perspectives through in-depth qualitative enquiry, the study provides insights into the meanings caregivers attach to their roles, the ways in which they negotiate everyday challenges, and the strategies they adopt to sustain long-term caregiving. Such an approach allows for a comprehensive understanding of caregiving within the natural family environment.

Although the findings are specific to caregivers residing in Thiruvananthapuram district and are not intended for statistical generalisation, they offer valuable contextual evidence regarding family caregiving in the local setting. The insights generated through this study may contribute to social work practice, disability rehabilitation, caregiver support programmes, community-based interventions, and future qualitative research focusing on adults with Intellectual Disability. The study therefore provides both contextual understanding and practical implications for professionals working in the field of disability and family welfare.

1.4 Significance of the study

This study is important as it provides a deeper understanding of caregiving practices and experiences of caregivers of adults with Intellectual Disability, which is an area that has received limited attention in research. Most existing studies focus on parenting stress, emotional development, and caregiving during childhood or adolescence (Sopingi et al., 2024; IJIP, 2023). However, there is a lack of qualitative research that explores caregiving in adulthood, especially in the Indian and Kerala context.Caregiving is often a long-term responsibility that affects the emotional, social, and financial well-being of caregivers.

The significance of the present study lies in its contribution to understanding the long-term realities of family caregiving in the context of Intellectual Disability. According

to the World Health Organization (2023), individuals with developmental disabilities often require varying levels of support throughout their lifespan, making family caregivers a crucial component of the care system. While formal services provide limited assistance, the responsibility for meeting daily needs, ensuring safety, and promoting social participation largely remains within the family. Examining the experiences of caregivers therefore helps in understanding not only the needs of adults with Intellectual Disability but also the challenges faced by the family members who provide continuous care. Such knowledge is important for developing family-centred approaches within disability services and community welfare programmes.

The study is significant from a social work perspective because caregivers frequently encounter emotional stress, social isolation, financial strain, and uncertainty regarding future care arrangements. The International Federation of Social Workers (IFSW, 2024) emphasises that strengthening family support systems is an essential component of social work practice with vulnerable populations. By documenting caregivers' lived experiences, the study provides valuable information regarding areas where social work intervention may be required. This includes emotional support, family counselling, crisis intervention, caregiver education, advocacy for disability rights, and facilitation of access to welfare schemes. Understanding these concerns enables social workers to develop interventions that address both the needs of adults with Intellectual Disability and the well-being of their caregivers.

The findings of the study may assist social workers in planning and implementing appropriate intervention strategies at the individual, family, group, and community levels. At the individual level, social workers can provide counselling services to caregivers experiencing stress, anxiety, or emotional exhaustion resulting from prolonged caregiving responsibilities. At the family level, interventions may focus on strengthening family relationships, improving communication patterns, enhancing coping mechanisms, and promoting shared caregiving responsibilities among family members. Family-centred practice, as discussed by Turnbull et al. (2015), recognises the family as the primary unit of support and emphasises collaboration between professionals and family members in decision-making processes. The present study can

contribute to such practice by identifying the specific needs and concerns of caregivers within the local context.

The study is also relevant for group work and community organisation methods of social work. Findings related to caregiver stress, social isolation, and lack of support can guide the formation of caregiver support groups where members can share experiences, exchange practical knowledge, and receive emotional encouragement from others facing similar situations. According to Toseland and Rivas (2017), support groups help reduce feelings of isolation and enhance coping capacity among caregivers by promoting mutual aid and collective problem-solving. At the community level, social workers can utilise the findings to organise awareness programmes, community education initiatives, and advocacy campaigns aimed at reducing stigma associated with Intellectual Disability and increasing social inclusion.

The study further contributes to the development of disability welfare policies and programmes. The Rights of Persons with Disabilities Act, 2016, emphasises the rights of persons with disabilities to participate fully in society and receive necessary support services. However, families often continue to face difficulties in accessing adequate resources and specialised services. By highlighting the experiences of caregivers, the study can provide evidence regarding existing gaps in service delivery, accessibility, rehabilitation support, respite care facilities, and community-based programmes. Such evidence may assist policymakers, disability organisations, and service providers in designing interventions that are responsive to the actual needs of families caring for adults with Intellectual Disability.

The study also contributes to the existing body of social work and disability literature by generating qualitative evidence from Thiruvananthapuram district. Caregiving experiences are influenced by cultural values, family structures, economic conditions, and availability of support services. Therefore, locally generated evidence is necessary for understanding caregiving within a specific social and cultural context. The findings may serve as a reference for future researchers interested in disability studies, family caregiving, rehabilitation, mental health, and community-based social work interventions, thereby contributing to the expansion of knowledge in these areas.

The significance of the present study also lies in its emphasis on understanding caregiving through the lived experiences of caregivers themselves. By adopting a qualitative approach, the study captures the everyday realities, meanings, and interpretations attached to caregiving that are often not evident through quantitative investigations. The narratives presented by caregivers provide a deeper understanding of how caregiving responsibilities are negotiated within the family, how challenges are managed in everyday life, and how caregivers continue to adapt to changing needs over time.

Furthermore, the findings of the study may contribute to the development of more responsive disability services by providing context-specific evidence from Thiruvananthapuram district. The insights generated through the study can support professionals, service providers, non-governmental organisations, and policymakers in designing interventions that are sensitive to the practical, emotional, and social realities of caregivers. By recognising caregivers as active partners in the care and rehabilitation of adults with Intellectual Disability, the study reinforces the importance of strengthening family-centred practice, community-based rehabilitation, and inclusive social welfare initiatives.

1.5 Chapterization

This dissertation is organised into five chapters, each presenting a systematic account of the study on caregiving practices and experiences of caregivers of adults with Intellectual Disability. The chapters are arranged in a logical sequence to provide a comprehensive understanding of the research problem, the methodology adopted, the findings obtained, and the conclusions drawn from the study.

Chapter One, Introduction, provides the foundation of the study by introducing the concept of Intellectual Disability and the importance of family caregiving during adulthood. It presents the background of the study, statement of the problem, research objectives, research questions, scope of the study, significance of the study, operational and theoretical definitions of key concepts, research gap, theoretical framework, and chapterization.

Chapter Two, Review of Literature, presents a review of relevant national and international literature related to caregiving practices, caregiving experiences, caregiver burden, emotional well-being, support systems, and Intellectual Disability. The chapter also identifies the research gap that justifies the need for the present study.

Chapter Three, Research Methodology, explains the methodological framework adopted for the study. It includes the research approach, research design, study area, sampling technique, sample size, inclusion and exclusion criteria, tools and methods of data collection, method of data analysis, and ethical considerations followed during the research process.

Chapter Four, Data Analysis and Interpretation, presents the findings of the study based on the thematic analysis of the qualitative data collected from caregivers of adults with Intellectual Disability. The findings are organised under major themes and supported with verbatim quotations from the participants to provide a clear understanding of their caregiving practices and lived experiences.

Chapter Five, Findings, Discussion, Conclusion and Recommendations, summarises the major findings of the study and discusses them in relation to the existing literature and theoretical framework. The chapter concludes the study by presenting the conclusion, implications for social work practice, suggestions, scope for further research, limitations of the study, and recommendations for improving support services for caregivers of adults with Intellectual Disability.

CHAPTER II: REVIEW OF LITERATURE

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2.1 Introduction

A review of literature is an essential component of any research study as it provides a comprehensive understanding of the existing body of knowledge related to the research problem. It enables the researcher to examine previous studies, understand different theoretical perspectives, identify established findings, and recognise gaps that require further investigation. Through a critical review of earlier research, the researcher is able to position the present study within the existing body of knowledge and establish its relevance. For a study exploring the caregiving practices and experiences of caregivers of adults with Intellectual Disability, reviewing the literature is particularly important because caregiving is a multidimensional process influenced by psychological, social, cultural, economic, and environmental factors.

Intellectual Disability is a lifelong developmental condition characterised by significant limitations in intellectual functioning and adaptive behaviour, affecting communication, social interaction, learning, and independent living. Although advances in healthcare, education, rehabilitation, and disability services have improved opportunities for individuals with Intellectual Disability, the responsibility of providing continuous care largely remains with family members. As individuals with Intellectual Disability grow older, family caregivers continue to provide assistance with personal care, behaviour management, healthcare, emotional support, communication, social participation, and decision-making. Consequently, caregiving extends beyond childhood and becomes a lifelong commitment that influences nearly every aspect of the caregiver's personal and family life.

Existing literature indicates that caregiving is both a rewarding and demanding experience. Family caregivers frequently encounter emotional stress, physical exhaustion, financial burden, social isolation, and uncertainty regarding the future care of their family members. At the same time, several studies have highlighted positive caregiving experiences, including stronger family relationships, resilience, personal growth, and a sense of fulfilment derived from supporting a loved one. These findings

demonstrate that caregiving is a complex and dynamic process involving both challenges and positive adaptations rather than being limited solely to caregiver burden.

Although caregiving has been widely discussed within disability research, a considerable proportion of existing studies have focused on children and adolescents with Intellectual Disability. Comparatively fewer studies have explored caregiving during adulthood, particularly from the perspective of family caregivers. Much of the available research has also adopted quantitative approaches that primarily measure caregiver burden, stress, or quality of life. While such studies provide valuable statistical evidence, they often fail to capture the everyday realities, personal meanings, coping strategies, and lived experiences of caregivers. Qualitative research is therefore essential for understanding how caregivers experience their roles, respond to changing responsibilities, and adapt to the long-term demands of caregiving.

Within the Indian context, caregiving is predominantly family-centred, with parents, siblings, and close relatives assuming primary responsibility for supporting adults with Intellectual Disability. Cultural values, family expectations, social stigma, economic conditions, and limited availability of specialised support services significantly influence caregiving practices and experiences. In Kerala, despite improvements in disability welfare programmes, rehabilitation services, and community-based interventions, caregivers continue to encounter challenges related to long-term care, access to formal support services, respite care, community participation, and future planning. However, qualitative evidence focusing specifically on the caregiving practices and lived experiences of caregivers of adults with Intellectual Disability remains limited, particularly in Thiruvananthapuram district.

The present chapter provides a comprehensive review of relevant national and international literature related to caregiving practices, caregiving experiences, caregiver burden, emotional well-being, social support, family quality of life, and disability care. It also examines the theoretical perspectives that provide a conceptual understanding of caregiving and identifies the research gap that forms the foundation of the present study. The literature reviewed in this chapter has been organised into international, national, and Kerala-specific studies to provide a comprehensive understanding of caregiving

across different socio-cultural contexts. This organisation enables the researcher to compare existing evidence, identify similarities and differences across settings, and establish the need for the present qualitative study on the caregiving practices and experiences of caregivers of adults with Intellectual Disability in Thiruvananthapuram.

2.2 Review of Literatures

International Studies

Sopingi et al. (2024) conducted a study titled *"Parenting Style and Emotional Regulation in Children with Intellectual Disability"* with the objective of examining how different caregiving styles influence emotional and social development. The study used a quantitative correlational research design and applied tools such as the Parenting Styles and Dimensions Questionnaire (PSDQ) and Emotional Regulation Questionnaire (ERQ). The findings revealed that authoritative caregiving, which includes warmth, consistency, and structured guidance, is associated with better emotional regulation and social behaviour. In contrast, authoritarian caregiving was linked to behavioural problems and emotional instability. This study highlights the importance of caregiving practices in shaping emotional outcomes.

Scripps et al. (2025) conducted a systematic review titled *"Supporting Parents of Adolescents With Intellectual Disabilities"* to understand caregiving practices during adolescence. The study analysed 24 international research works focusing on individuals with Intellectual Disability. The findings showed that caregiving roles change over time, shifting from basic care to more complex roles such as guidance, emotional support, and advocacy. Caregivers also face challenges related to social interaction, behavioural changes, and independence. Peer support groups were identified as an effective support system. Although the study focuses on adolescents, it provides important insights into how caregiving evolves over time, which is relevant for adulthood as well.

Sopingi (2024), in a qualitative phenomenological study titled *"Parenting as the Enhancer of Subjective-Educative Experiences"*, explored the lived experiences of caregivers. The study used in-depth interviews to understand personal experiences and meanings attached to caregiving. The findings showed that caregiving requires both

emotional strength and practical skills. Caregivers described their experience as a continuous learning process, where challenges contributed to personal growth and resilience. This study is highly relevant as it focuses on lived experiences, which is a key aspect of qualitative research.

Kwong and Low (2025) conducted a scoping review titled "Family Support Experiences of Adult Persons with Intellectual Disability and Challenging Behaviour: A Scoping Review of Qualitative Studies" with the objective of synthesising qualitative evidence on the experiences of family caregivers supporting adults with Intellectual Disability who display challenging behaviours. The review followed a systematic scoping review methodology and examined qualitative studies retrieved from five electronic databases. The findings revealed that caregivers experienced a combination of emotional exhaustion, stress, social isolation, and uncertainty while managing challenging behaviours. At the same time, many caregivers reported developing resilience, stronger family relationships, and a sense of personal fulfilment through long-term caregiving. The review also identified inadequate formal support services, limited respite care, and the need for greater community-based resources for families. This study is highly relevant to the present research as it focuses specifically on the lived experiences of caregivers of adults with Intellectual Disability and highlights both the challenges and adaptive strategies associated with long-term family caregiving.

Egan et al. (2019) conducted a study titled "An Exploration of Care-Burden Experienced by Older Carers of Adults with Intellectual Disabilities" with the objective of examining caregiver burden among ageing family caregivers of adults with Intellectual Disability. The study adopted a quantitative cross-sectional design involving older family caregivers and utilised the Zarit Burden Interview (ZBI) to assess caregiver burden. The findings indicated that many caregivers experienced moderate to high levels of burden, particularly in relation to advancing age, declining physical health, prolonged caregiving responsibilities, and uncertainty regarding future care arrangements. Participants also expressed concerns about the absence of adequate long-term support services for adults with Intellectual Disability. The study concluded that ageing caregivers require greater psychosocial support, future care planning, and accessible community services to reduce caregiver burden. This study is relevant to the

present research because future uncertainty and long-term caregiving responsibilities also emerged as important themes in the experiences of caregivers.

Gutowska (2022) conducted a study titled "The Care of Adults with Intellectual Disabilities: Informal Support in Daily Life" with the objective of understanding the role and responsibilities of informal caregivers of adults with Intellectual Disability. The study adopted a qualitative research design and collected data through in-depth interviews with parents who provided long-term care to their adult children with Intellectual Disability. The findings revealed that caregiving involved continuous supervision, emotional support, assistance with daily living activities, and advocacy for the rights and well-being of the individual. Caregivers also reported concerns regarding ageing, future care arrangements, and the limited availability of formal support services. The study concluded that informal caregivers remain the primary source of support throughout adulthood and require greater recognition and assistance from health and social welfare systems. This study is relevant to the present research because it focuses specifically on the everyday caregiving practices and experiences of family caregivers of adults with Intellectual Disability.

Bahador, Farzi, Nasiri, and colleagues (2023) conducted a qualitative study titled "Experiences of Family Caregivers of People with Intellectual Disabilities" with the objective of exploring the positive experiences associated with long-term caregiving. The study employed a qualitative content analysis approach and collected data through semi-structured interviews with sixteen family caregivers. The findings showed that although caregiving involved considerable responsibility, caregivers also reported positive outcomes such as developing a new outlook on life, strengthening family relationships, experiencing personal satisfaction, and increasing resilience. Participants described caregiving as a meaningful life experience that contributed to personal growth despite everyday challenges. The study concluded that recognising both the positive and challenging aspects of caregiving can contribute to more effective family-centred interventions. This study is relevant because the present research also explores caregiving as a lived experience rather than focusing solely on caregiver burden.

Saretta, Alhambra-Borrás, Doñate-Martínez, and Garcés-Ferrer (2025) conducted a qualitative study titled “Older Family Caregivers and Health Professionals of Adults with Intellectual Disabilities” with the objective of identifying the support needs of older caregivers and adapting the Savvy Caregiver Programme for adults with Intellectual Disability. The study involved qualitative interviews with fifteen older family caregivers and twenty-two health professionals. The findings revealed that caregivers experienced prolonged emotional stress, uncertainty regarding future caregiving, limited access to specialised services, and concerns related to ageing. Participants emphasised the need for caregiver education, psychosocial support, and structured community services. The study concluded that interventions specifically designed for older caregivers are essential for improving caregiver well-being and sustaining long-term family care. This study is highly relevant because future uncertainty and long-term caregiving also emerged as major findings in the present study.

Hodgetts and colleagues (2025) conducted a qualitative study titled “A Qualitative Study Exploring Ways to Support Parent Caregivers of Adults with Intellectual and Developmental Disabilities” with the objective of understanding the support needs of parents caring for adult children with Intellectual and Developmental Disabilities. The study analysed qualitative responses obtained from a national survey completed by 315 parent caregivers using thematic analysis. The findings identified four major areas of support required by caregivers: tangible assistance, emotional and social support, guidance in navigating disability services, and support for future planning. Participants also highlighted the need for improved disability services, financial assistance, and opportunities to connect with other caregiver families. The study concluded that strengthening family support systems and improving access to community resources are essential for sustaining long-term caregiving. This study is relevant because the present research also identifies support systems and future concerns as important aspects of caregivers' lived experiences.

National (Indian) Studies

Ramasubramanian, Krishnamurthy, and colleagues (2020) conducted a study titled "Caregiver Burden in Children with Intellectual Disability" with the objective of comparing caregiver burden and depression among caregivers of school-going and non-school-going children with Intellectual Disability. The study adopted a cross-sectional comparative research design and utilised the Zarit Burden Interview (ZBI) and Beck Depression Inventory (BDI) for data collection. The findings revealed that caregivers experienced moderate to severe levels of burden and depression irrespective of school attendance. Emotional strain, financial difficulties, and continuous caregiving responsibilities were identified as major contributors to caregiver burden. The study concluded that family caregivers require psychological support and counselling services to reduce caregiver burden and improve their quality of life. This study is relevant to the present research because it highlights the emotional and practical challenges experienced by family caregivers of persons with Intellectual Disability in the Indian context.

Bunga and Raj (2020) conducted a study titled "Children with Intellectual Disability: Impact on Caregivers" with the objective of assessing the impact of caring for a child with Intellectual Disability on parents and family members. The study employed a descriptive cross-sectional design and collected data from caregivers using structured assessment tools. The findings indicated that caregivers experienced considerable emotional stress, financial burden, disruption of family routines, and reduced social participation. Mothers reported greater caregiving responsibilities than fathers and expressed concerns regarding the future care of their children. The study concluded that long-term caregiving significantly influences the psychological and social well-being of caregivers and emphasised the need for comprehensive family support services. This study is relevant because it demonstrates the multidimensional impact of caregiving on Indian families and highlights the importance of strengthening support systems for caregivers.

Ramachandran et al. (2020) conducted a study titled "Stress among the Caregivers of Mentally Disabled Children: Implications for Health Care Policy" with the objective of

assessing stress levels among caregivers of children with developmental disabilities, including Intellectual Disability. The study followed a descriptive cross-sectional research design and collected data using standardised caregiver stress assessment instruments. The findings showed that caregivers experienced high levels of physical fatigue, emotional distress, anxiety, and social isolation due to prolonged caregiving responsibilities. Limited social support, financial constraints, and behavioural challenges were found to increase caregiver stress. The study recommended strengthening caregiver counselling services, community support programmes, and policy interventions aimed at improving the well-being of caregivers. This study is relevant because it highlights caregiver stress as a major concern and supports the need for family-centred interventions in the Indian context.

State (Kerala)

A study conducted by IJIP (2023) titled *"Maternal Perspectives on Parenting Adolescents: Insights from Kerala, India"* adopted a qualitative approach to understand the lived experiences of mothers. The study used in-depth interviews as the primary method of data collection. The findings revealed that caregivers experience significant emotional stress while managing behavioural changes, mood swings, and communication difficulties among individuals with Intellectual Disability. Cultural expectations and lack of awareness were also found to influence caregiving practices. The study highlighted that caregivers often feel a continuous sense of responsibility, leading to emotional burden and stress. This study is highly relevant as it provides a strong contextual understanding of caregiving experiences within Kerala.

Similarly, another study conducted by IJIP (2020) examined resilience as a predictor of caregiver stress among mothers of individuals with Intellectual Disability in Kerala. The study followed a quantitative research design using standardised psychological scales to measure resilience and stress. The findings indicated that caregivers with higher resilience levels were better able to manage stress, while those with lower resilience experienced higher emotional burden, anxiety, and psychological distress. This study highlights the importance of coping mechanisms and emotional strength in caregiving.

Puliyakkadi et al. (2021) conducted a cross-sectional study in South India to examine caregiver attitudes towards individuals with Intellectual Disability. The study used the Rangaswamy Parental Attitude Scale for data collection. The findings showed that while caregivers generally have a positive attitude, there is a strong tendency towards overprotection. This overprotective behaviour often limits independence and social development. The study emphasises that caregiving attitudes play a significant role in shaping the development of individuals with Intellectual Disability, especially during adulthood.

Another study published in IJIP (2020) explored the emotional and psychological impact of caregiving on caregivers of individuals with Intellectual Disability. The study used a quantitative design and analysed stress levels among caregivers. The findings revealed that caregivers often experience emotional distress such as anxiety, sadness, and feelings of burden. At the same time, some caregivers develop coping strategies and acceptance over time. This study supports the idea that caregiving is both emotionally demanding and adaptive in nature.

Vincent et al. (2024) conducted a qualitative phenomenological study focusing on caregiver perspectives on sexual and reproductive health issues among individuals with Intellectual Disability. Data was collected through in-depth interviews with caregivers. The study found that caregivers face challenges in addressing sensitive topics such as sexuality due to lack of awareness, fear of abuse, and social stigma. Limited access to proper healthcare services further increases the burden on caregivers. This study highlights the cultural and social barriers present in caregiving practices.

Hassan, McConkey, and colleagues (2021) conducted a qualitative study titled “The Lived Experience of Carers Who Assist People with Disability in Ernakulam, Kerala, India” with the objective of exploring the everyday experiences of family caregivers providing long-term care to persons with disabilities. The study adopted a qualitative research design and collected data through semi-structured interviews with twenty family caregivers residing in Ernakulam district. The findings revealed that caregivers experienced continuous physical and emotional demands while balancing caregiving responsibilities with household and occupational commitments. Participants also

reported financial difficulties, limited social support, concerns regarding their own health, and uncertainty about the future care of the individual with disability. Despite these challenges, caregivers demonstrated resilience and a strong commitment towards caregiving. The study concluded that greater community-based support services, caregiver assistance programmes, and policy interventions are required to improve the well-being of family caregivers. This study is relevant to the present research because it explores the lived experiences of caregivers in the Kerala context and highlights many of the challenges identified in the present study.

Kochuvilayil et al. (2024) conducted a study titled "Understanding Caregiver Burden and Quality of Life in Kerala's Family Caregivers" with the objective of comparing caregiver burden and quality of life among ageing and younger caregivers. The study followed a mixed-method approach involving standardised caregiver burden and quality-of-life assessments together with qualitative exploration of caregiver experiences. The findings indicated that caregivers experienced emotional strain, physical exhaustion, financial pressure, and reduced quality of life due to prolonged caregiving responsibilities. Older caregivers expressed greater concern regarding future caregiving arrangements and declining physical health. The study recommended strengthening caregiver support services, psychosocial interventions, and community-based care programmes. This study is relevant to the present research because it demonstrates how prolonged caregiving influences both caregiver burden and overall quality of life within the Kerala context.

2.3 Theoretical Framework

The findings from the reviewed literature indicate that caregiving practices and experiences are closely associated with behavioural, emotional, and social aspects of development. These dimensions can be better understood through relevant theoretical perspectives.

Social Learning Theory

The second theoretical perspective guiding the present study is Albert Bandura's Social Learning Theory (1977). The theory proposes that learning occurs through observation, imitation, modelling, reinforcement, and continuous interaction with the surrounding

environment. According to Bandura, individuals acquire new behaviours by observing others, receiving guidance, practising learned behaviours, and obtaining positive reinforcement for appropriate actions.

Within the context of Intellectual Disability, caregivers serve as the primary source of learning and behavioural guidance. Adults with Intellectual Disability often require repeated instructions, demonstration of daily activities, behavioural guidance, and continuous supervision to perform everyday tasks. Through repeated interaction and encouragement, caregivers facilitate the development of communication skills, self-care activities, social behaviour, emotional regulation, and adaptive functioning.

The findings of the present study strongly support the assumptions of Social Learning Theory. Caregivers consistently reported that daily activities such as bathing, eating, dressing, household responsibilities, and personal hygiene required repeated instruction, demonstration, supervision, and encouragement. Behavioural challenges were commonly managed through calm communication, positive reinforcement, patience, and continuous guidance rather than punishment. Caregivers also described gradual improvement in skills through repeated practice and consistent support over time.

These findings indicate that caregiving involves much more than providing physical assistance. It is an ongoing process of teaching, modelling, reinforcing appropriate behaviours, and facilitating learning in everyday life. Social Learning Theory therefore provides an appropriate framework for understanding caregiving practices, behaviour management, skill development, communication, and adaptive functioning among adults with Intellectual Disability.

Together with Caregiver Stress Theory, Social Learning Theory provides a comprehensive understanding of the caregiving process by explaining both the practical caregiving activities and the experiences of caregivers who provide long-term support to adults with Intellectual Disability.

2.4 Research Gap Analysis

The review of literature indicates that caregiving for individuals with Intellectual Disability involves multiple dimensions, including emotional, social, and financial challenges. International studies have primarily focused on caregiving styles, emotional regulation, and developmental transitions, particularly during childhood and adolescence (Sopingi et al., 2024; Scripps et al., 2025). These studies highlight the role of caregiving practices in influencing behavioural and emotional outcomes.

Studies conducted in Kerala have provided insights into caregiver stress, resilience, and emotional experiences (IJIP, 2023; IJIP, 2020). While these studies contribute to understanding the regional context, they are often limited to specific variables such as stress or coping, and do not comprehensively examine caregiving practices in everyday life.

Despite the existing body of literature, there is a noticeable lack of qualitative research focusing on the caregiving practices and lived experiences of caregivers of adults with Intellectual Disability. Most studies are centred on children or adolescents, leaving caregiving in adulthood relatively underexplored. Furthermore, there is limited context-specific research in Thiruvananthapuram that captures the day-to-day realities of caregiving.

Therefore, the present study seeks to address these identified gaps by exploring the caregiving practices and lived experiences of caregivers of adults with Intellectual Disability in Thiruvananthapuram using a qualitative research approach. Unlike many previous studies that primarily examined caregiver burden, stress, or quality of life through quantitative methods, the present study focuses on understanding caregiving from the caregivers' own perspectives. By exploring their day-to-day caregiving practices, emotional experiences, challenges, coping strategies, and available support systems, the study aims to generate an in-depth understanding of long-term family caregiving within the local socio-cultural context. The findings are expected to contribute to social work practice, disability rehabilitation, and future qualitative research by providing context-specific evidence on caregiving during adulthood.

CHAPTER III: METHODOLOGY

CHAPTER III: METHODOLOGY

3.1 Introduction

This chapter presents the research methodology adopted for the present study. Research methodology provides the overall framework that guides the systematic collection, organisation, analysis, and interpretation of data in order to address the research problem. The chapter explains the research approach, research design, study area, sampling technique, sample size, inclusion and exclusion criteria, tools and methods of data collection, data analysis procedure, and ethical considerations followed during the study. A clear description of the methodology enhances the credibility, dependability, and transparency of the research process and enables readers to understand how the findings were generated.

3.2 Title of the Study

"Care giving Practices and Experiences of Caregivers of Adults with Intellectual Disability."

3.3 Research questions

General Research Question

How do caregivers of adults with Intellectual Disability experience and manage the caregiving process in their everyday lives?

Specific Research Questions

1. What are the caregiving practices followed by caregivers of adults with Intellectual Disability?
2. How do caregivers describe their daily caregiving experiences?
3. How do caregivers perceive their influence on the emotional and social behaviour of adults with Intellectual Disability?
4. What challenges do caregivers face in caregiving?
5. What types of support do caregivers receive?

3.4 Theoretical definitions

1) Intellectual Disability

According to the American Association on Intellectual and Developmental Disabilities (AAIDD)

"Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 22."

2) Caregiver

According to Zarit, Reever, and Bach-Peterson (1980)

"A caregiver is an individual who provides ongoing assistance and support to a person who is unable to function independently because of illness, disability, or age."

3) Caregiving Practices

According to Pearlin, Mullan, Semple, and Skaff (1990),

"Caregiving practices refer to the activities and responsibilities undertaken by caregivers in meeting the physical, emotional, behavioural, and social needs of the care recipient. These practices include providing assistance with daily living, supervision, emotional support, guidance, and other tasks necessary for the individual's well-being."

4) Caregiving Experience

According to Morse and Carter (1996),

"Caregiving experience refers to the lived emotional, social, psychological, and practical experiences of individuals who provide continuous care to another person over a period of time."

5) Social Support

According to Cobb (1976)

"Social support is information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations."

OPERATIONAL DEFINITIONS

1) **Intellectual Disability**

In the present study, Intellectual Disability refers to adults aged 18 years and above who have been clinically diagnosed with limitations in intellectual functioning and adaptive behaviour, affecting areas such as learning, communication, self-care, social interaction, and independent functioning. The study focuses on adults with Intellectual Disability who require varying levels of support in their everyday lives**.**

2) **Caregiver**

In the present study, a caregiver refers to a parent, sibling, guardian, or other family member who assumes primary responsibility for providing regular care, supervision, emotional support, and assistance in the daily lives of adults with Intellectual Disability.

3) **Caregiving Practices**

In the present study, caregiving practices refer to the routine activities, strategies, and supportive measures adopted by caregivers in assisting adults with Intellectual Disability in areas such as personal care, behavioural guidance, emotional support, daily living activities, supervision, and social participation.

4) **Caregiving Experience**

In the present study, caregiving experience refers to the personal perceptions, emotions, challenges, coping processes, and lived experiences of caregivers while providing long-term care to adults with Intellectual Disability.

5) **Social Support**

In the present study, social support refers to the emotional, informational, practical, and financial assistance received or perceived by caregivers from family members, relatives, friends, community organisations, healthcare professionals, government services, and other formal or informal support systems that assist them in their caregiving responsibilities.

3.5 Pilot Study

A pilot study was conducted prior to the main data collection to assess the suitability and effectiveness of the semi-structured interview guide. The pilot study was carried out with two caregivers of adults with Intellectual Disability who fulfilled the inclusion criteria of the study but were not included in the final sample.

The purpose of the pilot study was to evaluate the clarity, relevance, and sequence of the interview questions, identify any ambiguities, and estimate the time required for conducting the interviews. It also helped the researcher assess the feasibility of the interview process and establish rapport with participants.

Based on the responses obtained during the pilot study, minor modifications were made to the wording and sequence of a few questions to improve clarity and encourage more detailed responses. These changes enhanced the effectiveness of the interview guide and ensured that it was appropriate for the main study. The data collected during the pilot study were not included in the final analysis.

3.6 Research approach and Research Design

The present study follows a qualitative research approach. This approach is appropriate as the study aims to understand the caregiving practices and lived experiences of caregivers of adults with Intellectual Disability in depth.

Qualitative research allows the researcher to explore personal experiences, meanings, and perceptions, which are essential for understanding caregiving in a real-life context. The qualitative approach was considered appropriate because it enabled the researcher to obtain rich, descriptive, and context-specific information regarding caregiving practices, emotional experiences, challenges, coping strategies, and support systems

directly from the participants. The approach also provided flexibility for participants to describe their experiences in their own words, thereby facilitating a deeper understanding of caregiving within the family context.

The study adopts a multiple case study design. Each caregiver is considered as an individual case, allowing for detailed exploration of their experiences.This design helps in identifying both unique experiences and common patterns across different cases, which supports thematic analysis. The multiple case study design was selected because each caregiver represented a unique caregiving situation shaped by different family backgrounds, caregiving responsibilities, and personal experiences. Studying multiple cases enabled the researcher to compare similarities and differences across participants, thereby strengthening the credibility of the findings through cross-case analysis.

3.7 Universe and Unit of Study

The study is conducted in **Thiruvananthapuram district of Kerala**.

The area was selected due to the availability of caregivers of individuals with Intellectual Disability and access to institutions such as special schools, and community-based services. The region also reflects a mix of urban and semi-urban settings, providing a relevant context . Thiruvananthapuram district was considered suitable for the present study because it has a number of institutions, special schools, rehabilitation centres, and community-based organisations providing services for persons with Intellectual Disability. The district also represents diverse socio-economic and cultural backgrounds, allowing the researcher to understand caregiving experiences across different family settings. Accessibility to the study participants and institutional support further contributed to the selection of the study area.

3.8 Sampling Design

The study uses **purposive sampling**.

Participants were selected based on specific criteria relevant to the objectives of the study. This method ensures that only those caregivers who have direct experience in caregiving are included.

Sample size

The sample size consists of **multiple caregivers .**

The final number of participants was determined based on **data saturation**, where no new themes or information emerged from additional interviews.

Inclusion criteria

- Caregivers of adults (18+) diagnosed with Intellectual Disability
- Primary caregivers involved in daily care
- Residing in Thiruvananthapuram district
- Willing to participate in the study

Exclusion criteria

- Caregivers who are not directly involved in the day-to-day care of the adult with Intellectual Disability.
- Professional or paid caregivers (such as institutional staff, therapists, or support workers), as the study focuses specifically on informal, family-based caregiving experiences.
- Caregivers of individuals with Intellectual Disability below 18 years of age, since the study is limited to caregiving in adulthood.
- Individuals who have been in a caregiving role for a very short duration, as they may not have sufficient experience to reflect on caregiving practices and challenges in depth.
- Caregivers who are unable or unwilling to participate in an in-depth interview process due to personal or situational constraints.

3.9 Data Collection

Data was collected using a semi-structured interview guide.

The semi-structured format allowed flexibility for participants to express their experiences freely while maintaining focus on the objectives of the study.

3.10 Method of data collection

Data was collected through **in-depth interviews** with caregivers.

The researcher established rapport with participants and conducted interviews in a comfortable environment. Each interview lasted approximately 30-45 minutes. With consent, responses were noted and later transcribed for analysis. The interviews were conducted at locations convenient to the participants, ensuring privacy and comfort throughout the interaction. Open-ended questions encouraged participants to describe their caregiving experiences in detail, while probing questions were used whenever necessary to obtain greater clarity and depth. Field notes were also maintained to record non-verbal observations and contextual information that supported the interpretation of interview data.

3.11 Data Analysis

The data collected was analysed using **thematic analysis**.

The data collected for the study were analysed using thematic analysis. The process of analysis was carried out in a systematic manner based on the responses obtained from the caregivers.

Initially, the interview responses were transcribed and organised into detailed case descriptions. The researcher carefully reviewed the data multiple times to gain a clear understanding of the participants' experiences.

Meaningful units of information were then identified from the responses, particularly focusing on repeated statements and significant expressions related to caregiving practices, emotional behaviour, challenges, and support systems.

These meaningful units were further interpreted and grouped into codes based on similar patterns observed across cases. Although the coding process was not presented separately, it was carried out during the organisation and interpretation of the data.

The codes were then categorised into broader themes through cross-case comparison. Common patterns emerging across the cases were grouped together to form major themes.

Finally, the themes were interpreted in relation to the objectives of the study. The analysis resulted in four major themes, namely caregiving practices in daily life, emotional and social behaviour, skill development and daily functioning, and caregiver experiences, challenges, and support systems.

3.12 Ethical considerations

Ethical principles were strictly followed during the study.

- Informed consent was obtained from all participants
- Confidentiality and anonymity were maintained
- Participation was voluntary
- Participants were allowed to withdraw at any stage
- The data was used only for academic purposes

Prior to data collection, the purpose of the study was clearly explained to all participants, and informed consent was obtained before commencing the interviews. Confidentiality was maintained by removing personal identifiers from the interview transcripts and assigning pseudonyms during data analysis. Participants were assured that their responses would remain confidential and would be used solely for academic purposes. The researcher also ensured that participants were treated with dignity, respect, and sensitivity throughout the research process. Care was taken to minimise any emotional discomfort during the interviews, and participants were informed that they could decline to answer any question or withdraw from the study at any stage without any consequences.

3.13 Limitations of the study and Scope

Every research study has certain limitations that may influence the scope and interpretation of the findings. The present study is no exception and the following limitations should be considered while understanding the results.

The study was conducted with a limited number of caregivers selected through purposive sampling. While the qualitative approach enabled an in-depth exploration of caregiving experiences, the findings may not represent the experiences of all caregivers of adults with Intellectual Disability.

The study was confined to Thiruvananthapuram district. Social, cultural, economic, and service-related factors may vary across regions, and therefore the findings cannot be generalised to caregivers in other geographical settings.

The study focused exclusively on caregivers and did not include the perspectives of adults with Intellectual Disability. Consequently, the findings represent caregiving experiences primarily from the viewpoint of caregivers and may not fully capture the experiences of the individuals receiving care.

Data collection was carried out within a limited period of time. A longer duration of engagement with participants might have provided additional insights into caregiving practices, coping mechanisms, and changes in experiences over time.

The findings are based on self-reported experiences shared by participants during interviews. As with all qualitative studies, responses may have been influenced by personal perceptions, memory, emotional state, or the willingness of participants to disclose sensitive experiences.

Despite these limitations, the study provides valuable insights into the caregiving practices, experiences, challenges, and support systems of caregivers of adults with Intellectual Disability and contributes to the limited body of qualitative research in this area.The present study provides insights into the caregiving practices and experiences of caregivers of adults with Intellectual Disability in Thiruvananthapuram. However, several areas remain open for further exploration.

Future studies may be conducted with larger samples covering different geographical regions to obtain a broader understanding of caregiving experiences. Comparative studies examining differences between rural and urban caregiving contexts may provide additional insights into environmental and socio-cultural influences on caregiving.

Research involving both caregivers and adults with Intellectual Disability may help develop a more comprehensive understanding of caregiving relationships and support needs. Future studies may also examine the effectiveness of various intervention programmes, rehabilitation services, and support mechanisms in improving quality of life for both caregivers and beneficiaries.

Longitudinal studies may be undertaken to understand how caregiving experiences evolve over time, particularly in relation to ageing caregivers and changing support needs. Further research focusing on caregiver resilience, coping strategies, mental health, and quality of life may contribute to the development of more effective support programmes and policy interventions.

CHAPTER IV: DATA ANALYSIS AND INTERPRETATION

CHAPTER IV: DATA ANALYSIS AND INTERPRETATION

4.1 Introduction

This chapter presents the analysis and findings of the study based on the data collected from caregivers of adults with Intellectual Disability. The data was collected through in-depth interviews using a semi-structured interview schedule.

The responses were transcribed and analysed using thematic analysis. Based on coding and categorisation of responses, major themes and sub-themes were identified. These themes reflect caregiving practices, emotional and social experiences, challenges, and support systems of caregivers.

4.2 Demographic Profile and Verbatim

CASE A

Sociodemographic Profile

The respondent is a 40-year-old female caregiver. She is the elder sister of a 35-year-old adult with Intellectual Disability. She has completed schooling up to secondary level and is currently a homemaker. She lives in a joint family with her mother and the adult with Intellectual Disability. The family belongs to a low socio-economic background and depends on pension and limited financial assistance. She is the primary caregiver and is responsible for both household duties and caregiving.

VERBATIM

"My whole day actually starts with him only… early morning around 5 or sometimes even before that he will wake up, so I also have to wake up along with him. From that time onwards, everything is about him only. I have to make him brush, then for bathing my mother will help because he cannot do it properly alone. After that I give him food… even for eating also sometimes I have to remind him again and again. If we don't tell, he will just sit without doing anything. Like that the whole day goes… continuously I have to watch him. Even when I am doing kitchen work, my mind will be on him only because I cannot leave him alone.

Almost everything we have to guide him… small small things also. If we don't say, he will not do anything by himself. Sometimes he listens, sometimes he won't respond. Especially if mother calls, he listens more. Otherwise we have to repeat many times. Before his behaviour was very difficult… he used to throw things and run outside when he got angry. That time we also didn't know how to manage. Slowly we understood that if we shout, it becomes worse. Now we try to speak calmly and handle him patiently. When he gets angry, we don't react fast… we speak slowly or give him something he likes, then he becomes normal.

He is not very social. With us he is okay, but with others he will not go. If new people come, he will just sit quietly or move away. He doesn't like going outside also… he prefers staying at home only. When he is happy, he just smiles… sometimes he laughs, but mostly he shows it in a simple way only. We understand from his face. He will not say anything directly.

For me, managing everything is very difficult sometimes… house work also I have to do, his care also I have to manage. There is no break. Full day responsibility is there. Financially also it is difficult. Medicines and all expenses are there. We are somehow managing, but it is not easy. Mentally also I feel tired sometimes. Especially when I think about future… what will happen to him after us. That thought is always there. As long as we are there, we will manage somehow, but after that… I don't know."

"Sometimes people think that because we have been doing this for many years, it must have become easy for us. But caregiving does not become easy; we only learn how to manage it better. Every day there is something that needs attention. Even when I am doing other household work, I keep checking whether he is safe, whether he has eaten properly, or whether he needs help with something. There is never a moment when I can completely stop thinking about his needs. It has become a part of my routine and my responsibility."

Case Description

The respondent explained her caregiving experience in a very detailed and emotional manner, showing how deeply it is part of her daily life. She shared that from early

morning onwards her routine is fully connected to her brother's needs. She said, *"Morning itself I have to see everything… bathing, food, everything I have to manage,"* indicating that caregiving is continuous without any break.

She described that her brother is not fully independent in personal care, especially bathing, and requires step-by-step guidance. At the same time, she mentioned that he can eat on his own, but still needs reminders, saying, *"Food he will eat, but sometimes we have to tell again and again."*

While explaining communication, she pointed out that he does not always respond immediately and requires repeated prompting. She said, *"If we call once, he may not listen… mother calls again and again then only he will come,"* showing the level of patience required in caregiving.

Talking about his emotional behaviour, she reflected on changes over time. She shared, *"Before he used to throw things and run when angry… now it has reduced,"* indicating that caregiving practices have gradually helped in managing behaviour. She added that calm communication works better, saying, *"If we shout, it becomes worse… so we try to speak slowly."*

The respondent also expressed the physical and emotional burden she experiences. She mentioned, *"Everything I have to manage… house work also, his care also… sometimes it becomes tiring,"* reflecting the dual responsibility she carries.

She also spoke about her concern for the future in a very personal way, stating, *"Later who will take care of him… that thought is always there,"* showing ongoing anxiety and uncertainty.

Overall, her description reflects continuous caregiving responsibility, emotional involvement, and limited external support.

Researcher Observation

During the interview, the respondent appeared calm and cooperative. She provided detailed information regarding her caregiving responsibilities and frequently referred to the daily support provided to the beneficiary. While discussing behavioural

challenges and future care arrangements, the respondent became visibly emotional and paused several times before continuing. Her responses reflected a strong sense of responsibility and attachment towards the beneficiary. The interaction indicated that caregiving had become an integral part of her daily life, influencing personal, social, and emotional aspects of her routine.

Preliminary Interpretation

The narrative of Participant A suggests that caregiving extends beyond assistance with daily activities and involves continuous emotional involvement, supervision, and responsibility. The caregiver's experiences indicate that caregiving has become deeply embedded in everyday life, leaving limited opportunities for personal time or independence. The account also reflects the gradual adaptation of caregiving strategies, particularly in managing behavioural challenges through patience and understanding rather than punishment. Future uncertainty emerged as a major concern, indicating that long-term care planning remains a significant source of emotional stress. The case further highlights the limited availability of formal support systems, resulting in greater dependence on family-based care.

CASE B

Sociodemographic Profile

The respondent is a 53-year-old male caregiver. He is the father of a 21-year-old adult with Intellectual Disability. He has basic education and is engaged in small-scale work. He lives in a nuclear family and is the primary caregiver. The family belongs to a lower socio-economic group and receives limited financial support from local government schemes.

VERBATIM

"With him, daily life is not fixed like others… some days will go a little smooth, but some days will be very difficult. He doesn't sleep properly at night. Many times he will stay awake and move around the house. Because of that, even I don't get proper sleep.

Morning time also there is no proper routine. Some days he will wake up early, some days late, so everything depends on his mood.

He cannot manage things on his own. Cleaning, keeping things properly… nothing he will do by himself. Even basic things we have to tell again and again. Sometimes he understands, sometimes he just ignores. If he likes something, then he will show interest. Otherwise he won't respond. If we bring snacks or something he likes, then he will become calm and sit quietly. That is one way we manage him.

When he gets angry, it is very sudden. He may hit or throw things. That time it is very difficult to control him. We cannot predict also when it will happen. After some time, he will become normal as if nothing happened. That is also confusing for us. We have to always be careful around him.

He doesn't go near others. Even if someone comes home, he won't interact. He will stay away or just observe. He doesn't have any friends or peer connection. Outside also we cannot take him freely because we don't know how he will react.

He has not studied much… only went to school for few years. After that he could not continue. He doesn't know reading or writing. Sometimes he will just scribble something, that's all. Emotionally also sometimes he struggles. We can see that he feels something, but he cannot express it clearly.

For me, the biggest tension is about the future. Now I am there to take care of him. But later… what will happen, who will look after him… that thought is always there. Because he cannot live independently. Even going outside alone is not possible. So that worry is always in my mind."

"One of the most difficult situations is when he becomes upset and we do not know the reason. He cannot always explain what he feels, so we have to observe his actions and behaviour carefully. Sometimes it takes a long time to understand what is bothering him. During those moments, we also feel helpless because we want to help, but we are not able to understand immediately. Over time, we have learned to recognise certain signs, but every situation is different."

Case Description

The respondent described his caregiving experience with a mix of concern and acceptance, reflecting long-term involvement in his son's care. He explained that the condition was identified early and has influenced all aspects of life. He said, *"From small age itself we understood something is different,"* indicating early awareness of developmental issues.

He described his son's educational difficulties, stating, *"He went to school only for some years… after that he could not continue,"* showing the limitations in formal education. He also mentioned, *"Reading, writing… nothing he knows… only drawing like that,"* highlighting functional limitations.

In daily life, he explained that supervision is always required, especially for maintaining routines. He said, *"Cleanliness also we have to tell… otherwise he will not do properly,"* indicating dependence in daily functioning.

While discussing behaviour, he described both positive and challenging aspects. He said, *"He will smile and play… but when anger comes, he will shout or hit,"* showing emotional variability. He also explained how he manages behaviour, stating, *"If we give something he likes, he becomes calm,"* reflecting practical coping strategies used by the caregiver.

He highlighted social difficulties, mentioning, *"He will not go near others… only with us he stays,"* showing limited social interaction.

The respondent expressed emotional stress very clearly when discussing the future. He said, *"After us, who will look after him… that is the biggest worry,"* reflecting deep concern. He also added, *"Outside he cannot go alone… so everything we have to see,"* showing the level of dependency.

He also mentioned financial limitations, indicating that available support is not enough for long-term care.Overall, his description reflects long-term caregiving responsibility, emotional stress, and concern about future care.

Researcher Observation

The respondent actively participated in the interview and spoke openly about the challenges encountered in caregiving. He appeared concerned while discussing the beneficiary's behavioural difficulties and dependency in daily activities. The respondent frequently emphasised the unpredictability of the caregiving situation and the need for constant supervision. Emotional concern was particularly evident when discussing future caregiving arrangements. His narrative reflected both commitment towards caregiving and the burden associated with long-term responsibility.

Preliminary Interpretation

The experiences shared by Participant B indicate that caregiving is characterised by unpredictability and continuous vigilance. Behavioural difficulties, sleep disturbances, and dependency in daily functioning contribute to increased caregiver burden. The narrative reflects the emotional strain associated with managing situations that cannot always be anticipated or controlled. At the same time, the caregiver demonstrates a strong commitment towards ensuring the well-being of the beneficiary despite these challenges. Concerns regarding future caregiving responsibilities suggest a lack of confidence in available support mechanisms and highlight the need for sustainable long-term care arrangements.

CASE C

Sociodemographic Profile

The respondent is a 46-year-old female caregiver. She is the mother of a 22-year-old adult with Intellectual Disability. She is a homemaker and has completed basic education. She lives in a nuclear family and is the primary caregiver. The family belongs to a middle to lower socio-economic background.

VERBATIM

"Actually… with her, there is no fixed routine like other houses. Every day is almost the same but still different also. From morning onwards I have to be with her only. If I leave her and go for even small work, I have to keep checking. She won't do anything

by herself unless I tell her again and again. Even for eating also, sometimes she will just sit without touching the food. Then I have to remind her… sometimes even feed her slowly so that she finishes.

Bathing, changing dress, keeping things properly… all these I have to guide step by step. If I say one time, she may not do. I have to repeat… sometimes many times. Some days she listens better, some days she won't respond at all. That time I don't know what to do… I just wait or try again later.

She is mostly calm… she won't trouble much like shouting or all. But suddenly she will become restless. She will start walking here and there, not sitting in one place. If I ask, she won't answer properly. She will try to say something but we cannot understand clearly. That is one of the biggest difficulty… we feel she wants to say something, but it doesn't come properly. Then we have to guess and manage.

With us, she is comfortable… especially with me she stays close. But if anyone new comes, she will not go near. She will just move away or sit quietly and look. She doesn't mix with others. Even if relatives come, she will not interact much. Outside also I don't take her much because she won't adjust… she feels uncomfortable.

About studies… we tried when she was small. She went for some time, but it didn't continue. She couldn't follow like other children. Now also if we give pencil, she will just draw lines or scribble. Reading or writing she doesn't know. We also stopped forcing after some time.

For me… I don't even think much about myself now. My life is like adjusted to her needs. Whole day goes in that only. Sometimes I feel very tired… especially when things don't go smoothly. But still I don't show much because there is no use. I have to manage only.

Financially also it is not easy… we have expenses for her, and also other house expenses. We are somehow managing, but always there is tension. More than anything… what worries me is future. Now I am there, so I can understand her and take care. But later… who will have that patience… who will understand her like this… that thought will come again and again. That is the biggest tension in my mind."

"In the beginning, I used to worry a lot about what other people would say and how they would react. There were times when I felt isolated because not everyone understood our situation. Gradually, I learned to focus more on her needs rather than other people's opinions. Even now there are difficult days, but I have become more patient and accepting. Looking after her has taught me many things about responsibility, understanding, and persistence."

Case Description

The respondent described her caregiving experience as something that has become a natural part of her life over time. She explained that most of her daily routine revolves around caring for her daughter. She said, *"My whole day is with her… I have to see everything,"* showing how caregiving is integrated into her everyday life.

She mentioned that her daughter attended a special school earlier, which helped in developing some skills. She explained, *"School helped a little… now she can eat and dress,"* indicating gradual improvement.

However, she also pointed out that continuous guidance is still needed. She said, *"Everything I have to tell again and again… only then she will do,"* showing dependence in daily functioning.

While describing emotional behaviour, she shared that her daughter expresses happiness in simple ways, saying, *"If she is happy, she will smile and laugh,"* but also becomes upset easily. She added, *"Sometimes she cries and won't listen… then I have to calm her,"* indicating emotional sensitivity.

She explained that she avoids strict discipline and prefers a calm approach, stating, *"If I shout, she becomes more upset… so I speak slowly,"* showing adaptive caregiving practices.

In terms of social interaction, she mentioned, *"With family she is okay… but outside she is very shy,"* indicating limited social exposure.

The respondent also reflected on her own experience, stating, *"I don't get time for myself… always I have to be with her,"* showing personal sacrifice.

She expressed emotional acceptance along with concern, saying, *"Now I have adjusted… but future thinking is always there,"* reflecting both adaptation and anxiety.Overall, her description shows continuous caregiving involvement, emotional attachment, and concern about long-term care.

Researcher Observation

During the interview, the respondent maintained a reflective and composed manner while sharing her experiences. She often referred to caregiving as a lifelong responsibility and described her daily routine in considerable detail. The respondent appeared emotionally attached to the beneficiary and expressed concern regarding the beneficiary's dependence on family members. Several moments of silence were observed while discussing future uncertainties. The interaction suggested that caregiving had significantly shaped her personal life and daily functioning.

Preliminary Interpretation

The case of Participant C reflects the close interconnection between caregiving responsibilities and everyday family life. The caregiver's experiences reveal that caregiving involves constant guidance, emotional support, and efforts to understand needs that are not always clearly communicated. The narrative suggests that communication limitations create additional caregiving demands, requiring patience and continuous observation. Emotional attachment appears to be a major factor influencing caregiving practices. The caregiver's concerns about the future indicate an awareness of the beneficiary's continued dependence and the absence of clear alternatives for long-term support. The case illustrates how caregiving can shape personal routines, social interactions, and emotional well-being over an extended period.

CASE D

Sociodemographic Profile

The respondent is a 49-year-old female caregiver. She is the mother of a 24-year-old adult with Intellectual Disability. She is a homemaker and lives in a nuclear family. She

belongs to a lower socio-economic background and is the primary caregiver responsible for all caregiving activities.

VERBATIM

"With him, it is not like we can relax at any time… always we have to be alert. Even if he is sitting quietly, we cannot leave him and go freely. Suddenly he may get up and do something, so someone has to be there near him. My day starts like that only… I will first check what he is doing, then only I can start my work.

He can do some small things, but not fully. Eating he will do, but sometimes he will leave in between or make a mess. Cleaning or keeping things properly he will not do at all. We have to do everything after him. Even for simple things, we have to remind many times. If we say once, he won't respond. If we repeat again and again, then maybe he will do slowly.

One difficulty is his mood… it changes suddenly. Sometimes he will be very calm and sit quietly, but sometimes without any reason he will become irritated. He may shout or push things. That time it is very difficult to control him. We cannot argue with him… if we do, it becomes worse. So mostly we stay quiet and wait for him to calm down. After some time he will become normal like nothing happened.

He doesn't like going outside. If we take him somewhere, he becomes uncomfortable. He won't stay in one place and will try to come back home. So we stopped taking him much outside. Even with neighbours also he doesn't mix. He just stays inside the house.

Studies didn't go much for him. He went for some years, but he couldn't continue. He doesn't know reading or writing. Even now if we try to teach something, he won't sit for long. He will lose interest very fast.

For us, managing him along with daily life is not easy. There is always some tension. We cannot plan anything freely. If we have to go somewhere, we have to think who will stay with him. Financial side also there is pressure… his needs are there, house expenses are there.

Sometimes I feel tired… but what to do, this is our responsibility. More than anything, I am worried about later. Now we are managing somehow. But after us, how he will live, who will take care… that thought is always there. That is the biggest concern for me."

"Apart from the emotional responsibility, there are practical difficulties as well. We have to think about medical expenses, travel expenses, and many small things that people may not notice. Sometimes we postpone our own needs because his needs come first. We somehow manage everything, but there are times when the pressure feels heavy. Even then, we continue because there is no alternative and because he depends on us."

Case Description

The respondent described her caregiving experience as something that requires constant attention and patience throughout the day. She explained that her son is dependent on her for most daily activities and cannot manage independently outside the home. She said, *"I cannot leave him alone even for a short time… I have to be there always,"* which clearly shows the continuous nature of her caregiving responsibility.

She mentioned that daily routines such as bathing, dressing, and maintaining cleanliness require supervision. She said, *"Everything I have to tell and watch… otherwise he won't do properly,"* indicating the need for repeated guidance.

While talking about behaviour, she explained that her son expresses happiness through simple actions like smiling and clapping, saying, *"If he is happy, he will just smile and be calm,"* but when he becomes angry, it is more difficult to manage. She stated, *"Sometimes he will shout or throw things… then I have to calm him slowly,"* showing the challenges in emotional regulation.

She also explained that she avoids strict discipline and prefers a calm approach, stating, *"If I get angry, it becomes worse… so I try to handle him patiently,"* which reflects her caregiving strategy.

The respondent expressed physical and emotional exhaustion due to continuous caregiving. She said, *"Day and night I am thinking about him… it is tiring sometimes,"* showing the impact on her well-being.

She also shared concern about the future, saying, *"After me, who will take care of him… that is my biggest fear,"* reflecting long-term anxiety.Overall, her experience highlights constant supervision, emotional burden, and lack of external support.

Researcher Observation

During the interview, the respondent appeared attentive and willing to share experiences related to caregiving. The respondent frequently referred to the need for constant supervision and monitoring of the beneficiary, indicating the intensity of caregiving responsibilities. While discussing behavioural changes and daily challenges, the respondent showed signs of concern and occasionally paused before responding. The interview reflected the caregiver's familiarity with the beneficiary's routines and needs. The overall interaction suggested that caregiving responsibilities significantly influence the respondent's daily activities and decision-making processes.

Preliminary Interpretation

The experiences shared by Participant D suggest that caregiving involves constant supervision and monitoring to ensure the safety and well-being of the beneficiary. The caregiver's narrative reflects the challenges associated with behavioural unpredictability and limited independence in daily functioning. The need for repeated instructions and continuous observation indicates a high level of dependency, which significantly influences the caregiver's daily routine. The case further demonstrates that caregiving responsibilities often restrict personal freedom and require adjustments in family life. Concerns regarding the future care of the beneficiary emerged as a recurring issue, reflecting the emotional burden associated with long-term caregiving responsibilities.

CASE E

Sociodemographic Profile

The respondent is a 44-year-old female caregiver. She is the mother of a 20-year-old adult with Intellectual Disability. She is engaged in small-scale work along with caregiving responsibilities. She belongs to a lower middle socio-economic background and is the primary caregiver.

VERBATIM

"For me… I feel like my life has slowly adjusted around him. Earlier I used to think I will manage everything separately, but now everything is connected. From morning itself, I have to check on him first. Whether he woke up, whether he ate, whether he is sitting properly… like that only the day starts.

He will not come and ask anything directly. If he wants something, he will just stand or show by action. Sometimes we understand, sometimes we don't. That makes things a little difficult. We have to observe him all the time to understand what he needs. If we ignore, he may get upset or just withdraw.

He can eat by himself, but not properly always. Sometimes he will spill, sometimes he will stop in between. For bathing also, we have to help. If we tell him, he will do some part, but not fully. Everything has to be supervised. If we leave him alone, things will not go properly.

He is not very expressive… he won't talk much. But we can understand his mood from small changes. If he is happy, he will be calm and sit quietly. If something is wrong, he will become silent or move away. Sometimes he gets irritated also, but not very aggressive. Still we have to be careful and handle him gently.

Outside interaction is very less. He doesn't go and talk to others. Even if someone talks to him, he may not respond. So mostly he stays within the house. We also don't force him much because he gets uncomfortable.

Studies didn't continue for him. After some time we realised he cannot follow like others. Even now, he doesn't know reading or writing. We tried earlier, but slowly we stopped forcing him.

For me, the main difficulty is managing everything together. House work, his care, and other responsibilities… everything comes together. Some days it feels manageable, some days it becomes too much. But still we continue because there is no other way.

I don't usually talk about this much, but inside there is always a worry… especially about future. Now we are there to take care. But later, who will understand him like this… who will have this patience… that thought is always there in the back of my mind."

"Support from family members makes a difference, even if it is only for a short period of time. There are days when I feel physically tired or emotionally exhausted, and during those times even a small amount of help feels valuable. At the same time, most of the responsibility remains with the primary caregiver. Because of this, there is always a need to balance caregiving duties with other family and household responsibilities."

Case Description

Participant **E** is a caregiver whose daily life is closely structured around the needs of an adult individual with intellectual disability. The caregiving role is continuous and requires constant observation to understand non-verbal cues and behavioural changes.

The beneficiary shows partial independence in basic activities but requires supervision and assistance for proper completion. Communication is largely non-verbal, requiring the caregiver to interpret needs through behaviour and gestures.

Emotional expression is subtle, with limited verbal communication. Behaviour is generally calm with occasional irritation. Social interaction is minimal, and the individual remains within the home environment due to discomfort in external settings.

The caregiver experiences cumulative burden from balancing caregiving with household responsibilities. While the stress is not always openly expressed, there is a persistent underlying concern about the future care and well-being of the individual.

Researcher Observation

The respondent participated actively in the interview and provided detailed descriptions of caregiving experiences. Throughout the interaction, the respondent appeared calm and reflective while discussing the beneficiary's needs and daily routines. Particular attention was given to understanding the beneficiary's emotions and behaviours, suggesting a close and observant caregiving relationship. The respondent appeared thoughtful when discussing future concerns and support systems. The interview indicated a strong sense of commitment towards caregiving despite the challenges encountered.

Preliminary Interpretation

The narrative of Participant **E** highlights the importance of observation and understanding in the caregiving process. The caregiver's experiences suggest that communication difficulties require continuous attention to non-verbal cues and behavioural expressions. Caregiving appears to involve not only assistance with daily activities but also emotional responsiveness to the beneficiary's needs. The case indicates that caregiving responsibilities have become deeply integrated into the caregiver's daily life, resulting in personal sacrifices and increased responsibility. Underlying concerns regarding future care arrangements and the absence of dependable support systems further contribute to emotional stress and uncertainty.

CASE F

Sociodemographic Profile

The respondent is a 51-year-old male caregiver. He is the father of a 25-year-old adult with Intellectual Disability. He is employed and shares caregiving responsibilities with his spouse. He belongs to a middle socio-economic background.

VERBATIM

"Taking care of him has become part of our life now. From morning itself, we have to see whether he has woken up, whether he has brushed, eaten food and all those things. My wife spends more time with him because I go for work, but after coming back home I also have to look after him. We both share the responsibility, but still it is not easy. Every day we have to plan things according to him.

He can do some things by himself. He can eat, wear clothes and do a few small activities. But we cannot leave him alone completely. Even if he knows how to do something, somebody has to be there to supervise. Otherwise he may forget steps or do things in an unsafe way. For example, if he is eating, sometimes he will get distracted and leave it halfway. If we remind him, then only he will continue.

Most of the time he is calm and quiet. If he is happy, he will smile and sit peacefully. He likes simple activities and spends time at home. But sometimes he becomes upset suddenly. If something does not happen the way he wants, he may shout, become restless or move around continuously. During those times we cannot force him or argue with him. We have to understand his mood and wait patiently. Slowly he becomes calm again.

He does not mix much with people outside the family. With relatives whom he knows well he is comfortable, but with strangers he keeps a distance. Even when we go outside, he prefers staying close to us. He does not start conversations with others and usually avoids social situations.

Regarding studies, he attended school for some years, but he could not continue like other children. He learned a few basic things, but reading and writing are still difficult for him. We have accepted that and now focus more on helping him manage daily life skills.

For us, the biggest concern is about the future. Now both of us are there to take care of him. We understand his needs and can manage his behaviour. But later what will happen is always a worry. There are not many facilities available for adults like him.

Sometimes we feel anxious thinking about who will support him after us. That thought is always there in our minds."

"Over the years, I have learned that caregiving is not only about difficulties. There have been moments that gave me happiness and encouragement. When I see even a small improvement or when he manages something independently, I feel proud. These small moments may seem ordinary to others, but for us they are meaningful because we know the effort behind them. Those experiences help me continue despite the challenges."

Case Description

The respondent described caregiving as a long-term responsibility that requires continuous attention and adjustment. He explained that although he shares responsibilities with his wife, the overall burden remains significant. He said, *"We both are taking care… but still it is not easy,"* showing shared but demanding caregiving.

He mentioned that his son is able to perform some daily activities independently but still requires supervision for safety. He said, *"He can do some things… but we cannot leave him alone,"* indicating limited independence.

While describing behaviour, he explained that his son is generally calm and expresses happiness through smiling, saying, *"He will be quiet and happy most of the time,"* but sometimes shows anger. He added, *"When he gets upset, he will shout or become restless,"* showing emotional fluctuations.

He explained that managing behaviour requires patience and understanding, stating, *"We have to adjust according to his mood,"* reflecting adaptive caregiving.

He also discussed social limitations, saying, *"He does not mix much with others… he stays within family,"* indicating restricted social interaction.

The respondent expressed strong concern about the future, stating, *"Our biggest worry is what will happen after us,"* showing long-term anxiety.

He also mentioned lack of support services, saying, *"There are not many facilities for adults… that is a problem,"* highlighting systemic gaps.

Overall, his experience reflects shared caregiving, concern about future, and lack of structured support.

Researcher Observation

During the interview, the respondent spoke openly about both the positive and challenging aspects of caregiving. The respondent appeared experienced in managing the beneficiary's daily needs and frequently described caregiving as a continuous responsibility. Emotional involvement was evident when discussing the beneficiary's dependence and future well-being. The respondent maintained a cooperative attitude throughout the interview and provided examples from personal experiences to explain caregiving practices. The interaction reflected a strong caregiving bond and a high level of personal investment in the beneficiary's welfare.

Preliminary Interpretation

The account provided by Participant F suggests that caregiving is shaped by a combination of practical responsibilities, emotional commitment, and ongoing adaptation to the needs of the beneficiary. The caregiver's experiences indicate that dependency in daily activities requires sustained involvement and patience. The narrative also reflects the challenges of balancing caregiving responsibilities with other household and family obligations. Emotional resilience appears to have developed over time as the caregiver adapted to the demands of long-term care. Nevertheless, concerns about the future, availability of support, and the beneficiary's continued dependence remain significant sources of anxiety.

CASE G

Sociodemographic Profile

The respondent is a 43-year-old female caregiver. She is the mother of a 23-year-old adult with Intellectual Disability. She is a homemaker and the primary caregiver. She belongs to a lower socio-economic background.

VERBATIM

"For me, my whole day is connected to him. From morning itself I have to see everything. Whether he wakes up on time, whether he brushes, takes bath and eats food properly. If I do not remind him, many things will not happen. So I have to keep checking and guiding him throughout the day.

He depends on me for almost everything. Even for small activities I have to tell him what to do. Sometimes he listens immediately, but sometimes I have to repeat many times. If I leave him alone for a long time, he may just sit without doing anything. Because of that I cannot completely focus on other work. My attention is always on him.

Emotionally he is a sensitive person. If he is happy, he smiles and stays calm. We can easily understand when he is comfortable. But when something troubles him, he becomes very quiet. Sometimes he will sit alone and not talk to anyone. On some occasions he may cry without explaining what happened. That is difficult because he cannot express everything clearly. Then I try to sit with him, speak slowly and make him feel comfortable.

He does not interact much with people outside the family. If visitors come to the house, he usually stays away or remains silent. Even when relatives talk to him, he may not respond much. Because of this, his social circle is very limited. Most of his time is spent at home with family members.

He studied only for a short period. Later it became difficult for him to continue. Even now he cannot read or write properly. We tried to teach him many things, but progress was very slow. So now we focus mainly on daily living skills and helping him manage routine activities.

Financially also there are difficulties. We have household expenses and expenses related to his care. Sometimes it becomes hard to manage everything. There are days when I feel physically and mentally tired. But as a mother I continue because there is nobody else who understands him the way I do.

More than anything, I worry about the future. As long as I am here, I can take care of him. But later who will understand his needs, who will be patient with him and who will support him? That fear is always there in my mind. Whenever I think about the future, I feel worried."

"As I grow older, I find myself thinking more about the future than before. Earlier, I focused mainly on managing each day, but now I think about long-term care and security. The question of who will take responsibility in the future remains in my mind. I want to make sure that he will continue to receive care, support, and understanding even when I am no longer able to provide it myself. That concern is something I carry with me every day."

Case Description

The respondent described her caregiving experience as emotionally demanding and continuous. She explained that her daily routine revolves around her child's needs. She said, *"From morning to night I am with him… everything I have to see,"* indicating full-time caregiving involvement.

She mentioned that her son requires assistance in daily routines and cannot manage independently. She said, *"I have to guide him for everything… otherwise he won't do,"* showing dependence.

While discussing emotional behaviour, she explained that he expresses happiness through smiling and staying calm, saying, *"If he is happy, he will just smile,"* but shows distress through withdrawal or crying. She added, *"Sometimes he will not talk and just sit quietly,"* indicating emotional withdrawal.

She explained that she handles such situations with care, stating, *"I try to talk slowly and make him comfortable,"* showing supportive caregiving.

She also mentioned financial difficulties, saying, *"Money is always a problem… we have many expenses,"* highlighting economic strain.

She expressed emotional stress, stating, *"Sometimes I feel very tired… but I have to continue,"* reflecting resilience.

She also shared concern about future care, saying, *"After me, who will look after him… that fear is always there,"* showing deep anxiety.

Overall, her experience reflects emotional burden, financial strain, and continuous caregiving responsibility.

Researcher Observation

The respondent demonstrated a thoughtful and composed approach while sharing caregiving experiences. Throughout the interview, the respondent emphasised the importance of providing support, guidance, and protection to the beneficiary. Emotional expressions became noticeable when discussing ageing and concerns regarding future caregiving arrangements. The respondent frequently referred to family responsibilities and the long-term nature of caregiving. The interview suggested that caregiving has become a central aspect of the respondent's life and identity, influencing both personal and family experiences.

Preliminary Interpretation

The experiences of Participant G reveal that caregiving extends beyond meeting physical needs and includes continuous emotional support, guidance, and advocacy. The caregiver's narrative reflects a strong sense of responsibility and commitment towards ensuring the well-being of the beneficiary. The case suggests that caregiving has influenced various aspects of the caregiver's personal and social life, requiring ongoing adjustments and prioritisation of the beneficiary's needs. The limited availability of formal support services has increased reliance on family-based care. Concerns regarding ageing, future caregiving arrangements, and long-term security of the beneficiary emerged as central themes within the caregiver's experiences.

4.3 cross-case thematic analysis

The analysis of the seven cases revealed both similarities and differences in caregiving experiences. Although each caregiver had unique circumstances, several common patterns emerged regarding caregiving responsibilities, emotional experiences, challenges, and support systems.

A prominent similarity across the cases was the continuous involvement of caregivers in the daily lives of adults with Intellectual Disability. Most caregivers reported providing assistance with personal care, supervision, behavioural guidance, and emotional support. The beneficiaries were largely dependent on family members for daily functioning, requiring varying degrees of monitoring and assistance.

Another common pattern observed across the cases was the emotional attachment between caregivers and beneficiaries. Caregivers frequently described caregiving as a responsibility that extended beyond physical care and involved patience, understanding, and emotional commitment. Many respondents expressed concerns regarding the long-term well-being of the beneficiary and the uncertainty surrounding future caregiving arrangements.

Financial challenges were also evident in several cases. Caregivers reported difficulties in managing household expenses alongside expenses related to healthcare, transportation, and other support needs. The burden was particularly noticeable among families with limited income sources.

Despite these similarities, differences were observed in the level of dependency, behavioural characteristics, availability of family support, and coping strategies. Some caregivers received assistance from family members, while others managed caregiving responsibilities with minimal support. Variations were also observed in the ways caregivers responded to behavioural challenges and adapted to caregiving demands.

Overall, the cross-case analysis indicates that caregiving is a multifaceted experience shaped by personal, familial, social, and economic factors. While the intensity of caregiving varied across cases, the narratives collectively highlight the central role of caregivers in supporting adults with Intellectual Disability.

A closer examination of the cases revealed that caregiving was not limited to meeting the physical needs of the beneficiaries. Caregivers described their role as a continuous process of supervision, emotional support, decision-making, and advocacy. Many respondents reported that they had gradually developed personalised approaches to caregiving based on the beneficiary's behaviours, preferences, and daily routines. This suggests that caregiving is shaped not only by the needs of the individual but also by the caregiver's accumulated experiences and understanding developed over time.

The narratives further indicated that caregiving responsibilities influenced multiple aspects of the caregivers' lives. Several respondents reported adjusting their daily schedules, social interactions, employment opportunities, and personal aspirations to accommodate caregiving responsibilities. In many cases, caregiving had become a central aspect of family life, influencing household routines and family relationships. These findings highlight the extensive impact of caregiving beyond the immediate provision of care.

Another pattern that emerged across the cases was the gradual adaptation demonstrated by caregivers. Although many respondents initially described feelings of uncertainty, emotional distress, or difficulty in managing caregiving responsibilities, they also reported developing coping strategies through experience. Patience, observation, acceptance, and family cooperation were commonly mentioned as factors that helped caregivers manage challenges encountered in daily life. This adaptation process reflects the dynamic nature of caregiving experiences.

The cases also revealed variations in the availability and utilisation of support systems. While some caregivers received support from family members, neighbours, or community networks, others reported managing caregiving responsibilities with limited external assistance. Formal support services were mentioned less frequently than informal support mechanisms, indicating the continued reliance on family-centred care. This finding suggests the importance of strengthening community-based and institutional support systems for caregivers of adults with Intellectual Disability.

Future-related concerns emerged consistently across nearly all cases. Caregivers expressed uncertainty regarding the long-term care, safety, and well-being of the

beneficiaries, particularly in relation to ageing and changing family circumstances. These concerns often extended beyond present caregiving challenges and reflected broader anxieties about continuity of care and social support. The recurrence of such concerns across multiple narratives highlights the need for sustainable support structures and long-term care planning for adults with Intellectual Disability and their families.

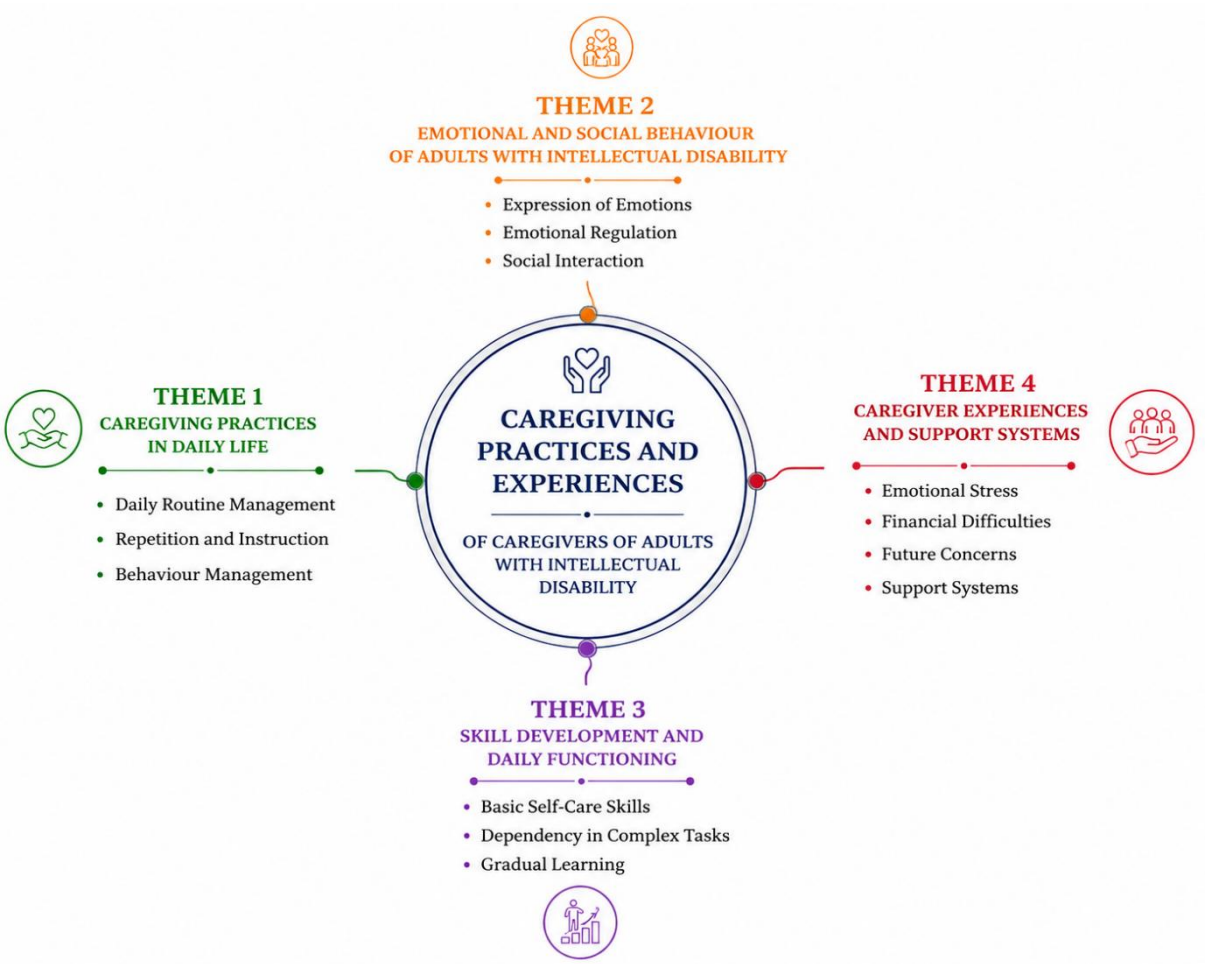

Figure 1 Themes and Sub themes

4.4 Theme Discussion.

THEME 1: CAREGIVING PRACTICES IN DAILY LIFE

Caregiving practices among the respondents were found to involve continuous supervision and active engagement in daily routines. Most caregivers reported that they are responsible for managing basic activities such as bathing, eating, dressing, and maintaining daily structure.

Several caregivers emphasised that caregiving begins from early morning and continues throughout the day. One caregiver stated, *"Morning itself I have to see everything… bathing, food, everything I have to manage"* (Case A), indicating the constant nature of caregiving. Similarly, another respondent mentioned, *"Everything I have to tell and watch… otherwise he won't do properly"* (Case D), showing the need for close supervision.

Caregivers also highlighted the importance of repetition and simple instructions in guiding daily activities. One respondent explained, *"Everything I have to tell again and again… only then she will do"* (Case C), reflecting the repetitive nature of caregiving practices.

Additional narratives further highlighted the extent of involvement required in everyday caregiving. One caregiver explained, *"Even if I am doing some other work in the house, I have to keep checking on her. If I don't remind her, she will just sit without doing anything. For every small thing, I have to guide her step by step."* (Case C). Similarly, another respondent shared, *"There is no fixed time when I can say my work is over. From morning until night, I have to see whether everything is going properly. If I leave him alone for too long, he may not complete even simple tasks."* (Case D).

The narratives also revealed that caregiving often involves anticipating the needs of the beneficiary before difficulties arise. One caregiver stated, *"After so many years, I can understand from his face itself if something is wrong. Sometimes he cannot tell us what he wants, so we have to observe carefully and find out."* (Case B). Another respondent mentioned, *"I know her routine very well. If there is any small change in behaviour, I notice it immediately because I spend most of my time with her."* (Case F).

In terms of behaviour management, most caregivers preferred a calm and patient approach rather than strict discipline.

Several caregivers described how their approaches to behaviour management had changed over time through experience. One respondent explained, *"Earlier we used to get angry quickly because we didn't know how to handle the situation. Slowly we understood that speaking calmly works better than shouting."* (Case B). Another caregiver shared, *"When he becomes upset, I try to distract him or talk slowly. If I react immediately, the situation becomes more difficult."* (Case G).

Caregivers repeatedly emphasised that patience was an essential part of caregiving. As one respondent noted, *"Sometimes I have to explain the same thing many times. It takes time, but I have learned to be patient because getting frustrated will not help either of us."* (Case E). These accounts demonstrate that caregiving practices are shaped not only by the needs of the beneficiary but also by the caregiver's accumulated experience and understanding.

As one caregiver noted, *"If we shout, it becomes worse… so we try to speak slowly"* (Case A), while another mentioned, *"I don't scold much… I try to explain slowly"* (Case E).These findings indicate that caregiving practices are largely supportive, routine-based, and dependent on patience and continuous involvement.

A closer examination of the caregivers' narratives suggests that caregiving practices extend beyond the completion of routine tasks. The respondents described caregiving as an ongoing process that requires constant attention to the beneficiary's physical, emotional, and behavioural needs. Daily care activities were not performed as isolated responsibilities but were integrated into the overall functioning of the household. As a result, caregivers frequently adjusted their own schedules and priorities to accommodate the needs of the beneficiary.

The findings further indicate that supervision forms a central component of caregiving practices. Many caregivers reported that beneficiaries required repeated reminders, guidance, and monitoring to complete daily activities. This continuous involvement reflects the varying levels of dependence experienced by adults with Intellectual

Disability and highlights the significant role played by caregivers in maintaining daily structure and routine.

Another important aspect emerging from the narratives was the use of patience and positive guidance in managing behaviour. Rather than relying on punishment or strict control, caregivers commonly adopted supportive approaches such as reassurance, repetition, and calm communication. These practices appear to have developed through experience and observation, enabling caregivers to respond more effectively to behavioural challenges encountered in everyday life.

The narratives also suggest that caregiving practices are shaped by familiarity with the beneficiary's individual needs, preferences, and behaviours. Caregivers demonstrated detailed knowledge of routines and behavioural patterns, allowing them to anticipate difficulties and adapt their caregiving approaches accordingly. This highlights the experiential nature of caregiving and the gradual development of practical skills through long-term involvement in care.

The theme highlights that caregiving practices are not limited to physical assistance but encompass supervision, emotional support, behavioural guidance, and continuous adaptation to the needs of the beneficiary. The findings demonstrate that caregiving is a dynamic and demanding responsibility that requires sustained involvement and commitment from caregivers.

THEME 2: EMOTIONAL AND SOCIAL BEHAVIOUR OF ADULTS WITH INTELLECTUAL DISABILITY

This theme focuses on how adults with Intellectual Disability express emotions and interact socially, as perceived by caregivers.

Caregivers reported that positive emotions such as happiness are expressed through simple behaviours like smiling, laughing, or playful actions. One caregiver stated, *"If he is happy, he will just smile and be calm"* (Case D), while another mentioned, *"She will smile and be happy with small things"* (Case E).

However, negative emotions such as anger or frustration were more difficult to manage. Additional narratives revealed that emotional expressions were often communicated through behaviour rather than verbal communication. One caregiver explained, *"He cannot always tell what he is feeling. We understand mostly from his face and behaviour. If something is bothering him, he becomes quiet or starts moving around the house."* (Case B). Another respondent shared, *"Sometimes she wants to tell something but cannot explain properly. Then she becomes restless and we have to understand what she needs."* (Case C).

Several caregivers reported that emotional regulation required continuous support from family members. One respondent stated, *"When he gets upset, I stay with him and talk slowly. If we leave him alone, he becomes more disturbed."* (Case G). Similarly, another caregiver mentioned, *"We have learned to recognise the signs before she becomes very upset. That helps us manage the situation better."* (Case F).

Caregivers described behaviours such as shouting, crying, or throwing objects. For instance, one respondent stated, *"Sometimes he will shout or throw things… then I have to calm him slowly"* (Case D), and another explained, *"Sometimes she cries and won't listen… then I have to calm her"* (Case C).

Social interaction was found to be limited across most cases. Caregivers further noted that familiarity played an important role in social interactions. Most beneficiaries appeared comfortable with immediate family members and individuals they encountered regularly, but showed hesitation when interacting with unfamiliar people. One caregiver explained, *"With family he is okay, but if new people come, he will move away and stay by himself."* (Case D). Another respondent stated, *"She prefers staying with people she already knows. In new situations she becomes very quiet and avoids interaction."* (Case E).

The narratives also suggested that limited social interaction was influenced by both personal and environmental factors. Some caregivers reported avoiding social gatherings because they were concerned about how others might react to the beneficiary. Others explained that beneficiaries themselves preferred familiar surroundings and routines, resulting in reduced participation in community activities

and social events. Caregivers reported that individuals are comfortable within the family but hesitant or withdrawn in social situations. One caregiver explained, *"He will not go near others… only with us he stays"* (Case B), while another stated, *"Outside she is very shy"* (Case C).

These findings suggest that while emotional expression is present, it often requires caregiver support, and social interaction remains restricted.A closer examination of the narratives indicates that emotional expression among adults with Intellectual Disability is often communicated through non-verbal behaviours, facial expressions, and changes in routine rather than through direct verbal communication. Consequently, caregivers play a significant role in interpreting emotional states and responding appropriately to the needs of the beneficiary. This highlights the importance of close observation and familiarity within the caregiving relationship.

The findings further suggest that emotional experiences are closely linked to the quality of caregiver support. Participants described various strategies used to comfort, reassure, and guide beneficiaries during periods of distress. Such responses demonstrate that caregivers serve not only as providers of practical assistance but also as important sources of emotional security and stability.

With regard to social behaviour, the narratives indicate that social interaction remains largely confined to familiar environments and trusted individuals. While beneficiaries demonstrated the capacity to form meaningful relationships, their participation in wider social contexts appeared limited. Factors such as communication difficulties, lack of confidence, dependence on caregivers, and restricted opportunities for social engagement may contribute to reduced interaction beyond the family setting.

The findings suggest that emotional and social behaviour among adults with Intellectual Disability is shaped by both individual characteristics and the surrounding social environment. Caregivers play a central role in supporting emotional well-being, facilitating social interaction, and helping beneficiaries navigate everyday social experiences.

THEME 3: SKILL DEVELOPMENT AND DAILY FUNCTIONING

This theme highlights the level of independence and ability of adults with Intellectual Disability to perform daily life activities.

Caregivers reported that individuals are able to perform some basic self-care activities such as eating and dressing, although supervision is still required. One caregiver stated, *"He can do some things… but we cannot leave him alone"* (Case F), indicating partial independence.

However, more complex tasks such as travelling independently, maintaining cleanliness, and managing responsibilities were reported as difficult. Additional narratives indicated that the level of independence varied across individuals and often depended on the nature of the activity being performed. While some beneficiaries were able to complete familiar tasks with minimal assistance, others required continuous reminders and supervision. One caregiver explained, *"He can eat by himself, but I still have to watch because sometimes he will stop in between or forget what he is doing."* (Case E). Another respondent stated, *"If I tell her step by step, she can do many things. But if I leave her alone, she gets confused and does not finish the task properly."* (Case C).

Caregivers frequently emphasised that independence was not a fixed ability but something that changed depending on the situation. Several respondents reported that beneficiaries managed routine activities more successfully when tasks were familiar and repeatedly practised. However, unfamiliar situations often required greater support and guidance from caregivers.

One respondent mentioned, *"Cleanliness also we have to tell… otherwise he will not do properly"* (Case B), showing dependence in daily routines.

Caregivers also observed gradual improvement over time with consistent guidance. Many caregivers described skill development as a slow and continuous process that required patience and repetition. One caregiver explained, *"Earlier he could not do many things on his own. Now he can manage some small tasks because we have been teaching and guiding him for many years."* (Case F). Another respondent shared,

"Progress is slow, but we notice small changes. Even learning one new thing gives us confidence and motivation to continue helping her." (Case A).

The narratives suggested that family members play an important role in reinforcing daily living skills through encouragement, repeated instruction, and practical demonstration. Caregivers viewed even minor improvements as meaningful achievements because they contributed to greater participation in everyday activities and reduced dependence in certain areas of functioning.

One caregiver explained, *"School helped a little… now she can eat and dress"* (Case C), indicating the role of structured support in skill development.

These findings suggest that skill development is gradual and largely dependent on caregiver involvement and continuous practice. A closer analysis of the narratives indicates that skill development among adults with Intellectual Disability is closely associated with opportunities for learning, repetition, and ongoing support. Caregivers described themselves as active participants in this process, providing guidance, encouragement, and supervision to help beneficiaries acquire and maintain daily living skills. The findings suggest that the development of functional abilities is influenced not only by the individual's capabilities but also by the consistency of support available within the family environment.

The narratives further demonstrate that independence exists along a continuum rather than as a fixed condition. While beneficiaries were able to perform certain activities independently, most continued to require varying levels of assistance in more complex areas of daily functioning. This reflects the importance of recognising both abilities and support needs when understanding the daily lives of adults with Intellectual Disability.

Another significant observation is that caregivers often measured progress through small improvements rather than major changes. Incremental achievements such as improved self-care, greater participation in household activities, or increased confidence in completing routine tasks were viewed as important indicators of development. These experiences highlight the value of continuous support and structured opportunities for skill enhancement.

Overall, the findings suggest that skill development is a gradual and ongoing process shaped by caregiver involvement, repeated practice, environmental support, and individual capacity. Although complete independence may not always be achievable, meaningful improvements in daily functioning contribute positively to the quality of life of adults with Intellectual Disability and their families.

THEME 4: CAREGIVER EXPERIENCES, CHALLENGES AND SUPPORT SYSTEMS

This theme brings together the lived experiences of caregivers, including emotional stress, challenges, and available support systems.

Caregivers described caregiving as a continuous and demanding responsibility that affects their personal, social, and emotional well-being. Additional narratives revealed that caregiving responsibilities often extended beyond physical assistance and became deeply embedded in the caregivers' everyday lives. One caregiver explained, *"My whole routine depends on him. Before doing anything else, I have to make sure he is okay and everything is arranged for him."* (Case C). Another respondent shared, *"Sometimes I feel there is no separate time for myself because most of my day is connected to her needs and daily activities."* (Case E).

Several caregivers also described the emotional impact of long-term caregiving. One respondent stated, *"Some days I feel very tired, not physically alone but mentally also. There is always something to think about."* (Case A). Another caregiver explained, *"We become used to the responsibility, but that does not mean it becomes easy. There are still difficult days and worries."* (Case F).

One respondent stated, *"Everything I have to manage… house work also, his care also… sometimes it becomes tiring"* (Case A), reflecting the burden of caregiving. Another caregiver mentioned, *"I cannot go anywhere freely… always I have to think about her"* (Case E), indicating restriction in personal life.

A major concern expressed by caregivers was related to the future of the individual. Many caregivers shared similar worries. One respondent stated, *"After us, who will look after him… that is the biggest worry"* (Case B), while another said, *"After me, who will*

take care of him… that is my biggest fear" (Case D). Future uncertainty emerged as one of the most consistent concerns across the narratives. Caregivers frequently expressed anxiety regarding the long-term safety, care, and well-being of the beneficiary. One respondent shared, *"As long as I am there, I can manage. But I keep thinking about what will happen later and whether someone will understand his needs in the same way."* (Case G). Another caregiver stated, *"That thought is always in my mind because he depends on us for many things. I do not know who will take responsibility in the future."* (Case B).

These concerns appeared to be closely connected to the ageing of caregivers and the continued dependence of adults with Intellectual Disability on family support. The narratives suggest that future planning remains a significant source of emotional stress among caregivers.

Financial difficulties were also reported as a significant challenge. One caregiver explained, *"Money is always a problem… we have many expenses"* (Case G), highlighting economic strain.

In terms of support systems, most caregivers relied on family members, while formal support services were limited. One respondent stated, *"There are not many facilities for adults… that is a problem"* (Case F), Although family members were identified as the primary source of support, the level of assistance available varied across cases. Some caregivers reported receiving practical and emotional support from spouses, siblings, or extended family members, while others described managing caregiving responsibilities largely on their own. Informal support from neighbours and local community members was mentioned occasionally, but formal support systems appeared limited.

Several respondents expressed the need for additional services and resources specifically designed for adults with Intellectual Disability. Caregivers highlighted the importance of accessible support programmes, opportunities for skill development, recreational activities, and guidance for families. The limited availability of such services was perceived as an additional challenge within the caregiving experience. These findings demonstrate that caregiving is associated with emotional burden,

financial strain, and limited external support system. A deeper examination of the narratives indicates that caregiving is a multifaceted experience involving emotional, social, financial, and practical dimensions. While caregivers described significant challenges, they also demonstrated resilience, commitment, and a strong sense of responsibility towards the beneficiaries. The findings suggest that caregiving is not experienced solely as a burden but also as a long-term relational commitment shaped by affection, responsibility, and concern for the well-being of the individual.

The narratives further reveal that emotional stress often stems from continuous caregiving responsibilities, uncertainty regarding the future, and concerns about the beneficiary's long-term security. These experiences highlight the psychological demands associated with caregiving and the need for adequate emotional and social support for caregivers.

Another significant observation is the central role of family-based support. In the absence of extensive formal services, family members continue to function as the primary source of assistance, guidance, and care. While such support contributes to the sustainability of caregiving, it may also increase the burden on caregivers when responsibilities are concentrated within a small number of family members.

The findings also indicate that financial challenges and limited access to support services can intensify caregiving difficulties. Expenses related to healthcare, transportation, daily living needs, and long-term care planning create additional pressure for families. The limited availability of specialised services for adults with Intellectual Disability further reinforces dependence on informal support networks.

Overall, the experiences shared by caregivers reflect both the challenges and strengths associated with long-term caregiving. The narratives demonstrate the importance of strengthening support systems, improving access to services, and recognising the significant contribution of caregivers in promoting the well-being and quality of life of adults with Intellectual Disability.

CHAPTER V: FINDINGS, SUGGESTIONS, AND CONCLUSIONS

5.1 Introduction

The present chapter brings together the major findings of the study and provides an overall interpretation of the caregiving practices and experiences of caregivers of adults with Intellectual Disability. The study was undertaken to explore the everyday realities of family caregivers in Thiruvananthapuram district, with particular emphasis on their caregiving practices, lived experiences, challenges encountered, and the support systems available to them. Through a qualitative inquiry, the study sought to understand caregiving from the perspective of those who provide continuous care and support to adults with Intellectual Disability.

Caregiving for adults with Intellectual Disability is a lifelong responsibility that extends far beyond meeting physical needs. It involves providing emotional support, supervising daily activities, managing behavioural concerns, promoting independence, facilitating social participation, and ensuring the overall well-being of the individual. These responsibilities require continuous commitment, patience, and adaptability, making caregiving a significant aspect of the caregiver's everyday life. The findings of the present study demonstrate that caregiving is not merely a routine activity but a dynamic and evolving process shaped by the changing needs of the individual, family circumstances, available support systems, and the broader social environment.

The thematic analysis of the data revealed four major themes that represent the lived experiences of caregivers. These themes highlight the nature of caregiving practices in daily life, the emotional and social behaviour of adults with Intellectual Disability as perceived by caregivers, the development of daily living skills and functional independence, and the experiences, challenges, and support systems associated with long-term caregiving. Collectively, these themes provide a comprehensive understanding of the realities of family caregiving and illustrate the multifaceted role performed by caregivers.

The findings also reveal that while caregivers experience emotional stress, financial burden, uncertainty regarding future care, and restrictions in their personal and social lives, they continue to provide care with dedication, resilience, and a strong sense of responsibility. Their experiences reflect both the challenges and the strengths associated

with long-term caregiving and emphasise the central role of family caregivers in promoting the well-being of adults with Intellectual Disability.

This chapter begins by presenting the major findings of the study in relation to the research objectives. The findings are then discussed with reference to the theoretical framework and relevant literature reviewed in the earlier chapters. Based on the findings, the chapter presents the conclusion, implications for social work practice, suggestions for improving services and support systems, scope for further research, and limitations of the study. These sections collectively provide a comprehensive understanding of the caregiving experiences of family caregivers and offer practical recommendations for strengthening family-centred care, community support services, and professional social work interventions for adults with Intellectual Disability and their caregivers.

5.2 Findings and Discussion

The analysis of data reveals that caregiving for adults with Intellectual Disability is not merely a set of daily practices, but a structured and continuous process shaped by dependency, emotional negotiation, and limited support systems. The findings indicate deeper patterns beyond surface-level caregiving activities.

5.2.1 Caregiving as Continuous Surveillance Rather Than Routine Care

The findings suggest that caregiving extends beyond routine assistance and functions as a form of continuous monitoring or surveillance. Caregivers repeatedly expressed that they cannot leave the individual unattended, indicating a lack of functional independence.

Statements such as *"I cannot leave him alone even for a short time"* (Case D) and *"everything I have to see from morning"* (Case A) reflect that caregiving is not time-bound but constant.

This indicates that caregiving is structured around risk prevention rather than developmental support, where the primary focus is on avoiding harm rather than promoting independence.

5.2.2 Repetition as a Core Mechanism of Caregiving

Across cases, repetition emerged as a dominant caregiving strategy. Caregivers consistently reported the need to repeat instructions multiple times for basic tasks.

Statements like *"I have to tell again and again"* (Case C) and *"everything I have to say and watch"* (Case D) indicate that learning is not internalised easily and requires constant reinforcement.

This suggests that caregiving is not linear but cyclical, where the same actions are repeated daily without significant progression, leading to caregiver fatigue.

5.2.3 Emotional Regulation is Managed by Caregivers, Not the Individual

The findings show that emotional expression exists, but emotional regulation is largely controlled externally by caregivers.

Caregivers described managing anger through distraction or calming strategies, such as *"if we give something he likes, he becomes calm"* (Case B).

This indicates that emotional control is not internalised by the individual but is dependent on caregiver intervention, highlighting a form of external emotional regulation system.

5.2.4 Social Isolation is Structurally Maintained

The findings reveal that limited social interaction is not only due to individual limitations but also due to protective caregiving practices.

Statements like *"he will not go near others"* (Case B) and *"outside she is very shy"* (Case C) show restricted social exposure.

However, this also reflects a pattern where caregivers avoid social situations due to fear, stigma, or safety concerns, leading to structural isolation rather than natural withdrawal.

5.2.5 Caregiving Leads to Role Restriction and Identity Shift

Caregivers reported reduced personal freedom and limited social participation. Statements such as *"I cannot go anywhere freely"* (Case E) indicate that caregiving restricts mobility and personal life.

This suggests that caregiving results in a shift in personal identity, where the caregiver role becomes dominant, often replacing other social and personal roles.

5.2.6 Future Anxiety as a Central Emotional Theme

A strong recurring pattern across cases is concern about the future of the individual.

Statements like *"after us, who will look after him"* (Case B, D, G) indicate that caregiving is shaped not only by present responsibilities but also by uncertainty about long-term care.

This reflects anticipatory anxiety, where caregivers experience stress related to future caregiving gaps.

5.2.7 Informal Support Dominates Over Formal Systems

The findings indicate that caregiving is primarily supported by family members, with minimal reliance on formal systems.

Caregivers reported limited access to structured services, as seen in statements like *"there are not many facilities for adults"* (Case F).

This shows that caregiving exists within an informal support structure, with institutional support playing a minimal role.

The present study explored the caregiving practices and experiences of caregivers of adults with Intellectual Disability in Thiruvananthapuram. The findings reveal that caregiving is a complex and continuous process that extends beyond the provision of physical assistance and encompasses supervision, emotional support, behavioural guidance, and long-term responsibility. The experiences shared by caregivers highlight the multifaceted nature of caregiving and demonstrate how caregiving responsibilities influence personal, social, emotional, and economic aspects of life.

5.2.8 Caregiving as a Continuous and Intensive Responsibility

One of the major findings of the study is that caregiving is not limited to specific tasks or time periods but functions as a continuous responsibility. Caregivers described their role as requiring constant monitoring, supervision, and involvement in the daily lives

of adults with Intellectual Disability. The narratives indicate that caregivers remain attentive to the needs of the beneficiary throughout the day and often organise their daily routines around caregiving responsibilities.

This finding is consistent with the study conducted by the Research Synthesis Collaborative (2024), which reported that caregiving in the Indian context involves constant vigilance and active participation in daily activities. The present study similarly found that caregivers often assume responsibility for personal care, behavioural supervision, and decision-making, reflecting the ongoing dependence of adults with Intellectual Disability on family members.

From the perspective of Caregiver Stress Theory, continuous caregiving responsibilities can act as persistent stressors that influence the psychological and emotional well-being of caregivers. The theory suggests that prolonged caregiving demands may result in cumulative stress, particularly when support systems are limited. The findings of the present study support this view, as caregivers frequently described caregiving as a responsibility that extends into nearly all aspects of their lives.

5.2.9 Repetition and Guided Learning as Central Caregiving Practices

The study revealed that repetition forms a core component of caregiving practices. Caregivers consistently reported the need to provide repeated instructions, reminders, and demonstrations to assist beneficiaries in completing daily activities. Learning was described as a gradual process that required continuous reinforcement and supervision.

This finding can be understood through Social Learning Theory, which emphasises the role of observation, modelling, and reinforcement in learning behaviour. In the context of the present study, caregivers function as primary agents of learning who repeatedly guide and reinforce desired behaviours and skills. The findings suggest that the acquisition and maintenance of daily living skills among adults with Intellectual Disability depend significantly on caregiver involvement and structured guidance.

The findings also indicate that caregivers view even minor improvements in functioning as meaningful achievements. Progress was often measured through increased participation in daily activities, improved self-care abilities, and greater familiarity with

routine tasks. This highlights the importance of sustained support and reinforcement in promoting functional development.

5.2.10 Emotional Regulation and the Role of Caregivers

The findings demonstrate that emotional expression is present among adults with Intellectual Disability; however, emotional regulation is frequently supported by caregivers. Participants reported that emotional outbursts, frustration, and distress were often managed through reassurance, distraction, calm communication, and other supportive strategies.

This finding corresponds with the observations of Sopingi et al. (2024), who reported that caregiving approaches significantly influence emotional adjustment and behavioural outcomes among individuals with Intellectual Disability. The present study further suggests that caregivers serve as important sources of emotional stability and security, particularly when beneficiaries experience difficulties expressing or regulating emotions independently.

Erikson's Psychosocial Theory provides additional insight into this finding. The theory emphasises the role of supportive relationships in facilitating emotional development and psychosocial adjustment. The narratives obtained during the study indicate that caregivers play a central role in creating supportive environments that promote emotional well-being and stability.

5.2.11 Social Interaction and Social Isolation

The study found that social interaction among adults with Intellectual Disability remains largely restricted to familiar family members and trusted individuals. Many caregivers reported that beneficiaries were hesitant to interact with unfamiliar people and often preferred familiar environments.

This finding is consistent with previous research highlighting the social isolation experienced by individuals with Intellectual Disability. The Research Synthesis Collaborative (2024) identified stigma, limited opportunities for participation, and social exclusion as significant concerns affecting families. Similar patterns were

evident in the present study, where caregivers frequently described concerns regarding safety, acceptance, and social participation.

The findings further suggest that social isolation is not solely the result of individual limitations but is also influenced by environmental and societal factors. Limited community acceptance, lack of inclusive opportunities, and protective caregiving practices may contribute to restricted social engagement. This highlights the need for community-based initiatives that encourage inclusion and meaningful participation.

5.2.12 Caregiving Burden and Changes in Personal Life

Another important finding of the study relates to the impact of caregiving on the personal lives of caregivers. Participants reported reduced personal freedom, limited social participation, and difficulties balancing caregiving responsibilities with other aspects of life. Many caregivers described caregiving as a central aspect of their identity and daily routine.

These findings are consistent with the IPHB Research Group (2025), which reported high levels of caregiver burden and reduced quality of life among caregivers of individuals with Intellectual Disability. The concept of "loss of self" identified in previous research is reflected in the experiences of participants who described prioritising caregiving responsibilities over personal needs and interests.

Caregiver Stress Theory further explains how prolonged caregiving responsibilities may contribute to emotional exhaustion, role strain, and reduced well-being. The findings indicate that caregiving affects not only practical aspects of life but also personal identity, relationships, and emotional health.

5.2.13 Future Anxiety and Long-Term Uncertainty

Future-related concerns emerged as one of the most significant emotional themes across the narratives. Caregivers consistently expressed concerns regarding who would care for the beneficiary in the future, particularly as they themselves age or become unable to provide support.

This finding is supported by Scripps et al. (2025), who identified future planning and long-term caregiving arrangements as major concerns among families of individuals

with Intellectual Disability. The absence of structured long-term support systems contributes to uncertainty and emotional distress among caregivers.

The findings suggest that caregiving is shaped not only by present responsibilities but also by concerns regarding future care, safety, and well-being. Such concerns reflect anticipatory stress and highlight the need for sustainable support mechanisms and long-term care planning services.

5.2.14 Limited Formal Support Systems

The study found that family members remain the primary source of support for caregivers, while formal support systems are limited. Although some respondents reported receiving assistance from relatives and informal networks, structured services specifically designed for adults with Intellectual Disability were perceived as insufficient.

This observation is consistent with both the Research Synthesis Collaborative (2024) and the IPHB Research Group (2025), which emphasised the continued reliance on family-centred caregiving in India. The limited availability of formal services increases caregiver burden and restricts opportunities for independent functioning and community participation among adults with Intellectual Disability.

The findings underscore the importance of strengthening institutional support, community-based programmes, respite services, and caregiver assistance initiatives. Such measures may reduce caregiver burden and enhance the quality of life of both caregivers and adults with Intellectual Disability.

Summary of Discussion

The discussion demonstrates that caregiving is a multidimensional experience involving continuous responsibility, emotional investment, behavioural management, and long-term planning. The findings highlight the central role played by caregivers in supporting adults with Intellectual Disability and reveal the challenges associated with limited support systems and future uncertainty. The study reinforces the importance of recognising caregivers as key contributors to the well-being and social inclusion of

adults with Intellectual Disability and highlights the need for comprehensive support mechanisms at family, community, and institutional levels.

5.3 Suggestions

1. Community-based support services should be strengthened to provide continuous assistance to adults with Intellectual Disability and their caregivers.

2. Day-care centres, vocational training programmes, and skill development initiatives should be expanded to promote independence, social participation, and productive engagement among adults with Intellectual Disability.

3. Caregiver support programmes should be developed to provide counselling, stress management training, and opportunities for peer support and experience sharing.

4. Government agencies should strengthen financial assistance schemes and welfare benefits to reduce the economic burden experienced by families.

5. Awareness programmes should be conducted at community and institutional levels to reduce stigma and promote positive attitudes towards Intellectual Disability.

6. Long-term care planning services should be developed to address caregivers' concerns regarding future caregiving arrangements and beneficiary welfare.

7. Educational and training programmes should be provided to caregivers to enhance knowledge regarding behaviour management, communication strategies, and skill development techniques.

8. Collaboration between government departments, non-governmental organisations, healthcare institutions, and community organisations should be strengthened to improve service accessibility and support networks.

5.4 conclusion

The present study focused on understanding the caregiving practices and experiences of caregivers of adults with Intellectual Disability in Thiruvananthapuram. The findings reveal that caregiving is a continuous and long-term responsibility that extends beyond routine care and involves constant supervision, emotional support, and behavioural management.

Caregivers play a central role in maintaining the daily functioning and well-being of adults with Intellectual Disability. The study shows that caregiving practices are largely based on repetition, patience, and close monitoring. Emotional and behavioural management is primarily handled by caregivers, indicating a high level of dependency.

The study also highlights that caregiving has a significant impact on the personal, social, and emotional lives of caregivers. Many caregivers experience stress, fatigue, and restrictions in their daily life. Concerns about the future care of the individual and the lack of structured support systems further increase this burden. The study concludes that caregiving for adults with Intellectual Disability is shaped by continuous responsibility, limited support systems, and socio-cultural factors. There is a clear need for stronger institutional support, community-based services, and interventions to support both caregivers and individuals with Intellectual Disability.

The study highlights that caregivers play a central role in supporting adults with Intellectual Disability in their daily lives. Their responsibilities extend beyond physical care and include supervision, emotional support, behavioural guidance, skill development, and social assistance. The findings demonstrate that caregiving is deeply integrated into everyday family life and requires continuous commitment and adaptation.

The study further reveals that caregiving experiences are shaped by multiple factors, including the level of dependency of the individual, availability of support systems, financial resources, and future concerns. While caregivers demonstrated resilience and dedication, they also reported emotional strain, restricted personal freedom, and

uncertainty regarding long-term caregiving arrangements. These experiences illustrate the complex realities associated with family-based caregiving.

The findings also emphasise the importance of recognising caregivers as key stakeholders in disability care and rehabilitation. Strengthening support services, promoting community participation, and improving access to resources can contribute significantly to the well-being of both caregivers and adults with Intellectual Disability.

5.5 Implications for social work practice

The findings of the present study have significant implications for social work practice at individual, family, community, and policy levels. The experiences shared by caregivers demonstrate the need for professional interventions that address both the needs of adults with Intellectual Disability and the challenges faced by their caregivers.

Implications for Social Case Work

The findings indicate that caregivers experience emotional stress, uncertainty regarding the future, and difficulties associated with long-term caregiving responsibilities. Social workers can provide individual counselling and psychosocial support to caregivers to help them manage stress, strengthen coping mechanisms, and improve emotional well-being. Case work interventions can also assist families in identifying available resources, accessing welfare benefits, and developing long-term care plans for adults with Intellectual Disability.

Implications for Social Group Work

The study highlights the importance of peer support among caregivers. Social workers can facilitate caregiver support groups where family members can share experiences, discuss challenges, and learn effective caregiving strategies from one another. Such groups can reduce feelings of isolation and provide emotional support through collective learning and mutual assistance.

Implications for Community Organisation

The findings reveal limited community participation and social interaction among adults with Intellectual Disability. Social workers can organise community-based

programmes aimed at promoting inclusion, awareness, and acceptance. Community initiatives can help reduce stigma and create supportive environments for individuals with Intellectual Disability and their families.

Implications for Social Welfare Administration

The study identifies gaps in formal support systems and services available for adults with Intellectual Disability. Social workers involved in administration can advocate for the development of day-care centres, vocational training programmes, respite care services, and community-based rehabilitation initiatives. Effective programme planning and resource mobilisation can contribute to improved service delivery and support for caregivers.

Implications for Social Work Research

The findings highlight the need for further research focusing on adults with Intellectual Disability and their caregivers. Future studies can explore intervention models, support systems, quality of life, and long-term caregiving experiences. Research can contribute to the development of evidence-based policies and programmes that address the needs of this population.

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ANNEXURES

Semi-Structured Interview Guide

Title of the Study

Caregiving Practices and Experiences of Caregivers of Adults with Intellectual Disability

Basic Information

1. Participant Code:
2. Age:
3. Gender:
4. Educational Qualification:
5. Occupation:
6. Relationship with the Adult with Intellectual Disability:
7. Age of the Adult with Intellectual Disability:
8. Duration of Caregiving:
9. Place:

Section A: Caregiving Practices

1. Can you describe your daily caregiving routine?
2. What kind of support do you provide to the adult with Intellectual Disability?
3. How do you help them in their daily activities?
4. How do you manage their health and medical needs?
5. How do you encourage them to become independent?

Section B: Caregiving Experiences

6. How has caregiving influenced your personal life?
7. What have been your most memorable experiences as a caregiver?
8. What positive changes have you experienced through caregiving?
9. How has caregiving affected your emotional well-being? s

Section C: Emotional and Social Behaviour

10. How would you describe the emotional behaviour of the adult with Intellectual Disability?
11. How do they interact with family members?
12. How do they interact with other people in the community?
13. Have you noticed any behavioural changes over the years?

Section D: Challenges

14. What are the major challenges you face while providing care?
15. Have you experienced financial difficulties because of caregiving?
16. Have you experienced stress or emotional exhaustion?
17. What concerns do you have regarding the future?

Section E: Support Systems

18. Who supports you in providing care?
19. Have you received any support from government agencies, NGOs, or rehabilitation centres?
20. What type of support do you feel is still lacking?
21. What suggestions would you like to give for improving services for caregivers?