# JETIR.ORG



# ISSN: 2349-5162 | ESTD Year : 2014 | Monthly Issue JOURNAL OF EMERGING TECHNOLOGIES AND INNOVATIVE RESEARCH (JETIR)

An International Scholarly Open Access, Peer-reviewed, Refereed Journal

# A Systematic Review of Qualitative Studies: Understanding the Lived Experiences of Parents in Raising Their Intellectually Disabled Children

Dr. Arup Kumar Goswami, Ph.D

Teacher- in- charge, Jyoti Pratibondhi Punarbasan Kendra, Bankura (A residential Institute for children with Intellectual Disability & Hearing Impairment) Sponsored by Mass Education Extension Dept. Govt. of West

Bengal. India

Post Doctorate (D.Litt)Research Fellow, Department of Education Manipur International University (MIU), Imphal. Email: <u>goswamiarup252@gmail.com</u>

Arupkumar.goswami@rediffmail.com

# Abstract:

Raising intellectually disabled children is a unique and often challenging journey that profoundly impacts the lives of parents and families. This systematic review of qualitative studies aims to provide a comprehensive understanding of the lived experiences of parents in raising their intellectually disabled children. By synthesizing the findings of multiple qualitative studies, this review seeks to uncover the emotional, social, and practical dimensions of parenting in this context, shedding light on the challenges faced, coping mechanisms employed, and the impact on family dynamics. The review also explores parents' experiences in accessing healthcare, education, and support services for their intellectually disabled children. It examines the barriers and facilitators in accessing these services, highlighting the systemic challenges that parents encounter. Furthermore, the review delves into the sociocultural influences on parents' experiences, acknowledging the diversity of backgrounds, beliefs, and socioeconomic statuses among parents. It explores how these factors shape their perceptions and decision-making processes. Additionally, this systematic review aims to identify gaps in the existing literature and areas for further research. It seeks to inform policymakers, service providers, and support organizations about the needs and challenges faced by these families, advocating for more inclusive and empathetic policies and services. The findings of this systematic review contribute to a deeper understanding of the emotional and practical aspects of parenting intellectually disabled children. By amplifying the voices and experiences of parents, this research underscores the need for support systems that are more comprehensive, reduced stigma, and a society that embraces and includes individuals with intellectual disabilities and their families.

Keywords: Intellectual Disabilities, Parenting, Lived Experiences, Caregiving, Support Services.

# 1. Introduction

Raising a child is a profound and transformative journey, filled with joys, challenges, and a myriad of emotions. However, when parents are faced with the unique responsibility of raising intellectually disabled children, the path they navigate becomes distinctly complex, requiring exceptional resilience, adaptability, and an unwavering commitment to their child's well-being. This systematic review aims to shed light on the intricate and deeply personal experiences of parents who have embarked on this extraordinary journey, offering insight into the multifaceted dimensions of their lives. Intellectual disability is a condition characterized by limitations in cognitive functioning and adaptive behaviors, which often manifest during the developmental stages of childhood. Parents of intellectually disabled children are often confronted with a wide range of challenges, including navigating the healthcare system, advocating for their child's educational needs, and coping with the emotional toll of caring for a child with unique requirements. These challenges have a profound impact on parents' lives, shaping their identities, relationships, and overall well-being. While quantitative research has provided valuable insights into the prevalence and broad characteristics of intellectual disabilities, qualitative studies offer a deeper understanding of the lived experiences of parents in this context. Qualitative research allows exploring the rich tapestry of emotions, coping mechanisms, and support networks that parents rely on as they navigate the intricate terrain of raising intellectually disabled children. This systematic review serves as a comprehensive examination of the existing body of qualitative research on the subject, synthesizing findings from various studies to paint a holistic picture of the challenges, triumphs, and unique perspectives of parents raising intellectually disabled children. By exploring the narratives, themes, and commonalities that emerge from these qualitative studies, we aim to provide a nuanced perspective that inform policy, practice, and support systems for families affected by intellectual disabilities. In this review, we will engage with a range of qualitative research articles, focusing on the diverse experiences of parents from different cultural backgrounds, socioeconomic statuses, and geographical locations. By incorporating this diversity, we aim to capture the universal as well as context-specific aspects of parenting intellectually disabled children. As researcher delve into the narratives of these parents, it is our hope that this systematic review will not only deepen our understanding of their experiences but also contribute to the development of more compassionate and effective support systems. By amplifying the voices of parents who have faced these unique challenges, it is aspire to foster a greater sense of empathy and solidarity within our society, ultimately enhancing the quality of life for intellectually disabled children and their families.

# 1.1.<u>Statement of the Problem</u>

There is a significant gap in the existing literature regarding the comprehensive understanding of the lived experiences of parents raising intellectually disabled children. While there are studies on specific aspects of caregiving, a holistic examination of these experiences is lacking. Raising intellectually disabled children can have a profound emotional impact on parents, including feelings of love, joy, stress, anxiety, guilt, and resilience. However, the depth and nuances of these emotional experiences remain insufficiently explored. Parents often

## www.jetir.org (ISSN-2349-5162)

encounter substantial challenges when accessing healthcare, education, and support services for their children. These challenges may include navigating complex systems, inadequate resources, and a lack of awareness among service providers. The experiences of parents can significantly impact family dynamics, including relationships between parents, siblings, and extended family members. Understanding how these dynamics evolve is essential for providing holistic support. The influence of sociocultural factors, including cultural beliefs, norms, and socioeconomic status, on parents' experiences and decision-making processes is an area that requires in-depth examination. There is a need to identify gaps in policies and support systems for families with intellectually disabled children. This includes understanding the limitations and inadequacies in existing support structures. The stigma and misconceptions surrounding intellectual disabilities can perpetuate discrimination and isolation. Understanding the experiences of parents can help challenge these stereotypes and promote inclusivity. While there are undoubtedly challenges, there is a lack of focus on documenting stories of resilience and success among parents and their children. These stories can provide inspiration and guidance for others facing similar circumstances. In light of these issues and gaps, this study aims to comprehensively explore and document the lived experiences of parents raising intellectually disabled children. By addressing these challenges and shedding light on the complexities of this journey, the research seeks to contribute to improved support systems, reduced stigma, and a more inclusive and empathetic society. Thus, the study entitled as "A Systematic Review of Qualitative Studies: Understanding the Lived Experiences of Parents in Raising Their Intellectually **Disabled Children**."

# 1.2. The Need and Significance of the Study

Raising intellectually disabled children presents a set of complex challenges that extend beyond the boundaries of conventional parenting. These challenges encompass emotional, social, economic, and healthcare aspects of daily life for parents and caregivers. Recognizing the need for a systematic review of qualitative studies exploring the lived experiences of parents in this context is crucial for several reasons, underlining the profound significance of this study Understanding the nuanced experiences of parents is vital for the development and improvement of support services. Service providers, educators, and healthcare professionals can benefit immensely from insights into the emotional and practical needs of these families. By addressing these needs more effectively, support services can enhance the quality of life for both the child and the parents. This review can inform the development of policies that better accommodate the needs of families with intellectually disabled children. Policymakers can gain a deeper understanding of the challenges these families face, leading to the creation of more inclusive and comprehensive policies that promote equity and access to resources. Parents of intellectually disabled children often encounter stigma and societal misconceptions. By shedding light on their lived experiences, this study can challenge stereotypes and promote greater acceptance and empathy within society. Reducing stigma is not only essential for the well-being of these families but also for promoting social inclusion. Parenting a child with intellectual disabilities can be emotionally and physically draining. Insights gained from this systematic review can provide parents with a sense of validation, knowing that their experiences are recognized and understood.

# www.jetir.org (ISSN-2349-5162)

Additionally, by identifying effective coping strategies used by other parents, this study can offer valuable guidance for improving parental well-being. This systematic review can also guide future research efforts by highlighting gaps in the existing literature. It may uncover areas where further qualitative research is needed to gain a more comprehensive understanding of specific aspects of parenting intellectually disabled children. The experiences of parents in different cultural and socioeconomic contexts can vary significantly. By including a diverse range of studies in this review, we aim to recognize the cultural and contextual factors that influence the experiences of parents, thus promoting a more globally relevant understanding of the issue. Sharing the stories and experiences of parents in this situation able to promote greater empathy and solidarity among communities, healthcare professionals, and society as a whole. A more compassionate understanding of the challenges faced by these families can lead to increased support and social inclusion. In conclusion, this systematic review of qualitative studies is essential to address the multifaceted needs and experiences of parents raising intellectually disabled children. By providing a comprehensive synthesis of existing research, it offers a platform for enhancing support services, policy development, reducing stigma, improving parental well-being, and advancing our collective understanding of the unique journey these families undertake. Ultimately, the significance of this study lies in its potential to contribute to a more inclusive and empathetic society that values and supports families raising intellectually disabled children.

# **1.3. The Objectives of the Study**

Identifying various research agendas related to lived experiences of parents in raising intellectually disabled children

- 1. To find out the emotional experiences of parents in raising intellectually disabled children.
- 2. To understand the parents' experiences on confronting with accessing the health care facilities related challenges for their intellectually disabled children.
- 3. To understand the parents' experiences on confronting with accessing the educational challenges for their intellectually disabled children.

# 1.3.1. The emotional experiences of parents in raising intellectually disabled children

The emotional experiences of parents raising intellectually disabled children are multifaceted and complex, encompassing a wide range of feelings and responses. These emotions can vary from one parent to another and can evolve over time as the child grows and their needs change. Raising an intellectually disabled child can be physically and emotionally taxing. Parents raising intellectually disabled children often face a unique set of emotional challenges due to the complexities of caregiving and the lifelong nature of their responsibilities. These emotional problems can significantly affect their mental health and well-being. The constant demands of caregiving, including managing appointments, therapies, and educational needs, can lead to chronic stress. This stress can be both physical and emotional, taking a toll on parents' overall health. Parents may experience heightened anxiety about their child's future, safety, and well-being. Concerns about how their child will navigate

#### www.jetir.org (ISSN-2349-5162)

the world as they grow older can be particularly anxiety-inducing. The emotional strain of caring for an intellectually disabled child can lead to feelings of sadness, hopelessness, and depression. Coping with ongoing challenges and the potential for social isolation can contribute to depressive symptoms. Parents may experience grief and a sense of loss for the life they had envisioned for their child. The realization that their child may face limitations or difficulties in achieving certain milestones can be emotionally painful. Some parents may feel guilty or blame themselves for their child's condition, even though intellectual disabilities are typically not caused by parental actions. They may also experience guilt if they believe they are not doing enough to support their child. The unique challenges of caring for an intellectually disabled child can lead to social isolation. Parents may have limited opportunities for social interactions, and they may feel that others do not understand their experiences. The physical and emotional demands of caregiving can lead to exhaustion and burnout. Parents may reach a point where they feel emotionally drained and overwhelmed. Raising an intellectually disabled child can place strain on relationships, including marriages and partnerships. Differences in caregiving approaches, coping mechanisms, or feelings of grief and stress can contribute to relationship challenges. However, Chaturvedi (2020) discovered that data on the global intellectual disability population is limited and at times unreliable, which is complicated and influenced by a variety of factors, such as poor recognition of individuals with intellectual disabilities, educational levels, cultural aspects, and socio-environmental factors, which may affect intellectual disability recognition and identification. Despite a severe lack of reliable information on the nature and prevalence of intellectual disability globally, McKenzie et al. The daily demands of caregiving, managing appointments, therapies, and educational needs can lead to high levels of stress and overwhelm. There can be moments of frustration when parents encounter difficulties in finding appropriate services or therapies for their child. Feeling helpless in certain situations is not uncommon. Kerr, J., Sharry, J., & Wilson, C. (2023). Parents of children with intellectual or developmental disabilities have unique challenges in navigating the developmental period of adolescence. The present study explored the experiences of parents connected with disability services throughout the island of Ireland of parenting their child during adolescence. Sekar, N., & Valsala Gopalakrishnan, A. (2016). The parents reported primary reactions of shock, and an inability to accept the fact that their child was disabled. They asked repeated questions about the cause and possible medical treatments to cure their child's condition, even after being informed that the condition in question was incurable by doctors. Parents reported fears of their child's condition affecting their position in the society, especially because IDD is still considered a social stigma in India. The socioeconomic status of the population surveyed was low; hence they also expressed fears regarding the additional finances that would be incurred in the course of their child's treatment/management of the disease. Mngadi, L. C. (2018). Major findings were that most parents were happy and satisfied with the education of their children, though some lacked understanding and thorough knowledge about autism and special education. Parents raised concerns about lack of therapists in special schools when their ASD children need the intervention of speech and language therapists and occupational therapists.

# **1.3.2.** To understand the parents' experiences on confronting with accessing the health care facilities

# related challenges for their intellectually disabled children.

Parents find themselves navigating complex and bureaucratic healthcare systems. This may involve coordinating care between multiple specialists, clinics, and hospitals, which can be overwhelming and confusing. Finding healthcare providers who are knowledgeable and experienced in treating intellectually disabled children were challenging one. Many parents have to travel long distances to access specialized care, which can be logistically difficult and expensive. Intellectual disability-related healthcare services often have long waiting times for appointments and treatments. This delay can be frustrating and affect the child's health outcomes. Some intellectually disabled children may have communication difficulties, making it challenging for healthcare providers to understand their needs and symptoms. Parents often serve as advocates and interpreters for their children, which can be emotionally draining. Coordinating care between various specialists and services can be a daunting task. Parents need to ensure that all healthcare providers are aware of their child's unique needs and are working together effectively. El Sherbini, H. H., Ahmed, A. A., & Mohammed, N. Y. (2016) revealed that mothers as a main family caregiver play a vital role in caring for mentally disabled individuals including children and adolescents. Intellectual disability of the child causes a great amount of challenges to the mother. Presence of behavior problems in mentally disabled children is a serious concern for the mothers. It produces variant forms of challenges among them including; social, emotional, economic, and physical challenges. Some mothers shamed to participate in social functions with their mentally disabled child. Even though, some mothers cope well and are adjusted to their situation, but some cannot cope better. One of the main concerns of mothers of mentally retarded children is about how their children will be taken care of when they die. Most of the respondents were anxious, worry, and have fear from the future. Varying degrees of emotional distress were experienced by mothers as feelings of sadness and inner pain or bitterness, feel unhappy, guilty and have hopelessness. According to Shabalala (2000), the Swazi people like many others of different cultures, in the past looked at disability as a curse from the gods as a sign of bad omen. People with disability were excluded from all spheres of life. When a child with some disabilities was born, he or she was killed at birth. Culturally this practice was not viewed as killing, but as a way of life for dealing with abnormalities. If for some reason the child survived this ordeal daily survival was very difficult because the child would be neglected to a point of death. The very few that made it to adult life were kept hidden from general society.

# 1.3.3. <u>To understand the parents' experiences on confronting with accessing the educational challenges</u> for their intellectually disabled children

Intellectual disability, sometimes called cognitive disability, formerly referred to as mental retardation, is described as a disability characterized by significant deficits both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills that occur before the age of 18 in which needs for supports become imperative (Schalock et al., 2010; Tass, et. al, 2012). As Schalock et al. (2010) pointed out, intellectual disability results in impaired cognitive abilities and adaptive skills and the need for extraordinary

## www.jetir.org (ISSN-2349-5162)

supports for a person to participate in activities involved with typical human functioning. Intellectual disability is, therefore, not only an inherent trait of any individual, but also is characterized by a combination of deficits in both cognitive functioning and adaptive behavior in which systems of support become imperative. For children with intellectual disabilities, the development of perception is uneven, the acquired standards are often unstable, vague, and there is no transfer of the learned mode of action from one situation to another. The relationships between the perception of a property, the ability to act with this property in mind, and the ability to make simple generalizations are quite complex. Children who successfully distinguish properties during classes cannot pick up paired items at the request of the teacher. They do not select them at all in everyday life, in independent activity, when you need to find a certain object in the room Parents find that there are limited educational options available for intellectually disabled children in their area. This resulted in a lack of suitable schools or programs that can meet their child's specific needs. Special education systems is a complex and confusing for parents who are unfamiliar with the process. Parents may struggle to understand the Individualized Education Program (IEP) or Individualized Family Service Plan (IFSP) process and their rights within it. Schools may lack the necessary resources, including trained staff, specialized materials, and assistive technology, to adequately support intellectually disabled students. This hinder a child's educational progress. Inclusion in mainstream classrooms can be challenging for both students and parents. Parents encounter resistance or lack of understanding from school staff or other students' parents regarding their child's placement. Intellectually disabled children can be vulnerable to bullying and stigmatization by their peers. Parents experience distress and frustration when addressing these issues with school authorities. Some parents face transportation challenges when attempting to get their child to and from school, especially if specialized transportation services are required. Parents need to be tireless advocates for their child's educational needs. This ongoing advocacy is emotionally and mentally draining over time. Not all educators are adequately trained to teach children with intellectual disabilities. This result in suboptimal educational experiences for these students. The quality and availability of special education services vary widely between school districts and regions, leading to disparities in educational opportunities for intellectually disabled children. In some cases, parents need to engage in legal battles or due process hearings to secure appropriate educational services for their child. These legal processes were stressful and time-consuming. Witnessing their child's educational challenges and barriers can take an emotional toll on parents. They experience frustration, anxiety, and sadness as they work to ensure their child receives an appropriate education. According to Carrasco et al., (2019), parents of children with disabilities usually have negative views about them. These feelings include pessimism, humiliation, withdrawal, and even rejection of the presence of children with disabilities. Adult children with Down syndrome who were raised in families with high levels of cohesion, harmony, and child-supportive practices displayed more adaptive behavior, fewer behavioral problems, and less social isolation when compared to children with Down syndrome raised in families with the lowest levels of these qualities (Danino & Shechtman, 2012). This study underlines the need for greater support for parents of children with disabilities. Unfortunately, it appears that professionals typically concentrate their attention and aid on the child and their illness.

# 2. <u>Materials of the Study</u>

Kerr, J., Sharry, J., & Wilson, C. (2023). Five focus groups were conducted with twenty-five parents of adolescents and young adults with intellectual or developmental disabilities. Parents were asked open-ended questions about their experiences of raising their adolescent child. Transcripts of the focus groups were coded using reflexive thematic analysis Sekar, N., & Valsala Gopalakrishnan, A. (2016). The study was conducted based on two levels. The first level involves one to one interview with parents of 53 children attending a special school in the Coimbatore district of Tamil Nadu state in India and was followed by a second level of the study which involved group discussions. Merla, Shirisha., & Kumar, Naveen. (2021) conducted on patients of children have intellectual disability Hyderabad, in India. Nomothetic (Quantitative Approach) Psychology research method will be used for the study. The total sample consisted of 40 patients of children have intellectual disability i.e., 40 mothers and 40 fathers. For the purpose of our study, 8SQ Scale was administered upon patients of children have intellectual disability in individual situation and general instructions were given in the beginning of the test. Merla, Shirisha, & Kumar, Naveen. (2021). 8SQ scales were administered on these samples, eight emotional States levels was measured in both mother and father of intellectually disabled children. Mngadi, L. C. (2018). EA thematic content analysis was used to extract common themes from the collected data. El Sherbini, H. H., Ahmed, A. A., & Mohammed, N. Y. (2016) used two tools were used for data collection. The first tool was personal and socio-demographic structured interview questionnaire for the mothers of mentally disabled child to assess personal and sociodemographic data about the participants and their children. The second tool was focus group discussions guide for the mothers of mentally disabled child that used to identify challenges experienced by the mothers.

# 3. <u>Result of the Study</u>

Kerr, J., Sharry, J., & Wilson, C. (2023). On the journey from childhood to adolescence parents have to manage a number of different stressors with and for their child. These occur at societal, service provision, familial, and personal levels, with each stressor interacting with others to create vicious circles of struggle. Parents' struggles are multi-fold, and are not discreet entities that can be separated. The struggle is dynamic and continuous. Asagi, R. E. (2018). Majority of 68% of the respondent told child healthy during nurturing after baby birth is good and 2% of the respondents they have given the respond is not healthy. Majority of 82% of the respondents said feel sad their regarding child disability remaining 18% of the respondents said no feel sad their regarding child disability. Majority of 74% of the respondents they accepted they feel stress to concern their children and 26% of the respondents they did not accepted. Majority of 62% of the respondents they will take them their child to come out the home every day and 38% of the respondents they have hesitating to take their baby to outside the home. Majority of 86% of the respondents of the parents feel embarrass to attend the social programme with their baby and 14% of the respondents they did not embarrass. Majority of 70% of the respondents they have faced criticism from society and 30% 0f the respondents they didn't criticized. Majority of 86% of the respondents they have faced structure is low and 14% of the respondents they didn't disappoint. Majority of 90% of the respondents explore their information regard psychiatric suggestions regarding their child illness nature

## www.jetir.org (ISSN-2349-5162)

and 10% of the respondents they have uninformed. Sekar, N., & Valsala Gopalakrishnan, A. (2016). Among all the IDDs, only Down syndrome can be recognized at the birth. Parents of a mentally disabled daughter have their fears further compounded. Due to such fears, parents have reported covering their daughter's identity in public and have thought about the removal of their daughter's reproductive organs. To avoid mismanagement of the child's condition, basic medical training of the parents becomes imperative and they should be educated on the reproductive rights of daughters. Hence a holistic approach involving addressing the psychological, medical and financial issues facing affected families is necessary to bring about the healthy development of the IDD child. Merla, Shirisha., & Kumar, Naveen. (2021). Parenting a child with intellectual disability brings a lot of change in psychological makeup of the parents, owing due to irreversible condition of the nature of intellectual disability. An attempt is made to understand whether parents of the child having intellectual disability are affected or not, if effected whether mother and father of the child are equally affected or not. Mothers perceive the perception of the condition of child differently and fathers was taken for the study. There is no significant difference in emotional states levels that mothers and fathers are subjected, emotional states persistently existent in both female and male gender, emotional states. Mngadi, L. C. (2018). Parents raised concerns about lack of therapists in special schools when their ASD children need the intervention of speech and language therapists and occupational therapists. It was also found that parents struggle to access preprimary education for their children. It is recommended that special schools create forums where parents have a platform to voice their opinions and concerns. In conclusion, the study was able to give insight into parents' experiences, views and concerns with regard to the education of autistic children. . El Sherbini, H. H., Ahmed, A. A., & Mohammed, N. Y. (2016) revealed that slightly less than quarter of the mothers have more than one mentally disabled child. 60% of them were unable to pay for health services. Inadequate and poor quality health care and rehabilitative services for intellectual disabled children were the most challenging issue reported by the majority of mothers. Most of them spent a lot of time looking for hospitals and rehabilitative centers that could accommodate the child physiotherapy needs. The majority of mothers in this study believe that the junior physicians in the general hospitals had no skills in diagnosis and management; especially for mentally disabled. In addition, they added that improper diagnosis delay the care which leads to subsequent complications for their children.

# 4. Discussion

The study provides invaluable insights into the day-to-day experiences of parents, which can be instrumental in shaping and improving support services for both parents and their intellectually disabled children. By understanding the specific needs and challenges faced by these families, support services can be more tailored and effective. Sharing the lived experiences of these parents can foster greater empathy within society and reduce stigma surrounding intellectual disabilities. Through these narratives, society can gain a deeper understanding of the unique struggles and joys experienced by these families. The study's insights can lead to improvements in healthcare, educational services, and other support systems. According to Smith (2002) parents of children with disabilities experience greater stress and a larger number of caregiving challenges, such as health problems, greater

# www.jetir.org (ISSN-2349-5162)

feelings of restriction, and higher levels of parental depression than parents of children without disabilities. Some families have trouble in financial assistance and inadequate support from the members of the family and communities. Parents can find themselves overwhelmed by various medical, caregiving and educational responsibilities. Beresford et al. (2007), state that no matter how severe the special needs of the child is, the parents are inevitably affected in one way or the other. Most of the parents are affected emotionally. Parents often struggle with guilt; they feel as though they somehow caused the child to have disability, whether from genetics, alcohol use, stress or other logical or illogical reasons. This guilt can harm the parent's emotional health if it is not dealt with. Some parents experience a spiritual crisis or blame the other parent for not giving the support, which is needed. Most parents have aspirations for their children from the time of birth and can experience severe disappointment that the child will not be an actor, a nurse, a teacher or whatever they had in mind. In order for these parents to cope with this experience they have to deal with the "death" of the perfect child who existed in their minds and learn to love and accept the child they have. They have to stop feeling ashamed or embarrassed that their child is mentally challenged. Smith (2002) concurs with (Blachar & Bakar, 2007) that even after diagnosis; parents often face a whole gamut of emotions before they can grapple effectively with the stark truth that their child has learning disabilities. Parents of children with disability experience challenges, which may lead them to make mistakes in upbringing of their children and which can give rise to learning difficulties and other problems. They need to be motivated to become involved in the education of their children. Parents play a greater role in the education of their children because they know their children better and are able to inform the teachers about their learning problems. They can help teachers to understand their children better and they can give advice about individual behaviour, and they can contribute to the design and implementation of joint learning support strategies (Lewis & Doorlag, 2006).

# 5. Conclusion

In conclusion, the study on "Understanding the Lived Experiences of Parents in Raising Their Intellectually Disabled Children" represents a significant and poignant exploration into a realm of life that is often marked by both challenges and resilience. This research journey has provided valuable insights into the multifaceted and deeply personal experiences of parents who care for intellectually disabled children. Through the narratives and experiences shared by parents, this study has fostered a deeper sense of empathy and understanding within society. It has illuminated the unique joys, struggles, and complexities faced by parents and their intellectually disabled children. The study's findings hold the potential to inform and transform support services for families in this context. By uncovering the specific needs and challenges faced by parents, it paves the way for more tailored and effective support systems. The stories of these parents challenge stereotypes and misconceptions about intellectual disabilities. They contribute to the reduction of stigma and discrimination, promoting a more inclusive and accepting society. This study offers a compelling case for policy development that prioritizes the needs of families with intellectually disabled children. Policymakers can draw on these insights to advocate for policies that promote equity, access to resources, and enhanced support networks. By shedding light on the emotional experiences of

#### www.jetir.org (ISSN-2349-5162)

parents, this study underscores the importance of support for their mental health and overall well-being. It emphasizes the need for caregivers to receive the necessary assistance and respite to navigate the challenges they face. The study recognizes the diversity of experiences among parents from various cultural backgrounds, socioeconomic statuses, and geographical locations. This diversity underscores the importance of considering individual and contextual factors in providing support. Insights into the coping mechanisms employed by parents offer a valuable resource for families facing similar challenges. These strategies can provide inspiration and guidance for others navigating similar journeys. Through the sharing of stories, this study highlights the remarkable resilience and moments of triumph within the context of raising intellectually disabled children. It emphasizes the strength and determination of parents and their capacity to overcome obstacles. In sum, the study on the lived experiences of parents raising intellectually disabled children is a testament to the power of storytelling and the importance of listening to the voices of those who often go unheard. It calls for greater empathy, awareness, and support for families facing these unique challenges and reinforces the notion that every individual, regardless of their abilities, has a valuable place in our society. This study is not just a research endeavor; it is a testament to the enduring love, dedication, and resilience of parents and their children, and it serves as a call to action for a more inclusive and compassionate world.

## **Reference**

Abosi, O. C. (2001). Trends and issues in special education in Botswana. The Journal of Special Education, 23(3), 11-16.

Baker, J., & Fenning, R. M. (2007). Prediction of social skills in 6 year old children without development delays. American Journal of Intellectual & Developmental Disability, 112, 375-91. <u>http://dx.doi.org/10.1352/0895-8017(2007)112[0375:POSSIY]2.0.CO;2</u>

Bender, W. N. (2008). Learning disabilities: Characteristics, identification and teaching strategies. Boston, Pearson Beresford, B., Rabiee P., & Sloper, P. (2007). Outcomes for parents with disabled children. York, Social Policy Research Unit: University of York.

Blachar, J., & Bakar, B. (2007). Positive impact of intellectual disability on families. American Journal of Mental Retardation, 112, 330-48. http://dx.doi.org/10.1352/0895-8017(2007)112[0330:PIOIDO]2.0.CO;2

Brikci, N., & Green, J. (2007). A guide to using qualitative research methodology. London, Health Services Research Unit: London School of Hygiene and Tropical Medicine.

Dobson, B., Middleton, S., & Breardworth, A. (2001). The impact of childhood disability on family life. New York: Joseph Rowntree Foundation.

Gona, J. K., Mingala-Odera, V., Newton, C. R., & Hartley, S. (2010). Caring for children with disabilities in Killifish Kenya: What is the career's experience? Child: Care, Health, and Development, 37(2), 175–183.

#### www.jetir.org (ISSN-2349-5162)

Heiman, T. (2002). Parents of children with disabilities: resilience, coping and future expectations. Journal of Developmental and Physical Disabilities, 14(2), 159-171. http://dx.doi.org/10.1023/A:1015219514621 Hill, C., & Rose, J. (2009). Parenting stress in mothers of adults with an intellectual disability: Parental cognitions in relation to child characteristics and family support. Journal of Intellectual Disability Research, 53(12), 969–980. Retrieved from <a href="http://dx.doi.org/10.1111/j.1365-2788.2009.01207.x">http://dx.doi.org/10.1023/A:1015219514621 Hill, C., & Rose, J. (2009). Parenting stress in mothers of adults with an intellectual disability: Parental cognitions in relation to child characteristics and family support. Journal of Intellectual Disability Research, 53(12), 969–980. Retrieved from <a href="http://dx.doi.org/10.1111/j.1365-2788.2009.01207.x">http://dx.doi.org/10.1111/j.1365-2788.2009.01207.x</a>

Kubler-Ross, E. (1980). Death the final stage of growth. New York: Simon and Schuster. Lewis, R. B., & Doorlag,D. H. (2006). Teaching special students in general education classrooms (7 th ed.)

New Jersey: Pearson Merrill Prentice Hall. Mazibuko, G. F. (2011). The received training and psychosocial needs of parents of children with special needs in Nhlangano Area, in the Shiselweni region. (Unpublished master's thesis).

University of Swaziland, Kwaluseni, Swaziland. Mdziniso, P. (2001). Teachers' attitudes, gender differences and parental attitudes towards inclusive education in primary schools in Swaziland. (Unpublished master's thesis) University of Swaziland, Kwaluseni, Swaziland.

Norwich, B. (2003). Management of inclusion, Exeter, University of Exeter: School of Education and Lifelong Learning.

